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NARRATIVES OF STROKE AND APHASIA: AN ETHNOGRAPHIC INVESTIGATION

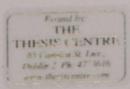
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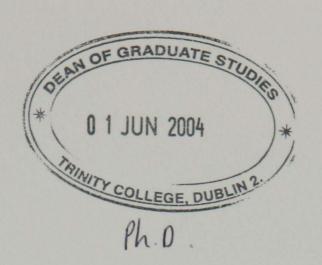
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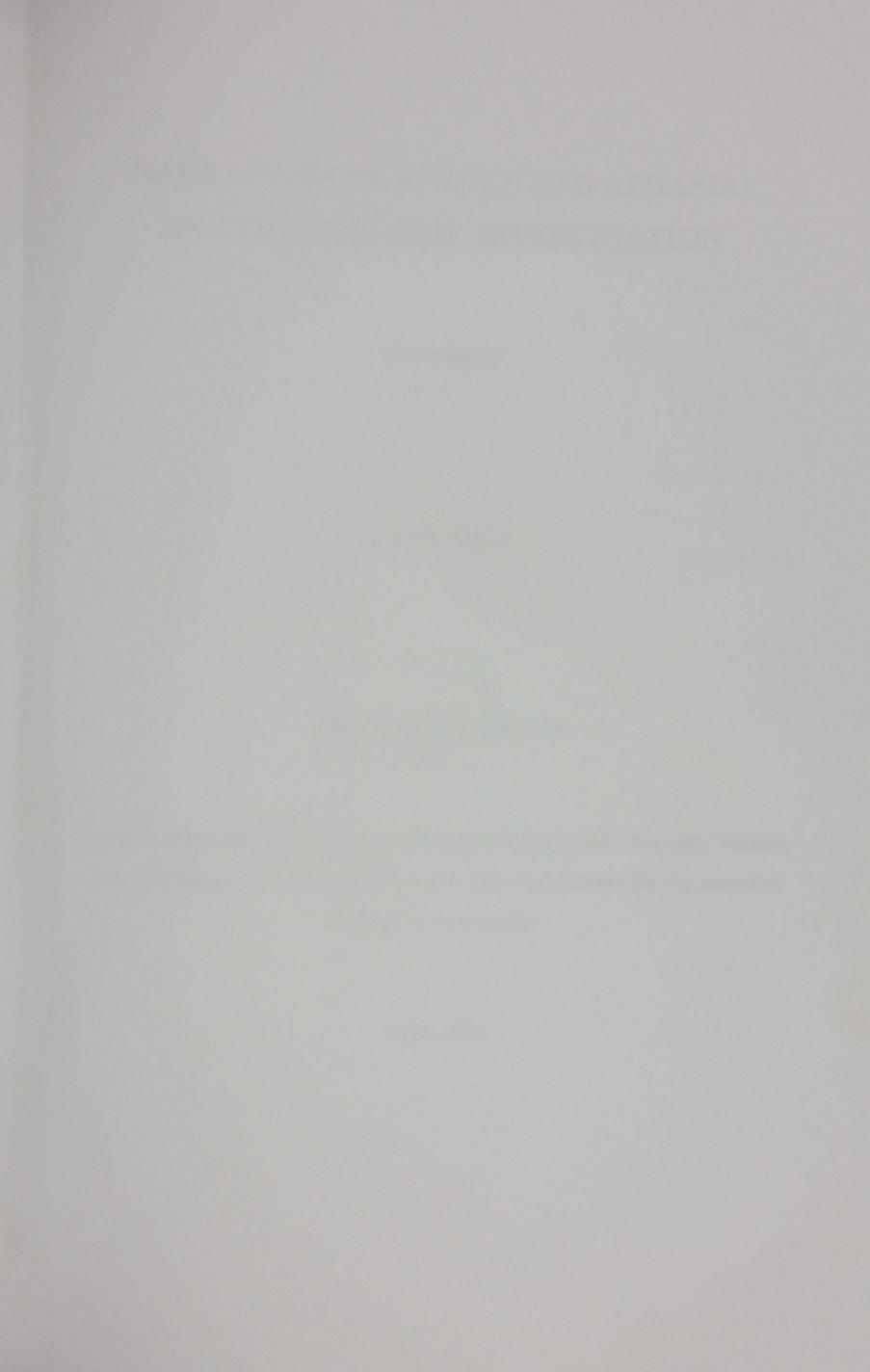
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NARRATIVES OF STROKE AND APHASIA: AN ETHNOGRAPHIC INVESTIGATION

(2 Volumes)

VOLUME I

Alice Rozanne Barrow

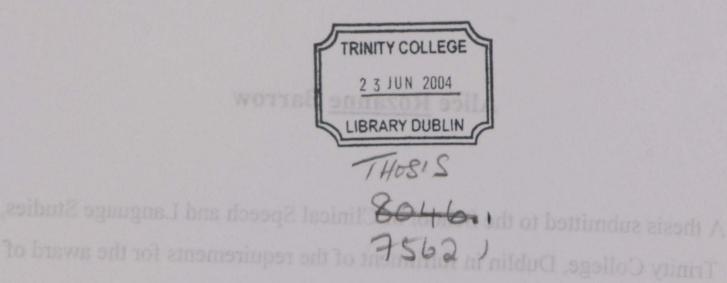
A thesis submitted to the School of Clinical Speech and Language Studies,
Trinity College, Dublin in fulfilment of the requirements for the award of
Doctor of Philosophy.

April 2004

NARRATIVES OF STROKE AND APHASIA: AN ETHNOGRAPHIC INVESTIGATION

(2 Volumes)

VOLUMEI



Doctor of Philosophy

April 2004

Declaration

I declare that this thesis has not been submitted as an exercise for a degree at this or at any other university. I also declare that this thesis is entirely my own work. I agree that the Library of Trinity College, Dublin may lend or copy this thesis upon request.

Alice Rozanne Barrow

Date: 10 April 2004

Dedication

This thesis is dedicated to my parents Winifred Barrow and the late Barney Barrow.

ACKNOWLEDGEMENTS

Many people have contributed to this thesis either by participating in it or lending their support and advice. Without them it would not have been possible.

Thank you seems insufficient to express my appreciation to my supervisors Margaret Leahy and Susie Parr. They gave of themselves so freely and spent much time and energy in helping me to clarify my frequently muddled ideas and thoughts. Their feedback on work done was always constructive and clear. They also provided emotional support when the going got tough. Without their help and guidance this research would not have been possible.

I would like to thank the support, advice and encouragement of a number of speech and language therapy colleagues who were always there in person or at the other end of a line. They are Irene Walsh, Margaret Walshe, Clothra Ní Cholmain, Carole Pound and Sally Byng. They always seemed equipped with helpful hints and words of wisdom in my hour of need. In addition Yvonne Fitzmaurice was particularly helpful in putting me in contact with potential participants.

This study would not have been possible without the support of my employer, Beaumont Hospital, who was generous in allowing me some time off to pursue this research. I would particularly like to acknowledge the speech and language therapy team who, good naturedly, put up with my absences and were always there to provide support. They are Antonia Hussey, Deirdre Kidney, Ciara McWeeney, Anne Healy, Anne Marie Aberg, Sinéad Twomey, Caitriona Munier, Jennifer Robertson and Sinéad McClay.

I would like to acknowledge the Beaumont Foundation and the TCD Quartercentenary & RCSLT Fund for Research on Speech & Language Disabilities for financial assistance.

Above all the participants, particularly 'Anne', 'Tony' and 'May', deserve special mention. They opened up their lives in the hope of helping other people with aphasia. They gave freely of their time and expertise and always made me feel welcome and never an intruder. Collaborating with them has enriched my understanding of aphasia and human nature.

Finally I would like to acknowledge my family, particularly my sister Daphne and my mother, who have shown great patience throughout and have always been there to give support and encouragement.

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SUMMARY

Exploration of the resources that people draw on to make sense of aphasia and manage it in day-to-day life is the focus of this thesis. Acquired aphasia is an impairment in language processing brought about through brain injury, frequently as a result of stroke. It affects the person's ability to communicate through language and so masks competence normally revealed through conversation (Kagan, 1998). As communication is central to the way we live our lives, the consequences of aphasia are enormous; it affects the person's ability to participate in all domains of life (i.e. familial, social, vocational). Accounts of aphasia by those with aphasia and their conversation partners highlight that the personal meanings of communication impairment, as well as the impairment itself, influence the quantity and quality of day to day interactions.

This study represents a journey in exploring narratives of stroke and aphasia. Narrative in this context means the stories, constructions or ways of thinking that one lives by in order to make sense of experience (Somers, 1994). So the study addresses the personal meanings of aphasia and how they affect the way the person lives her/his life with aphasia. The study uses ethnographic methods to determine the narratives that three people with aphasia – Anne, Tony and May – and some of their conversation partners draw on to make sense of aphasia and manage it in day-to-day life. Ethnography is essentially eclectic and so this study draws on data from in-depth interviews, casual conversations, observation, health care records, diaries, pictures, leaflets on aphasia and stroke, information accessed on the internet, and newspaper articles on illness and disability.

Findings reveal that people draw on multiple narratives in their quest to make sense of stroke and aphasia. An intricate and elusive tapestry of narratives is woven which surrounds the person and is created by them. Some threads are strong and vibrant while others are weaker and less dominant, but all combine to form a complex composite picture of what it is like to live with aphasia. While each participant came with this narrative tapestry, each had a dominant narrative that shaped and guided the way they

behaved although other narratives remained as background threads. The data reveal that all the narratives, except one, stemmed from the meta-narrative of modern medicine which influences our health service. This illustrates the strength and power of modern medicine in our society in determining how we think about disability. This meta-narrative of modern medicine also guides how illness and disability are written about in the public domain. With a few exceptions, all public narratives of disability are underpinned by the individual or medical model of disability. The social model of disability, on the other hand, views disability as a social creation and social model thinking is not generally evident in the information available to the public. Rather, with a few exceptions, it is trapped within the academic disability literature and so such counter narratives of disability are not readily accessible to people with stroke, their families and friends.

The findings of this study, and the realisation that the narratives the individual lives by affect the way she/he behaves, have implications for speech and language therapy working practice. Currently the predominant way of working is guided by an individual or medical model of disability with a focus on repairing language abilities. A narrative way of working calls for a different focus, a focus on living healthily with aphasia and living by a narrative that contributes, rather than negates, feelings of well-being. Such a way of working may incorporate supporting the telling of narratives as well as providing ways to access counter narratives of disability. It has implications for training of speech and language therapists and for collaborative work with other disciplines. The thesis concludes by proposing a narrative reframing of aphasia therapy.

CHAPTER 1 INTRODUCTION

About twelve years ago I was working with a young man called John who had sustained a head injury which left him with mild dysarthria². His speech was clear and easy to understand although it had a slightly distorted quality, so that most listeners would detect that his speech was not 'normal'. I felt there was nothing more that speech and language therapy had to offer this man and so I went into negotiations with him with regard to discharge from therapy. However during the course of this process, John made me aware that he avoided many speaking situations, particularly in public, for fear of being judged as "mentally retarded". Indeed, he rarely went out, which was in complete contrast to his pre-injury lifestyle where he was described as quite gregarious and outgoing. It dawned on me that it was this internalised belief that if your speech is abnormal then you are learning disabled that was more disabling for John than the impairment itself. He had an enormous fear that he would be judged as learning disabled, as that was how he would have judged others before his injury. It was this that prevented him from going out and talking in public. I realised that therapy, far from coming to a close, was only just beginning. John and I embarked on a journey of creating a new way of talking and thinking about communication impairment which was intertwined with identity and sense of self; a way of thinking that would enable him to feel free to go out into the community and mix and talk with people.

While in the past I had been aware that people held definite beliefs about what it meant to have a communication impairment, it was not until John's comments that I really began to understand the impact of it. This led me to wonder at a deep level how people make sense of impairment and the ramifications this may have in their day-to-day lives. John's remarks and his beliefs about what it meant to have 'funny speech' continued to haunt me and I could find nothing in the literature at the time that related to his predicament. Thus the idea for this study was formed.

All names throughout the thesis have been changed to protect identity.

² Dysarthria is a "neurogenic motor speech impairment which is characterised by slow, weak, imprecise, and/or uncoordinated movements of the speech musculature" (Yorkston, Beukelman & Bell, 1988, p.2).

While John had dysarthria, the majority of my time is spent in working with people who have aphasia. I had no doubt they too entertained their own personal beliefs about what it meant to have aphasia. The overall aim of this thesis therefore is to explore what resources or narratives a person draws on to make sense of aphasia and manage it in day to day life. Narrative in this context means the stories or ways of thinking that one lives by in order to make sense of experience (Somers, 1994) (for example, believing that one lives in an unsafe world may guide the way in which one experiences events and the way in which one behaves). The study represents a journey into the lives of three people with aphasia, and some of their conversation partners, as to what having, or knowing someone with, aphasia means to them. Intertwined in this journey is my own more personal journey of what it means to be a researcher and how this seems to be at odds with my role as speech and language therapist. Undertaking this study has helped me to clarify my role as a speech and language therapist and challenged my role in the therapy process.

This chapter is designed to give a brief introduction to the area under study. I will outline what aphasia is before going on to introduce the reader to notions of disability and narrative. I will start, however, by placing myself in the context of the overall work.

1.1 PLACING MYSELF IN CONTEXT

The construction of any work always bears the mark of the person who created it. (Riessman, 1993, p.v)

I am a speech and language therapist with over twenty five years' experience of working with people with communication impairment, particularly those with acquired neurological communication impairment. I have worked throughout these years, except for one year of travel and one year to complete a Masters degree. Otherwise I have been in employment continuously. Since 1986 I have been responsible for managing a hospital-based speech and language therapy service as well as continuing to work with people with communication impairment.

I found my way to specialising in acquired neurological communication impairment by accident, rather than by design. I wanted to work in New Zealand or Australia, but could not afford to get there. In the late 1970s if one was successful in applying for a position in New Zealand one's air fare would be paid. I secured a post there working with adults with acquired communication impairment. It was this turn of events that led me to specialise in the area of aphasia.

I have only minimal and transient experience of disability, having had a broken arm and a broken ankle – both of which I found troublesome at the time. I always knew, however, that this disability was only temporary in nature. While I am short-sighted, I do not find this disabling as the impairment is corrected by contact lenses or glasses. Therefore I have minimal experience of disability and certainly no experience of communication disability, and I rely on the people I work with to provide me with insight into what it means to become disabled.

1.2 APHASIA³

The National Institute on Deafness and other Communication Disorders (n.d.⁴) describes aphasia as a language impairment that results from damage or injury to portions of the brain, usually in the left hemisphere, that are responsible for language. Aphasia impairs the expression and understanding of language as well as reading and writing. Kagan (1995) extends this description to include the fact that aphasia can "mask competence" normally revealed through conversation.

Aphasia is quite a common but little-known condition. It is estimated that 150 people in every 100,000 of the population have an impairment in communication following a stroke (Enderby & Philipp, 1986). In the United States of America it is estimated that there are over one million people with aphasia (National Aphasia Association, n.d.) and

³ In line with current usage the term aphasia is used throughout rather than the term dysphasia.

⁴ n.d. = no date. This notation is advocated by the American Psychological Association in their guide to referencing (APA, n.d.) when the particular internet site being cited has no date. Many of the sources from internet sites do not provide dates.

250,000 in the United Kingdom (Speakability, n.d.). No figures are available for Ireland. It is more common than such conditions as Parkinson's Disease, Multiple Sclerosis and Muscular Dystrophy (Elman, Ogar & Elman, 2000), yet the population at large are much more aware of these conditions than they are of aphasia. There is poor understanding and awareness of aphasia in the USA (Elman *et al*, 2000), the UK (Parr, Byng, Gilpin & Ireland, 1997) and Ireland (Ní Dhonnabháin, 2002).

This difficulty with language leads to difficulty in interacting with others. Typically people with aphasia experience frustration as they struggle to get across what they want to say. They frequently refer to themselves as "stupid" yet they are clear in their mind about what they want to convey. Like John, many people have beliefs and attitudes about communication impairment. I remember one person, David, coming to therapy with a narrative of *striving to be normal* (Barrow, 2000). His struggle to communicate as normally as possible inhibited the fluency of his speech. Society's expectation is that people with impairments want to do everything in their power to overcome obstacles and be as normal as possible (Phillips, 1990). Such expectations of regaining a sense of normalcy are counterproductive for the individual with an acquired impairment who is unlikely to regain their previous abilities. Certainly this was the case for David. Therefore counter-narratives (i.e. narratives that refute such expectations that it is desirable to be "normal") are required to facilitate the person to live healthily with disability. The disability rights movement in the UK and around the world has developed such counter narratives.

1.3 DISABILITY

The 1970s and 1980s saw the emergence of a strong disability rights movement. Disabled activists voiced concern with a number of ideas that had been privileged as accepted wisdom, such as the notion that to lead a fulfilling life the person with an impairment should strive to live in conditions that are as close as possible to the way the majority of people live their lives (Chappell, 1998). There are times, as with David, that to try and conform as much as possible to 'normal' is not conducive to healthy living. However people tend to live by narratives that have developed in the main from

living in a society where the majority of people do not have impairments. Finkelstein and French (1993) comment:

Disabled people may feel negative and depressed about their situation because they have absorbed negative attitudes about disability both before and after becoming disabled, and much of the depression and anxiety they feel may be the result of social factors such as other people's attitudes, poor access, non-existent job prospects and poverty. In addition, people who acquire substantial impairments frequently experience serious problems with their relationships. (p.31)

The disability rights movement offers alternative views of disability. Activists and writers in the field, many of them disabled people, propose the view of 'disability as difference' rather than 'deviance from the norm'. They argue that society should facilitate and make changes to accommodate the needs and rights of disabled people, rather than the onus for change resting with the person with the impairment.

In the USA, the disability rights movement was highly influenced by the civil rights movement of the 1950s and so many public demonstrations were held. For example many disabled activists joined with the highly politicised Vietnam War Veterans to hold demonstrations to demand civil rights for disabled people. Such demonstrations were successful in drawing attention to the plight of people with disabilities who had served their country, and resulted in legislation that addressed the issue of discrimination against disabled people.

This way of thinking about disability (i.e. as a rights issue) has been termed the 'social model of disability'. Disability is viewed as a social construction rather than an individual problem. People who align to the 'individual' or 'medical' model of disability, on the other hand, believe that disability stems from the impairment itself rather than the disabling barriers erected by society. This latter model holds more influence and guides much of the publicly available literature on disability as well as many of the disability news stories in the media. In addition it underpins the practice of rehabilitation.

While the disability rights movement is having a growing influence on some disabled people's lives, people with aphasia feel apart from it (Parr et al, 1997). This may be

because the main voice of the movement has been through highly articulate disabled activists using language to write about it in academic journals. An academic style of writing is not accessible to the majority of people with aphasia. That being said, people with learning difficulties would have similar difficulties in accessing such literature yet there is now a flourishing self-advocacy movement which is underpinned by social model thinking.

Most of the people with aphasia with whom I work come with individual or medical model notions about disability, in that they view themselves as deviating from the norm and tend to take sole responsibility for any breakdown in communication. In addition, they come to therapy with the expectation of regaining their language abilities and not with the notion that therapy may have a role to play in enabling them to live healthily with aphasia. They expect the therapist to make it better; to fix it, and this is not always possible. So other stories need to be told. I became preoccupied with how to facilitate the telling of such stories.

1.4 NARRATIVE

Narrative theory offers another way of conceptualising illness and disability. At the time of working with John I had never heard of Arthur Frank and his illness narratives. Many years later I read *The Wounded Storyteller* (Frank, 1995), a book that made a great impression. In it he describes three principal illness narratives: *chaos* (where the person is sucked into the undertow of illness), *restitution* (where the illness is viewed as transitory and remedy is sought), and *quest* (where suffering is met head-on). The book made me reflect on the people with whom I had worked as well as my own way of dealing with illness. On a personal level, I am very much aware that if I become ill I want to get better; I seek *restitution*. From a work point of view my impression was that many people with aphasia lived by such narratives. I meet people who seem to be in *chaos* as they struggle to make sense of what has happened to them, and also people who seem to be in *restitution* as they actively seek ways to make their language better. *Quest* is not so common, but I only tend to see people in the first couple of years postonset of aphasia and so perhaps aphasia has not had time to become incorporated into

daily life. Nonetheless there are a few people I remember who do meet aphasia head on and integrate it into their lives.

While these narratives are useful as — to use Frank's (1995) words — "listening devices", I feel that people come to therapy with many other narratives as yet unidentified. It was this that began to intrigue me and I wanted to investigate more. How influenced are people with aphasia by narratives such as those described by Frank (1995) or are there other narratives that they draw on to make sense of aphasia and manage it in day-to-day life? What about other people close to the person? Do they draw on particular narratives that could affect the way in which they behave towards the person with aphasia? What about the prevailing public narratives? How do they influence personal narratives? And what role do narratives have to play in the therapy process? These are the questions that I asked and they form the basis for this study.

Having posed these questions the next challenge was to explore ways of investigating them.

1.5 METHODOLOGICAL CONSIDERATIONS

I was quite naïve and inexperienced in undertaking research and had very little idea how to find answers to the questions I had posed. The one study I had undertaken, as part of my Masters degree, used a traditional quantitative research methodology. I could not see how such an approach could allow me to explore narratives of aphasia. However at this time I was aware of the work of Susie Parr and her colleagues (Parr, Byng, Gilpin & Ireland, 1997) who were using in-depth qualitative interviews to gain the views of people with aphasia. I began to think that a qualitative research methodology might allow me to explore the questions I wanted and so I started to investigate further. The literature told me that qualitative research methods were more suited to exploring the social world than quantitative methods.

Quantitative methods have enabled the extent and range of chronic illness in the community to be known whilst qualitative methods have shown the subjective impact of this type of illness on the patient. (Armstrong, 1990, p.1225)

Armstrong (1990) reiterates this point further by saying:

Where quantitative method had enabled the extent and variability of the population to be plotted, qualitative method explored the subtleties of personal meanings and subjective experience. (p.1227)

I wanted to investigate the personal meanings and subjective experience of aphasia. I hoped to explore narratives from a variety of angles; for example, from the perspective of the individual with aphasia, from the perspective of some of those close to the individual, and from the perspective of therapists and day-care workers. In addition I wondered how narratives influenced behaviour. A multi-method or ethnographic approach was decided upon. Ethnography involves the researcher:

participating, overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking questions – in fact, collecting whatever data are available to throw light on the issues that are the focus of research. (Hammersley & Atkinson, 1995, p.1)

This study relies on a variety of methods to explore narratives of aphasia. These methods include in-depth interviews, participant observation and the analysis of artefacts (e.g. health records, newspaper articles, pictures). Such a variety of methods calls for a variety of analytical methods. For the analysis this study particularly draws on the work of Ritchie and Spencer (1994), Lieblich, Tuval-Mashiach and Zilber (1998) and Fairclough (1989, 1992). What is said and how it is told are central to the analysis.

To summarise, managing and making sense of a communication impairment such as aphasia is a highly complex endeavour. People seem to draw on a variety of resources in order to do so. While a number of illness narratives have been identified this does not provide the full picture as, in the course of my work I have been aware of many different stories or narratives that people bring to the therapy encounter which seem to influence the way in which they manage their situation. At the time this study was initiated there had been no work done (to the best of my knowledge) exploring narratives of aphasia or disability. Since the start of the study, however, I have become aware of the work of Simpson (2000) who, for her Masters dissertation, looked at narratives of aphasia and how they relate to identity. However she did not use multi-

methods to access narratives, but relied on interview alone. Neither did she involve others close to the person with aphasia in the process. While she was interested in the identity reconstruction process, I am more interested in how people make sense of and manage their aphasia in day-to-day life and how the narratives they draw on are influenced by public narratives of disability and illness. The key questions I have asked are:

- i. What personal and public narratives do people with aphasia draw on to make sense of aphasia and disability and manage it in day-to-day life?
- ii. What personal and public narratives do those close to the person with aphasia draw on to make sense of aphasia and manage it in day-to-day life?
- iii. How do narratives affect the way in which the person with aphasia behaves and how others behave towards her/him?
- iv. What is the relationship between public and personal narratives?

In addition I want to consider the implications that exploring narratives may have on the therapy process, as well as the relationship between models of disability and narrative.

A qualitative research methodology was used to investigate these questions.

1.6 STRUCTURE OF THE THESIS

This thesis consists of four main areas: review of the literature (3 chapters), methodology (2 chapters), findings (3 chapters) and discussion (3 chapters).

Following this introductory first chapter, Chapter Two provides an introduction to aphasia, outlining the history of modern aphasiology. It goes on to describe the main perspectives from which aphasia is viewed today – the psycholinguistic or cognitive neuropsychological perspective, the functional perspective and the psychosocial perspective. It then introduces another perspective which I have termed the sociological perspective. Chapter Three discusses the disability literature and, in particular, the two most dominant models of disability – the individual or medical model and the social

model which has been pioneered by disabled people themselves. It outlines the International Classification of Functioning, Disability and Health (ICF) proposed by the World Health Organisation (WHO, 2001) which before its revision was known as the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980). The final literature review chapter (Chapter Four) focuses on narrative. It provides definitions of narrative and describes a number of narrative perspectives and narrative studies.

The first of the methodology chapters, Chapter Five, begins by answering a number of questions regarding research design posed by Mason (1996) before going on to introduce qualitative research in general. It then describes narrative research and ethnography. Finally it touches on issues surrounding reliability and validity in qualitative research. Chapter Six outlines the research design in detail. It provides the background to the key participants (i.e. those participants with aphasia), the methods used and how the data were analysed. In addition it discusses the ethical issues that need to be considered.

Chapters Seven, Eight and Nine present the findings in the form of stories about the key participants, Anne, Tony and May. Each chapter outlines changes in lifestyle, prior to describing the dominant narratives that emerged from the data. A general overall theme in the form of a principal narrative type (Lieblich *et al*, 1998) is identified. Finally the management of threatened identity, aphasia and disability is discussed. Each participant presents with and is surrounded by a complex tapestry of narratives that they draw on to make sense of aphasia and manage it in day-to-day life.

The discussion opens with Chapter Ten, which is the story of my role in the research process. In it I outline the highs and lows of my personal journey from practising speech and language therapist to researcher. It reflects on the data generation methods and data analysis and how they affected me on a personal level. Chapter Eleven then draws Anne, Tony and May's stories together and discusses their narratives in the context of public narratives. The final Chapter Twelve discusses specific findings in

relation to the literature and, in particular, some of the narrative frameworks proposed by Frank (1995), Stainton Rogers (1991) and Crossley (2000) as well as issues surrounding disability and aphasia. It goes on discuss the advantages, disadvantages and limitation of using the eclectic methods employed in this study. The implications of what emerged from the study to future speech and language therapy practice is discussed and a framework for a narrative way of working is proposed. Finally it concludes by suggesting areas for future research.

CHAPTER 2 LITERATURE REVIEW: APHASIA

I have worked with people with aphasia since I graduated in 1977. During this time I have become more and more intrigued with thinking about how people with aphasia make sense of and manage their aphasia in day to day life and what my role, as a speech and language therapist, is in that process. This chapter describes how aphasia has come to be understood and represented though the years. It presents both historical and current perspectives, before touching on the more personal aspects of living with aphasia. It begins with an outline of how aphasia has been defined.

2.1 DEFINITIONS OF APHASIA

The Concise Collins Dictionary (Revised third edition, 1995) defines a definition as a formal and concise statement of the meaning of a word. Therefore a definition specifies the essential properties of something and in so doing says what something is and what it is not. Definitions of aphasia change according to how aphasia is viewed.

Aphasia has been defined as an acquired neurogenic language impairment resulting from damage or injury to the left cerebral hemisphere. It is generally agreed that it is an impairment that in some way affects the "normal processing of language in one or more of the language modalities" (Methé, Huber & Paradis, 1993, p.3). This definition, however, gives only an outsider perspective that does not capture the essence of the meaning of aphasia from an insider point of view. I sought other definitions that would encompass the meaning of aphasia from this insider perspective. Kagan's (1995) extends the 'traditional' definition by saying that aphasia can result in difficulties in interpersonal communication which can "mask competence" usually revealed through conversation. This definition acknowledges the interpersonal influences but does not capture the insider view of aphasia, a view that encompasses aspects central to what it means to experience and live with aphasia. I then looked at how people with aphasia describe it and I talked with some of the people with whom I worked. They provided me with rich and varied descriptions of

aphasia. I quote below just one such account. At the time of this description, Catherine had been living with aphasia for over a year and we had been working together on and off during that time. Her language processing was extremely slow, but if given sufficient time she was able to communicate what she wanted to say through spoken language. Part of therapy involved the development of a personalised handout to explain what aphasia meant to her and ways that other people could help. This is how she described her stroke and aphasia:

A stroke is desperate – your speech can go and your legs and arms can become paralysed. I had a stroke in August 1999 – I woke up to find I couldn't talk. Everybody would come in to see me but I would end up crying because I couldn't talk.

A stroke is all about knowing what I want to say but not being able to say it quick enough. I can't be as spontaneous in my speech as before my stroke and it even takes me a long time to answer questions. Even though I know the answer, it takes me time to find and say the words.

Because of my speech some people tend to avoid me. Out of all my friends before the stroke I only have two left – you know who your friends are.

Having had a stroke has made me grow up a little bit! However having a stroke is terrible. (Catherine, November 2000)

While very personal and not a definition *per se*, this account caught the insider perspective. Not only did it encompass the difficulties in language processing and the ramifications of that in terms of broken relationships, but it described the impact of aphasia in personal terms; it gave the insider view. How individuals with aphasia view and live with aphasia was of interest to me and this description of aphasia allowed me to consider what aphasia meant in personal terms, the 'official' definitions did not. It encompassed the notion that aphasia is more than impairment, it is a social issue that affects the individual and others who come into contact with her/him, in a variety of ways on a personal level.

Aphasia is difficult to comprehend as it involves communication abilities, but not thought, intelligence or experience (Parr *et al*, 1997). Over the years, aphasia has been viewed from a variety of perspectives. The historical writings concerning aphasia focus on medical aspects and impairment. Only in recent years has the actual impact of aphasia been considered more closely. I now sketch a brief outline of the history of aphasia, starting with historical perspectives and moving on to discuss more recent approaches to aphasia therapy.

2.2 HISTORICAL PERSPECTIVES

The recognition of aphasia goes back to the distant past. Benton (1981), in his review of the historical sources of aphasia, outlines how the first references to it go as far back as 1700 BC, when it was mentioned in the Edwin Smith Surgical Papyrus, an Egyptian manuscript. Later the Hippocratic writings of 400 BC included many descriptions of speech disturbances.

2.2.1 Fifteenth to Nineteenth Centuries

The fifteenth to the nineteenth centuries witnessed further writings about aphasia. In the fifteenth century a number of physicians wrote about brain disease that could cause a non-paralytic speech impairment. During the eighteenth century there were many reports of different forms of aphasia, and in 1770 a monograph by Gesner (cited in Benton, 1981) was published entitled 'speech amnesia', in which he described six people with aphasia. Early in the nineteenth century, Bouillard (cited in Benton, 1981) classified aphasia into two basic types – articulatory and amnesic. This division is still generally accepted today under the rubric of non-fluent (articulatory) and fluent (amnesic) types of aphasia.

However, it was not until 1861 that the traditional birth of modern aphasiology was heralded with the publication of papers in Paris, France, by Broca (1824-1880) (Code, 1991). Broca's focus was to localise aphasia to a particular area of the brain. From his autopsy findings he concluded that the posterior part of the frontal lobe (now known as Broca's area) was damaged in motor (articulatory or non-fluent) aphasia. In the UK, Dax (cited in Code, 1991) made the same observation in 1836, but his paper was not published until 1865. However Broca and Dax's works did not account for those people who had 'fluent' aphasia with compromised comprehension. Then in 1874 Wernicke (1848-1905) described two patients with an impairment in comprehension but with fluent speech characterised by 'sound production errors' (now known as paraphasias). He concluded that such an impairment was a result of damage to the left temporal lobe (now known as Wernicke's area). Wernicke went on to propose a model of language comprehension and production which was later developed by Lichtheim

in 1885 (cited in Code, 1991). This model views aphasia in terms of loss of function and types of aphasia are recognised through a combination of loss and preservation of language functions. This model still provides the basis of much standard neurolinguistic research today.

2.2.2 Twentieth Century (1900~1980)

In his review of the historical origins of aphasiology, Benton (1981) reports that this classical locationist approach (i.e. Broca and Wernicke's aphasia) which assumed that intellectual function remained in tact in aphasia, flourished until the 1920's. However not everyone was happy with it. Hughlings Jackson (1835-1911) (cited Benton, 1981) challenged the assumption that thinking per se was not affected in aphasia. He proposed that there were two levels of speech - automatic/emotional and propositional/intellectual - and that it was the latter that was affected in aphasia, and that this capacity for propositional speech was an intellectual and not a narrowly linguistic ability. Similarly Marie (1853-1940), Head (1861-1940) and Goldstein (1878-1965) viewed aphasia as a single disorder that involved some degree of intellectual defect. In 1935, Weisenburg & McBride (cited in Benton, 1981) found that there was a positive relationship between the extent of the impairment in non-verbal tests and the severity of aphasia. However, even given these findings, they concluded that aphasia did not necessarily involve impairment in intellectual function since some people with severe aphasia performed adequately on the non-verbal tests. This is the view still generally held today.

Code (1991) outlines how the development of the Geschwind disconnection model in 1965 and 1971 saw a renaissance in the classical (locationist) model of aphasia. This led to an expansion of research into the area in the 1960s, centring on the work of Goodglass and his colleagues at the Boston Aphasia Research Centre. Their work stems directly from Broca, Wernicke and Lichtheim with their emphasis on aphasia characteristics as the result of damage to the cortical centres themselves or their connecting pathways. An essential feature of this school of thought (i.e. the classical and the neo-classical) is the belief that the anterior part of the brain is responsible for

processing. This led to the classification of motor aphasia characterised by non-fluent speech (i.e. Broca's aphasia) and sensory aphasia characterised by fluent speech (i.e. Wernicke's aphasia). However the classical and neo-classical locationist theory has undergone change with the improvement in imaging techniques which indicate the role that the right hemisphere, thalamus and basal ganglia play in language processing.

In 1970 Luria (cited in Code, 1991) proposed a complex theory of aphasia in which he described that language has its foundation in the activity of a complex interaction of systems which have responsibility not just for language, but other cognitive functions as well. Essentially Luria proposed a processing model whereby particular areas of cortex are not seen as responsible for the execution of entire functions, as they are in the classical locationist model, but rather cognitive functioning is viewed as being processed through modular subcomponents. For example, a naming impairment may arise from damage to separate subcomponents and not just a single subcomponent. Luria's notions of information processing, modularity and subcomponents are features of the more recent cognitive neuropsychological approach of the 1980s (see 2.3.1).

In summary, up until the mid twentieth century, the main focus in the study of aphasia was on the localisation of aphasia in the brain and the nature of the impairment (i.e. the actual language processing difficulties). This is captured in the definitions of the time which define aphasia in terms of breakdown in language abilities. More recent perspectives take these aspects into account, but go further in encompassing and considering other aspects of aphasia: aspects which were of more interest to me in my work with people with aphasia.

2.3 CURRENT PERSPECTIVES (1980-)

Currently there are three main perspectives to aphasia: psycholinguistic or cognitive neuropsychological, pragmatic or functional, and psychosocial. These are considered and outlined. I then go on to outline what I consider to be a fourth perspective which I

call the sociological perspective. This has only really evolved in the past decade and is closely aligned to both the functional and psychosocial perspectives.

2.3.1 Psycholinguistic or Cognitive Neuropsychological Perspective

This perspective focuses on the impairment of aphasia in terms of disruption to language processing. Psycholinguistics looks at *how* language is processed. It studies language in relation to the psychological processes thought to influence it (Crystal, 1987). This approach to aphasia has also been termed the cognitive neuropsychological approach, as it is informed by the discipline of cognitive neuropsychology which seeks to explain cognitive performance in brain injured people in terms of damage to components of a theory of normal cognitive processing and draws conclusions about normal cognitive processes from patterns of impairment seen in brain injured people (Ellis & Young, 1989). Cognitive neuropsychology is an "approach to understanding cognitive dysfunction" (Riddoch & Humphreys, 1994, p.5, emphasis in the original) and has provided those working with people with aphasia with a framework to explore impaired and intact language processing.

This perspective acknowledges that people with aphasia present with a different array of abilities and difficulties in language processing, each unique to that individual. It aims to identify, through appropriately targeted assessment, the impaired and preserved language processes that account for the person's difficulties. Proponents of this approach argue that such an in-depth understanding of the nature of the difficulties will then provide a basis for therapeutic intervention, targeting those key areas. In part it supports the view that after brain damage the areas subserving language remain intact but are not easily accessible and therefore there is an assumption that one can relearn what has been lost. This is similar to the stimulation approach advocated by Schuell and her colleagues (Schuell, Jenkins & Jimenez-Pabon, 1975), with its rationale that aphasia interferes with proper language processing and language can be reactivated through stimulation.

In terms of assessing the impairment of aphasia there are a number of assessment procedures which have been published based on this theory of language processing. These include the PALPA (Psycholinguistic Assessments of Linguistic Processing in Aphasia) by Kay, Lesser and Coltheart (1992), the Action for Dysphasic Adults Comprehension Battery by Franklin, Turner and Ellis (1992), the Pyramids and Palm Trees Test by Howard and Patterson (1992), the TRIP (Thematic Roles in Production) by Whitworth (1996) and the Sentence Processing Resource Pack by Marshall, Black and Byng (1999). It is usual to use one or more of these tests in a clinical context to determine the degree and nature of the impairment in language processing.

This cognitive neuropsychological model of language processing has been found to be helpful in identifying different levels of impairment to account for word retrieval difficulties (Lesser, 1989; 1993), in differentiating paraphasic errors (Buckingham, 1991) and exploring the semantic and phonological processes affecting sentence production (Perlman Lorch, 1991). Numerous studies (e.g. Jones, 1986; Byng, 1988; Behrmann & Lieberthal, 1989; Marshall, Pound, White-Thomson & Pring 1990; Nickels, Byng & Black 1991; Best, Howard, Bruce & Gatehouse 1997; Annoni, Khateb, Custodi, Debeauvais, Michel & Landis 1998), using this approach to assessment and therapy, have provided evidence for the efficacy of aphasia therapy targeting language processing. Ellis, Franklin & Crerar (1994) provide a comprehensive overview of the cognitive neuropsychological model of language processing and give examples of impairment at different levels in aphasia.

However the cognitive neuropsychological perspective has been criticised as not being clinically viable due to time constraints in day to day practice (Goodglass, 1990), its poor applicability to people with severe aphasia affecting all language modalities (Kertesz, 1990) and for focusing on deficits and not on 'functionality and communication need' (Frattali, 1992). Byng, Kay, Edmundson & Scott (1990) acknowledge that this approach to aphasia does not provide a theory of therapy, but that, while requiring further refinement, it does provide a useful means to gain insight into the nature of a person's language abilities in aphasia. Hillis and Caramazza (1994)

conclude from their study that, while a cognitive neuropsychological approach is necessary for diagnosis of the 'locus of impairment' within the model, it is not sufficient to guide therapy effectively. However the number of studies, identified above, demonstrating the effectiveness of using this approach refutes this notion.

The cognitive neuropsychological perspective focuses on the assessment of aphasia in terms of the nature of the disruption to language processing brought about by the brain injury and therapy centres on bringing about change in the impairment. In this perspective the person with aphasia is expected to take on the role of patient whereby she/he follows the direction of the professional expert with the expectation that compliance will lead to improved language abilities. The role of the therapist, therefore, is that of expert and the role of the person with aphasia is that of learner.

As mentioned earlier, Frattali (1992) has criticised the cognitive neuropsychological perspective for not taking into consideration communication need and ability to get a message across. The following perspective focuses on these aspects of aphasia.

2.3.2 Pragmatic or Functional Perspective

Interpersonal communication involves more that just the ability to process language. It involves both an exchange of information (i.e. a transactional component) and social connection or fulfilment of social needs (i.e. an interactional component) (McTear, 1985; Kagan, 1995; Simmons-Mackie, 2000). It is these components, and particularly the former, that are the focus of a pragmatic or functional approach to aphasia. This perspective, which I will refer to as the functional perspective, recognises the importance of 'pleasurable communication experiences' (Shewan & Cameron, 1984), as it is based on maximising and capitalising on the person's retained abilities rather than highlighting the person's weaknesses.

Pragmatics focuses on the study of language in use and takes into account the factors that govern our choice of language in social interaction and the effects of our choice on others (Crystal, 1987). It is now generally acknowledged that the study of the

pragmatic and sociolinguistic aspects of language is as important as studying more traditional aspects of language in aphasia (Holland, 1991; Gallo & Vallesc, 1992). Pragmatic language models involve the complex interrelationships between knowledge of language and its structure, knowledge of the world and social knowledge (Penn, 1993). Worrall (1995) states that a functional perspective of aphasia encompasses pragmatics but she contends that pragmatics is primarily concerned with the use of verbal language in context. She suggests that a functional approach has its main emphasis on the reduction of the person's 'handicap', thereby increasing participation. A functional approach utilises numerous compensatory strategies to this end.

Later Worrall (1999) defines a functional approach as "the ability of an *individual* to *communicate* in his or her *own everyday environment*" (p.2, emphasis in original). This definition does not, however, take into account the role of others in successful interaction. A definition that takes this into account is put forward by Byng, Pound and Parr (2000) when they say that a functional perspective encompasses "being able to communicate competently through your own communication skills and those of others (see, for example, Kagan, 1998), and feeling comfortable that you are representing who you are" (p.53).

The functional approach supports the view that certain language functions are lost and are not recoverable. There is an assumption that the language that remains is subserved by undamaged brain tissue and therefore therapy is aimed at compensating for what has been lost. Some specific early methods include Promoting Aphasic's Communicative Effectiveness (PACE) (Davis, 1980) and Visual Action Therapy (VAT) (Helm-Estabrooks, Fitzpatrick & Barresi, 1982). Both take advantage of functions that remain and view language as being an important, but not the only, aspect of communication.

There are a number of assessments of functional communication some of which draw on different approaches to pragmatic assessment including pragmatic theory, speech act theory and conversation analysis. Both the Profile of Communicative Appropriateness (Penn, 1985) and the Pragmatic Protocol (Prutting & Kirchner, 1987) are based on speech act theory, although they use principles of pragmatic theory with regard to their use of the notion of 'appropriateness'. Conversation analysis provides the theoretical base for the Assessment Protocol of Pragmatic Linguistic Skills (Gerber & Gurland, 1989) and the Conversation Analysis Profile for People with Aphasia (Whitworth, Perkins & Lesser, 1997). Other assessment procedures which aim to assess functional communication in people with acquired aphasia include the Functional Communication Profile (Taylor, 1969), the Communicative Abilities of Daily Living (Holland, 1980), the Edinburgh Functional Communication Profile (Skinner, Wertz, Thompson & Davidson, 1984; Wertz, Skinner & Dean, 1990 revised version) and the Functional Communication Therapy Planner (Worrall, 1999). However the earlier assessment procedures were found not to meet the needs of practising speech and language therapists (Smith & Parr, 1986). Some assessments (e.g. Communicative Abilities of Daily Living - Holland, 1980) use role play to predict how the person will behave in the real life situation. However role play items for the purpose of assessment of communication abilities have been criticised as failing to give a true reflection of communicative behaviour in corresponding real life situations (Barrow, 1985).

Functional approaches to aphasia have focused on the use of strategies and techniques based on retained abilities, to facilitate communication (Doyle & DeRuyter, 1995), the behaviour of conversational partners in communicative breakdown (Kagan, 1995, 1998; Booth & Swabey, 1999) and the use of gesture and drawing (Rao 1995; Sacchett, Byng, Marshall & Pound, 1999). Parr (1991, 1992) extends the functional perspective by studying reading and writing in aphasia using an ethnographic approach. Lesser & Algar (1995) take a significant step towards combining both a psycholinguistic and a pragmatic approach in the treatment of aphasia whereby both methods were used in assessment and intervention.

The main strengths of a functional perspective lie in its validity, flexibility, the fact that it is strength centred and that it promotes the involvement of others (Holland, 1991). Penn (1993) outlines some of what she considers to be important aspects inherent in a pragmatic approach to aphasia; these include the incorporation of linguistic, social and cognitive factors in assessment and therapy, the relevance to both social and employment contexts, and the value of discourse as a method of analysis and basis for therapy. In their review of functional assessments, Manochiopinig, Sheard & Reed (1992) concluded that normative data, standardisation and reliability of functional assessments are not realistic goals because of the nature of the contexts in which people communicate and that their main value lies in their validity. However Lesser and Algar (1995) warn that a functional perspective tends to be too global and that there is a need to be more specific in our therapy.

Just as in the cognitive neuropsychological perspective, the person with aphasia is expected to follow the therapist's lead and is guided by her/him in how best to get her/his message across. The therapist is again viewed as expert.

The functional perspective, while addressing the experience of disability in more depth than the cognitive neuropsychological perspective, does not claim to address in depth the impact of aphasia in personal as well as functional terms. The following perspective held some promise in this regard.

2.3.3 Psychosocial or Social-Emotional Perspective

While a cognitive neuropsychological perspective focuses on the nature of language processing and the functional perspective focuses on the person's ability to get the message across, a psychosocial perspective focuses on the impact of aphasia in terms of the person's social and mental well-being. In their review of the different types of approaches to aphasia Methé *et al* (1993) failed to mention a psychosocial perspective, although they mentioned, as an aside, that therapy needs also to be aimed at coping with aphasia in affective and social contexts. Sarno (1993) contended that while psychosocial issues may be frequently alluded to, they are rarely the focus of

academic pursuit. Why is this so, when one considers that how well we establish and maintain key relationships in life affects our sense of well-being and that difficulty in communicating affects this ability to establish and maintain relationships, and in so doing affects feelings of well-being? A psychosocial perspective on aphasia focuses on it in the context of that person's overall life; it takes a holistic view (Lyon, in press).

Language and communication abilities are central to daily living in that they enable us to control our lives and go about our day to day business. They mediate our ability to establish and maintain relationships and are the very essence of our being as social communicators and humans. The presence of aphasia affects a person's ability to communicate and so potentially carries penalties for the individual concerned thus diminishing their power and autonomy. It is this impact of aphasia that lies at the heart of a psychosocial perspective on aphasia, and yet it is this aspect of aphasia that receives less attention in therapy (Sarno, 1993). Speech and language therapists working with people with aphasia are aware that there are significant areas of the impact of aphasia that are not given adequate attention in assessment and therapy. Kagan's work (1995; 1998) particularly attempts to bridge the gap between communication and personhood, with her focus of revealing and acknowledging competence.

The following extract from Sarno (1993) encompasses the issues that are central to a psychosocial perspective on aphasia.

The deep and unexpected changes associated with aphasia initiate a series of reactions that impact on every aspect of the individual, including reactions to illness, disability, sense of self, ability to cope with being socially different, feelings of loss, lowered self-esteem, and possible depression in the face of impaired behaviour. It is never possible to determine the extent to which some of these feelings may have already existed, and are magnified by the real social and vocational restrictions aphasia creates. (p.323)

The term psychosocial refers to the "grounding of emotional experience in social context" (Hemsley & Code, 1996, p.568); Währborg (1991) describes psychosocial reactions as those reactions that have interactional and social consequences. Such reactions are a general response to the condition itself and to how others react to the

condition within the community and social context of that individual and those with whom she/he comes in contact. It has been suggested that verbal impairment, more than motor disability, is more difficult to accept due to the privileged role that language plays in our society (Lemay, 1993). Zraick & Boone (1991) found that spouses of people with aphasia tend to use significantly more adjectives with negative connotations, compared with spouses of those who do not have aphasia. Such attitudes to aphasia may play a role in the quality of relationships when one considers the role that communication plays in the maintenance and growth of relationships. This is highlighted by Sparkes (1993) in her discussion of the impact that aphasia may have on key relationships. Hemsley & Code (1996) found that the type and degree of emotional and psychosocial responses to stroke and aphasia were unique to each individual.

Psychosocial consequences of aphasia include feelings of anxiety, depression, poor self-confidence and self-esteem, inferiority, social isolation as well as feelings associated with the threat to one's place in society and the fear of how others may judge one. Psychosocial consequences of aphasia in terms of professional, social, familial and psychological changes were explored by Herrmann, Johannsen-Horbach & Wallesch (1993), who found changes across all parameters. Like Sarno (1993) they concluded that the psychosocial perspective of aphasia is the most "underdeveloped and yet is fundamental in the rehabilitation process" (p.201).

It has been found that social restriction is only loosely related to the degree of disability in aphasia and that 'social stigmatisation' may be the key factor (Herrmann & Wallesch, 1989). Goffman (1963/1990) states that "failure to sustain the many minor norms important in the etiquette of face-to-face communication can have a very pervasive effect upon the defaulter's acceptability in social situations" (p.154). Such a situation can lead to negative reactions to the person with aphasia, and such reactions and the current intolerance of society to difficulties in communication (Lemay, 1993) will have a direct impact on the social and mental health of the individual. Low feelings of well-being pervade all aspects of life, and it has even been suggested that

there is a relationship between mood and progress in rehabilitation (Code & Müller, 1992).

Brumfitt (1993) highlights the sense of loss that the person with aphasia experiences and how this may lead to loss of that person's status in society. She contends that speech is a central part of the self concept and that aphasia, by its very nature, threatens this sense of self. Like Kagan, she also emphasises the importance that competency is revealed if one is to maintain a positive sense of self.

To develop a positive sense of self after becoming aphasic, the person therefore needs to function within a social context where close personal relationships confirm competence and adequacy. (Brumfitt, 1993, p.573)

Loss of speech has been cited as the most difficult impairment resulting from a stroke (Clarke, 1997). A number of authors (e.g. Tanner & Gerstenberger, 1988; Währborg, 1991; Herrmann *et al*, 1993) propose that a 'grief response' model as used for death and dying (Kübler-Ross, 1973) provides a useful framework to explore losses associated with aphasia. However such models have been criticised as being over simplistic, too prescriptive and failing to address some of the central issues associated with being disabled (Frank, 1991; Lenny, 1993; Ireland, 1995). Lenny (1993) highlights that numerous studies have demonstrated that not all disabled people experience their disabilities as loss. She goes on to state that "loss models lock disabled people into stereotypes as pathetic victims overwhelmed by, or superheroes battling to overcome, this loss" (p.235). Frank (1991) criticises grief response theories as allowing for professionals to think they understand without having to become involved. He proposes that "the caregiver's art is finding a way to allow the ill person to express his needs" (p.47).

Brumfitt (1993) acknowledges that the onset of aphasia threatens the sense of self. Pound and her colleagues (e.g. Pound et al, 2000) take up Brumfitt's challenge by their development of therapies that focus on the promotion of a positive sense of identity that incorporates aphasia. The importance of storytelling has long been recognised as having 'healing powers' (e.g. Kleinman, 1988; Phillips, 1990;

McAdams, 1993; Elwyn & Gwyn, 1999; Pound, 1999) in that it helps one to make sense of events that have happened. Pound (1999) advocates "really listening" to the story that the person with aphasia comes with, as it allows one to access the lived experience of that person's life. This storytelling function is a vital component of one of the identity therapies undertaken at Connect⁵: the development of personal portfolios⁶ (Penman, 1998; Pound *et al*, 2000). In this the person is actively encouraged to tell their story (both pre- and post-onset of aphasia) in any way which she/he sees fit. It gives a tangible record of their life and so provides a means to enable the person to tell her/his own story.

One of the primary therapeutic aims of personal portfolio work is the exploration, affirmation and concrete representation of a person's past and present as a means of moving more confidently and hopefully into the future. Unlike therapeutic approaches in which discussion of past lives and achievements is incidental, attention is focused on the person's biography and way of telling his or her life story. (Pound *et al*, 2000, p.204)

The development of personal portfolios has been found to contribute to feelings of increased self-esteem and confidence (Penman, 1998).

In terms of assessment there are few published assessment procedures that address the psychosocial issues of aphasia. This lack of assessments reflects the complexity of this area and the difficulty in developing traditional standard tools to assess it. However there are two published assessments that are available to speech and language therapists. The Code-Müller Protocols (Code & Müller, 1992) aim to gain information on individual perceptions of psychosocial adjustment of the person with aphasia and others who are in frequent contact with that person in terms of how much the person will get better/worse. However only a small sample of psychosocial states considered to be important by a group of speech and language therapists are included. More recently the Visual Analogue Self-Esteem Scales (VASES) (Brumfitt & Sheeran, 1999) has been published. This procedure involves the person with aphasia rating how they are feeling along a variety of visual analogue scales. In addition to these

⁵ Formerly the City University Aphasia Centre.

⁶ A personal portfolio is a collection of information about a person's past, present and aspirations for the future which is usually presented in a folder or ring binder (Pound et al, 2000)

published assessments, Simmons-Mackie & Damico's (1996a) Communicative Profiling System (CPS) also addresses psychosocial state and goes further to propose the use of an in-depth ethnographic interview to establish the person's view of aphasia and the impact of it on their daily life. Together with the ethnographic interview, participant and anecdotal observation and video recordings in real-life contexts are employed to explore the impact of the impairment on the actual behaviour of the person concerned.

It is the disabling experience of aphasia (i.e. the way in which it affects day-to-day life) that is of most concern to people with aphasia and their relatives (e.g. LeDorze & Brassard, 1995; Parr *et al*, 1997). In Sarno's (1993) review of the literature on psychosocial aspects of aphasia, she commented that while many authors allude to such responses, few study or research the psychosocial variables themselves. She suggests that this may be because traditionally medical research tends to focus on and value the 'high-tech' aspects of illness. She adds that the effects of physical and cognitive impairment take priority in therapy and that this also reflects the dominance of the "impairment model" in our current health care system. LeDorze and Brassard (1995) also found that health professionals tended to focus on the impairment and not the disabling experience of it.

While Sarno and others have highlighted the lack of research in this area, there have been a number of studies which have addressed the psychosocial impact of aphasia directly. Mulhall (1978) was one of the first to look systematically at the psychosocial impact of aphasia in terms of the influence of another person's behaviour on communication abilities in aphasia. Other issues that have been addressed include methods of reducing anxiety in aphasia (Pachalska, Knapik, Smolak & Pytel, 1987), the potential value of family therapy in the treatment of aphasia (Nichols, 1993; Burns, Dong & Oehring, 1995; Nichols, Varchevker & Pring, 1996) and a study to explore how people with aphasia cope (Parr, 1994), in which the diversity of how individuals cope was highlighted. Ireland (1995), in her paper on aphasia from both a

'patient's and a counsellor's perspective, reflects on and stresses the importance of addressing the impact of living with aphasia.

This perspective demands more of a counselling relationship between the person with aphasia and therapist, whereby her/his needs are what guides therapy. However the therapist is still viewed as expert and maintains control of the interaction.

The psychosocial perspective has the impact and experience of aphasia at the forefront of its agenda. While the personal meaning of aphasia is at the heart of my interest, I am also intrigued by the part that societal, as well as personal, attitudes and beliefs play in living with aphasia. Therefore I have watched with interest as these ideas have developed over the past decade. This contemporary perspective is sociological in nature and has much in common with the psychosocial perspective.

2.3.4 Sociological Perspective

Sociology looks beyond obvious explanations to gain a deeper understanding of social issues. It considers ways in which personal issues are influenced by social, economic and political factors (Earle, 2001). Sarno (in press) states that a sociological view is to consider and help restructure the person's identity and sense of self with resultant enhancement of social experience and interaction.

This perspective is closely aligned to both the psychosocial and functional perspectives, but it extends both these approaches in that it is broader and more encompassing. The sociological perspective considers the person from a truly holistic stance as someone living within a society that does not necessarily value disabled people. The person with aphasia is viewed as part of "a personal environment which is embedded in a larger communal/societal context" (Sarno, in press). It focuses on the wider aspects of life which enhance attitudes and feelings, social connections with others and participation in chosen daily routines (Lyon, in press). Its aim is not just to bring about change in the person with aphasia and her/his conversation partners, but sets its sights on the bigger picture of bringing about change in the attitudes and

behaviour of people in society at large. It promotes partnership between the person with aphasia and those close to her/him and the speech and language therapist. Byng (2001) sums it up:

Much of the attraction of socially based therapies results from the nature of the relationship between health care worker and recipient. In a socially motivated therapy, for example, the consultation, the appreciation of functional practicalities, and the focus on context all lend themselves to being applied within a respectful partnership relationship, where mutual expertise is acknowledged and the professional clearly acts as a resource. (p.69)

The sociological viewpoint differs from those previously discussed in that it aligns itself to the social model of disability as developed and advocated by disability rights activists. The practical application of the sociological perspective can be seen in the work of Connect the disability network in London (e.g. Parr, 1996; Parr *et al*, 1997; Parr, Pound, Byng & Long, 1999; Byng, Pound & Parr, 2000; Parr & Byng, 2000; Pound, Parr, Lindsay & Woolf, 2000; Pound, Parr & Duchan, 2001). The Life Participation Approach to Aphasia (LPAA, 2000) also mirrors the practical application of this perspective in North America.

Another way in which this perspective differs from the cognitive neuropsychological and functional perspectives is that it tends to use a qualitative, rather than the more traditional quantitative, research methodology to gain access to issues of interest of those with aphasia and their conversational partners. Like the psychosocial perspective, it is concerned with gaining insight into the insider view of what it means to have aphasia. However unlike the psychosocial perspective it focuses on societal attitudes and beliefs about aphasia and disability and addresses the ramifications of these for the person concerned. Therefore as well as being concerned with the insider view this perspective is also concerned with the outsider view particularly with regard to barriers to communication.

LPAA (2000) calls for a broadening and refocusing of clinical practice and research on the consequences of aphasia. It focuses on re-engagement with life throughout the continuum of 'care'. Like Connect, LPAA places the person's life concerns at the centre of decision making, with a focus on real-life goals and strengthening

participation in activities. They highlight how the person's sense of disability can be heightened or lessened depending on the supportiveness of their environment. Both LPAA and Connect call for a change in role of the speech and language therapist to ensure that the therapy process is based on a partnership between the person with aphasia and the speech and language therapist. This demands that the speech and language therapist relinquishes her/his role as expert and takes on the role of "facilitator" (Pound 1999). While retaining the role of professional expert may be appropriate if one is working directly on the impairment in the short term, it is less appropriate when one is working with a person who will have to live with aphasia in the long term; the person's perspective then is central in guiding therapy.

Parr et al (1997) highlight the individual nature of aphasia and outline the barriers people with aphasia face in their day to day life. Garcia, Barrette & Laroche (2000) also found barriers for the person with aphasia particularly in relation to integrating back into work. The main barriers they identified were related to attitudes and behaviours. Interestingly in their study the employers were the ones who focused on organisational strategies to overcome the barriers, while the people with aphasia and the speech and language therapists focused more on strategies that the individual could employ. The sociological perspective is making strides to address some of the issues surrounding dismantling barriers to communication.

Lubinski (1981) noted that people find it difficult to talk to people with specific communication difficulties, and so people with communication impairment have decreased opportunities to communicate meaningfully and so reveal competence. This ability to reveal competence has been of particular concern to Kagan and associates (Kagan & Gailey, 1993; Kagan, 1995; 1998) and they have done much to develop systems that enable the person to have increased opportunities for meaningful conversation. Kagan and colleagues have developed the *Pictographic Communication Resources Manual* (Kagan, Winckel & Schumway, 1996) with the aim that it can be used to support conversations with people with aphasia. A little later, Parr and her colleagues in the UK (Parr *et al*, 1999) developed the *Aphasia Handbook*, another

resource aimed at supporting the person with aphasia in conversation. Both manuals provide information about aphasia and stroke, benefits and issues surrounding living with aphasia in an aphasia-friendly⁷ format. Such manuals have been found to have a positive effect on helping the person to get their message across and to reveal competence through conversation. Hamilton (1994), in her interactional sociolinguistic study of a person with Alzheimer's Disease, highlights how the conversation partner's communicative behaviour with regard to how she/he accommodates to the disabled partner's abilities can make the person seem more or less disabled. The importance of creating an environment that will enhance retained communication abilities has also been advocated by Barrow & Kennedy (1990).

More recently Lock, Wilkinson & Bryan (2001) developed a programme called SPPARC: Supporting Partners of People with Aphasia in Relationships and Conversation. This aims to promote effective communication between the person with aphasia and their partner through the use of conversation analysis.

All of these systems aim to reduce or eliminate barriers to communication by bringing about change in the behaviour of the conversational partner of the person with aphasia. The focus therefore is not on bringing about change in the person with aphasia, but rather to their surrounding environment and the people in that environment. Therefore it aligns with the social model of disability perspective with its emphasis on dismantling disabling barriers. Communication and conversation play a key role in maintaining social and mental well-being (Kagan & Gailey, 1993; Kagan, 1995; 1998) and without opportunities to participate in conversation to reveal their inherent competence, people with aphasia risk isolation and diminished feelings of self-worth. The work undertaken by Kagan and her colleagues and the work being undertaken at Connect take a significant step toward dismantling barriers to conversation, thus

⁷ Aphasia-friendly means that every effort has been made to make the literature accessible to the person with aphasia who may have difficulty in reading text. Creative use of pictures and diagrams are used, together with simplified text, to get the message across.

facilitating the person to reveal their competence and so promote their social and mental well-being. Others are beginning to follow suit. For example, Stirling (2003) taught staff how to engage in supported conversation in an acute hospital setting with the result that staff felt much more confident in communicating with people with aphasia.

Lyon, Cariski, Keisler, Rosenbek, Levine, Kumpula, Ryff, Coyne and Blanc (1997) took a slightly different standpoint. Their study focused on increasing the activities of people with aphasia rather than on conversation *per se*. They trained volunteers in supported conversation, who then introduced people with aphasia to activities of their choice. The aim was to increase the person's participation in life because life experiences give one something to talk about. They found significant positive changes in terms of confidence in communication and in feelings of well-being, though not on measures of impairment.

While taking the stance of a social model of disability, people who align to the sociological perspective to aphasia are of the opinion that aspects of aphasia cannot be viewed in terms of barriers alone, but rather that the actual disabling experience of the impairment itself needs to be taken into account. There are some activities that demand the use of language for their enjoyment – for example, the sheer joy one gets from being able to read a book or have a gossip. There is no doubt that a life-changing event such as the onset of aphasia brings with it an array of reactions including grief for what one has lost, anxiety about doing things and depression, to name but a few. This is taken into consideration in the range of services that Connect offers. For example there is a service provided by counsellors who themselves have experience of aphasia. In a counselling project undertaken by Ireland & Wooton (1996) fifty-six percent of participants found counselling beneficial overall.

Parr and Byng (2000) advocate taking the emphasis away from the priority of independence toward "facilitation of autonomy and choice" (p.64). Secondly, they highlight the need to consider interventions that focus on institutional, environmental

and societal changes and not just adaptations made by the individual, if one is to address the barriers encountered by people with aphasia in these contexts. Such an approach is in keeping with the social model of disability. Therefore there is a need to focus on the structures and social systems surrounding the individual that can either have an enabling or disabling effect.

In terms of assessing the person with aphasia, a sociological perspective advocates a qualitative approach, as well as the more traditional quantitative approach, to assessment so as to capture the lived experience of aphasia. As outlined earlier, Simmons-Mackie & Damico (1996a; 2001) propose the use of an ethnographic interview which is open ended and informant driven. The key to such an interview is really listening to the person's perspective with the primary goal of learning from them rather than thinking in terms of fixing. Brief encounters, telephone calls and other opportunities of learning more about the person are viewed as sources of data. This is the process that occurs at Connect, whereby each person with aphasia participates in an in-depth qualitative interview to determine the individual's concerns and priorities. If indicated other assessment procedures will be undertaken (e.g. visual analogue scales to determine mood, plotting oneself on the 'tree of life's, impairment based assessments) (Pound et al, 2000). McNeil (2001) criticises a sociological perspective for failing to use reliable and valid methods that can measure change as an effect of a specific intervention. In her response to McNeil, Duchan (2001) infers that such an approach to evaluation may not be appropriate for this type of work.

In their qualitative study of people with aphasia, Parr et al (1997) found that participants wanted their needs to be addressed in an integrated way and based on understanding the person as a complex social being rather than an isolated set of impairments. The view of the person as a complex social being living in an environment that does not necessarily value disability underpins the sociological

⁸ The 'tree of life' is a diagram of a tree with numerous figures on it in a wide variety of stances, for example clinging on to the trunk, sitting out on a branch all alone, together with someone else with

perspective. The importance of viewing the person in context is also taken up by Brumfitt (1999):

On meeting with a client we see a person with an individual identity but set in a family structure and influenced by other factors that arise out of growing older and experiencing good or bad health. We cannot therefore view the dysphasic speaker as nothing but a dysphasic speaker (...). Each client who we meet comes with a multidimensional set of views and experiences and we need to incorporate those into our professional perception of them. (p.108)

The sociological perspective differs from other perspectives in that people who align to it take the view that the person with aphasia is the expert and that the therapist takes on more of a role as facilitator or collaborator in the quest to live life healthily with aphasia.

This section has outlined the current perspectives of aphasia therapy. It began by outlining the impairment based cognitive neuropsychological and functional perspectives before moving on to discuss the psychosocial perspective and the more contemporary disability based sociological perspective.

The psychosocial and sociological perspectives take into consideration personal meanings of aphasia and explore how the person adapts and manages their situation of living life with aphasia. The following sections will address 'personal meanings of aphasia' and 'managing aphasia'.

2.4 PERSONAL MEANINGS OF APHASIA

Language and communication abilities are key skills that enable us to control our lives and go about our business. Parr *et al* (1997) highlight the important role that language plays:

language is the currency of relationships. It is used to invite, to suggest, to question, to advise, to argue, to reprimand, to bargain, to joke and to reassure. The changing needs and attitudes of each person are expressed and responded to, largely through the medium of language. As an obstacle to the sending and receiving of such messages, aphasia reduces the influence of one person in what was once a two-way process. (p.44)

arms around each other, falling off, being supported on a ledge, etc. It provides a useful means to gain insight into the lived experience of aphasia. It can also provide a useful outcome measure.

Language plays a privileged role in our society in that it mediates our ability to reveal competence through conversation (Kagan, 1995; 1998) and allows us to achieve recognition as an individual (Lemay, 1993). Thus there are high expectations of a person's ability to communicate clearly and with ease in a wide variety of speaking situations and the presence of an impairment of verbal communication, such as aphasia, is likely to influence how the person and others may approach, participate and behave in an interaction.

Goffman (1963/1990) states that "failure to sustain the many minor norms important in the etiquette of face-to-face communication can have a very pervasive effect upon the defaulter's acceptability in social situations." (p.154). Language has been cited as an "especially important trigger of evaluations and beliefs in initial impression contexts" (Bradac, 1990, p.387) and one of the main factors affecting such impressions is the adherence/non-adherence to valued norms (Bradac, 1990). The presence of aphasia affects a person's ability to communicate through both the spoken and written word and so may violate expectations about language behaviour. Such a situation may increase the risk of that individual being judged negatively with regard to their credibility and competency. Knowledge of such norms will affect the person's subjective evaluation of their situation and they will attach particular meanings to their aphasia linked to these expected norms. Those with an acquired impairment may have fully internalised the viewpoint of the 'normal' and may be particularly vulnerable to developing a 'disapproval of self' (Goffman, 1963/1990). According to Gainotti (1997) there is no direct relationship between the impairment and depression, rather, depression is "mediated by the meaning that the patient attributes to his or her functional and social impairment" (p.640). Therefore, among other things, it may be that the meaning that the person attributes to having aphasia - more than the impairment itself – is what affects social and mental well-being.

Many people with communication impairment frequently report that their impairment, and the responses of others to it, has a significant impact on their day to day life (e.g. Ireland & Black, 1992; Murphy, 1992; Cant, 1997; Newborn, 1997; Parr *et al*, 1997).

Factors such as others' embarrassment and attitudes may be more relevant to communication breakdown than the communication impairment itself (Mitchell & Preece, 1993). In writing about her experience of aphasia, Ireland (1995) highlights the influence of others' views and reactions when she says:

The scale of vulnerability and difficulties that are affected also by others' understanding and reactions and society's views of disability. (p.36)

Simmons-Mackie's ethnographic study of compensatory strategies in aphasia revealed that social factors were instrumental in both the acquisition and use of compensatory strategies and that strategies taught in therapy were not generalised into everyday life (Simmons, 1993; Simmons-Mackie & Damico, 1997). The personal meanings a person holds about what constitutes good communication skills may be one of the factors that determine the degree to which certain compensatory strategies are/are not carried over into everyday life. Obtrusive compensatory strategies may highlight the degree of 'differentness' in the person, which may account for why they are not used.

Personal meanings of aphasia are tied up with how one views the self. Language is more than a practical tool, it is an integral part of our personal identities (Létourneau, 1993) and speech is seen as a central part of the self concept (Brumfitt, 1993; 1999). Newborn (1997) writing about her experience of aphasia states:

Communicating in verbal language separates us from all other animals. This unique ability gives us shape and defines us. (p.33).

She goes on to say:

The stroke had emptied me of my own identity. (p.49).

Others link their ability to speak clearly and coherently with self-esteem (e.g. Cant, 1997; McCrum, 1998).

Therefore it is vital that we take into consideration the personal meanings that an individual attributes to their aphasia, as it is this that might be the defining quality in how they manage and adapt to their situation. Both the psychosocial and sociological

perspectives take this into account in the way in which they advocate the use of indepth qualitative interviews, as well as other methods, to access the personal experience of aphasia.

This section has touched on the literature available pertaining to personal meanings of aphasia. Other than the personal accounts of those with experience of aphasia (e.g. Ireland & Black, 1992; Ireland, 1995; Newborn, 1997; Boazman, 1999) there are no studies other than Parr *et al* (1997) that go into any depth about what it means to have aphasia. However it seems that the privileged role that language plays in our society plays a part in how aphasia is viewed and experienced. The next section will briefly explore issues surrounding managing aphasia.

2.5 MANAGING APHASIA

The majority of individuals who experience aphasia following brain injury have to learn to integrate it into their lives in the long term. This section will discuss in brief managing a chronic illness, before going on to address issues such as stigma, depression and the carer's perspective. Finally it will outline some studies that have focused on coping with aphasia.

2.5.1 Managing Chronic Illness

If illness is of sudden onset, as is the usual case in aphasia, then the person's sense of continuity may 'completely unravel' as it brings with it a sudden shift in one's perception of one's body and self (Becker, 1999). Therefore any acute illness with chronic sequalae such as stroke brings with it a number of challenges for the individual and their family (i.e. losses, disruptions to future plans, etc.). The way in which the individual copes with it is influenced by such things as the society and culture within which she/he lives (Anderson & Bury, 1988). For example western culture tends not to value embodied distress and values the person's ability to put on a 'brave face' (Becker, 1999). Bury (1988) proposes two levels of meaning experienced in chronic illness: 'meaning as consequence' (i.e. the impact on day to day life) and 'meaning as significance' (i.e. the significance that having aphasia and being disabled

carries). Therefore a chronic illness, of which aphasia may be a part, is not just about the symptoms of that condition, but rather it is about living with those symptoms and what the condition means in terms of consequence and significance. He suggests that family, social and other relationships are threatened as a result of meanings being put at risk in chronic illness. In a later paper Bury (1991) explores the role that 'disrupted biographies' (i.e. the interaction of the chronic illness with the age of the individual and his/her position in the 'life course') plays in the meaning of the illness and the context in which it occurs.

Differences in preferred coping strategies were explored in a study by Viney & Westbrook (1984). They found that those who did not have a chronic illness tended to prefer "interpersonal" coping strategies, while those with a chronic illness tended to use "fatalism" coping strategies. In general it was found that responses to chronic illness are diverse. Restriction in social life has been found to be the most significant contribution to the feeling that life is less enjoyable in stroke patients and their carers and this was influenced by the quality of the relationship prior to the stroke (Anderson, 1988). Due to the nature of the impairment, people with aphasia are particularly vulnerable to a restricted social life as aphasia is inherently isolating (Newborn, 1997). Past events and pre-illness relationships played a role in how people with rheumatoid arthritis coped with their condition (Bury, 1988) and social isolation was found to be the most distressing feature in Parkinson's disease (Pinder, 1988). Robinson (1988) highlighted that there is no standard adjustment process when one has Multiple Sclerosis. Anderson and Bury (1988) stress the importance that we need to recognise the complexity of coping. Parr et al (1997) also highlight the complexity of coping with aphasia.

2.5.2 Aphasia as Stigma

An attribute that reduces the person from "a whole and usual person to a tainted discounted one" is known as a stigma (Goffman, 1963/1990, p.12). Therefore stigma is associated with those attributes that are incongruous with our stereotype of what a given individual should be. Communicating differently to the norm could therefore

count as stigma and this is particularly pertinent given that language plays a privileged role in our society, as it "enables one to carve out one's place in society, and to achieve recognition as an individual" (Lemay, 1993, p.201). Thus stigma may play a key role in coping with chronic illness (Anderson & Bury, 1988), and with aphasia in particular (Herrmann & Wallesch, 1990; Sarno, 1993). People with aphasia have fewer opportunities to participate in conversations as a result and this may lead to "profound psychosocial consequences for mental and social health" (Kagan, 1995, p.17). The level of anxiety in individuals with aphasia has been found to be related to the severity of aphasia (Pachalska, Knapik, Smolak & Pytel, 1987).

2.5.3 Depression in Aphasia

Aphasia is an upheaval that profoundly affects the whole person. Its severity should not be underestimated. The psychological problems stem from the privileged role of language in our society and the key role language plays in the definition of the personality and human identity. (Létourneau, 1993, p.84)

Out of all the psychological problems that accompany aphasia depression is the most frequently reported one. It has been found that fifty percent of people with left sided brain lesions are depressed (Währborg, 1991). The effect of aphasia on communication means there is a sudden loss or interruption to interactions and the impact of this loss is depression (Létourneau, 1993). Herrmann, Johannsen-Horbach and Wallesch (1993) identified three types of depression in people with aphasia:

- i. Primary depression which is organic and is a consequence of the lesion and the biochemical changes that occur early post-stroke (i.e. the acute phase).
- ii. Secondary depression which is reactive in that it is a result of the realisation of functional limitations brought about by the impairment (i.e. the rehabilitation phase).
- iii. Tertiary depression which is also reactive but is a result of the realisation of the psychosocial alterations in life in terms of returning to the community living with the limitations produced by lasting impairment. Létourneau (1993) contends that depression may actually increase when the person with aphasia is confronted with her/his previous way of life (i.e. on returning home).

A person's emotional state can affect motivation, physical performance and cognitive and language processing (Hemsley & Code, 1996). Therefore the presence of depression can affect the person's ability to participate in rehabilitation. Counselling has been found to be effective in dealing with depression and other psychosocial factors associated with aphasia (Ireland & Wooton, 1996). Similarly emotional and social isolation as well as depression have been found to diminish with family therapy (Währborg & Borenstein, 1989). In addition it has been noted that depression tends to decrease as adaptation increases (Létourneau, 1993).

2.5.4 The Family's Perspective

The sudden loss of the usual ability to communicate, as with the onset of aphasia, affects nearly all aspects of life but particularly the interactions within the family (Boisclair-Papillon, 1993; Parr *et al*, 1997; Cant, 1999; Servaes, Draper, Conroy & Bowring, 1999; Wells, 1999; Lyon & Shadden, 2001; Pound *et al*, 2001).

Of all known illnesses, aphasia is probably the one which affects the family most directly. Because of the abrupt, unexpected, and often permanent damage to communication, the entire network of family interaction is disturbed. (Boisclair-Papillon, 1993, p.175)

In their qualitative study to explore the consequences of severe aphasia on spouses, Michallet, Tétreault and Le Dorze (2003) found that context played a vital role. Particular personal, family and social resources of each individual determined how they dealt with the situation. However in general the consequences of aphasia were experienced in the lifestyle realms of communication, interpersonal relationships, responsibilities, leisure activities and finances as well as feelings of isolation being common. Spouses referred to fatigue, sadness and discouragement in their efforts to try to adapt to living with someone with severe aphasia.

Out of the papers that Servaes et al (1999) reviewed, most concluded that carers of people with aphasia experience more difficulties than carers of people who have had a stroke but who do not have aphasia. Family members most frequently cited communication and role changes as problems. Other problems experienced by close relatives included feelings of guilt, depression, anxiety, stress and overprotection as

well as feelings of isolation and lack of companionship. Pound *et al* (2000) highlight that the cultural expectations of caregivers is that they should be tolerant, uncomplaining, dedicated and self-sacrificing. Such a situation can leave little room for families to express such things as anger, guilt and resentment which have been found to be part of the process of living with someone with aphasia. It has been suggested that facilitated discussion may allow these powerful emotions to emerge and so address their lack of acceptability. This may be a "first step to validating the caregiver as an individual" (Pound *et al*, 2000, p.216).

Servaes et al (1999) advocated three main approaches to working with relatives of people with aphasia: educational programmes, group and individual counselling and skill training. Speech and language therapists have long been aware of the needs of the immediate family and have responded along these lines. For example, they have responded by providing information (Parr et al, 1997; Pound et al, 2000), by focusing on skills training (Kagan, 1998; Lock et al, 2001; Cunningham & Ward, 2003), by running support groups (Rice, Paull & Müller, 1987; Pound et al, 2001) and by providing counselling and family therapy (Währborg & Borenstein, 1989; Nichols et al, 1996).

Approaches such as those outlined by Servaes *et al* (1999) tend to be medically oriented in that they view the relative of the person with aphasia as a 'patient' whereby the professional assesses the needs and then selects and delivers the appropriate programme to meet those needs. An alternative approach which emphasises an equal partnership between the relative and professional has been proposed by Pound *et al* (2001). This perspective is based on Byng *et al's* (2000) living with aphasia framework which highlights the complexity of living with aphasia as well as the notion that partners need to 'create meaning in a chaotic world' (Becker, 1999). Pound *et al* (2001) used this model in the design of their support group for spouses of people with aphasia. They based the course on the autobiographical accounts of participants and found that following the course participants reported positive changes in well-being. Similarly research carried out at the York-Durham

Aphasia Centre in Canada has demonstrated that intervention in a community setting improves the psychosocial well-being of both people with aphasia and their relatives (Wells, 1999).

While a variety of approaches have been undertaken with relatives of people with aphasia it is important, as Pound *et al* (2001) suggest, that the approach taken should meet the immediate concerns of the individual. The type of psychosocial support needed by relatives may change with time (Herrmann and Wallesch, 1999).

The review above highlights how the consequences of aphasia extend into all realms of life, particularly family life. Those close to the person with aphasia experience reactions to it which affect feelings of well-being. Speech and language therapists, as well as other professionals, are exploring ways to address these issues.

2.5.5 Coping with Aphasia

Parr (1994) has highlighted the importance of enabling the person with aphasia to integrate the effects of the aphasia and its impact on her/his situation so that she/he can begin to attach meaning to their condition. She goes on to state that exploring how people cope is a "necessary precursor to the establishment of therapeutic goals" (p.465). Kagan (1995; 1998) believes that adaptation to aphasia is facilitated by others revealing the person's competence through conversation. Prigatano (1989) proposes that the three symbols of 'normality' (love, work and play) should be taken into account in the rehabilitation process if the individual is to cope with the true realities of her/his condition and to achieve a sense of wholeness.

Only a few studies have been undertaken that specifically explore how people cope with aphasia. Oranen, Sihvonen, Aysto & Hagfors (1987) looked at changes in the lives of family members from the spouse's perspective, families' coping mechanisms and adjustment to aphasia. They found five main coping patterns – depression, nervousness, optimism, protectiveness and guilt. These tended to be associated with the life situation of the person with aphasia at the time, which lends support to the role

of Bury's (1991) notion of 'disrupted biographies' in coping with a chronic condition. For example, Oranen *et al* (1987) found that the best adjusted families tended to have an optimistic coping pattern, that they were younger and that the aphasia was of recent onset. The least well adjusted families on the other hand tended to have a depressive coping pattern. Other studies have found that coping responses to aphasia are diverse (e.g. Parr, 1994; LeDorze & Brassard, 1995). Parr (1994) investigated how twenty people with aphasia and their partners coped with aphasia and found that life satisfaction had deteriorated in 55% of them. The main reasons given for deterioration were physical, material, social and emotional factors. All respondents used a combination of strategies to cope, with fatalism being the most common.

This section has outlined issues surrounding how to manage aphasia in day to day life. Little specific information is available but what is available highlights the complexity of managing aphasia in day to day life.

2.6 SUMMARY

This review began by discussing definitions of aphasia. It then presented the historical origins of aphasiology in which the impairment of aphasia and where it was localised in the brain was emphasised. More contemporary perspectives still take account of the impairment particularly in focusing on how language processing is compromised in aphasia. However other aspects of aphasia have been the centre of attention in recent times. The functional perspective of the 1980s and early 1990s stresses the importance of getting the message across regardless of means. The psychosocial perspective, on the other hand, focuses on the psychological and social consequences of aphasia and, in particular, on issues surrounding emotional state brought about by the onset of and experience of living with aphasia.

All of these perspectives tend to highlight the impairment or the consequences of the impairment in day to day life. None deal with the obstacles in society that might increase the experience of disability for the person concerned; for example, the patronising attitude of a conversational partner may not allow the opportunity for the

person with aphasia to communicate what they want to say. The contemporary sociological perspective takes disabling barriers into account and stresses the importance of supported conversation to acknowledge and reveal competence. The review then went on to present issues surrounding personal meanings of aphasia and managing aphasia in particular.

However none of the perspectives go into depth about the way a person thinks about communication impairment that might, as in the case of John introduced in Chapter One, impede the person's ability to live life healthily with aphasia. I was interested in this aspect of aphasia. I wanted to find out about the resources (in the form of narratives) that people, both those with aphasia and their conversation partners, draw on to make sense of aphasia and manage it in day-to-day life. To put it in another way: in what way(s) do people think about and experience aphasia and how does this affect behaviour? This is what this study aims to explore. O'Keefe (1996) calls for an increased awareness and knowledge about the way in which conversation partners communicate interactively with the person with communication impairment and how they are perceived overall. The sociological perspective is beginning to shed some light on this. For example Kagan's work (Kagan & Gailey, 1993; Kagan, 1995; 1998) addresses issues surrounding revealing and acknowledging competence when communicating with someone with aphasia. However less has been done on addressing how the person with aphasia is perceived overall. This study aims to explore this in terms of focusing on narratives of aphasia and disability from the perspective of the person with aphasia and others close to her/him. In this way it will contribute to our knowledge of aphasia and in particular the psychosocial and sociological perspectives.

I wondered how other disciplines have addressed issues of personal meaning in the context of disability and this led me to explore the disability literature. The next chapter therefore provides a review of issues surrounding disability.

CHAPTER 3 LITERATURE REVIEW: DISABILITY

I don't know rubbish leleleblublublub but you see in my mind and I hear that ok and take a take it slowly you know now the words blublublublublub and what's that you know [confused facial expression] (...) I don't know mad [taps index finger to temple] you know but why but er for me you know er double-dutch now (...) yea but er me em gobbledegook (Tom, November 2000)⁹

Tom seems to be saying that he knows what he wants to say in his mind, but that when he goes to speak it comes out "double-dutch". He is of the opinion that either he thinks he is mad or that other people do. Like John in Chapter One, Tom connects the ability to talk clearly and fluently with intelligence. Later on in the discussion he talked about the impact this has for him and others:

Just say on the pub and er one Heineken and er one cider and och [laughs] what yea? and em er God embarrassed because er look around- what the er my speech you know gobbledegook you know (Tom, November 2000)

Tom: But see the barman er what? [questioning facial expression] you know nudge nudge what's the is you know or is he drunk as skunk you know

Rozanne: Why do you think they react like that?

Tom: I think they're scared

Rozanne: Scared- and what do you think they're scared of?

Tom: No because er my speech you know oh God the- you know I don't know er make understand it you know

The extracts given above give some indication of the impairment of aphasia and the disabling experience of it from the perspective of one person who has been living with aphasia for a number of years. Tom feels others may judge him as being drunk and he believes that they react like this because of his speech and that they are "scared". What he is experiencing is a reaction to being different, a reaction that brings with it uncertainty about how the interaction will progress and how he will be judged. People come to an encounter with the expectation that the other person will be able to speak clearly and fluently and when this expectation is denied reactions – usually negative – occur. To Tom this is what it means to be disabled. It is to the issue of the relationship between impairment and disability that I now turn.

⁹ Please refer to Appendix 1 for transcription conventions.

The publicly available definition of disability can be found in the Collins Concise Dictionary (Revised third edition, 1995) which defines disability as "the condition of being physically or mentally impaired". According to disability activists this is an oversimplistic and misleading view of disability as it locates the cause of disability as the impairment.

Barnes, Mercer and Shakespeare (1999) define impairment as a "medically classified condition" (p.7) and disability as a "generic term used to denote the social disadvantage experienced by people with an accredited impairment" (p.7). Others have described disability in similar terms, for example:

Disability is not a condition of the individual. The experiences of disabled people are of social restrictions in the world around them, not of being a person with a 'disabling condition'; rather it is to assert that the individual's experience of 'disability' is created in interactions with a physical and social world designed for non-disabled living. (Swain, Finkelstein, French & Oliver, 1993, p.2)

To be disabled means to be discriminated against. It involves social isolation and restriction. Disability is a significant means of social differentiation in modern societies. (...) How a society excludes particular groups or individuals involves processes of categorisation in which the inabilities, and the unacceptable and inferior aspects of a person are generated and legitimated. (Barton, 1996a, p.13)

Compared to the dictionary's definition of disability, Swain *et al* (1993) and Barton's (1996a) descriptions are more sophisticated and political in that they locate the cause of disability as socially imposed restrictions.

There is much debate in the literature about what disability means. This debate and the issues surrounding disability are the focus of this chapter. I outline the two main models of disability: the individual model¹⁰ and the social model¹¹. Issues are also discussed in the context of the International Classification of Functioning, Disability and Health (ICF) proposed by the World Health Organisation (WHO, 2001), formerly known as the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980). Finally, I attempt to make links between models of disability and narrative.

¹⁰ Also known as the medical or biomedical model.

¹¹ Also known as the social barriers model.

3.1 BACKGROUND

In the past people with impairments have been the object of fascination, entertainment and ridicule (i.e. freak show, court jester). It was not until the nineteenth century that the emergence of disability in its present form occurred. The rise of scientific medicine saw the beginnings of the medicalisation of illness and disability which led to a shift in how disabled people were treated (Barnes *et al*, 1999).

The emergence of modern biomedicine came about with the achievements of people such as Pasteur (1822-1895), who discovered causes of disease. Up until the middle to the end of the nineteenth century most approaches to medicine were holistic and were based on a sociological and environmental understanding of disease causation and prevention (Nettleton, 1995; Tucker, 1997). However from the 1850's on this holistic approach was gradually marginalised and replaced by a "narrow focus on specific pathogens – the doctrine of specific aetiology" (Tucker, 1997 p.35). This reductionist focus is central to modern medicine, though in recent times there has been a growing interest, even within the medical field, of more holistic approaches.

According to Nettleton (1995) modern biomedicine has five main assumptions:

- i. There is mind-body dualism in that there is the assumption that these can be treated separately.
- ii. It uses a mechanical metaphor in that it treats the body as a machine that can be repaired.
- iii. There is a technological imperative in that there is an assumption of the merits of technology.
- iv. It is reductionist in that there is an assumption that explanations of diseases lie in biological change, while virtually neglecting social and psychological factors.
- v. There is a doctrine of specific aetiology in that there is an assumption that each disease is caused by an identifiable agent.

This narrative¹² of biomedicine has been flourishing since the late nineteenth century and is a guiding narrative in our society today. Its emergence coincided with the industrial revolution of the late eighteenth and early nineteenth centuries which had a significant impact on the lives of disabled people. In pre-industrialisation times agricultural and cottage industry did not preclude people with impairments from participation in production. However with the industrial revolution production was centred in factories which demanded dexterity and speed. This precluded the involvement of people with impairments (Oliver, 1993a; Barnes, 1996a). Industrialisation saw the development of poor houses and houses of correction, and people with impairments were then admitted to these institutions, thus leading to segregation. Doctors then took over the running of the institutions and so took control of people with impairments. Such individualisation of social problems gave rise to the individualistic medical approach to disability (Barnes, 1996a). Thus the individual model of disability was born.

3.2 INDIVIDUAL MODEL OF DISABILITY

According to Barnes et al (1999) "the central thrust of the individual model is to cast disability as a personal tragedy where the individual concerned must depend on others for support" (p.27). The medicalisation of disability represented the establishment of an individual model of disability. The central tenet of this model is that the impairment causes disability and that the more severe the impairment the greater the disability (Corker, 1996). The social model, on the other hand, proposes that the cause of disability is the disabling barriers within society. The individual model has evolved to encompass disability in terms of individual responsibility; it is up to the person with the impairment to adapt to their immediate environment (Swain et al, 1993; Barton, 1996; Hales, 1996; Rioux, 1996). Disability is viewed in personal tragedy terms, that the defining feature of the individual is their disability and that she/he is regarded as a victim and as someone who needs care and attention (Barnes et al, 1999). Language

¹² Narrative in this instance means the stories or ways of thinking that one lives by in order to make sense of experience (Somers 1994) as opposed to a narrative involving characters, events and plots (Labov, 1981)

that defines a person in terms of their impairment or disability devalues their social self and damages their private self (Phillips, 1990). The individual model only views the person in medical and individual terms (Barton, 1993).

3.2.1 'Normalisation'

The thrust of the philosophy underpinning the individual model is to cure and 'normalise' and thus it affirms the extraordinariness of being disabled (Finkelstein, 1998). Illness and disability are about learning to live with loss of control and society expects that the person attempts to regain control and, if this is not possible, to conceal the loss of control as effectively as possible (Frank, 1995). Therefore there is a public expectation that the person with an impairment will act in such a way as to minimise their difference.

The social reality of disability is that there is a tendency to elicit feelings of discomfort, confusion and even resentment, especially toward those who resist normalisation (Phillips, 1990). The idea of 'normality' is tied up with notions about "what is right, what is desirable and what belongs" (Morris, 1991 p.16). People with acquired impairments usually carry these public notions or narratives with them when they become disabled. This leads to a desire to return to the previous non-disabled state as this is what is 'right and desirable'. There is an assumption and expectation among non-disabled people and those with acquired disability that disabled people want to be 'normal' (Morris, 1991). Goffman (1963/1990) noted that the stigmatised individual has lost her/his 'wholeness' in the eyes of society. It is this 'wholeness' that people want to regain. This view of wanting to be seen as 'normal' is supported by Marr's (1991) qualitative study of people with Parkinson's Disease in which she found that they engaged in activities that would make them feel as 'normal' as possible. Also Nijhof's (2002) study found that participants, again with Parkinson's Disease, spoke in terms of shame brought about by their assumed rule breaking and fear of being judged deviant. It was shame that discouraged them from appearing in public.

With disability becoming the domain of medicine there followed the development of new medical specialisms (i.e. rehabilitation physicians) and other professionals (e.g. therapists) began to appear whose job it was to rehabilitate disabled people and to 'normalise' the disabling consequences of impairment (Barnes *et al*, 1999). Their goal was to identify ways to help disabled people fit in with 'normal' life so that they did not become a burden on the rest of society. The onus was on the person with the impairment to adapt. Phillips (1990) found that society believes that disabled people should try harder to overcome obstacles. However it is recognised that in rehabilitation there is more of an active collaboration between therapist and 'patient' than is the norm in biomedicine, as 'patients' are very much involved in their own recovery (Mattingly, 1998). Disability is about experience and cannot be separated from the person.

This notion of normalisation is also evident in the many charities *for* people with disabilities whose underpinning philosophy is the restoration to 'normal' or as near to 'normal' as possible. This is in contrast to charities *of* people with disabilities whose underpinning philosophy is to do with issues surrounding the rights of disabled people who live in a society where disability and difference are not valued.

However this is only one view of normalisation, Brechin and Swain (1988), drawing on their work with people with learning difficulties, propose that there are a number of interpretations. They outline the following approaches to normalisation:

- i. The most common interpretation is the one just outlined whereby one takes it to be about normalising people (i.e. making people as normal as possible). In this interpretation normalisation is about professional practices that are designed to change the individual. This is at odds with an approach, such as in the self-advocacy movement, which values the person for who she/he is.
- to view people with learning difficulties as people who live an ordinary life. A life where they are seen to live in ordinary homes, travel in ordinary vehicles, wear attractive clothes and so on as well as be seen to have appropriate valued roles in society. However the danger of this interpretation is that, in market

terms, the packaging becomes more important than the product (i.e. in this case the person). Therefore in this view the image is the key factor. This interpretation then can make it difficult for the person to be as she/he wishes as they are encouraged to comply with a particular value system in order to gain acceptance. "Normalisation in this sense begins to sound like superimposing a currently fashionable veneer without any attention to the detail of what lies underneath" (Brechin & Swain, 1988, p.220). With this interpretation the goal of therapy is to work with the individual to make her/him as socially acceptable as possible. Like with the previous interpretation of normalisation, this interpretation is in danger of loosing sight of the individual.

iii. Brechin and Swain's (1988) preferred interpretation of normalisation is one which "focuses on opening up a range of life-style opportunities which are available to the rest of the population but which have tended to be closed to people with learning difficulties" (p.221). While admitting that there are some inherent problems in a concept that desires normality, Brechin and Swain contend that if it is used to stimulate a move away from commonly experienced deprivations and restrictions towards a range of life-styles and service provisions that are viewed as more desirable and more valued in society then normalisation can offer a breakthrough in how one works with people with learning difficulties. "Such an emphasis shifts the focus away from modifying or repackaging the individual, onto a concern to minimise the restrictiveness of opportunities" (Brechin & Swain, 1988, p.221). This interpretation of normalisation as well as being more at one with the philosophy of the selfadvocacy movement, promotes a working alliance between the person with learning difficulties and the professional.

While there are a number of views of normalisation, the one that takes it to be about 'normalising' people so that they will fit in with the rest of society is the most evident in the field of acquired disability.

3.2.2 Other Cultural Views of Disability

In western societies disability is viewed at a biological level, but not all cultures view it in this way (Banja, 1996). For example the Hmong view epilepsy as an illness with some distinction and as an honour bestowed on the individual, making that person special (Fadiman, 1997). The Navajo in North America do not view disabled people as incompetent, but rather define them by their unique traits (Connors & Donnellan, 1993). Similarly the Masai in Kenya do not stigmatise impairment in that the traditional community organisation of Masai society ensures that impairment is not a major obstacle to activity (Barnes *et al*, 1999). There have been one or two examples of impairment bringing social benefits in western society. For example, Oliver (1996b) and Quinn (1998) cite the community in Martha's Vineyard and its pervasive use of sign language in the seventeenth to twentieth centuries to accommodate the large population of deaf people on the island, with the result that both deaf and non-deaf people in the community did not experience disability. However in general, modern western culture views disability as tragedy and disabled people are responded to by non-disabled people as victims of a tragic event (Hughes, 2002).

This dominance of the biomedical view in western society is strong and is reflected in how many people with impairments view their situation in personal tragedy terms. For example, McCrum (1998) views his stroke as a "calamity" and an "affliction". While this view may be the case in many instances, particularly of those with acquired disability, strong counter views of disability are emerging which reflect disability in more positive terms. The disability rights movement has been responsible for many of these counter narratives.

3.2.3 Criticisms of the Individual Model

There have been many critics of the individual model of disability, particularly from disabled people themselves. Oliver (1996b), a disabled writer and activist, says:

There are two fundamental points that need to be made about the individual model of disability. Firstly, it locates the 'problem' of disability within the individual and secondly it sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability. These two points are underpinned by what might be called 'the personal tragedy theory of disability' which suggests that disability is some terrible chance event

which occurs at random to unfortunate individuals. Of course nothing could be further from the truth. (p.32)

It was the emergence of counter views of disability and the contemporary post-modern society in which heterogeneity is celebrated that gave rise to the social model of disability. "Disabled people have challenged prejudice with pride" (Hughes, 2002, p.578).

3.3 SOCIAL MODEL OF DISABILITY

In the UK the seeds of the modern disability rights movement were sewn at the very end of the nineteenth century when organisations controlled by disabled people came into being – for example, the British Deaf Association and the National League of the Blind (Hasler, 1993). However it was not until the 1970s and 1980s that disabled activists really started to voice concern about the individual model of disability. These debates led to the birth of the social model of disability which demanded societal change to adapt to the person with the impairment, rather than the onus being on the person to adapt. The emphasis was on the notion that it was the environment that disabled people with impairments rather than the impairment alone. In his seminal paper Brisenden (1986), himself disabled, comments:

On the whole, it is the organisation of society, its material construction and the attitudes of individuals within it, that results in certain people being *dis*-abled. We are only people with different abilities and requirements, yet we are disabled by a society that is geared to the needs of those who can walk, have perfect sight and hearing, can speak distinctly, and are intellectually dexterous. (p.175-176, emphasis in the original)

Therefore the focus of the social model is on oppression of people with impairments due to society being structured around non-disabled human activities.

3.3.1 Disability as a Social Construction

It was in 1976 at a UPIAS (Union of the Physically Impaired Against Segregation) meeting that a formal statement about disability was developed. The statement read as follows:

In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from

full participation in society. Disabled people are therefore an oppressed group in society. (cited in Oliver, 1996b, p.33)

This was later extended to include sensory and intellectual impairments. Finkelstein and French (1993) redefined impairment and disability within social model terms.

Impairment is the lack of part of or all of a limb, or having a defective limb, organ or mechanism of the body. (p.28)

Disability is the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers. (p.28)

The disability rights movement has focused on 'de-biologisation of disability' (Hevey, 1993a) by a focus away from individual responsibility toward societal responsibility. It highlights the barriers within society that have a disabling effect on people with impairments. In terms of speech and language therapy the social model provides a new way of looking at disability and our work with people with communication impairments such as aphasia. It forces us to identify barriers to communication within a person's immediate and extended social environments. Many of the barriers faced by people with aphasia are compounded in the modern era of telecommunications – for example, the increase in purchasing items online, the increase in the use of elaborate menus of voice message systems. There is an increasing emphasis on dismantling barriers and increasing participation in our work (e.g. Kagan, 1995, 1998; Lyon et al, 1997; Pound et al, 2000) and such a focus has been influenced by the social model of disability. The social model of disability goes beyond the focus on loss and adjustment.

The media can exert a powerful influence on social attitudes and behaviour and so this shift to social model thinking is also reflected in the disability arts movement which is one of the first signs of a post-tragedy disability culture (Hevey, 1993b). This has come in the form of theatre companies, dance companies and visual arts. People with aphasia are also contributing to the arts in the form of poetry (Pound *et al*, 2000; Ireland & Pound, 2003; Pound, in press). This movement has challenged the traditional view of disability in the media as being of personal misfortune and in need of care. Thus a disability culture has grown, and continues to grow, which produces new ways of thinking about disability that are more positive and which do not cast the disabled

person as victim in need of care or hero bravely undertaking the struggle to be 'normal'. The arts can help redefine disability by adding a different text or context around the impairment (Hevey, 1993a).

Participants in Phillips' (1990) qualitative study involving people with disabilities recounted the liberating effect that philosophies, which promoted their social minority status rather than their deviance, had on their self-image.

3.3.2 Disability Rights Movement in the USA

The disability rights movement in the USA was influenced by the civil rights movement of the 1950s which focused on the struggles of African American people. These rights were eventually achieved and the movement then became concerned with social rights generally and had influence on other groups such as women and now disabled people (Oliver, 1996b). These groups used similar methods (e.g. demonstrations) to achieve equal rights. However disability politics only really began to flourish in the US in the 1960s with the revitalisation of the woman's movement, the movement against the Vietnam War and the gay and lesbian movement (Malhotra, 2001).

The Independent Living (IL) movement began in the late 1960s when a group of students at Berkeley, California, known as the Rolling Quads sought to promote the empowerment of disabled people by organising a class called 'strategies for independent living' (Morris, 1991; Russell & Malhorta, 2002). The group focused on structural barriers within the environment rather than on the impairment of individuals. By 1972 the first Independent Living Centre (ILC), based on the social-political model of disablement, was founded in Berkeley. Within a few years Independent Living Centres had developed across the states as well as in a number of other countries (e.g. the UK, Canada, Brazil) (Russell & Malhorta, 2002). Partly as a result of the Independent Living movement the character of the home residential care service in the US changed away from the vast majority of disabled people living in large congregate care facilities to living in smaller settings. However although the congregate care

system had reduced in capacity it still received consistent levels of funds. Therefore more funds were substantially supporting fewer people. It is recognised that there is a need to strengthen the individual and family support systems and that this requires additional funding (Braddock & Fujiura, 1991).

In the UK and Ireland there are now a number of Independent Living Centres whereby appropriate housing and personal and other support services necessary for independent living are provided. Such centres are not underpinned by the individual or medical model of care but rather a social model philosophy dominates which promotes the empowerment of disabled people and which emphasises that disabled people are experts in disability (Morris, 1991). Therefore the Independent Living movement has provided the basis for a vital social movement by redefining what most people regard as private troubles as political issues.

The Vietnam War Veterans movement also helped to get disability rights issues on to a political platform by ensuring that funding was available to care for the injuries, illnesses and disabilities sustained in the course of action. This was seen as a national obligation (Vietnam Veterans of America, 2003). Vietnam War Veterans demonstrated to ensure realisation of these rights.

Many disabled people joined with the Vietnam War Veterans in their struggle for civil rights and became more militant. In 1970 Disability in Action was founded. This organisation adopted the tactic of direct political protest. In 1972 during the presidential election, militants from Disability in Action demanded an on camera debate with President Nixon (Malhorta, 2001). This was followed in 1973 by congress passing the Rehabilitation Act. Section 504 of this act made it illegal for any disabled person to 'be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance' (cited Hahn, n.d.). However this legislation was only signed in 1977 following massive demonstrations by disabled activists (Hahn, n.d.; Oliver, 1996b). Later in 1990 the Americans with Disabilities Act (ADA) was passed. This act

extended the Rehabilitation Act to include other areas and not just federally funded schemes. Again this legislation was only signed following mass demonstrations by disabled people (Oliver, 1996b). While this act resulted in real improvements in physical access, it places the onus on the person to make complaints and allows employers and businesses lengthy 'phase in' periods during which they are exempt from compliance. Therefore despite the ADA disabled people in America continue to remain largely outside the workforce (Malhorta, 2001).

3.3.3 Self-Advocacy Movement

The focus on self-advocacy with people with learning difficulties constitutes a "thriving sociocultural and political movement" (Goodley, Armstrong, Sutherland & Laurie, 2003, p.157). This movement is underpinned by a social model of disability and probably began in Sweden during the 1960s where people with learning difficulties were supported to form and lead their own leisure clubs (Shoultz, n.d.). Later at national conferences for members of these clubs, participants developed statements about how they wanted to be treated. By 1972 the idea had spread to the UK and North America. Around this time a group of people with learning difficulties from Oregon attended a conference in Canada. This conference purported to be for people with learning difficulties yet was dominated by professionals. The group from Oregon were unhappy about this and on their return home they formed a self-advocacy group calling themselves People First (Shoultz, n.d.). People First groups are now flourishing around the world. The movement has done much to highlight the rights of people with learning difficulties. For example the aims of the Central England People First Organisation (2001) include: to help people with learning difficulties to speak up for themselves, with support if required; to inform people about the concerns and needs of people with learning difficulties; to make sure that people with learning difficulties know about their rights; and to make sure that people with learning difficulties are involved in the planning and development of the services they receive. Other People First organisations have similar aims (e.g. People First Lambeth, n.d.; Self-Advocacy Sydney Inc., n.d.). All groups highlight that people with learning difficulties are "individuals with the same human value and rights as everyone else" (People First Lambeth, n.d.).

People with learning difficulties who take up the active role of self-advocate challenge society's understanding of disability (i.e. that people with learning difficulties only play a passive role). Facilitating the self-determination of self-advocates is at odds with an individual or medical model approach, rather it feeds into the political aims of the social model (Goodley, 1998). Self-advocacy and People First groups are an important development for the opportunity they offer to develop "the confidence of individuals and groups to enable them to speak out for human rights and challenge oppression in a disabling society" (Goodley *et al*, 2003, p.149). Through shared action planning (i.e. a plan which is created by an adult with learning difficulties working in partnership with a supporter) the balance of power is gradually shifting from professionals to adults with learning difficulties (Sutcliffe & Simons, 1993).

3.3.4 Criticisms of the Social Model

While the social model has been welcomed by many people with disabilities in the way in which it promotes a different view of disability as compared to the individual model, there have been a number of criticisms of it in the disability literature. For example a number of writers (e.g. Morris, 1991; French, 1993a; Shakespeare, 1994; Abberley, 1996; Hughes & Paterson, 1997; Corker & French, 1999; Thomas, 1999a) argue that the experience of the impairment is neglected in the experience of disability and for locating it solely within society. French (1993a) highlights that some problems associated with an impairment may be difficult to solve by social manipulation alone, yet they contribute to the experience of disability. As an example she outlines her own experience of being visually impaired and being unable to judge people's reactions to what she is saying, so that she has difficulty in making the appropriate repairs. Similarly Parr et al (1997) comment how the impairment of aphasia can be disabling in itself, for example, not being able to experience the joy of reading or having a gossip. The social model needs to account more for the experience of the impairment itself and one cannot separate the two - "disability therefore is experienced from the perspective of impairment" (Hughes & Paterson, 1997, p.335). Shakespeare (1994) states that a social model of disability should seek to explore, not ignore, the individual experience of impairment. The present study addresses this issue as it seeks to explore how people with aphasia make sense of their impairment and manage it in day to day life.

The social model of disability has also been criticised on grounds of not meeting the needs of certain groups of society, for example those with learning difficulties (Chappell, 1998), those who are deaf (Corker, 1998) and those with aphasia (Parr et al, 1997). The social model has been developed by articulate individuals, usually with physical or sensory impairments, debating and writing about issues surrounding disability. The vehicle they use to promote disability issues is language, which by its very nature excludes those who have particular difficulties in language (i.e. those who have aphasia, those who have learning difficulties). This is supported by Corker's (1998) comment that the disabled people who are most marginalised from the disability rights movement are those groups for whom language is critical in some way. The written word excludes people with learning difficulties as much as steps exclude those with a physical impairment (Walmsley, 1994). The same could be said of people with aphasia.

Initially in the development of the social model there was a focus on the structural dimension of disability, but Thomas (1999a) highlights how such a restricted focus fails to consider the emotional consequences of disability. She proposed an extended social relational understanding of disability to include both the structural and psychoemotional dimensions of disability, and redefines disability as follows:

disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being. (p.3 & p.156)

She describes the psycho-emotional dimension of disablism as the socially imposed restrictions which operate to shape "personal identity, subjectivity or the landscapes of our interior worlds" (p.46). Thomas believes that there are social barriers that place limits on psycho-emotional well-being – for example, feeling hurt by the reactions of others, being made to feel worthless – all of which might make the person avoid going out. One person with aphasia reported to me how others' reactions made him feel like

"never saying anything again", suggesting a barrier to psycho-emotional well-being. A social model of disability that encompasses both the structural and psycho-emotional dimensions of disability, as suggested by Thomas (1999a), acknowledges the personal experience of living with disability and impairment from a social standpoint. This study encompasses issues surrounding the psycho-emotional dimension of disability in relation to people with aphasia.

3.3.5 Acquired Impairments

It has been proposed that people with acquired impairments experience both externalised and internalised oppression in terms of attitudinal barriers (Woolley, 1993). They face attitudinal barriers from outside in the form of others' reactions and attitudes to their impairment, but they also have their own internalised barriers in the form of their old non-disabled attitudes to impairment. Phillips (1990) found that disabled people felt a pressure to hide their disability and fit in with the valued societal view of being 'normal'. Prejudice toward disability, particularly if it is acquired, also resides in disabled people's heads (Morris, 1991). Woolley (1993) contends that this can lead to coping strategies such as denial, bargaining for 'normalcy' and looking towards modern medicine to provide a cure. Pound (in press), a practising speech and language therapist working with people with aphasia, comments that most people come to her with requests to "make my speech better", rather than a request to "help me learn to lead a new life as a disabled person". Aphasia is an acquired impairment of communication, therefore the person has lived most of their life as a non-disabled person, carrying with them generally accepted public views linked to biomedicine of cure and make-well-again.

To summarise this section, the social model of disability was developed to provide a critique of the powerful social perceptions of disability that view it as a personal tragedy or individual deficit (Barton, 1998). It aims to affirm some alternative positive images of disability. The social model view is that impairment is a particular form of social oppression. People who align to it assert that it is society's responsibility to dismantle barriers that increase the experience of disability.

the disabled people's movement has become a powerful voice arguing for radical changes in the ways in which disabled people are treated by society. (Barnes et al, 1999, p.180)

Table 3.1 summarises the differences between an individual model perspective and a social model perspective.

Table 3.1: Individual model and social model perspectives

Individual Model	Social Model
Locus of problem rests with the individual	Locus of problem rests with societal
with the impairment. Onus on person to	barriers. Onus on change of societal
change.	beliefs and practices.
Disability viewed as a medical condition.	Disability viewed as a social reality.
Focus on impairment as the cause of disability.	Focus on discrimination and prejudice as the cause of disability.
Underpinned by personal tragedy theory.	Focus on oppression due to the way in which society is structured around normal activities.
Functionally defined (i.e. disability looked	Experientially defined (i.e. disability
at in terms of fulfilling social roles).	looked at in terms of self & experiences).
Operates with notion of normalcy: if one	Operates with notion of difference and
cannot return to this then affirms the extraordinariness of disability.	being a member of a minority group.
Assumption of wish to return to normalcy or as near as possible to this.	Challenges the assumptions of normalcy.
Product of exclusion (i.e. person with the	Demands inclusion regardless of
impairment must strive for normalcy to be	impairment.
included).	
Focus on needs.	Focus on rights.
Charities for (i.e. needs focused).	Charities of (i.e. rights focused).

According to the sociological literature we are in the process of a paradigm shift moving away from an individual model of disability towards a social model of disability (Nettleton, 1995; Leach, 1996; Oliver, 1996a; Reeve, 2002). The emergence and strength of the disability rights movement has played a significant role in this shift of focus (e.g. Swain *et al*, 1993; Barton, 1996b; Oliver, 1996b). This paradigm shift is reflected in the different emphasis of the more recent ICF (WHO, 2001) as compared with the individual model emphasis of the ICIDH (WHO, 1980).

While the preceding two sections have addressed the two main models of disability the following section outlines the World Health Organisation's view and classification system of disability and how it has evolved since its inception in 1980.

3.4 INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF)

The ICF (WHO, 2001) is a framework for the description of health and health-related states. Before its significant revision it was known as the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980). The aim of this multipurpose classification system is to provide a scientific basis for understanding health and health related states; to establish a common language for the description of such states; to allow for comparison of data; and to provide a systematic coding scheme for health information systems (WHO, 2001, p.5). The ICIDH (WHO, 1980) came under heavy criticism from disability activists and writers and this in part led to significant changes being made which resulted in the publication of the ICF. This section outlines in brief the ICIDH and criticisms of it before going on to address the ICF.

3.4.1 International Classification of Impairments, Disabilities and Handicaps (ICIDH)

The ICIDH (WHO, 1980) was motivated by an individual model of disability in that it located and defined the problem in terms of the person with the impairment (e.g. Oliver, 1993a; Finkelstein & French, 1993). It identified *impairment* as the 'loss or abnormality of psychological, physiological or anatomical structure or function' (WHO, 1980, p.27); *disability* as the 'restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being' (WHO, 1980, p.28); and *handicap* as the 'disadvantage for a given individual, resulting from impairment or disability, that limits or prevents fulfilment of a role that is normal for that individual' (WHO, 1980, p.29).

Badley (1995) discusses the limitations of ICIDH with particular reference to the term handicap and his review emphasises the importance of considering external factors in the experience of handicap. However social model proponents rejected the notion of handicap altogether and redefined the ICIDH term disability as being "the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers." (Finkelstein & French, 1993, p.28). Thus they highlight the barriers in society that have a disabling effect on people with impairments. As previously touched upon, there are many barriers for people with aphasia that limit their opportunities to take part in the normal life of the community on an equal level as others. For example Lewis and Rosenberg (1990) state that people with "significant expressive or receptive language disorders are not suitable candidates for [psychoanalytic psychotherapy] in which the primary medium of exchange is language" (p.70). Thus in this instance, barriers were erected by professionals to a particular service for those people who have impairments in language processing such as aphasia. The situation is now changing as it is recognised that people with aphasia should also have access to counselling (Ireland & Wooton, 1996; Pound et al, 2000) and strategies to dismantle barriers to communication along the lines advocated by Kagan and colleagues (e.g. Kagan & Gailey, 1993; Kagan, 1995, 1998) can be used to allow this to happen successfully. The ICIDH would have taken the view that the barrier to such participation was the impairment rather than the professionals' inability to reduce barriers to communication.

The ICIDH failed to acknowledge barriers within the person's environment that may account for disability; rather it located the reason for disability with the impairment.

3.4.2 International Classification of Functioning, Disability and Health (ICF)

In response to such criticisms the World Health Organisation set about revising the ICIDH. This resulted in the development of the ICF (WHO, 2001) which differs significantly from the ICIDH and places a great deal more emphasis on environmental and social factors as having an influence on the experience of disability.

The overall aim of the ICF classification is to provide a unified and standard language and framework for the description of health and health-related states. (...) The domains contained in

ICF can, therefore, be seen as health domains and health-related domains. These domains are described from the perspective of the body, the individual and society in two basic lists: (1) Body Functions and Structures; and (2) Activities and Participation. (WHO, 2001, p.3)

The terms 'body functions and structures' and 'activities and participation' replace the old terms of *impairment*, *disability* and *handicap* in the ICDIH classification system. The ICF uses the term *functioning* as an umbrella term to encompass all "body functions, activities and participation" and the term *disability* as an overarching term to refer to "impairments, activity limitations or participation restrictions" (WHO, 2001, p.3). The ICF defines *impairments* as "problems in body function or structure as a significant deviation or loss" (WHO, 2001, p.12). They go on to make the following definitions:

Activity is the execution of a task or action by an individual.

Participation is involvement in a life situation.

Activity limitations are difficulties an individual may have in executing activities.

Participation restrictions are problems an individual may experience in involvement in life situations. (WHO, 2001, p.14)

The ICF is inherently a health and health-related classification system and for this reason it is anticipated that disabled activists will take issue with it, as they see disability as being socially constructed. That being said, the ICF does go to some lengths to consider the disabling effects of the environment and context. It does this by organising information in two parts. Part one deals with Functioning and Disability while part two deals with Contextual Factors. The contextual factors component takes into consideration the environmental and personal factors that may have an impact on functioning and experience of disability in terms of facilitating or hindering functioning.

A person's functioning and disability is conceived as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors." (WHO, 2001, p.8)

Disability itself is described in terms of impairment, activity limitation or participation restriction rather than as impairment, disability and handicap as in the old ICIDH classification system.

Disability is characterised as the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives. Because of this relationship, different environments may have a very different impact on the same individual with a given health condition. An environment with barriers, or without facilitators, will restrict the individual's performance; other environments that are more facilitating may increase that performance. Society may hinder an individual's performance because either it creates barriers (e.g. inaccessible buildings) or it does not provide facilitators (e.g. unavailability of assistive devices). (WHO, 2001, p.17)

With regard to working with people with aphasia, speech and language therapists work in partnership with the person on each level, depending on the priorities of the individual concerned. For example, taking Tom's perception and interpretation of other people's reactions, a focus of therapy could be to collaboratively identify possible reactions he may get to his language difficulties and to explore ways he might deal with such reactions that would enable him to build his self-esteem and sense of well-being.

Both the ICDH and ICF classification systems have been very influential in the way in which therapists approach rehabilitation. Although in general therapy practice there still tends to be a focus on addressing the impairment, there is increasing interest in addressing the level of activities and participation (e.g. Byng et al, 2000; LPAA, 2000; Pound et al, 2000; Worrall & Frattali, 2000).

3.4.3 Comparing the Social Model with the WHO Model

Oliver (1993b) provides a useful framework to compare the social model with the ICIDH and ICF approaches. He states that disability can be viewed in three distinct ways:

- As an individual problem to which the person should adapt to society demands.
 This would be in line with the individual model of disability and the old WHO ICIDH (WHO, 1980) which views the impairment as causing disability.
- ii. As more socially constructed whereby the social dimension is acknowledged and that the process of changing attitudes is enough to bring about positive change for disabled people. This is more in line with the new ICF (WHO, 2001) where environmental, contextual and social factors are taken into consideration in the disabling experience of the individual.

iii. As a social creation whereby disability is created by institutions, organisations and environments and which demands action within the political arena. This is in line with the social model with its emphasis on social change.

3.4.4 ICF and Social Model Links to Aphasia Perspectives

In terms of the different perspectives to aphasia and how they fit with the ICF and social model of disability, the following is the case:

- The psycholinguistic perspective works at the level of the impairment.
- The functional perspective works at the level of activities from an ICF viewpoint
 but at the level of the impairment from a social model perspective though it
 addresses communication difficulties in context, the focus is on the person with the
 impairment to adapt rather than society.
- The psychosocial perspective operates at the level of participation from an ICF standpoint, but does not focus on dismantling barriers to communication so fails to fully address the disability from a social model perspective.
- The sociological perspective addresses the levels of activities and participation as well as contextual factors from an ICF viewpoint and the level of disability from a social model perspective.

While the key aim of the present study is to explore the resources that people draw on to make sense of aphasia and how to manage it in day to day life, in the process it will also address issues surrounding activity and participation and so contribute to our knowledge of the degree of activity limitation and participation restriction imposed upon people with aphasia.

It remains to be seen how this new classification system of ICF will be received by disabled activists and writers. In my opinion, they will take issue with the fact that disability is classified as a health-related condition as this is at odds with their contention that disability is a social creation.

This section has outlined the internationally known ICF (WHO, 2001) and ICIDH (WHO, 1980) systems of classifying health and health related states. I discussed them in relation to both the individual model and social model of disability.

3.5 DISABILITY AND NARRATIVE

Narrative is one way of exploring personal and societal meanings of disability and this is discussed in the next chapter. However French (1994) considers that there are four factors that are important to the experience of disability. They are:

- i. The point at which the impairment is acquired: in the case of aphasia it is nearly always acquired in adult life. This brings with it the necessity to move from a non-disabled role to that of being disabled. Therefore the person may bring with her/him internalised prejudices regarding disability (Woolley, 1993), thus compounding the experience of disability.
- ii. The visibility of the impairment: aphasia is invisible until the person opens her/his mouth to speak, when it becomes apparent. French contends that a person with an invisible impairment may experience more social difficulties as their disability is not clearly defined. The person can decide whether to reveal or conceal the impairment, both of which carry risks. If the person reveals then she/he risks rejection, if she/he conceals then there is the risk of discovery.
- iii. The comprehensibility of the impairment and disability to others: the invisibility of aphasia and the actual nature of the impairment together with its fluctuating tendency makes it difficult to understand. For example the functional ability of the person may depend on the situation she/he finds her/himself in, thus making it difficult to fully comprehend what she/he is able to do. The social and psychological environment must always be considered.
- iv. The presence or absence of illness: in the early days post-stroke the person with aphasia could be described as ill and therefore people will allow for that fact in how well the person communicates. However once she/he is well again she/he may still experience fatigue that affects their language abilities negatively. However this may be less well understood by others if the person is seen to be well.

With regard to French's (1994) first point Tom, introduced at the beginning of this chapter, strives to speak fluently as not to speak 'normally' brings with it negative reactions. Therefore there is a natural desire to regain speaking abilities as they were pre-onset of aphasia. Some people with aphasia do 'get better', but many do not and they have to learn to live with aphasia in the long term. There is a need to be able to live life healthily with aphasia. If this is so, then alternative views of disability need to be told.

Kleinman (1988) proposes a narrative view on illness when he calls for a redefinition of medicine. He states that the purpose of medicine is both control of the disease processes and care of the illness experience. However it is the former that has received most attention and which has been viewed as more important, even though the interpretation of illness meanings and the handling of emotions within intimate personal relationships are the point of medicine. Therefore illness must be seen to be as important as disease. To redress the balance one needs to make "the patient's and family's narrative of the illness experience more central in the educational process" (Kleinman, 1988, p.255).

3.6 SUMMARY

This review of the disability literature identified and discussed the two main models of disability: the individual model driven by the narrative of modern medicine, and the social model developed by disability rights activists. The individual model locates disability within the individual while the social model locates disability within society which imposes restrictions and obstacles for the person with the impairment. The main public view of disability is one that regards the person as less than whole in a society which values wholeness. There is an expectation that the individual should seek to be whole again or as near as possible to this. The social model of disability provides a counter view to this in the way it values difference and places the responsibility for the experience of disability on society at large.

The review went on to discuss the contribution that the ICIDH (WHO, 1980) and the more recent ICF (WHO, 2001) have made to our understanding of disability. The ICIDH is underpinned by an individual model philosophy while the ICF takes more account of the effects of environmental and contextual factors that may play a role in the experience of disability. Perspectives in aphasia follow along similar lines with more 'traditional' approaches such as the cognitive neuropsychological and functional perspectives taking an individual model perspective while more contemporary approaches such as the sociological perspective taking more of a social model perspective.

This review has highlighted the dominant narrative of modern medicine which underpins the more traditional ways of understanding disability. However strong counter views are emerging via the disability rights movement. Nonetheless there have been no studies that have explored in depth personal narratives of disability and how these may relate to public narratives. A study of how people, those with impairment and those close to them, view, understand and experience disability on a personal level would enrich our understanding of disability in general. This study aims to do just that with regard to aphasia. It explores in depth narratives of aphasia from the point of view of the person with aphasia and those close to her/him in terms of how they make sense of and manage aphasia in day to day life. An understanding of the narrative literature is important in order to be able to do this. The following chapter therefore provides a review of narrative.

CHAPTER 4 LITERATURE REVIEW: NARRATIVE

From a biomedical perspective the main character of illness and disability is the *pathology* from which the professional expert makes a diagnosis and treats the condition. A narrative perspective, on the other hand, proposes that the main character is the *person* with the pathology in that the focus is on the illness or disability experience and all that this entails (Lieblich *et al*, 1998; Mattingly, 1998).

Patients' narratives give voice to suffering in a way that lies outside the domain of the biomedical voice. (Hydén, 1997, p.49)

The last chapter addressed models of disability and discussed the biomedical perspective in some depth. This chapter addresses the narrative perspective. In it I explore the meanings of narrative and the narrative frameworks that have evolved before going on to outline some narrative studies that have been undertaken.

4.1 INTRODUCTION TO NARRATIVE

Chronic illness and disability can take on specific meanings that can be understood through the narratives of the person concerned, members of their family and other relevant people (Kleinman, 1988). Kleinman goes on to say that all too often the voice of medicine drowns out the voice of the person's lifeworld, therefore careful attention to the illness or disability account is essential. Narrative addresses this issue of paying attention to the illness or disability experience, and is gaining increasing popularity in the practice of medicine (e.g. Greenhalgh & Hurwitz, 1998).

But, when sickness is more or less chronic, we cannot understand a right and good healing action without understanding what the sickness is doing to the person's self-respect, to his life plan, and to the narrative account of his life. (Brody, 1987, p.192)

This statement infers that we need to delve beneath the symptom in order to establish how the illness or impairment is affecting the individual in personal terms.

The onset of aphasia, as with the onset of any disability or illness, upsets one's sense of order. One may not be able to continue with those routine aspects of daily living which generally serve to establish a sense of continuity and order (Becker 1999). With such a

change in life circumstances the person needs some means to re-establish a sense of order to her/his life. It has been proposed that narrative can facilitate this process (Brody, 1987; Kleinman, 1988; Frank, 1995; Becker, 1999, Clouston, 2003). As outlined in the previous chapter, the individual or medical model has been criticised for managing the disease without recognising what the person is experiencing. Narrative is one approach that can be used to explore individual experience and to address issues surrounding the onset of disability in an attempt to understand the way in which people adapt and respond to traumatising events (Crossley, 2000). It is very much grounded in the attempt to understand the specific experiences undergone by individuals. Frank (1995) uses the analogy of a map and suggests that one's life map is lost with the onset of illness or disability and that recovery is about re-drawing this map and finding new directions and destinations. Drawing on her personal experience of traumatic brain injury, H. Hill (1999) believes that rehabilitation should focus more on the development of new maps rather than restore the original pattern of behaviour. She proposes that the original pre-injury maps are no longer valid. She personally needed a new set of navigational skills.

Becker (1999) suggests that illness reflects a narrative structure in which there is a beginning (the onset of illness), a middle (the chaos associated with disruption) and an end (return to normalcy). However she goes on to say that in chronic illness there is a "limbo-like" state whereby one may enter as one sort of person and emerge altered in some essential way. Mattingly (1998) refers to this as "liminal space" where the person is neither who she/he once was, but not yet some new person. It is usually in this "liminal space" that a speech and language therapist, among others, might become involved in working with the person in making the transition from illness reality to a new reality.

C. Hill (1997) thinks about illness in a different way; she uses a thread metaphor to reflect illness and recovery. A single thread made up of many strands interwoven together depicts a single life; parallel threads depict that life with other people – some more closely connected than others. With the onset of illness the strands of the thread

become all unravelled with some bits broken – suggesting that some of life's narrative remains intact while other parts do not – resulting in a loss of stability, 'taken-for-grantedness' and sense of continuity. Finally with recovery, strands join up again to reflect a return to meaningful life. She suggests that a return to meaningful life is more important than achieving functional independence.

Narrative, it seems, looks beyond the mask of disease or disability to the actual experience of it on a personal level. However the term 'narrative' means different things to different people. The following section describes some definitions of narrative.

4.2 DEFINITIONS OF NARRATIVE

There are two main contrasting definitions of narrative. One suggests that a narrative is like a story and involves a plot (e.g. Labov, 1981), while the other proposes that a narrative is a set of arbitrary metaphors for making sense of a situation (e.g. Donald, 1998). I call these the *story-type narrative* and *metaphor-type narrative* respectively. Each will be addressed briefly.

4.2.1 Story-Type Narrative Perspective

Labov (1981) provides the traditional approach to narrative when he describes most narratives as giving orienting information that include time, place, participants and behaviour that surround a plot. Every narrative is about something and when someone decides to tell a narrative she/he has normally decided to tell a story about an event. Thus he equates narrative with story. Similarly Riessman (1990) defines narrative as a "discourse organized around time and consequential events in a 'world' recreated by the narrator" (p.1195). However she contends that there are different kinds of narrative and not just story narrative. In her opinion other narrative types include the habitual narrative, which tells of the general course of events, and non-narrative segments which report thoughts or actions. Like Riessman, Gabriel (1997) treats story as just one particular type of narrative. He proposes that stories constitute facts-as-experience (i.e. how things are experienced) while other narratives (e.g. opinions, descriptions) are

facts-as-information. There can be many different accounts or stories of the same incident depending on the person's role and how threatened they feel by the event (Gabriel, 1995). Therefore both Riessman and Gabriel view narrative as the text of something that the person is relating.

Similarly C. Hill (1997) defines narrative as being more like a story, she describes it as "the recreation of events and actions in a symbolic structured way so that the motives of the actors and the morality of the situation can be understood by self and others" (p.132). She outlines four main interdependent characteristics which have been attributed to narrative and how these are affected by stroke. Firstly, there is temporality, whereby narrative is our primary way of organising our experience of time and time is disrupted in many ways, following a stroke, in that the rhythms of life may be broken as it takes much longer to say or do things. Secondly, there is identity, whereby people tend to create stories that reinforce their sense of who they are. A stroke affects identity through changes in relationships and in acquiring a different label (i.e. disabled, 'aphasic'). Thirdly, there is understanding of the world, in that people use stories to understand their social world. The taken-for-grantedness aspects of our social world are potentially lost following a stroke. And fourthly, there is unity, whereby narratives help us to link events together to form a complete whole. In the experience of stroke there is a lack of a sense of unity as the body has failed suddenly for no clear reason, thus making it more difficult to include the event of stroke in a story which creates meaning.

This notion of narrative as story is reflected in the increasing literature on life story whereby:

Life story is the interface between life as lived and the social times; like Erikson's concept of identity, life narrative interweaves individual experience with historical reality and thus interfaces with approaches in sociology, anthropology, and the burgeoning field of oral history. (Josselson, 1993, p.xiii)

A person's life story is usually elicited through interview and Atkinson (1998) proposes the life story interview as a means of gaining information about the person's individual life which provides a means for that person to increase her/his working knowledge of her/himself. Compared to Labov's notion of story pertaining to a particular event,

story-type narrative has evolved to include a very loose story plot so that it reflects the account a person gives of life or particular aspects of life. Booth (1996) defines narrative methods as:

methods aimed at depicting people's subjective experience in ways that are faithful to the meaning they give to their own lives. (...) [They] provide access to the perspectives and experiences of oppressed groups who lack the power to make their voices heard through traditional modes of academic discourse. (p.237)

Booth (1996) goes on to outline the characteristics of narrative methods. Firstly, they provide an insider view of the person as she/he is the expert witness. Secondly, they make abstract claims more tangible by grounding them in lived experience. Thirdly, they help to ensure against the 'disappearing individual'. Fourthly, they form a bridge between the individual and society, as it allows one to listen beyond what the information actually says (i.e. *how* it is said) in that it links to public and cultural narratives that are within society at large. And fifthly, they unmask the confusion, ambiguities and contradictions that characterise people's lives. In terms of illness and disability, narrative provides meaning, context and perspective to the person's situation. While all these points are relevant to the present study it is the fourth point that is of particular interest here, in that the study aims to address what public as well as personal narratives the person draws on to make sense of aphasia and how these interrelate. A life story of a person with aphasia would therefore provide insight.

It defines how, why, and in what way he or she is ill. The study of narrative offers a possibility of developing an understanding that cannot be arrived at by any other means. (Greenhalgh & Hurwitz, 1999, p.48)

Frank (1995) outlines how in pre-modern times the official illness stories were the lay stories, but in the modern era these were eclipsed by the professional's story with its focus on pathology having greater voice. Now in post-modern times the lay person's story is once again re-emerging and is beginning to be viewed on equal terms with the professional story. This situation is reflected in the literature with the emergence of many published stories of illness and disability and with professionals taking greater account of the lay story (e.g. Greenhalgh, 1999; Greenhalgh & Hurwitz, 1999; Launer, 1999). According to Clouston (2003) an illness narrative has three purposes. First, it enables understanding of the illness experience for the self through the telling of the story. Second, it enables understanding for others of how individuals deal with illness

and disability and issues of disruption to identity. And third, narrative shapes the perception that the individual has of the illness and so has an impact on the plot of the story.

In summary the term narrative in this perspective can be used to refer to what and how the person relates events, experiences and feelings. It is, for example, the text of a life story interview.

4.2.2 Metaphor-Type Narrative Perspective

This definition of narrative encompasses the notion that narratives are "just a set of arbitrary (although conservative) metaphors for organising and making predictable infinite permutations and combinations of sensations" (Donald, 1998, p.22). This type of narrative is less frequently referred to in the literature. Atkinson (1998) refers to 'submerged stories' which he says tell us more about issues relating to for example class, gender and disability. In identifying submerged stories one needs to focus on how the person is telling their story, as well as what they are saying. This involves paying close attention to grammar, vocabulary and metaphor. One person with aphasia once said to me "you can run the country from a wheelchair". This was said in the context of having aphasia and inferred that one could not run the country if one could not speak. This suggests the privileged meaning he assigned to language and the ability to communicate in our society. Such submerged stories interwoven in a life story can provide rich insight into lived experience and how the person views self. Becker (1999) also highlights how looking at metaphor provides one way of locating new meanings which may then facilitate efforts to reorganise life after a life changing event. Metaphor type narratives tell us about how life's problems are created, controlled and made meaningful, and about

the way cultural values and social relations shape how we perceive and monitor our bodies, label and categorize bodily symptoms, interpret complaints in a particular context of our life situation; we express our distress though bodily idioms that are both peculiar to distinctive cultural worlds and constrained by our shared human condition. (Kleinman, 1988, p.xiii)

Somers (1994) outlines a number of metaphor-type narratives.

- i. Ontological narratives are the stories we use to make sense of life and which we use to define who we are and for knowing what to do. They are the personal narrative we hold about life. They guide us in how to behave and respond to situations as they occur. They may draw on public narratives.
- ii. Public narratives are attached to cultural and institutional formations larger than the single individual. In relation to disability such narratives would include the view that disability is a personal tragedy, narratives of abnormality and as lives not worth living (Thomas, 1999b).
- iii. Metanarratives are the master narratives such as 'Progress', 'Industrialisation' and 'Capitalism'. As biomedicine is such a powerful and pervasive narrative in our culture it could also be classified as a metanarrative.

These narratives are the stories we live by that allow us to make sense of things around us and things that happen to us. Somers (1994) states that:

it is through narrativity that we come to know, understand, and make sense of the social world, and it is through narratives and narrativity that we constitute our social identities. (...) All of us come to be who we are (however ephemeral, multiple and changing) by being located or locating ourselves (usually unconsciously) in social narratives rarely of our own making. (p.606, emphasis in original)

People try to make sense of what has happened by attempting to assemble or in some way integrate these happenings within one or more narratives. It is the tapping into the social, public and cultural narratives that then guides behaviour (Somers, 1994).

This section has presented two different, though connected, ways of looking at narrative. I outlined what is meant by story-type narrative and what is meant by metaphor-type narrative. This study draws on both.

Some authors address the issue of these types of narratives in relation to how one can explain and make sense of illness and disability. The next section outlines some of these perspectives.

4.3 NARRATIVE PERSPECTIVES

Greenhalgh and Hurwitz (1999) make the comment that the patient's narrative has become increasingly repressed in medical practice over the past two hundred years. Prior to that time doctors based a large part of their diagnosis on what the patient told them (Hogarth & Marks, 1998). However more recently the important role that narrative has to play in medicine is (re)gaining attention. This interest has cumulated in the publication of the seminal book entitled Narrative Based Medicine edited by Greenhalgh and Hurwitz (1998). In the Forward Greenhalgh and Hurwitz talk about narrative in terms of being a bridge between teller and audience by which the two connect and across which stories travel (for example doctors travel across the bridge seeking parts of the narrative that fit with the stories of disease). Heath (1998) comments how "stories are the basic tool and the great reward of general practice, with the capacity to enrich the lives and the experience of both patient and doctor" (p.83). She advises that the doctor should allow time for the patient to develop the narrative to include the psychosocial context in which the symptoms are embedded. Not only is narrative recognised as having a role to play in diagnosis in medical practice it is also recognised that one's story-telling capacity enables one to make order out of chaos (Donald, 1998). Thus listening and responding to the patient's narrative is both diagnostic and therapeutic and is once again being recognised as critical in our understanding of disease and the illness experience.

This section outlines a number of different perspectives with regard to narrative explanations; they include the work of Frank (1995), Stainton Rogers (1991) and Crossley (2000). Frank (1995) proposes a number of illness narratives which he suggests are useful to help the practitioner make sense of the illness experience. Stainton Rogers (1991) takes a different stance in her studies of the way in which people explain health and illness. Finally Crossley (2000) draws on her research with people with a diagnosis of HIV in which three narratives emerged that were characteristic of the way in which participants dealt with their diagnosis. Each is addressed below.

4.3.1 Illness Narratives

Frank (1995) states that there are two main types of stories: 'outside' stories which tell about the illness and are generally told to professionals, relatives and friends; and 'inside' stories that repair, re-draw maps and find new destinations. It is these latter stories that have a healing quality. Frank goes on to identify three main illness narratives which he says are useful as listening devices to determine the person's perspective. Each of these is described in turn.

a) Restitution narrative

The storyline of this narrative is that one is well, one gets sick and one gets well again; it is the story that others most want to hear. It links with the metaphor of body as machine which can be repaired. This storyline is particularly relevant to those who have recently become ill and is supported by the cultural expectations of restoring to 'normal'. The story is interrupted with tests and treatments that occur on the road to restoring health. Illness is therefore viewed as transitory and the active player is the remedy; it affirms that breakdowns can be fixed. The metanarrative of modern biomedicine is strongly aligned to the restitution narrative. In addition we are bombarded by this storyline in the media (particularly advertising) and, together with its strong alignment to biomedicine, it influences one to feel that it is the most acceptable narrative. It is compelling, as many people do get well again. However a problem arises when the person does not find restitution, as is the case of many people following a stroke who may have to live with aphasia in the long term, and so other stories need to be told.

b) Chaos narrative

This narrative is difficult to hear as it has a fragmented quality to it. In it one imagines life never getting better and in the lived chaos there is only immediacy. There is an incessant present in the telling with no memorable past or discernible future and what is actually told only provides a glimpse of all that is wrong. In a chaos narrative one is 'sucked into the undertow' of illness and the story remains the person's own; suffering is too great to tell and the voice of the teller is lost. It is as if experience and feelings

outstrip the person's capacity to distinguish and describe them and without intelligible narratives we are lost (Donald, 1998). Frank maintains that it is important to hear the chaos and not steer the person away from their feelings: "To deny a chaos story is to deny the person telling this story, and people who are being denied cannot be cared for." (p.109). However in modern medicine with its restitution bias, there is a tendency to redefine chaos in terms of a new diagnosis or label (i.e. depression) that can be controlled in some way (i.e. with drugs). The alternative would be to witness and accept the chaos story before it can be rebuilt.

c) Quest narrative

"Quest stories meet suffering head on; they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest." (p.115, emphasis in the original). The person may not always be clear about what is quested but there is a belief that something is to be gained through the experience. Therefore in a quest narrative illness or disability is incorporated into daily life and there is a sense of purpose. The ill or disabled person has a voice and is the teller of her/his own story. There are three main types of quest stories. Memoir where the illness story is told with other life events, trials are not minimised but told in a resigned way without flourish, it has the gentlest style; manifesto where the emphasis is on social reform has least gentle style; and automythology which involves self-reinvention with its emphasis on individual change.

In quest narratives the interruption is reframed as a challenge. The story is told in the ill person's voice though restitution and chaos may remain background voices.

Frank goes on to describe *testimony* whereby the person is a 'witness' and is responsible for telling what happened. These stories, by their very nature, are usually quest narratives. The restitution narrative is the least obvious testimony, being so bound up in being cured, and the chaos narrative prevents one from hearing oneself. Most published stories are testimony and there is now much interest in this with the abundance of published stories of illness and disability. Published stories of testimony include stories of aphasia (Ireland, 1990; Ireland & Black, 1992; Newborn, 1997;

Boazman, 1999), stroke (Cant, 1997; McCrum, 1998), head injury (Rice, 1992; Raynor, 1993; Hill, 1999), locked-in syndrome (Bauby, 1997), physical disability (Slack, 1999), leg injury (Sacks, 1984) and heart attack and cancer (Frank, 1991). In testimony the content of illness and disability stories is important firstly for the teller as it reorders life story, secondly as a guide for others, and thirdly to provide health professionals and care givers with an understanding of the illness or disability experience. In the post-modern era testimony has equal place alongside the professional story.

While Frank outlines only three main illness narratives, he highlights that many other narratives are told. In addition he stresses that people do not move from one type of narrative to another in a linear fashion, rather they oscillate between these and other personal and public narratives.

4.3.2 Meanings of Health and Illness

Stainton Rogers (1991) contends that people are "clever weavers" of stories who create order out of chaos. In her qualitative study exploring explanations of health and illness she identified eight different accounts ¹³ of health and illness. While some participants exemplified a specific account, most expressed a variety of accounts simultaneously. Some of these accounts drew directly on the meta-narratives of modern medicine and religion, while others took more of a political stance. Stainton Rogers' accounts differed from Frank's (1995) narratives in that they were not concerned with illness *per se* but rather they provided views of how people explain and make sense of health and illness. Each of the accounts will be described in brief.

a) Body as machine account

This is the most common media image of modern medicine – one which stresses its "scientific base, its technological sophistication and its triumphant conquering over the scourge of disease" (p.209). The image is of body as machine which can either run smoothly or break down; in the case of the latter biomedicine's role is to fix it. Therefore it supports biomedicine and perceives modern therapeutic achievements and

¹³ Stainton Rogers uses the term account as I use the term narrative when referring to the metaphor type.

progress made in pharmaceuticals as significantly contributing to health care. People who align to this account believe that technological excellence is more important than a bedside manner. This account most closely links to Frank's (1995) restitution narrative. The adoption of it renders the person or patient compliant and there is an unwillingness to accept responsibility. Participants who aligned to this account had a view that the person might in some way be responsible for their illness.

b) Body under siege account

In this account the individual is seen to be under threat of germs and disease, it regards biological and psychological aspects as leading to illness. There is a strong assertion that emotion can lead to physical illness and there is the idea of stress being central as a contributing factor. "The overall image is of a helpless individual trying to cope in a hostile and dangerous world, constantly liable to attack and having to rely on outside aid." (p.152-153). Those people who adopted this account denied there was any benefit to treating illness as a challenge.

c) Inequality of access account

In this account there is a belief that ill health is a product of injustices between rich and poor and the impact of capitalism, whereby the "poor and exploited in society were assumed to have little choice about the unhealthy lives they lead" (p.149). In addition there was a personal element, in that illness could be seen as a response to someone being unpleasant. The person was not seen as to blame for the illness. Those who aligned to this account were convinced of the benefits of modern medicine, but were concerned about the unfair allocation of health care.

d) Cultural critique of medicine account

This was articulated within the socio-political arena and explained health in terms of power, status and wealth. It is based on a world view of exploitation and oppression. Poor health is viewed as the product of inequality, exploitation and disadvantage and that such people have little choice about the unhealthy lives they lead. There is a belief that diseases are invented by doctors (e.g. drug addiction, alcoholism) and labelling

people as for example mentally ill, is a form of social control. There is strong cynicism about the supposed benefits of modern medicine and doctors are viewed as treating the symptoms but not the underlying causes. A good health service is seen as one that respects people's autonomy even if that puts people at risk.

e) Health promotion account

This account recognises both the personal and collective responsibility for health. It stresses a healthy lifestyle to maintain health and prevent illness. The focus is on health rather than illness and health is viewed as a fundamental human right. There is a belief that disease and bodily decay can usually be avoided or delayed by promoting changes in lifestyle, improving living conditions and gaining greater spiritual and psychological equilibrium. The importance of health education is stressed. This account acknowledges inequalities in health between rich and poor and concern is expressed about environmental causes of illness. There is guarded approval of modern medicine.

f) Robust individualism account

In this account there is a belief of a person's individual right for a satisfying life and their freedom to choose how to live their life. Health is highly valued and illness is seen as largely the result of stress and the pollution of modern life. There is the belief that people should take personal responsibility for health. A central theme is the importance accorded to individual freedom and there is a view that people should be free to do what they like, as long as they are prepared to live with the consequences. Health is viewed as a commodity that can be bought, sold, insured and squandered.

g) God's power account

This account views health as a product of 'right living', spiritual well-being and God's care. Recovery is a matter of regaining spiritual wholeness. Personal responsibility for illness is not considered and blame for illness is strongly denied. There is a view that bodily health cannot be divorced from spiritual well-being.

h) Willpower account

In this account the individual is in control. It stresses the individual's responsibility to use their will to maintain good health. There is an expectation that being healthy requires self-control. Unlike the robust individualism account, this account "assumes that moral standards are set by a higher authority (usually God) and that people should judge themselves according to how well they live up to those standards" (p.225). There is a positive view of medicine and modern drugs are seen as making a major contribution to health. Alternative forms of medicine are also viewed positively. The doctor's bedside manner is seen as important as their technical expertise. However the role of medicine is played down, except as a means to encourage the individual to strive for their own recovery. A positive state of mind and willpower are stressed.

Stainton Rogers states that as far as the individual is concerned, accounts are selected in part in terms of their explicatory power and to fit the context. She gives the example of being bitten by a rabid dog, for which probably only two accounts would fit: body as machine (find a doctor fast) and God's power (pray hard). Many people would draw on both. Therefore, as with Frank, people do not present with just one account but rather tend to draw on many to fit their circumstances, such as political ideology, religious beliefs, how one sees oneself and others, as well as the actual context of the individual's health status.

4.3.3 HIV narratives

Crossley (2000) undertook a qualitative study with people who were HIV positive. From this emerged three different stories ¹⁴ of illness and health. She contends that such stories are a means of making coherence and order out of possible chaos, they make meaning out of something. Crossley suggests that her HIV stories are closely aligned to Frank's (1995) illness narratives, though they must be viewed in the context of people with a limited life prognosis. Her stories are outlined below.

¹⁴ Crossley uses the term story as I use the term narrative.

This is where the individual grows spiritually and achieves a new appreciation of meaning of life. There is a sense of 'live for today', together with a sense of freedom from the shackles of everyday existence in which one is always fighting towards the future. The person is free from having to make a long-term plan and is able to enjoy the present for what it is. Crossley likens this story to Frank's (1995) quest narrative in that illness is a journey and the person experiences crisis and change, but is able to eventually open up to the contingency and mystery of life.

b) 'Living in the future' and the 'normalizing' story

In this story the individual acts as if she/he is not ill or does not carry a diagnosis of HIV. She/he assumes that she/he will live as long as everybody else – the person carries on as normal. There is a determination not to let their condition ruin their plans. People who align to this story refuse to relinquish their routine future orientation. In the case of HIV positivity they refuse to accept the possibility of their death. Crossley states that this story is similar to Frank's (1995) restitution narrative as it incorporates the modernist expectation that bodily breakdowns can be fixed. The key feature of a restitution narrative is that if one acts in a certain way, then a solution will be forthcoming. Therefore those people who aligned to this narrative believed that if they continued as normal then things would work out all right in the end.

c) 'Living in the empty present' and the story of 'loss':

This is where the present is held on to as if it is the only thing left. There is an increased focus on the past with no focus to the future and this can lead to a loss of sense of meaning to life. There is an inability to "project into the future, to live with hopes, possibilities and aspirations" (p.150). People aligning to this story do not feel able to commit themselves to future possibilities because they are afraid of disappointment. There is an increased focus on the past and a sense of wishing things to be as they used to be. In her study all those participants who expressed suicidal thoughts adopted this account. Crossley likens this story to Frank's (1995) chaos narrative as it tells of how one can be 'sucked under'.

People do not generally draw on just one single narrative. Simpson (2000) in her exploratory study of identity and aphasia found that participants drew on a diverse set of narratives, though Frank's (1995) predominated, for the identity reconstruction process. Her study is one of the few studies that have been undertaken exploring narratives of aphasia.

This section has outlined the types of narratives that have been used as a means of explaining health, illness and disability. The following section describes some narrative studies that have been undertaken.

4.4 NARRATIVE STUDIES

Many studies have been undertaken analysing narrative in order to explore a variety of issues. These are mainly divided into two types. First, there are studies that explore narratives of disability in terms of how disability is culturally represented and how it affects the way people live their lives. Second, there are studies that explore the narratives of professional practice and the influence these have on the lives of people with disabilities. With regard to communication impairment, a number of narrative studies have been undertaken and these are also presented.

4.4.1 Disability Narrative Studies

I will outline two studies which address narratives of disability. Phillips (1990) used interviews as a means of eliciting narratives, while Robinson (1990) requested participants to write the story of their life with multiple sclerosis. These studies are quite different in that Phillips identified representations of disability and Robinson identified a narrative pattern of how people lived their lives with multiple sclerosis.

Phillips (1990) interviewed twenty-nine disabled people and used their narratives elicited at interview to explore cultural representations of disability. Themes tended to be reiterated from person to person. The study revealed that three main cultural notions dominated the narratives. First, society perceives disabled people to be damaged;

second, society believes that disabled people should try harder to overcome their obstacles; and third, society assumes that disabled people prefer to be with their own kind. All these notions link in with the dominant individual model of disability in our society where the onus is on the individual with the impairment, they are viewed as less than whole, and it is their responsibility to try to do something in order to achieve as near a 'normal' status as possible. The narratives elicited at interview also revealed the liberating effects on participants' self-images of philosophies which demonstrate their minority status rather than their deviance and which strongly disavow the notion of 'disabled people as damaged goods' (i.e. those counter narratives of disability put forward by the disability rights movement and proponents of the social model of disability). Thomas' (1999b) study is similar in that she found that disabled people's personal narratives are bound up with public narratives of disability as being less than whole.

Robinson (1990), in his study of people with multiple sclerosis, looked at narrative from a different perspective. He studied the written life stories of participants in which he identified three main types of narrative structure. Firstly, there was the "progressive narrative" where the essence is of a positive construction of events and experiences and there is a reassertion of personal control. These progressive narratives accounted for fifty-two percent of the study sample, which would be more common than would be predicted by doctors. This narrative is similar to Frank's (1995) quest narrative, previously described. Secondly, there was a "regressive narrative" where the essence is of not being able to meet goals due to illness and related events. This accounted for only five percent of the sample, even though it would be the most commonly expected narrative in medical settings. Thirdly, there was the "stable narrative", written as a series of stable events and experiences showing neither progression nor regression. These accounted for twenty percent of the stories elicited. However he was unable to fit eighteen percent of people into these narrative types, which again highlights the complexity of how people live with illness and disability.

4.4.2 Practitioner Narrative Studies

Two practitioner narrative studies are described, quite different from each other. Abma's (1999) study highlights how practitioners can gain insight into the perspectives of "patients" by listening to and retelling patient narratives, to the extent of being able to change their original attitudes. Mattingly (1998), on the other hand, addresses narratives of occupational therapy and explores how the therapist and 'patient' together create a narrative of therapy that is embedded into the larger life narrative.

Abma (1999) describes a project looking at transforming professional practice in a "mental hospital" which was starting a vocational project to assist psychiatric "patients" in their social integration back into society. This project took the form of setting up a hospital shop. Abma elicited narratives through interviews and informal conversations and found that the professionals and the patients talked about the shop project quite differently. For the patients the shop project held existential meaning and touched their whole being, where they became subjects rather than objects. The meaning for the professionals, on the other hand, was in the context of a project and so was primarily functional. They talked about it using labels, narrow descriptive categories and toneless language – they did not seem to refer to the live experience, as the patients did. The patients felt that their story had not been heard while the professionals felt the patients were being non-compliant and framed their behaviour into symptoms of their illness. The professionals found it difficult to move away from the standard story of professional as expert. The stories elicited were then shared with each other so that each group could gain insight into the other's perspective. The professionals were asked to retell the patient's story that touched them the most. This tactic enabled the professionals to "live through the difficulties patients experienced during their process of rehabilitation" (p.191). This study shows how the professional's expert story can be changed quite simply to gain insight into the patient's perspective and so alter the way in which they approach rehabilitation. Listening to each other's narratives then proved a powerful method of changing attitudes.

Mattingly's (1998) study is somewhat different. She undertook an ethnographic study of the work of occupational therapists to explore how they determine clinical reasoning in terms of how they work out what a problem is and what their role is in solving it. She used narrative as a way of understanding the structure of clinical practice and was interested in the role of narrative in the creation of experience. She looked at the relation between narrative, action and experience as they play out in the world of clinical practice. She found that "to understand the actions of another, therapists struggle to identify those narrative contexts which render the particular actions they observe in others meaningful" (p.46). A checkers game is described in which two people with spinal injuries and an occupational therapist are participating. The focus is on the preparation for the game and narrative enters the session by the way the occupational therapist attempts to create a significant experience within the insignificant medium of a checkers game. Mattingly contends that "a narrative is being made through the combined efforts of all three players, but with the therapist very much in charge" (Mattingly, 1998, p.68). She asserts that the moves made in a therapy session constitute a narrative within an unfolding life story. Therapists must reason in a "narrative mode" about how to guide therapy in terms of where the person is at the time and where she/he may be in the future. This is highlighted when she says "for patients and therapists to be committed to a therapeutic plot, they must share some level of commitment to a particular version of a patient's life story" (p.71). She suggests that at the end of a therapeutic narrative there should be a beginning, as therapy should open up new things. If there is no beginning then it is a narrative failure. The study found that therapists and "patients" collaboratively play out this narrative drama to create meaning in the rehabilitation process, though with the therapist tending to be in control. Confusion and frustration usually occur when the therapist has lost her/his way in the projected story. Mattingly's study shows that a narrative structure is embedded in therapy, though it is the therapist who guides the story while the 'patients' are usually, though not always, active participants in the playing out of that story. She contends that the person is less likely to be involved as a human actor in clinical time structured from an individual or medical model perspective, as compared to time more narratively configured where the person is invited to be a human actor, capable of desire and motive.

Clinical time which suppresses narrative generally does so in the name of treating the diagnosis. In these anti-narrative times, the clinical task focuses on the treatment of discrete body parts or functional skills. (Mattingly, 1998, p.142)

Therefore therapy that involved the patient on a more personal level was more narratively structured and allowed for joint meaning to be created.

4.4.3 Communication Impairment Narrative Studies

A number of studies have been undertaken with people with communication impairment which take the narrative of the individual elicited at interview to explore the insider view of living with impairment. Corcoran and Stewart (1998) found the themes of helplessness, shame, fear and avoidance in their participants who stammered. The involuntary nature of stammering led to the feelings of helplessness and the insensitivity of conversation partners caused the experience of shame. Parr et al (1997) interviewed fifty people with aphasia and their findings illustrate the complexity of living with such an impairment. They highlight the vulnerability people with aphasia feel, particularly early post-onset. In addition they found that psycho-emotional factors (i.e. embarrassment, sense of incompetence, loss of confidence, depression, fear of other person's reaction), as much as the impairment in language, acted as barriers to taking up employment and pursuing leisure activities. The study highlighted the complexity of coping with aphasia and that coping involves the actual experience of aphasia, the pre-aphasia identity, knowledge of aphasia, personal and family attitudes and beliefs and the account of aphasia. While this study touches on personal and family attitudes and beliefs in relation to coping, it does not go into a great deal of depth.

In terms of studies of narrative of the *metaphor type*, few have been undertaken. As mentioned previously, Simpson (2000) interviewed eight people with aphasia and explored the role that the narratives which emerged had to play on the reconstruction of identity. She found that individuals drew on a diverse set of narratives with Frank's (1995) illness narratives predominating. I, on the other hand, explored what narratives

emerged as part of the therapy process and how narratives change and evolve as therapy progresses (Barrow, 2000). For example, I describe a person who initially was in a *chaos* narrative which was then followed by a predominant *restitution* narrative; it was this that guided the therapy focus. As progress in the impairment plateaued, the focus of therapy altered to centre on issues surrounding living with aphasia. Simultaneously a *quest* narrative began to dominate though *restitution* remained a background voice. I go on to describe another person with aphasia who I first saw eight years post-onset of aphasia. This person came to the therapy encounter with a narrative of *striving to be normal* and as this was an unrealistic goal therapy focused on changing this narrative to a *quest* narrative that would incorporate healthy living with aphasia. Pound *et al's* (2000) work also centres on the person having a means of telling her/his own story, thus promoting a new sense of identity incorporating aphasia more positively.

While some studies in aphasia have touched on narrative in terms of exploring narrative as part of the identity reconstruction process (Simpson, 2000) and how they change and evolve as part of therapy (Barrow, 2000), to the best of my knowledge no study has addressed specifically how people use narratives to make sense of and manage their disability in day to day life.

This section has described a number studies that approach narrative in a variety of ways. However as indicated in some of the studies above, narrative is not just a means of research, it also has a therapeutic role and it is to this that I now turn.

4.5 THERAPEUTIC VALUE OF NARRATIVE

Narrative has been used in clinical practice as a method to allow greater insight into the illness or disability experience. Kleinman (1988) advocates doing what he calls "miniethnographies" as a means to try to place oneself (i.e. the clinician) as far as possible in the lived experience of the individual. Listening carefully and openly to the stories

¹⁵ A mini-ethnography is a systematic description and interpretation of the life world of an individual (Kleinman 1988).

that people bring to therapy encounters provides us with insight into the experience of illness and disability from their perspective (Sacks, 1985, 1995; Coffey & Atkinson, 1996; Parr et al, 1997), as well as factors that contribute to their illness behaviour (Alonzo, 1984). Careful attention to the person's narrative helps to ensure that we hear the anomalous as well as the expected (Greenhalgh & Hurwitz, 1999) and fosters recognition of the complexity of coping with chronic illness (Anderson & Bury, 1988). In addition it allows one insight into any problems in how the individual views self.

Identity begins to become a problem in life when a person first notices incongruities between who he or she was at one time and who he or she is now. (McAdams, 1993, p.76)

If one fails to listen to the person's story then there is a danger of there being a conflict of narratives. This is particularly evident if the professional is viewing the person from a disease perspective and the person is relating the illness experience (Kleinman, 1988; Donald, 1998; Mattingly, 1998; Pound, 1999). If this occurs then therapy may not be targeting the areas of priority to the person concerned and the therapy may become part of the problem rather than the solution (Kleinman, 1988; Pound, 1999).

The process of telling one's story is healing in itself; people give meaning to their experiences by telling stories (Brody, 1987; Kleinman, 1988; McAdams, 1993; Riessman, 1993; Frank, 1995; Abma, 1999; Elwyn & Gwyn, 1999; Pound, 1999). Storytelling allows one a means of "re-drawing maps and finding new destinations" (Frank, 1995, p.53). Price-Lackey and Cashman (1996) relate how one person, following a traumatic brain injury, used narrative to interpret the events of the year following her head injury in a positive light.

According to Becker (1999) our culture tends not to value embodied distress (i.e. the outward expression of distressing emotion), therefore some other means to express distress is required and narrative is one mechanism by which one can 'give voice' to bodily experiences. Donald (1998) suggests that storytelling allows one to impose some order and predictability onto chaos.

without our story-making process, it would be difficult to survive, because narratives give us the capacity to navigate and to order our senses and thereby the world. (...) Narrative construction is a

lifelong process that enables adults also to navigate new experiences, as they also encounter new things they do not always have ready-made distinctions for. (p.20)

Donald (1998) goes on to stress that if one does not have the capacity to tell one's story then one is at risk of becoming ill. Similarly Becker (1999) states that not only does suffering arise from the disruption of illness itself, but it also arises from difficulty in articulating that disruption. This poses a particular problem for those with an impairment in communication who may not have the ability to translate their story easily into words; yet it is those people who most need to have their stories heard who may be least able to tell them (Booth, 1996). Rice (1992), with his personal experience of head injury, describes the impact of not being able to communicate.

This loss of the self created by the neversame¹⁶ was further complicated by the many known and unknown aphasias from which I suffered. These aphasias hindered my ability to tell anyone what was happening to me. I could not talk. I could not write to explain myself. Yet, I was cognitively alert and there. Maddeningly, I did try to be heard. I was trapped inside my body that was betraying me and would not respond. I felt as if I had only endless silent screams. The silent screams might never have been, if anyone had just once recognized the person behind the mask [of head injury]. (p.173-174)

Hydén (1997) describes this situation of not being able to give voice to the illness experience as 'narrative as illness' and it is this lack of ability to articulate events and experiences that is the basis of suffering. This issue of being able to tell one's story is considered by a few authors and a number of creative ways for the person to tell their story have been developed. Gray and Ridden (1999), in their work with people with learning difficulties, emphasise the value of developing "life maps" for those whose biographies are hidden. Life maps provide a pictorial and graphic representation of the person's story, mapping out where the person comes from and outlining key people and key experiences that have occurred along the way. They suggest that such a process gives a person a sense of who they are, where they have come from and where they hope to go. Life story books serve a similar function in that they recover lost histories and convey to the person that their history is of value (Gillman, Swain & Heyman, 1997). As described previously, from an aphasia perspective Pound *et al* (2000) focus on this issue specifically in their work on personal portfolios which aims to provide a medium for the person to tell their story as they wish. Eliciting narratives from people

¹⁶ Rice (1992) uses this term to refer to the concept of 'nothing ever being the same' after a head injury.

with aphasia is not an easy process and it requires creative methods to do so. This study addresses this issue by using a variety of methods, some quite novel, to elicit the narratives from people with aphasia and their conversation partners.

In addition to storytelling being healing in itself, narrative is also a particular method employed in therapy. Narratives are the main activities of the 'talking cure'. In the area of counselling, family therapy and psychotherapy Papadopoulos and Byng-Hall (1997) have noted a general shift from "historical truth" (i.e. that which is uncovered by the therapist) to "narrative truth" (i.e. that which is co-constructed by the therapist and the "client"). In this clinical context narrative is used as a therapeutic method whereby the therapist acts as narrator in the process of co-constructing a more coherent narrative of a particular event or experience (Byng-Hall, 1997). The practice of psychotherapy therefore is an "exercise in story repair", as the therapist assists the person in the reconstruction of life narratives that have become too restrictive (Crossley, 2000). I used narrative as a method in this sense when I worked with a person with aphasia eight years post-onset, whereby the focus of therapy was to shift the person from a narrative that was not contributing to his feeling of well-being to a narrative that would (Barrow, 2000). In this way therapy facilitated the person to draw on narratives to reframe aphasia and to change their perception of their personal experience.

4.6 SUMMARY

This review on narrative has touched on a number of factors surrounding narrative as an approach to research as well as a dynamic therapeutic tool. It began with defining narrative under two broad categories which I termed *story-type narrative* and *metaphor-type narrative*. The present study uses, among other things, story-type narrative to access metaphor-type narrative. The review then went on to describe different narrative perspectives – in particular those of Frank (1995), Stainton Rogers (1991) and Crossley (2000) – in terms of the narratives they identified as being relevant to health, illness and disability. It then outlined a number of different narrative studies that had been undertaken, each with slightly different perspectives on narrative. These included studies of the narratives of individuals and studies of practitioner narratives

and how these influenced the way in which people with disabilities lead their lives. Some studies of narratives of people with communication impairment were then presented. Finally it sketched narrative's therapeutic role. In essence narrative 'weaves disruption into the fabric of life' in that it allows the person to integrate the experience of illness or acquired disability with subsequent life experiences and to understand one's own and others' actions and behaviour in relation to the disruption (Becker, 1999). Narratives bind us with others and without shared narratives we become socially isolated (Donald, 1998). A person's experience of aphasia is woven in and within other narratives which both influence the experience of aphasia and are influenced by aphasia.

As referred to in this review, a number of studies have been undertaken to explore narratives of illness, disability and communication impairment. They have provided much insight into the lived experience of disability. However none explore in depth the narratives people draw on to make sense of disability and manage it in day to day life. While Simpson (2000) comes closest to this in her study of narratives in the reconstruction process of identity in aphasia, no-one, to the best of my knowledge, has explored narrative in terms of what narratives individuals with aphasia *and* their conversation partners tap into to make sense of aphasia and guide behaviour. This study addresses this issue. It explores the personal and public narratives that people draw on to understand their situation and how they influence the way in which they cope and live their lives. Using narratives elicited at interview and via other methods, this study involves the participation of people with aphasia and some of their conversation partners. The nature of the study demands a qualitative methodology and the following chapter will provide an introduction to the methodology used.

CHAPTER 5 METHODOLOGY

This chapter outlines some background to the methodology used in the form of addressing key questions. It goes on to discuss qualitative research, focusing on narrative and ethnography in particular. Some of the issues surrounding reliability and validity in qualitative research are outlined.

5.1 BACKGROUND

Mason (1996, p.11-18) suggests that the researcher asks five key questions in order to produce a useful and good research design:

- i. "What is the nature of the phenomena or entities, or social 'reality' which I wish to investigate?" (p.11) i.e. one's ontological position.
- ii. "What might represent knowledge or evidence of the entities to social 'reality' which I wish to investigate?" (p.13) i.e. one's epistemological position.
- iii. "What topic, or broad substantive area, is the research concerned with?" (p.13).
- iv. "What is the intellectual puzzle? What do I wish to explain? What are my research questions?" (p.14).
- v. "What is the purpose of my research? What am I doing it for?" (p.18).

I answer each of these questions in turn so as to provide a backdrop to what the research is about and the research methodology adopted.

What is the nature of the phenomena or entities, or social 'reality' which I wish to investigate?

Lemay's (1993) statement "language enables one to carve out one's place in society and to achieve recognition as an individual" (p.209) encapsulates the privileged role that language plays in our society. The very essence of relationships is communication; the two are mutually dependent as relationships are constructed and lived through language and communication. Language is the major cultural resource that people draw

on to jointly create reality (Riessman, 1990, 1993). Sacks (1991) echoes this position but in stronger terms.

And to be defective in language, for a human being, is one of the most desperate of calamities, for it is only through language that we enter fully into our human estate and culture, communicate freely with our fellows, acquire and share information. If we cannot do this, we will be bizarrely disabled and cut off – whatever our desires, or endeavours, or native capacities. And indeed, we may be so little able to realise our intellectual capacities as to appear mentally defective. (p.8-9)

Relating communication ability to being human is also emphasised by Tschudin (2000) when she says "we have to express ourselves in order to be, become, and remain human." (p.58)

Communication therefore opens doors to our family, social, educational and working lives. It plays a crucial part in how we go about our day to day business. Society demands and expects good communication skills (Lemay, 1993; Garcia, Barrette & Laroche, 2000) this is evidenced by the fact that a pre-requisite to many areas of study and employment is "good communication skills". This dominance of the importance of communication potentially fosters negative attitudes and beliefs that those who do not meet society's criteria for effective communication are less able and competent (Kagan & Gailey, 1993; Kagan, 1995, 1998). The reality is that people live and operate within personal social networks, and that the presence of aphasia affects not just one but many. Therefore the social reality is that society penalises those with communication impairment in terms of access to opportunities to fulfil their familial, social, vocational and educational lives and so potentially reduces their power and sense of autonomy. Whilst adaptation and re-adjustment are part of the penalty imposed on the person with aphasia, there is a belief among some disabled people and others who align to the disability rights movement, that minority groups (such as disabled people) have a right to opportunities to live life as they wish. As discussed in Chapter Three, they believe that it is society that needs to adapt rather than the person with the impairment, in order to facilitate realisation of these goals (e.g. Swain et al, 1993; Barton, 1996b; Hales, 1996; Oliver, 1996b).

What might represent knowledge or evidence of the entities to social 'reality' which I wish to investigate?

Research, knowledge and personal experience provide the basis for the following comments. It is evident that the amount of genuine social participation of someone with aphasia is reduced as compared to before the onset of aphasia (e.g. Hemsley & Code, 1996; Parr et al, 1997). This constitutes evidence that having aphasia affects full participation. Both the quality of interactions that people with aphasia engage in, and the balance within these interactions are affected (Parr et al, 1997). The way in which an individual relates his/her experience and views may provide evidence as to their life narratives i.e. the stories that one lives by (Somers, 1994), and these narratives in turn may influence the way in which she/he behaves. In the case of those with aphasia the relating of the story may be problematic because of the restrictions imposed by the language impairment itself.

What topic, or broad substantive area, is the research concerned with?

The study aims to gain insight into how ways of thinking about aphasia and disability affect the way in which people live their lives with aphasia, as well as how their conversation partners behave towards them. In particular it is about exploring the public and personal narratives that shape the way in which persons with aphasia and some of their conversational partners make sense of and manage aphasia in day-to-day life. It explores the correspondence and dissonance between these different narratives of aphasia and how personal and public narratives interweave.

What is the intellectual puzzle? What do I wish to explain? What are my research questions?

The key areas that I wish to investigate include:

- What narratives do people with aphasia draw on to make sense of aphasia and disability and manage it in day to day life?
- What narratives do those close to the person with aphasia draw on to make sense of aphasia and manage it in day to day life?

- How do narratives affect the way in which the person with aphasia behaves and how others behave towards her/him?
- What is the relationship between public and personal narratives?

What is the purpose of my research? What am I doing it for?

There are two main purposes to this research. Firstly, I wish to find out more about how people with aphasia make sense of it and manage it in day to day life. Secondly, it is towards achieving a higher degree and so extend my professional development.

This research is about increasing my understanding about what factors contribute to the overall experience of aphasia and how this may contribute to clinical practice. It will promote understanding of different narratives, how they may be expressed and how they may prepare and equip an individual to deal with potential conflict. It is hoped that the outcome of this study will potentially affect clinical practice in terms of extending the speech and language therapist's role with people with aphasia, to incorporate work on addressing their narratives of aphasia, and to facilitate a shift from 'unhelpful' narratives to 'helpful' ones. The work undertaken will contribute to the narrative literature in terms of extending our knowledge about narratives of disability, and of aphasia in particular. Links will be drawn with the work of Frank (1995) and his illness narratives, to Stainton Rogers' (1991) meanings of health and illness, and Crossley's (2000) HIV narratives. It is also hoped that it will contribute to the disability literature through the exploration of what it is like to live with aphasia from a variety of perspectives (i.e. conversation partners) and not just the person with aphasia.

My aim is to explore and identify narratives of aphasia which will be subtle, mercurial and manifested in different ways. Therefore an appropriate methodology was sought to suit my purpose. A qualitative research methodology best answered my needs as it draws on a number of methods to explore areas that are subtle in nature. It is best suited to exploring how the social world is experienced, constructed and represented by participants. The following section outlines what is meant by qualitative research methodology.

5.2 QUALITATIVE RESEARCH

Denzin & Lincoln (1998) define qualitative research as follows:

Qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meaning people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials – case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts – that describe routine and problematic moments and meanings in individuals' lives. Accordingly, qualitative researchers deploy a wide range of interconnected methods, hoping always to get a better fix on the subject matter at hand. (p.3)

The essence of qualitative research is that systematic inquiry occurs in a natural setting as opposed to an artificially constructed one. Qualitative researchers focus on social worlds and use a variety of methods to identify and reconstruct the perspectives and patterns of action and interaction (Silverman, 1993; Miller, 1997). Quantitative methods artificially screen out the "mess of everyday life", whereas qualitative research tries to deal with all the mess in all its complexity (Sanger, 1996).

5.2.1 Why Qualitative Research?

The British Aphasiology Society published a document entitled 'Where to begin in Aphasia Research' (1996), in which they differentiate between qualitative and quantitative research methodology.

Qualitative and quantitative research ask different questions in different ways. Quantitative research uses statistical methods to investigate the extent and location of phenomena and the relationship between them. It identifies discriminating variables in order to gain outcomes, model predictions and test hypotheses. Qualitative research explores the form and nature of phenomena. It investigates human experience in order to identify processes, attitudes, systems, pathways and obstacles and to generate theories and strategies. One aim of the qualitative approach is to deepen understanding of the views and perspectives of the people the research is about. It does not allow for quantification and should not be used to produce numerical information. (p.11)

Quantitative methods are appropriate for addressing questions of prevalence, causality, the relationship between variables, prediction, comparison and measuring outcomes. In contrast, qualitative methods are appropriate to address questions of process that would include such issues as perception, experience and understanding (Barbour, 1999). Quantitative methods have provided knowledge about the range and extent of chronic illnesses, while qualitative methods have focused on the subjective impact of the illness

for the person concerned (Armstrong, 1990). Qualitative research methods then allow one to understand social phenomena in natural settings while attending to the meanings, experiences and views of the participants. This study addresses and tries to access the meanings, experiences and views of participants.

Qualitative research methods are now recognised as having a key role in providing insights, explanations and theories of social behaviour (Ritchie & Spencer, 1994). There is an awareness that such methods, with the depth of analysis and restricted numbers, have poor generalizability – but it is equally well recognised that they provide a rich source of information about lived experience (e.g. Agar, 1986; Armstrong, 1990; Conrad, 1990; Layder, 1993; Coffey & Atkinson, 1996; Mason, 1996; Denzin & Lincoln, 1998).

This system of research is a rigorous, powerful and well-accepted scientific paradigm that has a place in clinical Aphasiology. With its strengths and objectives, it can assist in understanding and addressing the impairments, disabilities and the handicaps of aphasia. (Damico, Simmons-Mackie, Oelschlaeger, Elman & Armstrong 1999, p.663)

Guba & Lincoln (1998) assert that human behaviour cannot be understood without reference "to the meanings and purposes attached by human actors to their activities" (p.197-198). Communication is difficult to define as a physical entity as it is creative, social, complex and interactive. For this reason Eastwood (1988) cautions against the use of quantitative research methods in studying communication. Aphasia is an impairment that affects the person's ability to process language, the consequences of which lead to difficulties in communication. If our aim therefore is to gain insight into the lived experience of aphasia and so increase our understanding of it from the individual's perspective, then a methodology is required to enable us to do so. This could then pave the way for approaches to therapy and research that take the perspective of the individual more fully into account. The present study is exploring the consequences and impact of disability and this is best understood by "providing authentic data, namely, collecting and displaying evidence on the experiential side of how chronic illness and its treatment affect a person or family" (Gerhardt, 1990, p.1149). Qualitative methods are more appropriate than quantitative methods for this purpose.

Where quantitative method had enabled the extent and variability of the population to be plotted, qualitative method explored the subtleties of personal meanings and subjective experience. The object of this latter procedure was a new one: the target was not the community of bodies, but the discourse of suffering. (...) [Qualitative methods] demanded that the patient speak to fill the space where before there had been silence. (Armstrong, 1990:1227)

There is now wider use of qualitative methods in response to persistent requirements to understand complex behaviours, needs, systems and cultures (Ritchie & Spencer, 1994). Recognition of the contribution that qualitative research can make to health issues is reflected in the increasing number of studies in the literature that utilise qualitative research methods. For example, they have been used to gain information about children's knowledge and attitudes to health (Oakley, Bendelow, Barnes, Buchanan & Husain, 1995), to look at effective management of diabetes in the British Bangladeshi population (Greenhalgh, Helman & Chowdhury, 1998), to study how general practitioners recognise meningococcal disease (Granier, Owen, Pill & Jacobson, 1998), to explore people's experience of rehabilitation (Lewinter & Mikkelsen, 1995) and of aphasia (Parr et al, 1997).

5.2.2 Objectives, Strengths and Weaknesses of Qualitative Research

Damico et al (1999) outline the objectives, strengths and weaknesses of qualitative research.

a) Objectives of qualitative research

They provide five general objectives of qualitative research.

- i. Taking a learning role: the aim is to understand the various social actions and how they are accomplished.
- ii. Understanding procedural affairs: the understanding of how things function is key to the analysis of social action.
- iii. Presenting a detailed view: the use of rich descriptions of the behaviours and contextual elements to determine 'what's going on here'.
- iv. Focus on the individual: the primary interest is the micro features that are manifested in the immediate actions of the individual.

v. Understanding the mundane: there is a focus on the routine activities of the individual as this is where "the roots of society and the phenomena that define us as social in nature" (p.654) are to be found.

b) Strengths of qualitative research

Damico et al (1999) review the strengths of qualitative research. They outline seven characteristics.

- It studies phenomena in natural settings. Social actions are always contextually situated and cannot be studied adequately without attending to those variables that influence them.
- ii. There is a preference for open and relatively unstructured research design.

 There is flexibility to adjust methods of collection and analysis to suit the specific needs of the research at any given time.
- iii. The researcher is the key instrument of data collection. Data collection takes place in natural settings and so cannot be controlled, therefore the researcher has to adjust accordingly.
- iv. Descriptive data is collected. A better understanding of behaviour and patterns of interaction is accomplished through actual descriptions of social action rather than pre-determined categories or numbers.
- v. It is oriented towards a focused description rather than a broad one. The researcher tends to work with limited numbers of participants and more variables to enable a focus on the inter-dependence of social actions within the context in all its complexity.
- vi. The focus is on the process of accomplishing social action (i.e. how things happen rather than the fact that they happen).
- vii. The focus is on participants' perspectives to achieve a deeper understanding of the data.
- c) Weaknesses of qualitative research

 According to Damico et al (1999), the weaknesses of qualitative research include the following:

- i. It is labour intensive. There is always a need to verify the authenticity of findings using methods of triangulation and analytic induction. As the researcher is the primary instrument of data collection and analysis, much of the work cannot be assigned to an assistant.
- ii. It involves experience-based learning in that one needs hands-on experience to learn the many nuances of research strategy.
- iii. It operates from a different set of methodological assumptions. One needs to establish the credibility of findings. The naturalistic settings used and the complexity of the contextual variables mean that it is not possible to replicate to verify credibility. The key issue is the dependability and authenticity of the data collected. "The essence of qualitative research pivots on its descriptive and explanatory power" (Damico *et al*,1999, p.660).
- iv. It may be open to abuse. One needs to employ verification methods which involve relating or comparing multiple data types to support or contradict interpretations.

Quantitative research methods, appropriate for investigating physical entities, use mathematical models, statistical tables and third party accounts, whereas qualitative methods seek answers to questions that stress how social experience is created and given meaning and it uses ethnography, first person accounts and narratives (Denzin & Lincoln, 1998). This is a narrative study using ethnographic methods, exploring a number of different but related aspects of the experience of living with aphasia. The following sections briefly outline issues surrounding narrative research and ethnography.

5.3 NARRATIVE RESEARCH

Narrative approaches give prominence to human agency and so are best suited to studies of subjectivity. This is a study exploring narratives of aphasia in terms of ways of thinking and experiencing disability. Various narratives contribute and influence the way in which we constantly reconfigure ourselves and our world (Somers, 1994). Therefore a person's experience of aphasia is woven in and within other narratives

which both influence the experience of aphasia and are influenced by the aphasia. One needs some systematic way of identifying such narratives. The present study sets about analysing the text of interviews and fieldnotes for the purpose of discovering ways of thinking and experiencing disability. Narrative is one approach to research that allows one to do this as its aim is to restrain the dominant voice of health professionals to allow the person's voice to be heard (Riessman, 1993; Booth, 1996; Coffey & Atkinson, 1996; Elwyn & Gwyn, 1999; Jones, 1999). It allows for the systematic study of human experience (Riessman, 1993) and provides a framework and method to view things holistically (Greenhalgh & Hurwitz, 1998). In narrative research there is an assumption that there is neither a single absolute truth nor one correct reading or interpretation of a text, rather a narrative approach advocates pluralism, relativism and subjectivity (Lieblich et al, 1998). Lieblich et al (1998) go on to define narrative research as "any study that uses or analyzes narrative materials, the data can be collected as a story (a life story provided in an interview or a literary work) or in a different manner (fieldnotes of an anthropologist who writes up his or her observations as a narrative or in personal letters). It can be the object of the research or a means of the study of another question." (p.2).

According to Lieblich et al (1998), features of narrative research include the following:

- There are lengthy transcripts to analyse.
- There is usually no *a priori* hypothesis though there may be some general direction; specific directions emerge from reading the collected material.
- It requires dialogic listening to three voices: that of the narrator (i.e. the text), the theoretical framework (i.e. the concepts and tools of interpretation), and reflexive monitoring of the act of reading and interpretation.
- It does not require replicability of results as a criterion for its evaluation, rather it relies more on personal wisdom, skills and integrity of the researcher. However interpretative decisions require justification: "narrative work requires self-awareness and self-discipline in the ongoing examination of text against interpretation, and vice versa" (p.10).

While narrative studies are flourishing in the literature as a means of understanding the person, there are few prescriptive guides for understanding and evaluating narrative research. This is because of the relative infancy of this type of methodology in psychology and the social sciences (Lieblich *et al*, 1998). However most writers stress the importance of considering the 'how' of telling as well as the 'what' (e.g. Conrad, 1990; Riessman, 1990 & 1993; Coffey & Atkinson, 1996; Atkinson, 1998; Abma, 1999; Becker, 1999; Elwyn & Gwyn, 1999).

The analysis of narrative is a primary means of uncovering how disruption is expressed and how continuity is created, and for examining disparities between cultural ideals and people's experiences. (Becker, 1999, p.18)

Jones (1999) advocates asking a number of questions of the narrative concerning the angle the person is coming from, the reliability of narrative, whose voice is not being heard and why, what kind of language and images the narrator uses and what affects this may have in creating patterns of meaning.

I now address and outline two particular approaches to narrative research: Riessman's (1993) perspective and the approach taken by Lieblich and her colleagues (1998). Riessman provides a framework of the stages one goes through in the research process, while Lieblich *et al* focus on a model for the analysis of the narrative itself.

5.3.1 Riessman's (1993) Perspective

Riessman (1993) is one author who discusses the actual analysis of narrative. She outlines five main representations in the narrative research process.

- i. Attending to the experience which involves selecting phenomena to focus on.
- ii. Telling about the experience, whereby the narrative is co-produced with an audience.
- iii. Transcribing the experience so that the representation becomes text.
- iv. Analysing experience which involves three main functions:
 - Ideational function, whereby one analyses content (i.e. what is said).
 - Interpersonal function, whereby the context and role relationships are considered.

- Textual function, whereby structure and form are considered (i.e. how it is said).
- v. Reading experience, whereby readers bring their own meaning to bear.

At each level of representation different features are selected and other interpretative elements added.

The analysis of the narrative then leads to a rebirth of the story in "an alien tongue". All narratives are "limited portraits" in that "meaning is ambiguous because it arises out of a process of interaction between people: self, teller, listener and recorder, analyst, and reader. (...) Meaning is fluid and contextual, not fixed and universal." (Riessman, 1993, p.15). Therefore narratives are always "edited versions of reality".

5.3.2 Lieblich, Tuval-Mashiach & Zilber's (1998) Perspective

Lieblich *et al*, (1998) go into more depth in their framework for analysing narrative data. They propose four key ways of analysing narrative, all of which are interlinked.

- i. Holistic-content analysis: in this approach one uses the complete text and focuses on the content presented in it. One analyses a particular part in light of the context of the story in its entirety.
- ii. Holistic-form analysis: this approach focuses on the plot or structure of the whole story. There are four principal narrative types.
 - 'Romance' whereby the essence of the journey is the struggle itself, the hero faces a series of challenges en route to the goal and eventual victory.
 - 'Comedy' whereby the goal is the restoration of social order and the hero must have the skills to overcome the hazards that threaten that order.
 - 'Tragedy' whereby the hero is defeated by forces of evil and ostracised from society.
 - 'Satire' whereby the theme is a cynical perspective on social hegemony.

 They suggest that analysing the structure of a story will reveal the "individual's personal construction of his or her evolving life experience" (p.88).

- iii. Categorical-content analysis: this approach is traditionally referred to as 'content analysis' whereby bits of the text are extracted, classified, and gathered into categories. These bits of text are then submitted to either descriptive or statistical treatment. In the case of the present study it is submitted to descriptive treatment utilising the qualitative data analysis 'Framework' (Spencer & Ritchie, 1994). This is outlined in depth in the next chapter.
- iv. Categorical-form analysis: this approach focuses on the discrete stylistic or linguistic characteristics of defined units of narrative. Therefore it looks at such things as metaphor, nominalisation and agency. Structural aspects of the narrative are more attuned to the deeper levels of personality and are less easy to manipulate. This study is utilising Fairclough's (1989, 1992) Critical Discourse Analysis to address issues of form (to be discussed in the next chapter). The purpose of this form of analysis is to "learn something about the speaker that might not have been apparent from examination of the content alone" (p.141). Analysis is undertaken in the context of the rest of the text.

Lieblich et al (1998) advocate using both content and form analysis as:

Synthesis between form analysis and content analysis can prove very fruitful. Form analysis requires the researcher to engage in definition of criteria, classifications, and examination of the deep structure of a text, while consideration of these categories in terms of content often highlights dimensions and distinctions that would not have arisen from purely structural analysis. (p.163)

Lieblich et al (1998) acknowledge that content and form are linked, in that when exploring form one cannot ignore content and vice versa. Similarly separation of the whole and category is not clearcut.

In terms of the approaches outlined by Lieblich *et al* (1998), this study focuses on categorical-content and categorical-form analyses while paying some attention to holistic-content and holistic-form analyses.

People with aphasia, due to the very nature of their impairment, pose a particular challenge in the analysis of both form and content. For example they may not have the flexibility of language use to convey precisely what they mean and may rely on other

methods to get their message across effectively (e.g. the use of gesture, writing, drawing, pictures, environment, resources of the conversation partner). For this reason multiple methods using the principles of ethnography are being utilised here for data generation.

5.4 ETHNOGRAPHY

Ethnography is a qualitative approach to research with origins in the classical tradition of anthropology. Geertz (1973) provided a summary of what 'doing ethnography' means:

doing ethnography is establishing rapport, selecting informants, transcribing texts, taking genealogies, mapping fields, keeping a diary, and so on. But it is not these things, techniques and received procedures that define the enterprise. What defines it is the kind of intellectual effort it is: an elaborate venture in (...) "thick descriptions"." (p.6)

This early description of the ethnographic endeavour highlights the importance of looking at the subject from a variety of viewpoints in order to achieve detail and depth with the result that one gains a comprehensive knowledge of the lives of those under study. But more than this it emphasises the process of immersing oneself in the data and extrapolating themes in order to gain this understanding.

Elaborating on Geertz's (1973) summary, Agar (1986) provides a definition of ethnography as follows:

Ethnographers set out to show how social action in one world makes sense from the point of view of another. Such work requires an intensive personal involvement, an abandonment of traditional scientific control, an improvisational style to meet situations not of the researcher's making, and an ability to learn from a long series of mistakes. (p.12).

Ethnography is the research methodology of choice as it fits with the research questions and the exploratory nature of the study. It is a method 'of discovery'. Ethnography has been embraced by other traditions (e.g. sociology, psychology), in an attempt to study many other societal phenomena, because it proved to give insights into how people behaved and interacted together. Only a few ethnographic studies have been undertaken in the area of acquired communication disability (Simmons, 1993; Goodwin, 1995; Parr, Pound & Byng, 2001) and child language (Haas, 1994).

Ethnography involves the researcher participating in people's daily lives and collecting whatever data are available that might shed light on the issue in hand (Hammersley & Atkinson, 1995). This methodology adopts the stance that the researcher is not the expert, but rather learns from those she/he is studying. One sees things from the perspective of the participants and then one stands back for a more detached assessment. It involves commitment to the idea that "adequate knowledge of social behaviour cannot be fully grasped until the researcher has understood the 'symbolic world' in which people live." (Fielding, 1993a, p.157).

Hymes (1964) took ethnography into the realms of discourse analysis. His *Ethnography of Communication* is the most encompassing approach to discourse. It is concerned with holistic explanations of meaning and behaviour. It contends that communicative behaviour is never free of cultural belief and the system in which it occurs. It does not see communicative behaviour in isolation, but rather is concerned with the *what* (i.e. the situation), the *how* (i.e. the language and paralinguistic features used), and the *who* (i.e. the people involved) of communication. It acknowledges and assumes diversity within a speech community. Hymes (1972, cited in Schiffrin, 1994) proposed a methodology for investigating communication, the *SPEAKING Grid*. In this each letter is an abbreviation for a different component of communication; the smallest unit is the speech act and the larger ones are the situation or the scene itself. Categories of language use, not language structure, have theoretical priority. Schiffrin (1994) summarises an ethnographic approach to discourse by saying:

an ethnographic approach to discourse seeks to discover and analyze the structures and functions of communicating that organize the use of language in speech situations, events and acts. Knowledge of these structures and functions is part of our communicative competence: what we say and do has meaning only within a framework of cultural knowledge. (p.185)

5.4.1 Methods Used In Ethnography

A number of qualitative research methods are employed to investigate a person's social world. The emphasis of these methods is on depth, intensity and richness using a naturalistic stance (Fielding, 1993a). Methods include in-depth interviews, observation, use of artefacts and use of audio and video recording. Each of these is outlined in brief.

a) In-depth interviews

Qualitative interviews provide a means to explore the points of view of the participants. They allow one to generate information that would be otherwise difficult to obtain. Such interviews do not follow pre-determined questions, but take the form of a conversation with a purpose. They are characterised by an informal style, a thematic or topic centred approach and an assumption that data can be generated via the interaction (Mason, 1996). What is told at interview is mutually constructed between the teller and the listener according to what it means to both of them (Riessman, 1993; Gabriel, 1995; Byng-Hall, 1997). "A story is told in the context of listening. The way a family story is heard and responded to moulds the story itself" (Byng-Hall, 1997, p.105). Lieblich *et al* (1998) highlight that interpretation occurs all the time.

the mere acts of being together in a room, stating the purpose of the encounter, asking questions, relating to the responses and participating in the creation of an atmosphere, some interpretative choices have already been made (p.166)

To ensure that the voice of the person's life-world takes precedence McAdams advises one to 'simply listen', not to interfere in the telling, not to pass judgement, not to give advice, to affirm rather than threaten and to try to communicate in such a way as to allow the true story to be revealed. Therefore the object is for the person to have the opportunity to talk in her/his own terms. However it is still important to remember that what is told to the interviewer is constrained by the language of interviewing which "fracture" the stories being told (Miller & Glassner, 1997).

In general qualitative interviews have been a popular method to gain access to the meanings of experience within the context of the person's life-world. They have been successfully used in exploring attitudes and beliefs relevant to the management of diabetes (Greenhalgh *et al*, 1998), the role of contextual information in the recognition of meningococcal disease (Granier *et al*, 1998), the experience and meaning of disability (Phillips, 1990), the experience of rehabilitation (Lewinter & Mikkelsen, 1995), the meaning of stammering (Corcoran & Stewart, 1998) and the experience of living with aphasia (Parr *et al*, 1997).

b) Observation in natural settings

In participant observation the investigator is invariably poised between "stranger" and "friend" (Hammersley & Atkinson, 1995). Mason (1996) defines participant observation as:

methods of generating data which involve the researcher immersing herself or himself in a research setting, and systematically observing dimensions of that setting, interactions, relationships, actions, events and so on, within it. (p.61).

Sanger (1996) cautions one to ensure that the background is observed, as well as the foreground. He goes on to comment that all the information we see is sieved through what we feel is important at that particular point in time. Therefore since bias can affect what we observe and note, the importance of reflexivity becomes apparent (reflexivity is discussed in more depth later in 5.5.2).

Observation has been used in the study of compensatory strategies in aphasia (Simmons, 1993), in exploring the co-construction of conversation with someone who has aphasia (Goodwin, 1995) and in exploring the experience of severe aphasia (Parr *et al*, 2001).

c) Use of artefacts

Artefacts can be things that already exist (e.g. medical records, articles, diaries) or can be generated by the research process itself (e.g. diaries, drawings). They relate to some aspect of the social world. In her study of compensatory strategies in aphasia Simmons (1993) used artefacts, as did Parr *et al* (2001) in their study of severe aphasia.

d) Use of audio and/or video recording

This can involve the recording of behaviour and interactions of participants for later analysis which may include discourse analysis. Both Simmons (1993) and Goodwin (1995) used video recording in their studies of behaviour in aphasia.

The main idea for the use of multiple methods is to allow for a better fix on the issues under scrutiny. These methods together constitute the person's overall narrative of their experience and life-world. The individual, and all that they bring, shape both the content of the narrative and the way in which it is told (Jones, 1999). However as a narrator of that person's story I offer my representation of what I have heard the person tell me and what I have seen that they do (Riessman, 1993). My own social and cultural past, as well as my own personal story, inevitably moulds this representation (Barton, 1996a; Vidich & Lyman, 1998). Therefore what I hear and see is sifted through my social, cultural and vocational history.

5.4.2 Features of Ethnography

There are a number of features characteristic of ethnography. These include its cyclic nature, contextuality, grounded theory and authenticity. Each is outlined in brief.

a) Cyclic nature

The process of data generation and data analysis is not a linear endeavour, rather data analysis can inform and guide data generation and in so doing refines and develops the focus of the research (Agar, 1986; Hammersley & Atkinson, 1995).

In ethnography the analysis of data is not a distinct stage of the research. (...) Formally, it starts to take shape in analytic notes and memoranda; informally, it is embodied in the ethnographer's ideas and hunches. And in these ways, to one degree or another, the analysis of data feeds into the research design and data collection. (Hammersley & Atkinson, 1995, p.205)

The design is emergent as it unfolds as data are collected, analysed and verified. At the outset ethnographic studies do not know where they are going to end up.

b) Contextuality

In ethnography there is an assumption that realities cannot be understood without their context. "Understanding a behaviour or an event requires understanding the complex, interacting variables within the social system." (Simmons-Mackie & Damico, 1999a, p.682). Therefore authentic contexts and naturally occurring events are the sources of data generation. In general multiple data sources are accessed.

c) Grounded theory

All explanations are derived from the data rather than the researcher's prior viewpoint. The assumption underlying qualitative methods is that the 'social world must be discovered' (Layder, 1993). Therefore it is discovery driven in that one seeks to discover whatever emerges as important in order to understand the phenomena under study.

d) Authenticity

The criterion for acceptability is authenticity. Data must represent multiple instances of naturally occurring phenomena, collected from various sources and analysed at multiple levels. This ensures that the perspective is representative. The finished report should be a thick description that is plausible and credible, based on evidence which is grounded in the data (Simmons-Mackie & Damico, 1999a). (Please refer to discussion below on reliability and validity.)

5.5 RELIABILITY AND VALIDITY

There is some debate as to whether the criteria for reliability and validity used for quantitative research should be applied to qualitative methods. Some reject the issues of reliability and validity (e.g. Agar, 1986). Lieblich *et al* (1998) state that such criteria for evaluating research contradict the very nature of narrative research as "narrative materials – like reality itself – can be read, understood, and analyzed in extremely diverse ways, and that reaching alternative accounts is by no means an indication of inadequate scholarship but a manifestation of the wealth of such material and the range of sensitivities of different readers." (p.171). Alternatively, they outline four criteria on which to judge such research – width, coherence, insightfulness, and parsimony. However most writers believe that qualitative researchers should address this issue in some way (e.g. Kirk & Miller, 1986; Mason, 1996; Silverman, 1993, 2000; Barister, Burman, Parker, Taylor & Tindall, 1994; Mays & Pope, 2000; Barbour, 2001). Outlined below are some of the procedures that one can employ to enhance reliability and validity, but they are not without their problems.

5.5.1 Reliability

Reliability involves the degree of consistency with which something can be measured or rated (Silverman, 2000). Conventional measures of reliability are generally more comfortably associated with quantitative research where standardised instruments are used. Banister *et al* (1994) comment that the concept of reliability is not appropriate for qualitative research and that replication in this type of research is more to do with reinterpreting the findings from different standpoints or exploring the same issues in different contexts, rather than expecting or desiring consistent accounts. What is required is a clear and detailed account of the method and procedures (Kirk & Miller, 1986; Silverman, 1993; Mason, 1996). One needs to satisfy others that the data have not been misinterpreted.

Kirk and Miller (1986) propose a number of ways to increase reliability in qualitative research, these include:

- For reliability of observation one should have extended extracts of fieldnotes available for the reader to scrutinise. There should be a clear use of conventions.
- For reliability of texts some data should be given to other researchers for them to analyse them according to an agreed set of categories. Reports are then examined and differences discussed and resolved.
- For reliability of interviews it is helpful to pilot an interview schedule and compare how different people analyse the same data.
- For reliability of transcripts one should use standardised conventions.

Therefore the two main ways to address reliability are by using standardised methods to write fieldnotes and prepare transcripts and also by comparing the analysis of the same data by several researchers. This study attempts to meet these criteria.

5.5.2 Validity

Validity is another word for *truth* and one needs to convince others that the findings are based on critical investigation of all the data and do not depend on a few well chosen examples (Silverman, 2000). Therefore it is a means to ensure that you are observing

and identifying what you say you are (Mason, 1996). Banister *et al* (1994) state that validity in qualitative research has to do with "the adequacy of the researcher to understand and represent people's meanings" (p.143). Atkinson (1998) states "the narrative approach to the study of lives maintains emphasis on internal coherence as experienced by the person rather than external criteria of truth or validity." (p.61).

There are a number of interrelated methods that one can employ to increase credibility of one's findings, though these are not without their problems. These methods include triangulation, respondent validation, reflexivity, negative or deviant cases and transparency. Each of these is described in brief.

a) Triangulation

This refers to the use of a combination of methods to explore the research question(s). Multiple methods are used to "secure an in-depth understanding of the phenomena in question" (Denzin & Lincoln, 1998, p.4). One uses different methods and/or data sources to investigate the same phenomenon and one judges the validity by comparing the products. According to Banister et al (1994) "triangulation makes use of combinations of methods, investigators, perspectives, etc. thus facilitating richer and potentially more valid interpretations." (p.145). It reflects a commitment to thoroughness, flexibility and differences of experience. However triangulation has been criticised as a method to ensure validity on grounds that different methods and sources defy comparison, as they come in different forms. They shed light onto different social phenomena and so provide different versions of the answer to the question(s); different methods and sources give parallel datasets, each giving only a partial view of the whole picture (Silverman, 1993; Mason, 1996; Barbour, 2001). Therefore one cannot assume that a true fix on reality can be achieved by looking at it from different angles. Mason (1996) proposes that the concept of triangulation is useful in so far as it encourages one to approach research questions from different angles and in a multifaceted way. In this way validity is enhanced in that it suggests that social phenomena are more than onedimensional. Using diverse methods ensures comprehensiveness and provides a means

of exploring the complexity of the social world (Coffey & Atkinson, 1996), as well as adding "rigour, breadth, and depth to any investigation" (Denzin & Lincoln, 1998, p.4).

b) Respondent validation or member checking

This is a procedure whereby interim findings are cross checked with participants. It posits that credibility increases when the investigator's reconstructions are recognisable as adequate representations by the participants. However this assumes that participants have privileged status to act as commentators on their own actions (Mason, 1996; Silverman, 2000). Also one needs to consider that human stories are not static: "meanings or experiences shift as consciousness changes" (Riessman, 1993, p.66). The meaning and validity may be different for the one who has told their story than for the one who is recording it (Atkinson, 1998). The researcher and participants look at findings from different perspectives; the researcher gives a wide overview while participants are more concerned about whether the findings are compatible with their self image. Therefore accounts may differ. Respondent validation is best viewed as a process of error reduction and as another source of data and insight, rather than as a means to validate the report (Silverman, 1993, 2000; Mason, 1996; Mays & Pope, 2000).

c) Reflexivity

This is a key feature of qualitative research in that much is dependent on the perception that is shaped by the personality of the researcher and by the nature of the interaction with the participants (Punch, 1998). Therefore it is important to reflect on one's part in the process. Reflexivity has been described as:

an attempt to make explicit the process by which the material and analysis are produced. (...) The research topic, design and process, together with the personal experience of doing the research, are reflected and critically evaluated throughout. (Banister *et al*, 1994, p.149-150).

It is about acknowledging who one is as a researcher and how this influences the research process. It addresses how one's individuality shapes and directs the course of the research and how the personal qualities of the researcher are intertwined with the process and so is a product of the research. Therefore it acknowledges the central

position of the researcher in the construction of knowledge (Banister et al, 1994). Thus the level of personal engagement in the research process is revealed rather than concealed. Personal biases, values, etc. must be made clear at the outset and discussed in relation to how the research has progressed and interpretations found.

d) Negative or deviant cases

One way to improve quality is to search for and discuss elements in the data than contradict the emerging explanation is to search for negative cases. One purposefully seeks out negative or deviant cases that refute the findings, and in this way the analysis is refined until it can explain the majority of cases under scrutiny. Every bit of data has to be used until it can be accounted for (Mays & Pope, 2000; Silverman, 2000).

e) Transparency

It is important to give a clear and detailed account of methods of data generation and analysis. Enough information needs to be provided to make it possible for others to determine the trustworthiness of the work (Riessman, 1993). One needs to demonstrate how an interpretation was reached and spell out the logic of methodological choices as well as analytical decisions and practices (Mason, 1996; Mays & Pope, 2000). This allows readers to evaluate exactly how conclusions have been reached.

The procedures outlined above do not confer rigour in the traditional sense. However they strengthen rigour if they are embedded into a broad understanding of qualitative research design and data analysis (Barbour, 2001). Indeed Mays and Pope (2000) state that the basic strategy to ensure rigour and thus quality is systematic, self conscious research design, data generation, interpretation and communication.

5.6 SUMMARY

This chapter has outlined some of the issues surrounding qualitative research. It began by answering some questions posed by Mason (1996) about the research process and why one is embarking on it. It then went on to describe qualitative research in general before describing narrative research. It provided an outline of two particular approaches

to narrative research – those proposed by Riessman (1993) and Lieblich *et al* (1998). A brief description of ethnography was sketched and ethnographic procedures described. Finally, it discussed issues surrounding reliability and validity in qualitative research. The following chapter provides a full description of the study.

CHAPTER 6 DESCRIPTION OF STUDY

The preceding chapter outlined issues surrounding qualitative research methodology, narrative research and ethnography which are used in this investigation. This chapter presents the specific methods and procedures of the study. The main questions that the study attempts to answer are 'What narratives do people draw on to make sense of aphasia and manage it in day-to-day life?' and 'How are these influenced by societal and public narratives?'

6.1 PARTICIPANTS

Three individuals with aphasia agreed to take part in this study of narratives of aphasia. They are the focus of the investigation. Additional participants included a number of their conversational partners who provided different perspectives about what it is like to live with aphasia from the point of view of knowing someone with aphasia.

6.1.1 Criteria for Selection

The main participants (i.e. those with aphasia) were selected taking into consideration the following criteria:

- The practice of purposive or theoretical sampling was taken into account. Purposive or theoretical sampling is when participants are selected on the basis of their relevance to the research question, one's theoretical position and analytical framework (Mason, 1996; Silverman, 2000). It involves making every effort to include participants who are different from one another so as to access a broad range of experiences. In this way it is likely that 'deviant' cases are included in one's sample i.e. those cases that are unlikely to support your developing argument (Mason, 1996).
- People with aphasia were excluded from the study if they were known to me as it
 was felt that a prior relationship might affect disclosure in the interview as well as
 affect the way in which they may behave.

- Each participant had aphasia secondary to a stroke and of no less than two years
 duration. It was decided not to include people in the acute phase as the purpose of
 the study was to explore what it was like to live with aphasia in the long term.
- Each participant had no other condition that may affect communication (i.e. deafness, degenerative conditions, cognitive decline).
- Ultimately, a major consideration was the person's willingness to participate and to
 provide time to be interviewed and observed as well as to facilitate access to people
 who they were in regular contact with (i.e. family members, friends, professionals).

Participation was sought through contact with a speech and language therapist and a stroke association. In both cases an explanation of the study was given to the speech and language therapist or stroke co-ordinator who then explained the study in brief to people who they felt would be appropriate. If they expressed an interest, permission was sought to pass on their contact details. Contact with the speech and language therapist yielded two participants; the third participant was recruited through the stroke association. I met with all participants to determine if they were willing to participate and to consider if criteria for inclusion were met.

The view of persons with aphasia (or 'self' view) was sought as a key aim of the study was to gain an understanding of their perceptions in terms of their personal views of aphasia, stroke and disability and how these may affect the way in which they cope with their situation. However additional participants were also included in recognition of the fact that people with aphasia do not live in a vacuum but rather in a world filled with family, friends and acquaintances as well as health and social care personnel, all of whom bring with them their own views, beliefs and attitudes about aphasia, stroke and disability. The beliefs and attitudes they hold may affect the encounters they have with the person with aphasia in terms of the way in which they approach the person with aphasia and how they may communicate with her/him. In this way the study aims to gain insight into what it is like to live with aphasia, stroke and disability in a world where people have particular views about it. The criteria for selection of these participants were as follows:

- Inclusion of these additional participants was on the basis of conversations with the
 participant with aphasia as to who they are particularly close to and who they come
 into regular contact with.
- Their willingness to be available to participate and be prepared to give up time to be interviewed.

The details of each participant and their conversational partners, who participated in the study, are outlined in 6.1.3. Table 6.1 presents demographic details on each participant with aphasia. As can be seen each participant is different though they have some things in common. There are two female participants and one male. Two are in their forties while the third is in her sixties. Two are physically independent while one is a wheelchair user. Two have moderate-mild aphasia while one has moderate-severe aphasia. Each had a different occupation prior to their stroke reflecting a broad range. Only one participant is attending therapy, another one is attending a day centre and the third participant is attending neither. While each participant is living at home their living circumstances differ. Anne is a single parent living at home with a teenage son, Tony lives with his partner and May lives with her grown-up daughter and her family. Each was selected on the basis of accessibility and their differing circumstances. However there are a number of people with aphasia who live in a nursing home or other institution but no participant in this study did so. In addition a number of people with aphasia return to their previous or other employment, this was not reflected in this study as all are currently unemployed. Otherwise the profiles of participants selected are reflective of many people living with stroke and aphasia.

Each participant was aware that I was a practising speech and language therapist who was, however, not in the role of therapist but rather of researcher and collaborator. For this reason the impairment of participants with aphasia was not assessed, as that would have altered my role and relationship with them from that of learner (a core aspect of ethnography) to that of expert. Descriptions of their impairment therefore are based on my observations and what was gleaned from the health records.

Table 6.1: Demographics on participants with aphasia

	ANNE	TONY	MAY
Aetiology	Left CVA	Left CVA	Left CVA
Age	47	42	64
Sex	Female	Male	Female
Years post onset	2	5	6
Aphasia	Moderate-severe impairment	Mild-moderate impairment	Mild-moderate impairment
Physical disability	Residual right hand weakness	Residual limp	Wheelchair user
Handedness	Right	Right	Right
Previous employment	Architect	Clerical officer	Cleaner
Current employment	Unemployed	Unemployed	Unemployed
Attending SLT ¹⁷	Yes	No	No
Attending Day Centre	No	No	Yes

6.1.2 Ethical Considerations

Ethics is about what is good and right, especially in relation to power. When we are able to accept other people as they are, and be with them as we are, then we do not need to make labels or impose our values. When we do that, we are equal with others and human with others, and power does not play a big role. This, in my understanding, is what basic ethical listening is about and what leads to ethical relationships. (Tschudin, 2000, p.59-60)

When studying people's behaviour or listening to their thoughts and experiences, the researcher's responsibilities to those studied are of paramount importance. Mason (1996) highlights that the rich and detailed character of much qualitative research means intimate engagement with the public and private lives of individuals which thus make working in an ethical way imperative. It is therefore vital to ensure that the interests (i.e. the rights and welfare) of the participants are safeguarded. Mason (1996) advocates asking oneself a number of questions at the design stage of the study to ensure that one is acting ethically. This was undertaken and is outlined in Appendix 2. This process highlighted a number of issues that needed to be addressed to ensure that I was acting ethically.

¹⁷ SLT = speech & language therapist.

a) Informed consent

Prior to inclusion, an explanation of the study was given to each participant outlining what the study was about, what their participation would entail and what was going to happen to the information gained. An information sheet about the study was developed in an *aphasia-friendly* format to accompany this explanation (Appendix 3). Another explanation sheet was developed for the conversational partners (Appendix 4). The participants kept this to refer to in the future, should they wish to do so. My name, telephone numbers and email address were given and they were encouraged to contact me should they have any queries or concerns in relation to the study. Details of the research questions were not given, as I did not want to prejudice the research by signalling my expectations in the framing of the information (Hollway & Jefferson, 2000).

Following careful explanation of the study and answers to any questions the participants had, informed consent was requested and granted (see Appendix 5 for copies of the consent forms). In addition separate consent was gained from one of the participants (Anne) to interview her son who was a minor (Appendix 5). Hollway and Jefferson (2000) propose that informed consent should be continuous; for this reason every time an audio-recording was required, a visit undertaken or records accessed, verbal consent was gained. Verbal consent was sought again for permission for me to approach other participants (i.e. the conversation partners of the person with aphasia). Debriefing sessions, as advocated by Hollway and Jefferson (2000), were undertaken with key participants to deal with any ethical issues which arose from discrepancies between prior information and fuller information. Consent was gained to use the material.

b) Protecting anonymity

The depth of qualitative research means that considerable detail is given about individual participants, as it is relevant to the area of study. This means that it is more difficult to protect anonymity. In the present study, every effort has been made to protect anonymity by changing superficial details so that very few people could

recognise the participants of the study. However it is possible that close family members and others who have been closely involved in their care (e.g. therapists) might be able to do so. In all instances names have been changed of both people and places, as have some key biographical details that have no particular relevance to the area of study. Pseudonyms were always used when entering information onto the computer.

c) 'Care' of participants

Inflicting harm is unethical and contrary to rights and welfare. In qualitative research the participants are viewed as active agents in the relationship within which the interview data are produced. For this reason Hollway and Jefferson (2000) question whether or not being upset or distressed is necessarily harmful, as it can be reassuring and therapeutic to talk about an upsetting event in a safe context. However throughout this study every effort was made not to cause distress. Only one participant became really distressed during an interview and he was offered to be put in contact with a counsellor, which he refused. For this reason and due to his young age, it was decided not to return the interview transcript for his comments or to go through what was found at interview with him, as it was felt that it might lead to further unnecessary distress for which he was unprepared to seek help. One needs to constantly guard against harm – the researcher needs to create a safe context in which issues of honesty, sympathy and respect are central.

d) Exploitation

Sometimes it is claimed that research involves the exploitation of participants, in that they provide all the information but get little in return (Hammersley & Atkinson, 1995). While it is vital to protect the interests of the participants, Atkinson (1998) believes there are a number of benefits for the participants to be involved in research which has as a core part, the telling of one's life story. He outlines the potential benefits of sharing a life story. They include:

- Adding meaning to life through gaining a clearer perspective on experiences.
- Attaining greater self-knowledge, self-image, and self-esteem.

- Sharing of cherished experiences and insights with others.
- The satisfaction of sharing one's story with others.
- The validation of personal experience that can be central to recovery.
- Helping others to see one's life more clearly and to understand one better.

Self-awareness is key to acting and behaving ethically, as Tschudin (2000) writes:

It is in becoming self-aware that one becomes a 'concrete ethical being'. This means that becoming self-aware is a basic ethical duty. When we are self-aware, we have the ability to recognise real ethical needs and make real ethical decisions. (...) In order to become self-aware we have to listen to ourselves and to others. (p.57)

Central to this study is the process of reflexivity, as well as listening to the stories of the participants.

This study obtained ethics approval from the *Ethics (Medical) Research Committee*Beaumont Hospital (Appendix 6).

6.1.3 Participant Profiles

The following gives some background to each of the participants with aphasia. Much of the information was gained during interview and during the course of the study and is included here to give a flavour of what they are like as individuals. Names have been changed throughout and each participant with aphasia was asked to choose a name by which they wished to be known.

a) Participant 1: "Anne"

Anne is forty-seven years old and had a stroke about two years prior to being recruited to the study. She has been separated from her husband for approximately ten years and lives with her fourteen-year-old son. She has two other children both attending college and living some distance away. She has two brothers, one living in this country and one abroad, and one sister also living abroad.

Prior to her stroke she worked in a professional capacity and was described by family members as being quite "paranoid" before her stroke, whereby she would tend to focus

on a worry. While she was described as being quite stressed, she was also described as being "pleasant and jolly". There is a general feeling now that she is returning to the person she was. She still tends to focus on a worry even when there are more important matters to address. She is outspoken and was described by one participant as being someone who "stands out in a crowd".

Initially, following her stroke, Anne had a right hemiparesis and could only say a particular nonsensical phrase and the occasional 'yes' and 'no'. However by the time Anne joined the study her communication abilities had improved to the extent that she was able to get across some basic information, augmented by writing and drawing or by using her 'communication book' 18. She has significant difficulties in word retrieval and much of what she says is characterised by social and stereotypical speech. She has no significant difficulties in verbal comprehension. During the course of her involvement in the study, her verbal expression improved. She was able to say more content words and did not have to resort to pen and paper or her communication book quite so frequently. She is able to walk and is physically independent. although she still has some weakness in her right hand and she writes with her left (non-preferred) hand.

Anne's life before the stroke revolved around work, the children and holidays. She was secretary to an old college society and she enjoyed reading. She saw her brother rarely and saw friends from time to time. Now her life revolves around her children and going to the stroke clinic. She sees her brother much more frequently and at the beginning of the study she was seeing him about twice a month. However as she gained in confidence and independence this contact became less frequent. She now watches a great deal of television and, according to her son, she watches it "twenty-four seven". Anne lists shopping and swimming as other significant activities that take up her time now. However during the course of the study she gave up swimming due to the cold weather. She cites getting back to driving as the main thing that has made a difference to her since she had her stroke. Anne is currently not working, but vocational

¹⁸ A 'communication book' is a small notebook containing key information relevant to the person's day to day communication needs. Anne uses this notebook during conversation to convey particular bits of information.

opportunities are being investigated. Since her stroke Anne has been attending speech and language therapy on an ongoing basis and for some months this was intensive (i.e. every day). She now attends speech and language therapy twice a week and at the beginning of the study she was attending occupational therapy for work on the computer.

Significant others interviewed were:

- "Stephen" (14 years): Anne's son who lives with her and attends a nearby school.
- "Peter" (30's): her brother who lives some distance away. He helps Anne with things that she finds difficult to do.
- "Suzanne" (30's): the speech and language therapist Anne consults twice a week. The clinic is some distance away which entails Anne getting two buses; she prefers to do this than to drive due to parking restrictions.
- "Linda" (30's): her occupational therapist. During the initial phases of the study Anne was attending occupational therapy to work on computer skills.

In summary, Anne is in her forties and had a stroke two years ago. She has moderate-severe aphasia whereby she experiences significant difficulties in word retrieval. She lives with a teenage son and she attends therapy twice a week. She gives the impression of being confident and assertive. Her main social contacts are members of her family and therapists.

b) Participant 2: "Tony"

Tony is forty two years old and had his stroke five years prior to being recruited to the study. He lives with his partner of seventeen years. Prior to his stroke he worked in a large company in a clerical capacity. A year following his stroke he was advised to take early retirement on grounds of ill health. His mother is still alive and he sees her quite regularly. In addition he has two sisters whom he sees a few times a year.

Prior to his stroke Tony was described as being a quiet, easy going, caring and sensitive individual with a deep interest in politics and the environment. He was "articulate" and

was never one to panic about anything. There is a general feeling that Tony has not changed since he had his stroke and he remains easy-going, with a calm approach to things.

Tony was not admitted to hospital until eight days following his stroke. He was treated homoeopathically up until his admission. His speech at this time was described as "gibberish". Tony, however, was not aware of his difficulties and only realised something was wrong when he saw the reactions of others to the way he was talking. Communication at this time was mediated through his partner, Sue. His speech has since much improved and he now presents with a fluent type of aphasia, characterised by occasional word retrieval difficulties.

In the first three years post-stroke he attended speech and language therapy, initially on an intensive basis and then once or twice a week. He no longer sees a speech and language therapist and has not done so for the past two years. Initially he had some right-sided weakness, but this resolved and the only sign of it now is a slight limp.

Prior to his stroke Tony worked and was very involved with a political organisation, having been secretary and treasurer. His political activities took up most of his leisure time. However he was beginning to reduce his involvement just prior to his stroke. He still maintains some interest in politics and helps out from time to time in a politician's office doing basic office work (e.g. photocopying) and distributing leaflets. Prior to his stroke he would have been the one to write the leaflets. While his life revolved around work and his political activity before his stroke, now it revolves around home and going to the pub. He sees more of Sue, his partner, in that now they meet for lunch during the day.

Significant others interviewed were:

- "Sue" (40's): Tony's partner of seventeen years. They are very close.
- "Mary" (40's): his older sister who lives some distance away.
- "Ciara" (30's): his younger sister who also lives some distance away.

- "Fintan" (40's): long-time friend whom he meets about once a month.
- "Sarah" (40's): friend of Sue's whom he would see from time to time.
- "Lorraine" (40's): secretary to the politician and with whom Tony works when he is helping out at the politician's office. She has only known Tony since his stroke.

In summary, Tony was in his late thirties when he had his stroke five years ago. He has a mild-moderate aphasia whereby he experiences some difficulty in word retrieval but is usually able to get across what he wants to say by using the resources of his conversation partner. He has been described as easy-going, caring and sensitive. He has a deep interest in politics and he helps out in a politician's office. He lives with his partner.

c) Participant 3: "May"

May is sixty four years old and had her stroke approximately six years ago. She has a right hemiplegia and is a wheelchair user. She lives in her own home with her daughter, son-in-law and young granddaughter. She has two sons living nearby whom she sees regularly. In addition she has three sisters, two of whom she sees regularly. Immediately prior to her stroke she worked as a cleaner in a local college which she enjoyed. She has not been in employment since her stroke.

May is described by other participants as somebody who was good to everyone, though she would have tended to have kept to herself and one participant described her as "a worrier". May describes herself as a "yapper" before her stroke in that she loved to talk to people. It is generally agreed that May is now 'back to herself' and one participant even comments that her outlook on life is better now than before her stroke in that she no longer worries. She is someone who enjoys going out at every opportunity.

She had her stroke approximately six years ago. It occurred suddenly and she remained in hospital for some time before being discharged home. She then became an in-patient at a rehabilitation unit specialising in the treatment of stroke. Initially May's speech was "gone", but it improved enormously during her time at the rehabilitation unit. Her

social speech is now excellent and she can get much of what she wants to say across, although she may struggle to do so as she searches for words. She appears to be someone who is happy with the things that life has to offer her, though she remains frustrated by her speech and particularly misses being able to read. She is quite independent in that she is able to move around the house in her wheelchair and gets her own meals. When at home she spends most of her time in her room in which there is a television and a toilet.

Prior to her stroke May was very active. She worked as a cleaner and would cycle to the supermarket every day to do her shopping. Since her stroke her time is mainly taken up with her "clubs" (i.e. day centre, stroke club) during the day, which she enjoys. In the evening she likes to watch the soaps as she did before. In addition to this, her sisters bring her to the pub once a fortnight and they or her sons occasionally bring her to a local shopping centre. Also she has the opportunity to go to the supermarket and shops nearly every day that she attends the day centre. In her clubs she joins in anything that is going on and is considered an active social member. She enjoys going on outings with them and does so at every opportunity. May does not like to be on her own and finds the weekends, when she is not attending her clubs, the most difficult. She is a socialiser and enjoys going out and mixing with people. Prior to her stroke she was someone who gave advice to others if they requested it. This remains the case as she still gives advice to her daughter, her sisters and to club members when they seek it. She used to help people a good deal and this continues on into the present; she will do anything she can to help around the house and helps others should they need it.

Significant others interviewed were:

- "Yvonne" (30's): daughter with whom May lives.
- "Bridie" (60's): sister who lives some distance away, but who visits May and stays with her every second weekend.
- "Maeve" (60's): sister who lives nearby and whom May sees nearly every day.
- "Michael" (30's): son-in-law with whom May lives.
- "Bríd" (30's): the day centre manager who has known May for a number of years.

- "Sinead" (20's): May's key worker at the day centre who has known May for a few months.
- "Eleanor" (50's): the stroke club co-ordinator who has known May for a number of years.

In summary, May is in her sixties and had a stroke six years before participating in the study. She lives in her own house with her daughter and son-in-law. She has a mild-moderate aphasia characterised by some word retrieval difficulties and difficulties in reading. Her life revolves around her family and the clubs she attends during the week. She enjoys mixing with people and takes every opportunity to go out.

As can be seen, each participant represented slightly different profiles. Anne had her stroke more recently and is involved in active rehabilitation. Tony had his stroke some time ago and is making a life for himself with aphasia. While May, who also had her stroke some time ago, is also learning to live with aphasia, but in addition she attends a stroke club and a day centre.

This section has introduced the key participants of the study. In it I outlined the criteria for selection and ethical considerations. The following section presents the data generation methods that were used in the study.

6.2 DATA GENERATION¹⁹

In keeping with the technique of triangulation, data from a variety of sources were obtained in order to gain an in depth insight into narratives of aphasia from a variety of perspectives. Data included gaining information about participants' life before the stroke, as well as since. The following data generation methods were employed:

- In-depth interviews,
- Picture selection,
- Participant observation,

¹⁹ The term *data generation* is used rather than data collection, to encapsulate the relationship between researcher, the social world and the data which qualitative research spans (Mason 1996)

- Audio recording of interactions,
- · Artefacts,
- Personal research journal.

6.2.1 In-Depth Interviews²⁰

In-depth interviews are particularly valuable when the subject matter is sensitive or complicated (Fielding, 1993b). These were undertaken with each participant with aphasia and a number of their conversational partners. Tables 6.2-6.4 list the interviews undertaken. These comprised twenty interviews in all, lasting a total of sixteen hours and twenty minutes.

Table 6.2: In-depth interviews: Anne

Date	Interviewee	Venue	~Time
29/11/2000	Anne	Anne's house	1:00
28/02/2001 Suzanne (SLT)		Clinic	0:40
06/03/2001	Linda (OT ²¹)	Clinic	0:25
10/04/2001 Peter (brother)		Peter's house	0:45
18/04/2001	Stephen (son)	Anne's house	0:30
		Total time:	3:20

Table 6.3: In-depth interviews: Tony

Date	Interviewee	Venue	~Time	
20/02/2001	Tony	Tony's house	1:00	
16/03/2001	Fintan (friend)	Fintan's house	0:40	
09/04/2001	Sue (partner)	Hotel lobby	1:10	
30/05/2001	Mary (sister)	Mary's house	1:00	
07/06/2001	Lorraine (work colleague)	Lorraine's office	0:30	
25/06/2001	Ciara (sister) Ciara's house		1:00	
08/11/2001	Sarah (friend)	Sarah's house	0:30	
		Total time:	5:50	

²⁰ I attended an intensive course on the design, construct and analysis of interviews run by the Qualitative Research Unit of the Social and Community Planning Research, London.

²¹ OT = occupational therapist.

Table 6.4: In-depth interviews: May

Date	Interviewee	Venue	~Time	
06/04/2001	May	May's house	1:30	
27/04/2001	Eleanor	Eleanor's house	1:00	
	(stroke club co-ordinator)		1.00	
02/05/2001	Bridie (sister)	Bridie's house	0:45	
08/08/2001	Sinead	Day centre	0:40	
	(key worker, day centre)		0.10	
15/08/2001	Bríd	Day centre	0:35	
	(day centre manager)		0.00	
04/11/2001	Maeve (sister)	Maeve's house	0:40	
12/12/2001	Yvonne (daughter)	Yvonne's house	1:00	
19/12/2001	Michael (son-in-law)	Michael's house	1:00	
		Total time:	7:10	

The design, conduct and analysis of these interviews were undertaken utilising the qualitative data analysis *Framework* (Ritchie & Spencer, 1994) developed by the Qualitative Research Unit of the National Centre for Social Research, London. In this a topic guide is devised which acts as a memory aid for the conduct of the interview. The questions are not fixed but rather fluid, and they follow the teller's lead (Atkinson, 1998). They are open ended in order to elicit spontaneous information about the areas of concern. The object is to elicit data on which to find out what and why things are happening. Occasionally prompts (e.g. repeating or rephrasing the question) and probes (e.g. follow-up questions designed to elicit a fuller response, which may be verbal or non-verbal) may be necessary (Fielding, 1993b). The topic guide was designed using guidelines from a course on in-depth interviewing attended at the National Centre for Social Research, London. Therefore the following was undertaken in the formulation of the topic guide:

- Brainstorming the issues that need to be covered.
- Listing all potential issues, topics and points to explore.
- Grouping the issues into topics and sub-topics.
- Standardising the introduction and deciding on the initial topic.
- Ordering subsequent topics designed in such a way as to encourage topics to arise as naturally and spontaneously as possible.

An initial topic guide was drawn up and this was piloted on a sixty-two year old woman who had had a stroke seven years previously. It was found that the topic guide was too broad and did not effectively target the areas of concern. Therefore a second topic guide was devised and another pilot interview was undertaken with a fifty-two year old man who had had a stroke four years previously. This topic guide was used for the participants with aphasia. The topic guide was then further amended for particular participants (e.g. family, friend, speech and language therapist, occupational therapist, care worker). In addition it was specifically amended for Anne's son, Stephen. (Refer to Appendix 7 for copies of the topic guides.)

Interviews were conducted using guidelines outlined by Atkinson (1998) which included creating the right setting, being responsive and flexible, being a good guide, listening well, respecting the boundaries the teller presents and letting the person know the value of their story. Most interviews were conducted in a distraction-free environment, however a number were interrupted by other people or by telephone calls. Such interruptions were noted in the transcripts. An explanation of the study was given again just prior to the interview and permission was sought to audio-record it. It was emphasised that the recorder would be switched off at any time should they wish. No interviewee made this request. All interviews were recorded using a SONY TCS-580V stereo cassette recorder with a SONY ECM-F8 electret condenser microphone. The recorder was in full view of the person, but out of eye level. Each interview was transcribed using conventions based on conversation analysis (Psathas, 1995). (Refer to Appendix 1 for a copy of the transcription conventions; Appendix 8 for a sample of an interview transcript with a participant with aphasia; and Appendix 9 for a sample of an interview transcript with a conversation partner.)

When talking with people with aphasia it can at times be necessary to 'scaffold' their communication in terms of supporting their abilities and checking interpretations. On occasion one may have to resort to choice, or yes/no questions. For this reason there is greater risk of the interviewer asking leading questions and imposing words and choice of vocabulary. This was consciously avoided, although inevitably it occurred on

occasion. There will be some evidence of it in the transcripts and this must be considered in the interpretation.

Verification of transcripts was sought from all but two participants. In the case of Anne and May, a summary was made of what was found at interview and this was discussed with each of them and changes were made according to their wishes. In the case of Stephen (Anne's son) verification of his interview transcript was not sought for ethical reasons, as it was felt that it might cause him unnecessary distress. One participant (Linda, Anne's occupational therapist) was no longer in Ireland so it was not possible to gain verification of the interview with her. All other participants received a copy of their interview transcript and were encouraged to make amendments and comments as they felt appropriate. Many did so.

6.2.2 Picture Selection²²

Due to the nature of aphasia it was felt that different methodologies that did not rely so heavily on words were needed to access meaning of stroke and aphasia. This is in line with Oakley *et al's* (1995) recommendation of using drawing to access children's health beliefs. Radley (2002) and Radley and Taylor (2003) also used imagery to gain insight into the illness experience. Therefore a selection of greeting cards was used as a means:

- To facilitate participants in the expression of feelings around particular times and as a stimulant to converse about such times.
- To provide a window into personal identity as it allows for the personal expression of a uniquely individual experience (Pound et al, 2000).

This use of greeting cards as a means of facilitating expression of feelings is based on an idea of Carole Pound's (personal communication). In this instance participants chose from a collection of forty greeting cards to best reflect the person with aphasia at

²² Clearly there are many issues surrounding the meaning of imagery. However in this context it was used purely as a means for the person with aphasia and others to have an additional method of expressing how they felt at particular times, and as a stimulant for participants to converse about such times. It is acknowledged that from an art therapy perspective deeper meanings may be interpreted but this is not the brief of this study.

different times (see Appendix 10 for a copy of the pictures used). Cards were selected as follows:

- Participants chose from a collection of forty greeting cards which were selected on the basis of the need to try and encompass as wide a variety of styles as possible so as to allow the person plenty of choice in her/his selection. For this reason pictures were quite varied and included abstract art, cartoons, line drawings, grand masters' paintings and photographs. Therefore they consisted of cards which were abstract as well as realistic, cards which were colourful as well as black and white, and cards which were fun as well as serious.
- Every effort was made not to be biased in the selection of the bank of pictures from which participants made their choices. However inevitability there was some subjectivity to the process.
- Each participant was given the cards and asked to select one that best reflected the person with aphasia before the stroke, at the time of stroke, now, and in the future. They were given time to go through the cards and consider them before making their choice. They were encouraged to talk about their selection. It is recognised that there is a subjective element in the interpretation of the pictures the participants chose though every effort was made to verify my interpretation.
- Each participant who underwent an in-depth interview was asked to do this task.

 One refused.

A task similar to this was used by Abma (1999), when he used images to help people to talk about themselves.

6.2.3 Participant Observation

I participated in and observed participants in a variety of settings with several conversation partners. Observations are listed in Table 6.5 for Anne, Table 6.6 for Tony, and Table 6.7 for May. Total observation time amounted to twenty-one hours and fifty-five minutes.

Table 6.5: Participant observation for Anne

Date	Setting	Partner(s)	Activity	~Time	
29/11/2000	Anne's house	Investigator	Before and after interview	0:30	
31/01/2001	Anne's house	Son, Investigator	Visit 1		
14/02/2001	Clinic	OT	Therapy	1:15	
16/02/2001	Clinic	Nurse, Investigator	Waiting for SLT 0: appointment		
16/02/2001	Clinic	SLT	Therapy	1:15	
22/02/2001	Anne's house	Investigator	Before and after shopping		
22/02/2001	Car	Investigator	Driving to and from supermarket	0:20	
22/02/2001	Supermarket	Cashier, Investigator	Shopping	0:50	
09/03/2001	Clinic	Investigator	Waiting for appointment	0:10	
14/03/2001	Anne's house	Son, Investigator	Visit	0:40	
18/04/2001	Anne's house	Son, Investigator	Before and after interviewing son.	0:30	
20/11/2001	Clinic	Person with a stroke	Waiting to see investigator	0:10	
			Total time:	7:05	

Table 6.6: Participant observation for Tony

Date	Setting	Partner(s)	Activity	~Time	
20/02/2001	Tony's house	Investigator	Before and after the interview	0:45	
27/02/2001	Tony's house	Investigator	Visit	0:50	
12/03/2001	Pub	Partner, Investigator	Lunch	2:15	
09/04/2001	Pub	Partner, Investigator	Before and after interview with partner	1:05	
11/04/2001	Pub	Partner, Investigator	Lunch	1:30	
25/11/2001	Tony's house	Partner, Investigator	Visit	0:30	
			Total time:	6:55	

Table 6.7: Participant observation for May

Date	Setting	Partner(s)	Activity	~Time
05/04/2001	Stroke club	Co-ordinator, Members, Investigator	Visit	0:45
06/04/2001	May's house	Son-in-law, Investigator	Before, during and 1:	
25/04/2001	May's house	Son-in-law, Investigator	Visit	0:55
26/04/2001	Stroke club	Members, Co-ordinator, Volunteers, Investigator	Visit	1:30
10/06/2001	May's house	Sisters, Daughter, Granddaughter Investigator	Visit	1:05
01/08/2001	Day centre	Members, Staff, Volunteers, Investigator	Visit	0:40
08/08/2001	Day centre, Shop	Members, Staff, Volunteers, Shop keepers Investigator	Visit, Shopping	1:00
15/08/2001	Shop	Care worker, Investigator	Shopping 0:0	
12/12/2001	May's house	Daughter, Investigator	Before and after 0:1	
19/12/2001	Day centre	Members Investigator	Waiting to see investigator for verification of interview details	
19/12/2001	May's house	Investigator	Before and after interviewing son-in-law	0:10
06/04/2002	May's house	Investigator	Visit	0:25
			Total time:	7:55

In this study my participation ranged from being an active member (e.g. having lunch with Tony and his partner Sue) to being relatively passive (e.g. sitting in on a therapy session). The settings in which the participants were observed generally reflected the

variety of situations each individual experienced regularly. Unfortunately not all people and contexts were accessible (e.g. I was unable to observe Tony with his friend Fintan, as consent was refused). At all times I dressed and acted in such a way so as to blend into the setting as much as possible (Hammersley & Atkinson, 1995; Sanger, 1996). Each situation was treated as "anthropologically strange" so as to make explicit the presuppositions one takes for granted (Hammersley & Atkinson, 1995).

Wherever possible brief notes were taken during the observation period, however this was not always possible due to my feeling that such behaviour might be perceived as disruptive or threatening. It was only really possible when I was in the role of passive observer (e.g. therapy sessions). As soon as possible after each observation (usually within an hour of withdrawing) extended notes were written. These were done in a factual concrete style in an attempt to record what actually happened and to reduce personal bias. Accompanying these extended notes were methodological, interpretative and personal notes which reflected my ideas, feelings, mistakes, experiences, questions and immediate interpretations pertaining to that observation. This allowed one to evaluate the perspectives through which the data was collected. (Refer to Appendix 11 for a sample of participant observation notes.)

6.2.4 Audio-Recording of Interactions

In addition to participant observation, a number of interactions were audio-recorded. Initially it was hoped to video-record interactions, but this was refused on a number of occasions and was thus abandoned in favour of audio-recording. A SONY TCS-580V stereo cassette recorder with a SONY ECM-F8 electret condenser microphone was used and the recorder was placed in view of the participants, but out of eye level. Table 6.8 provides a list of audio-recordings. Excluding interviews, the total time amounted to four and a half hours.

All audio-recordings were transcribed using conventions based on conversation analysis (Psathas, 1995) (Appendix 1). Appendix 12 provides a sample of a segment of a transcript from an audio-recording of an interaction. An attempt was made to gain a

more representative sample, but this was either refused (e.g. Tony with his friend Fintan) or not possible (e.g. the noisy environment of the stroke club). Appendix 13 provides a brief description of each audio-recording.

Table 6.8: List of audio-recordings made (excluding interviews)

Date	Setting	Participants	Activity	~Time
14/02/2001	Clinic	Anne, OT	Therapy	1:15
16/02/2001	Clinic	Anne, SLT	Therapy	1:15
11/04/2001	Pub	Tony, Tony's partner, Investigator	Lunch	1:30
06/04/2001	May's house	May, Son-in-law, Investigator	Interruption during interview	0:30
			Total time:	4:30

6.2.5 Artefacts

A number of documents were sourced to explore how the person with aphasia was portrayed. Notes were taken from the clinic and day centre records that reflected the content and the facts as they were written. These were then typed up and interpretative notes were added (see Appendix 14 for a sample). Further documentation comprised a copy of Tony's diary written between 30 October and 24 November 2000 and between 20 and 27 February 2001. The latter was in response to my request to keep a diary of his activities and thoughts. Tony's partner had written an article for a newsletter and the edited and unedited versions were made available to me.

In addition to these 'personal' documents, samples of more general literature on stroke were accessed. Only information that was easily accessible to the public was sourced. This included information from a stroke association, a special association for people with aphasia and a number of internet sites. Also newspapers and magazines were trawled for stories relating to disability and illness in order to gain insight into how these were portrayed in the media. The aim of accessing information from associations, the internet and the media was to gain a picture of how stroke and aphasia were viewed

in the public domain. Appendix 15 provides a summary of the documents and internet sites sourced, with a brief outline of their content.

6.2.6 Personal Research Journal

A personal research journal was kept throughout the study. This provided a running account of the conduct of the research as well as a record of personal thoughts and feelings about the research process itself. Such a journal has analytic significance as our feelings enter into and colour the social relationships we engage in during our fieldwork. Such responses inevitably influence one's choice of what is noteworthy, what is 'strange' and problematic and what is mundane and obvious (Hammersley & Atkinson, 1995). Thus such a journal allows one to view the data that has been generated through the filter of the personal experience of the investigator.

There is a constant interplay between the personal and emotional on the one hand, and the intellectual on the other. Private response should be transformed, by reflection and analysis, into potential public knowledge. The fieldwork journal is the vehicle for such transformation. (Hammersley & Atkinson, 1995, p.192)

(Refer to Appendix 16 for extracts from my personal journal.)

6.3 DATA ANALYSIS

The preceding section focused on the data generation, this section will outline how data were analysed. As stated previously data generation and data analysis do not occur in a linear fashion in an ethnographic investigation rather it is cyclic in nature in that they are not separated distinctly and one informs the other. In this way the study moves progressively towards a central focal point. The purpose of qualitative analysis is to try to present and re-present the social world and the perspectives on that world, in terms of the concepts, behaviours, perceptions and accounts of those studied. Two main approaches were used to analyse the data. They were *Framework* (Ritchie & Spencer, 1994) and discourse analysis (Fairclough, 1989, 1992; Psathas, 1995).

6.3.1 Framework²³

The in-depth interviews and participant observation fieldnotes were analysed using the qualitative data analysis *Framework* (Ritchie & Spencer, 1994) which is an analytical process that involves a number of distinct, though interconnected, stages. It is systematic and disciplined but relies on the "creative and conceptual ability of the analyst to determine meaning, salience and connections" (Ritchie & Spencer, 1994, p.177). Using such a systematic procedure allows for re-consideration and re-working of ideas as the analytical process has been documented and is therefore accessible. There are five key stages to the qualitative data analysis *Framework*. They are familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation. Each of these stages will be outlined in brief.

a) Familiarisation

At this initial stage one immerses oneself in the data and lists key ideas and recurrent themes.

b) Identifying a thematic framework

At this stage one identifies key issues, concepts and themes according to which the data can be examined and referenced. In this way a thematic framework is set up within which material can be sifted and sorted. For this the investigator draws on priori issues, emergent issues raised by participants and analytical themes arising from recurrence or patterning of particular views or experiences. As the process deepens categories gradually become more refined and less reliant on priori issues and become more responsive to emergent and analytical themes.

c) Indexing

This is a mechanism for labelling data into manageable 'bites' for subsequent retrieval and exploration. It is a process whereby "the thematic framework or index is systematically applied to the data in its textural form" (Ritchie & Spencer, 1994,

²³ As part of preparation for this study I attended intensive training in the *Framework* method run by the Qualitative Research Unit, National Centre for Social Research, London, where the system was developed.

p.180). Indexing references are recorded in the margins of each transcript by a numerical system that links back to the index. (Refer to Appendix 17 for a copy of the interview index; Appendix 18 for an example of an indexed interview transcript; Appendix 19 for the participant observation index; and Appendix 20 for an example of indexed ethnographic fieldnotes.) Indexing involves making judgements as to the meaning and significance of data. Often different major topics are interwoven into one speech passage and so indexing provides a means of labelling these clearly and also helping one to see patterns and the contexts in which they occur.

d) Charting

This is a process by which "data are lifted from their original context and rearranged according to the appropriate thematic reference" (Ritchie & Spencer, 1994, p.182). In this way a picture is built up of the data as a whole by considering the range of attitudes and experiences for each issue and theme. Charts are devised with headings and subheadings which are usually drawn from the thematic framework, priori research questions or according to considerations about how best to present and write up the study. Each passage of text, with the relevant references, is studied and a summary of participants' views or experiences is entered into the chart with original text referenced so that the source can be easily traced. (Refer to Appendices 21 for a sample of an interview chart; and Appendices 22 for a sample of an ethnographic fieldnotes chart.)

A random selection of charts and their corresponding interview transcripts were given to an independent analyst to determine the degree of agreement of how things were charted. The same themes were identified though there was some variation in the way they were categorised. For example, for Tony's sister's transcript the co-coder had a category for 'loss', while I had placed issues surrounding loss under the headings 'participation' and 'experience of disability'. However there was overall agreement in the emergent themes.

e) Mapping and interpretation

This stage involves pulling together key characteristics of data, then mapping and interpreting the data as a whole. What one chooses will depend on the original research questions and the themes and associations that have emerged from the data. It is a process whereby one reviews charts and research notes, compares and contrasts experiences, searches for patterns and connections, and seeks explanations for these internally within the data. It involves defining concepts, mapping the range and nature of phenomena, creating typologies, finding associations, providing explanations and developing strategies.

A key aspect of *Framework* is its accessibility to the investigator and others. One can trace back to work out how and why the investigator reached certain conclusions. Each interview transcript and set of ethnographic fieldnotes were analysed using *Framework* as discussed above.

Framework was used to gain insight into a number of parameters of living life with aphasia. It was also used to identify issues of identity that might have been affected by stroke, making particular reference to Breakwell's (1986) principles of continuity (i.e. continuity across time and situation), distinctiveness (i.e. uniqueness, being different from others) and self esteem (i.e. feelings of personal worth and social value).

In addition to doing Framework, the interviews and fieldnotes were trawled through to identify any discourse that seemed to represent a narrative. These were then noted down. These excerpts were given to an independent reviewer to determine the degree of agreement. The meeting with the reviewer highlighted how some of the narratives related closely to one another for example in need of care and childlikeness and for this reason these two narratives were merged to form one: in need of care. Otherwise there was general agreement.

6.3.2 Discourse Analysis

In addition to analysing interview and participant observation data using 'Framework', I analysed interview transcripts and excerpts of discourse using discourse analysis.

Discourse analysis is an approach that focuses on talk as a social practice and explores the resources that are drawn upon to enable such practices to occur (Potter, 1996). There are many different approaches to analysing discourse and two distinct methods were used for the purposes of this study. They were Critical Discourse Analysis (CDA) and Conversation Analysis (CA). Both methods are outlined below.

a) Critical Discourse Analysis (CDA)

According to Titcher, Meyer, Wodak and Vetter (2000), the general principles of CDA are as follows:

- CDA is concerned with social problems and with the linguistic character of social and cultural processes and structures.
- CDA studies power in discourse and power over discourse.
- CDA assumes that society and culture are shaped by discourses and at the same time constitute discourse.
- CDA assumes that language use may be ideological.
- CDA assumes that discourses are historical, can only be understood in relation to their context and are connected intertextually to other discourses.
- CDA assumes that the connection between text and society is not direct.
- CDA is interpretative and explanatory. However interpretations are dynamic and open to new contexts and new information.
- CDA assumes that discourse is a form of social behaviour.

They summarise by saying:

From this complex meshing of language and social facts is derived the frequently unclear and hidden ideological effects of language use as well as the influence of power-relations. In discourse practice structures and ideologies are expressed which are not normally analysed or questioned. CDA is now seeking, by close and detailed analysis, to shed light on precisely these aspects. (Titcher et al, 2000, p.147)

For the purposes of this research Fairclough's (1989, 1992) approach to CDA was used. His approach is heavily influenced by Michel Foucault, a French historian and social theorist who viewed discourse in terms of the hidden power embedded within it. This influence underpins Faircough's framework for analysing discourse. Therefore one of the key features of Fairclough's CDA is that it looks at both power in discourse (i.e. what is said, social relations) and power behind discourse (i.e. knowledge, ideology, social identity). Fairclough maintains that ideologies are embedded in discursive practices in that they are implicit and taken for granted and are most effective when they are least visible. CDA aims to expose hegemonic power within discourse. This emphasis on power behind discourse illuminates how dominance is an integrated, rather than an overt, feature of it. Fairclough (1989) suggests that CDA does not just complement other approaches, but that it is an alternative orientation to language study in the way it is concerned with how both producing and interpreting discourses are socially shaped.

CDA, using the Fairclough approach, involves close analysis of the 'text' in terms of features such as vocabulary, grammar, turn-taking, type of speech acts, lexical choice, directness of expression and use of metaphor to increase understanding of the power relations and ideological processes involved in discourse. Fairclough and others (e.g. Lakoff & Johnson, 1980; Ng & Bradac, 1993; Goatly, 1997) emphasise the pervasiveness of the use of metaphors in language and how they provide us with a window to view how things are construed; they "reflect the values of a culture or society" (Ng & Bradac, 1993:138).

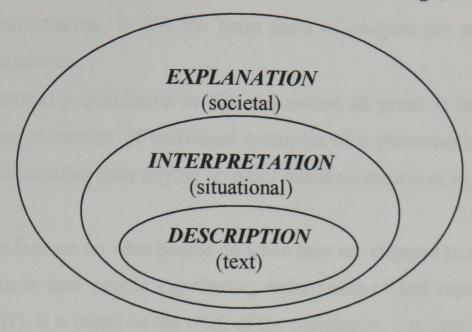
The framework for analysis proposed by Fairclough (1989, 1992) involves three main stages:

- Description of the formal properties of the text in terms of vocabulary, grammar and interactional conventions used, which itself involves a degree of interpretation.
- Interpretation to make sense of the features of the text in terms of what the producer and the interpreter bring to it, as well as taking account of the situational context.

• Explanation to make sense of the features of the text, one's interpretation of it and the relationship between the interaction and social context.

Figure 6.1 shows these three stages diagrammatically.

Figure 6.1: Stages of analysis in CDA (Fairclough, 1989, 1992)



Fairclough (1989, 1992) and others (e.g. Gill 1996) emphasise the importance of reflexivity and how one needs to be aware and sensitive to the resources one draws upon at all these stages. Any analysis of discourse is a product of the text and the interpreter's interpretation and explanation of it.

b) Conversation analysis (CA)

This is a procedure for the study of interaction and, in particular, talk-in-interaction, which uses a naturalistic observation-based approach to study actual verbal and non-verbal behaviour. It focuses on how people construct conversations collaboratively and specifically on such issues as turn-taking, sequences, repair, topic and the use of both language and non-verbal behaviour as resources in constructing conversations. Perkins & Wilkinson (1998) outline four main principles of CA:

CA is participant or data driven and therefore it tries to uncover the conversational
participants' methods and interpretations by careful observation and description of
participant behaviour and reactions to each other.

- CA assumes that conversation is orderly. Phenomena such as repetitions, repairs, overlaps, etc. are included as it is argued that they are treated by participants as systematic and relevant aspects of conversation and so should not be ignored.
- CA attributes a great deal of importance to sequential context. One of the key
 aspects of any contribution to the conversation is where it occurs within the context
 of the conversation. In CA the main units of analysis are sequences, and turns
 within sequences.
- CA is primarily qualitative in that the notion of proof is based on the analyst uncovering a number of individual examples of a phenomenon with spontaneous conversation rather than relying on proof based on statistical significance.

CA therefore focuses on what people do when they are engaged in social interaction, its main concern is how people experience, make sense of and report their interactions (Crystal, 1987). It is based on the work of the sociologist, Garfinkel, who developed the approach 'ethnomethodology', which seeks to discover how members of a society produce a sense of social order. This methodology was then applied to conversation which was viewed as a key source of social order. CA differs from CDA in that it avoids prior assumptions, as only the information that is present within the discourse is considered, since actions rather than context shape the conversation (Schegloff, 1995). Unlike CDA, it pays little direct attention to social relations, setting or personal attributes.

The organisation of turn-taking is fundamental to conversation and Sacks, Schegloff & Jefferson (1974) have made a significant contribution to CA in proposing a model of turn-taking in conversation. They assume that as a conversation occurs in a wide variety of situations, each with different interactional goals, there must be a formal set of context-free procedures to ensure that conversational flow is maintained. Within their model there is an assumption that talk is socially organised and demands collaboration between participants, as turn-taking is a basic form of organisation for conversation. They state that turn-taking is *locally managed* in that it deals with single transitions at a time; that it is *party administered* because it is under the control of the

participants; and that it is *interactionally determined*. Turn transfers are usually coordinated at 'transition relevant places' whereby the current speaker selects the next speaker, another participant self selects him/herself as the next speaker or the current speaker self-selects him/herself as the next speaker. Repair mechanisms deal with turn-taking violations and in general there is an overwhelming preference for self-repair (Schegloff, Jefferson & Sacks, 1977).

CA can be particularly useful in looking at the communication abilities of someone with aphasia, as it allows one to be

free to seek explanations for communicative success or failure in structured characteristics of a patient's language and in limitations imposed by the linguistic impairment, and CA provides tools for describing with some precision the observable communicative consequences of particular impairments. (Milroy & Perkins, 1992:28)

CA is useful to explore the impact of the impairment on the interaction.

It is generally agreed that CA is an effective method of analysing turn-taking in conversation (e.g. Fairclough, 1992; Schiffrin, 1994) and that a good knowledge of CA is a prerequisite to good discourse analysis, as it provides a powerful tool to understand interaction (Potter, 1996). It is useful to determine boundaries within talk and to map topic management and repair mechanisms. It is for this reason that it is being used to analyse discourse in this study.

In addition to the above methods of data analysis, data were viewed from a number of viewpoints as proposed by Layder (1993). In his research map he suggests that one links the *micro* with the *macro* by exploring issues at a number of levels:

- i. The self: the individual's sense of identity, personality, perception of the social world as influenced by social experience of the life career.
- ii. Situated activity: the dynamics of the interaction itself.
- iii. Social setting: the nature of the setting, the characteristic forms of power in that setting.
- iv. Macro context: consideration of elements such as gender, race, values, norms, codes of behaviour.

In this section I outlined how data were analysed in this study. I described the qualitative data analysis *Framework* before going on to discuss Critical Discourse Analysis and Conversation Analysis.

6.4 SUMMARY

This chapter has outlined a description of the study. It began by providing information about individual participants and issues surrounding ethics. It then described methods used in data generation and data analysis. Multiple methods are being used to gain access to the narratives that people draw on to make sense of aphasia and to manage it in day to day life. The following three chapters tell each of the key participants' stories in terms of the narratives they and their conversational partners draw on, as well as outlining how they managed threatened identity from a narrative perspective.

CHAPTER 7 ANNE'S STORY

"Slowly getting better but not good enough"

The findings of this investigation into narratives of aphasia are presented in three chapters. Chapter Seven presents and summarises the findings in relation to Anne, Chapter Eight in relation to Tony, and Chapter Nine in relation to May. The results presented in each of these chapters are my interpretations of their respective stories.

The data obtained from the participants was explored in order to identify the narratives that emerged. These will be looked at in the context of the overall life changes associated with stroke, as well as identifying how participants managed the aphasia and how identity principles were threatened. The framework for each of these chapters follows the same order:

- Firstly, they present changes in lifestyle since the stroke in terms of social network, social roles and participation.
- Secondly, they summarise the narratives that emerged from the data.
- Thirdly, they outline the overall theme that emerged in terms of the principal narrative type (Lieblich *et al*, 1998).
- Fourthly, they present how participants manage and deal with threatened identity, aphasia and disability and the role narrative plays in this.

Narratives are frequently complex, subtle and overlapping and can be difficult to access, particularly with those who have aphasia. Therefore an eclectic approach utilising a variety of methods was undertaken. These have been outlined in the preceding chapter.

The people who participated in the study of Anne include Anne herself, family members Stephen (her son) and Peter (her brother), two health professionals who were

working with Anne: Suzanne, her speech and language therapist, and Linda, her occupational therapist²⁴, and me as researcher.

To start Anne's story I will set her in the context of her overall lifestyle, focusing on the changes brought about by the onset of aphasia.

7.1 CHANGES IN LIFESTYLE

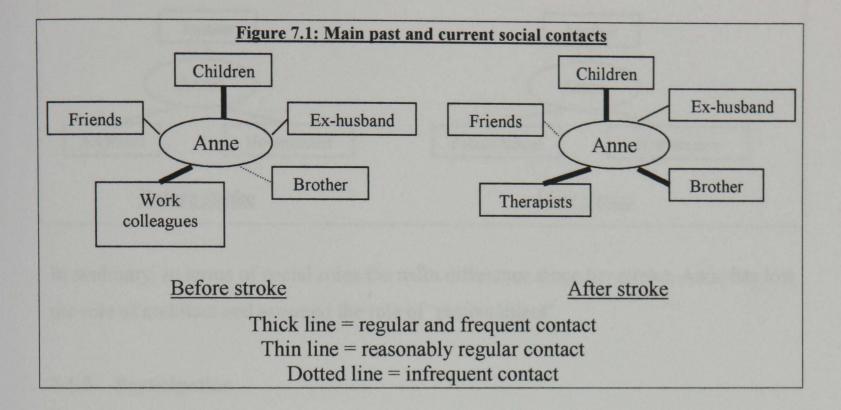
As described in 6.1.3, Anne is in her forties and prior to her stroke she held down a responsible demanding job as an architect. She is a single parent and one of her three children lives with her. She attends a clinic twice a week for speech and language therapy and occupational therapy. Anne has quite marked aphasia; she finds it extremely difficult to retrieve words and her verbal communication tends to be characterised by social and stereotypical speech. For this reason it was necessary to 'scaffold' her communication in terms of asking questions around what I thought she was telling me, clarifying meaning and checking out my interpretations.

7.1.1 Social Network

Anne's children feature strongly both before and after the stroke, with the main change in Anne's social network since the stroke being that she no longer sees work colleagues. These have been replaced by therapists playing quite a major role in her life now. The rest of her contacts remain the same, though the frequency and intensity of interactions has changed. For example, for the first two years post-stroke Anne was in frequent contact with her brother Peter who helped her out with things. Indeed he was the key contact person for the health professionals. Prior to the stroke Anne would have only seen him once or twice a year as compared to two to three times a month following her stroke. However one of the times when I met Anne after the interview she explained that she was by then seeing a lot less of him again since she had become more independent from a communication point of view. Therefore while he played a key role in the first two years post-stroke when Anne's communication abilities were

²⁴ Throughout the remainder of this and subsequent chapters the speech and language therapist will be referred to as SLT and the occupational therapist as OT.

very impaired, as she became more autonomous and learned to live with aphasia, his role diminished and the frequency of contact became less and might again return to what it had been prior to the stroke (i.e. once or twice a year). While she never had many friends, those she does have she sees less often. Figure 7.1 provides a diagrammatic representation of her main past and current social contacts.

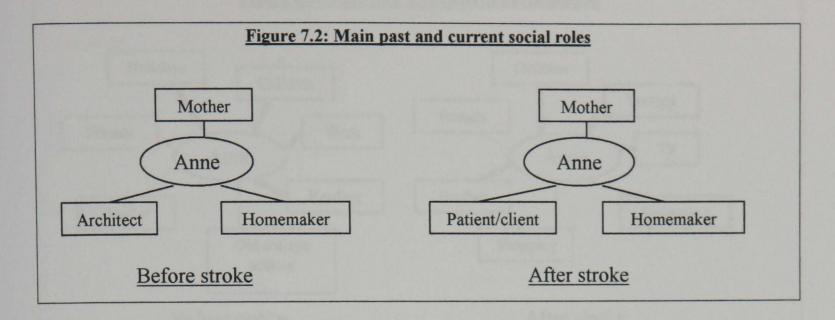


In summary, the main difference in Anne's social network is that she no longer sees and mixes with colleagues from work. In contrast since her stroke she sees a lot more of her brother and she sees therapists at the stroke clinic. Prior to her stroke she had no contact with therapists and only minimal contact with her brother.

7.1.2 Social Roles

Anne continues in her roles of mother and homemaker. However there have been a number of changes, the main one being from Anne as architect to Anne as 'patient/client'. Work used to play a big part in her life before the stroke; she was in a highly demanding job that required a great deal of expertise and decision making. Now she is unemployed (although she is currently attending vocational training focusing on computer skills) and frequently in the role of 'patient/client' which is quite different from her previous working role. A 'patient/client' role usually infers a degree of passivity with the therapist being in control and doing most of the decision making

(Simmons-Mackie & Damico, 1999b). This is in stark contrast to her previous working life where responsibility and decision making were key features. Figure 7.2 provides a diagrammatic representation of her key social roles before and after stroke.



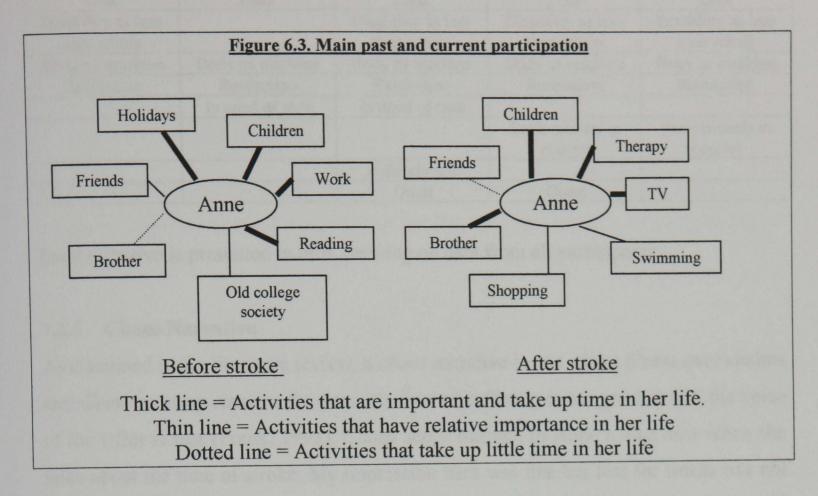
In summary, in terms of social roles the main difference since her stroke, Anne has lost the role of architect and assumed the role of 'patient/client'.

7.1.3 Participation

Prior to her stroke Anne was a successful career woman and sole parent who enjoyed going on regular holidays. Her life revolved around her children and her work. In addition she read a lot, was secretary to an old college society and saw her friends from time to time. This is in contrast to her life post-stroke, in which her children still dominate, but different things are considered important and take up her time. She attends a stroke clinic a few times a week and much of her life is worked around these appointments. She is now no longer able to read and television has taken on a greater importance – according to her son she watches it "twenty-four seven". Anne also listed shopping and swimming²⁵ as significant activities that she does now, whereas they were not something that she identified as being important before the stroke. So it seems that some activities like television and shopping have taken on greater significance than they had prior to the stroke. As stated previously she now sees much more of her brother than she did before her stroke, though this is diminishing, and she sees friends

²⁵ While at the time of interview Anne was swimming regularly, half way through the study she gave it up. The reason she gave for giving up was the cold weather.

from time to time, though less frequently than she did in the past. Figure 7.3 gives a diagrammatic representation of her activities before and after her stroke.



The dominant factor that makes Anne's life different now from before her stroke is the fact that she is no longer working as an architect and is not in any form of employment. This lack of income affects her ability to go on holidays, which she used to enjoy and now really misses. Becoming a 'patient/client' has taken over a great deal of her time as much of her life revolves around her therapy appointments and doing 'homework' for the speech and language therapist.

The next section will present the main narratives that emerged from the data. They give some insight into how the stroke has affected Anne's life and some of those around her.

7.2 EMERGENT NARRATIVES

The dominant narratives that emerged from the data obtained from Anne and the other participants were rich and varied in terms of ways of thinking and experiencing aphasia. They are summarised in Table 7.1.

Table 7.1: Emergent narratives (Anne)

Anne	Stephen (son)	Peter (brother)	Suzanne (SLT)	Linda (OT)
Chaos	Chaos			
Loss	Loss	Loss	Loss	Loss
Disability as less than whole		Disability as less than whole	Disability as less than whole	Disability as less than whole
Body as machine	Body as machine	Body as machine	Body as machine	Body as machine
Restitution	Restitution	Restitution	Restitution	Restitution
	In need of care	In need of care		
			Professionals in control	Professionals in control
		Philanthropic		
		Quest	Quest	

Each narrative is presented in turn, drawing on data from all participants.

Chaos Narrative 7.2.1

As discussed in the literature review, a chaos narrative is one where illness overwhelms and when the story remains the person's own as suffering is too great to tell; the voice of the teller is lost (Frank, 1995). Chaos seeps through in Anne's interview when she talks about the time of stroke. My impression here was that her loss for words was not just linked to her aphasia, but rather to her difficulty recalling and identifying her actual feelings at that time.

Interview extract 7.1: Anne – lines 181-189 [R = Rozanne]

R: Right so at the beginning it was very

A: It was very gr gr grey ... grey or?

R: Grey?

A: Grey

R: What do you mean by grey? ... very down? Or very ...

A: No em I can't I had a stroke but I I can't read em a long time this one was em hhh I can't say

R: I was just wondering cos you were saying that it was grey

A: It's grey it's grey [laughs]

Interview extract 7.2: Anne – lines 917-926 [R = Rozanne]

R: How did you react to your speech how were you feeling at the time?

A: Low

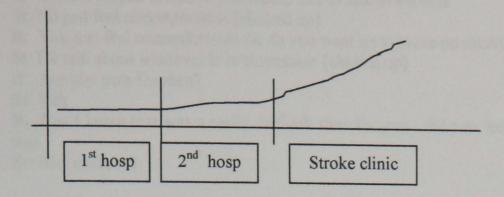
R: Very low?

A: Low yeh low

R: And what did you do?

A: I don't know em ... this is having a stroke it is quite impossible sometimes it is good and sometimes it's bad ok but this one and this one [points to the first two hospital times on the 'hospitalisation graph' where she has plotted progress - see Figure 7.4] not good

Figure 7.4: 'Hospitalisation graph'



Others were also in *chaos* around that time as is evidenced by the picture her son, Stephen, chose to represent Anne around the time of stroke. It reflects the confusion at that time.



Stephen (son)
"It just looks confusion confusion to what's going on"

While *chaos* was evident with Anne when she spoke of the time early on post-stroke, her son Stephen was living a *chaos* narrative. *Chaos* was particularly evident during his interview whereby he was choked up throughout, yet insisted on continuing. He had great difficulty in expressing his feelings other than to say he felt "uncomfortable". There was a 'stop-start' nature to his communication and that style suggests his difficulty in articulating his feelings surrounding his mother's stroke. In Donald's (1999) terms, it seemed that his experience and feelings seemed to outstrip his capacity to distinguish and say them.

<u>Interview extract 7.3</u>: Stephen (son) – lines 52-75 [R = Rozanne]

- R: Right so when you went to visit her what was it like visiting her?
- St: Sad [choked up]
- R: Was it sad ok Stephen . was it very different
- St: [Attempts to withhold sobbing]
- R: Ok would you prefer do you want me to stop it [indicates tape recorder]
- St: No [shakes head still trying to withhold sobbing]
- R: Are you sure? I think it is a very sad time .. is it still very sad?
- St: Not as much [choked up] no
- R: Right it must have been a very big shock for you?
- St: [Controlled sobs] (6secs)
- R: Do you not talk about it much

St: Not really

R: Is there maybe someone you would like to talk to about it

St: No just feel uncomfortable [choked up]

R: You just feel uncomfortable ok do you want us to move on thinking about now

St: I'll talk about whatever is in discussion [choked up]

R: Are you sure Stephen?

St: Yeh

R: Cos I know that was a really difficult time for you . did you fee- you felt very very sad what wa-

St: And confused

This is the picture Stephen chose to represent Anne now, but I felt that it was more a reflection of how *he* felt now. When going through the pictures he constantly referred to himself in his choices, rather than to his mother.

Picture 7.2.

Stephen (son)
"Being alone ... can't see anything"

Outwardly Stephen appears calm and helpful, constantly on the look out for when his mother gets into difficulties, and he is quick to act as interpreter when she requests it (ethnographic notes 29/11/2000, 31/01/2001 and 14/03/2001). However the private face tells a different story, one of *chaos* as he struggles to cope with the situation. Such conflicting narratives (i.e. public coping and private chaos) give rise to a number of issues and these are outlined in Chapter Eleven.

Chaos was not evident in Peter's (brother), Suzanne's (SLT) or Linda's (OT) interviews. A chaos narrative was only apparent when Anne and Stephen talked about the early days post-stroke. However there is evidence that Stephen is still in chaos.

The next narrative to be presented is *loss*, which identifies some of the losses Anne experiences since the onset of stroke.

7.2.2 Loss Narrative

Most people who acquire aphasia experience loss (e.g. Brumfitt, 1993; Herrmann, Johannsen-Horbach & Wallesch, 1993; Ireland 1995). Anne is no exception as she and her conversation partners spoke in terms of what Anne had lost as a result of the stroke. Throughout her interview Anne makes frequent references to loss of abilities such as talking ("I can't talk for the moment"), reading ("I can't read for the moment") and cooking ("I can cook but not – cook slowly"). In addition she refers to loss of holidays ("before holidays after no holidays") and to loss of friends ("I don't know anybody for the moment") with loss of one friend in particular due to not working anymore.

Interview extract 7.4: Anne - lines 633-636

A: Not from the stroke em no em this one [points to "Colin", "Mary" and "Anne Flynn"] are old friends but this one and this one [points to "Mary" and "Anne Flynn"] come with me but this one [points to "Colin"] no

Later in the interview she discusses her loss of status. Prior to this excerpt Anne had drawn a long arrow pointing upwards indicating the level of the doctor, and had drawn another arrow gradually moving upwards to the level of the doctor the bottom of which she wrote "patient".

Interview extract 7.5: Anne – lines 1049-1059 [R = Rozanne]

- A: Before the stroke [draws arrow the same height as the doctor's arrow] ok doctor
- R: So am I right then before the stroke you would have been at the same the same
- A: Level
- R: Yup absolutely but then when you became a patient then there was a different level?
- A: Yes yes
- R: And you're- the way you've marked here you're trying to get up to that level again
- A: Yes yes

Similarly she highlights the loss of previous lifestyle when she describes her life before and after her stroke.

Interview extract 7.6: Anne – lines 733-741 [R = Rozanne]

- A: Em this person [draws two arrows pointing up, one arrow longer than the other]
- R: Different so you've got one line there with a very long arrow and one with a very short one
- A: This was ve- this was before the stroke [points to long arrow]
- R: Right ok ... this one so it was big
- A: Big and this one [points to short arrow] is slowly getting better

Reading is something Anne used to enjoy and both her son, Stephen, and her brother, Peter, refer to her loss of reading abilities. Peter also outlines her loss in terms of work.

Interview extract 7.7: Peter (brother) - lines 242-244

P: It [job] was very technical very involved and very demanding and she's gone from that to sort of being stuck in the house what most of the time

Suzanne (SLT) and Linda (OT) also refer to her loss of job due to the stroke. Linda says:

Interview extract 7.8: Linda (OT) - lines 14-18

L: The thing that really strikes you is the fact that you know she was so capable she you know had a PhD I think it was research she was working I'm not sure exactly what the area was but that she was working at really quite a high level an- and that was just taken away from her so quickly

Linda also comments about Stephen's loss in terms of how there may be some loss of normal mother-son interaction, in that Anne would no longer be able to help Stephen with such things as his homework. Not only has Stephen lost the usual mother-son interaction, he has gained an additional set of responsibilities: that of interpreter and "minder".

Following the onset of aphasia Anne experiences and speaks in terms of loss. Her conversation partners also refer to this aspect of loss. With loss comes the experience of disability. The following narrative addresses how disability is viewed.

7.2.3 Disability as Less Than Whole Narrative

Goffman (1963/1990) noted that the stigmatised individual is one who has lost her/his wholeness in society's eyes. In this narrative there is an underlying theme that people with impairments are not whole, in that they are missing some essential element to be an acceptable member of the community (Phillips, 1990; Barton, 1993; Thomas, 1999b). This links in to the societal view that to become disabled is a personal tragedy (Oliver 1993a). Each participant, except for her son Stephen, talks about Anne in these terms at some stage during the interview. Anne herself remarks how much less her life is now compared to before (see interview extract 7.6). Later in the interview she compares herself to the status of the doctor (see interview extract 7.5) and discusses how she hopes to achieve the same status again. Anne has a PhD in architecture and this may be the guiding principle behind her comparison. It seems that due to her current situation she no longer feels of equal status, but that this status is re-attainable

when she becomes well again. Her brother Peter also states how her status has changed since her stroke, when he says:

Interview extract 7.9: Peter (brother) - lines 212-218

P: But its extremely hard for her she was a doctor of em architecture and she had quite a good job and that she enjoyed doing her work she was very very committed to it and she was very involved in her job and of course going from say being a very high professional to being a stroke victim must be extremely hard

He feels that she has gone from being very involved in a highly technical job to "being stuck in the house most of the time". He states that she would only be capable of some "undemanding" work in the future.

Owing to her "condition" Peter has some concerns about Anne buying a two-storey house, yet Anne is able to climb stairs without any difficulty.

Interview extract 7.10: Peter (brother) - lines 519-520

P: Well the stairs are very steep and so it's a two storey house I I had no part in actually choosing that house otherwise it would have been a bungalow.

And later he goes on to say:

Interview extract 7.11: Peter (brother) – lines 534-536

P: I would have chosen a single storey one because of her condition rather than say one with stairs

Linda, the OT, says how much slower she would go if someone has aphasia in terms of going through things step by step and making sure that the last step was learned completely. She differentiates her work with people with aphasia when she says:

Interview extract 7.12: Linda (OT) - lines 330-337

L: So I might find I would spend you know the first session doing you know just two or three very basic things whereas if someone was able to say to me yes I fully understand be able to repeat yes what you do is go in to the start menu and do X Y and Z if they're able to say that back to me er as well as demonstrate it I'd be very happy that they had and maybe move on and move through that bit quicker

Linda's choice of picture for 'now' seems to infer disability as less than whole in that there are "areas still missing". This picture has a disintegrated feel to it.

Picture 7.3



Linda (OT)

"Starting to bring colour back as a bit but some areas still missing work and so on"

Linda states that Anne's aphasia is a real "stumbling block" to employment and even to doing some form of work experience. She also infers that Anne has had a greater distance to fall because of her previous high level of functioning, and in some ways this makes her more disabled.

Interview extract 7.13: Linda (OT) - lines 358-361

L: Just given her previous level of functioning and the fact that she wa- she was so dysphasic at the start in that it caused her so much frustration and that em it affected her probably nearly every level of her life

The narrative of *disability as less than whole* is inferred in the language used by the SLT Suzanne. She suggests that progress is seen as measurable along a distance and that Anne falls short of this, although she is making progress. For example, Suzanne says that she finds progress "hard to gauge" and that she feels that she has "no yardstick to measure" progress. Clearly there must be some optimum abilities to measure against, and Anne does not yet meet these levels.

In line with the narrative of *disability as less than whole*, people with communication impairment are frequently misjudged as having a learning disability (Sacks 1991). Just after an occupational therapy session with Anne (participant observation 14/02/2001), Linda (OT) gives as a reason for Anne not trying the computer at home as the difference in her intelligence before, compared to how she is now – inferring that aphasia affects one's intelligence. This view is also supported by the fact that on asking a builder the way to Anne's house, he described her as the one who was "slow" but "very nice". Thus it seems that difficulty in verbal expression leads to a view that one is less intelligent.

In summary, there is some evidence that participants, Anne included, have the view that if one is disabled one is less than whole.

7.2.4 Body as Machine Narrative

This narrative links to the cultural meta-narrative of modern bio-medicine whereby the body is treated as a set of parts which, if broken down, can be fixed (Stainton Rogers, 1991). This narrative of *body as machine* permeates the interviews. Anne constantly refers to aspects of her abilities that have broken down. For example:

Interview extract 7.14: Anne - lines 85-86

A: I can't talk for the moment em em this one [points to books] but em I can't read for the moment

Interview extract 7.15: Anne – lines 131-133

A: But this one is good [shows right leg] and this one is good [shows right side of face] but this one [shows right arm] is not well

She goes on to remark on how they are going to be 'fixed'.

Interview extract 7.16: Anne – lines 838-843 [St = Stephen; R = Rozanne]

A: Em em do all the things necessary to have a stroke er [points to arrow going up in the 'hospitalisation' graph]

R: So do all the things necessary to have a

A: No do all the things

St: To get her speech back

A: Yes

Similarly other participants talk in terms of abilities that have broken down.

Interview extract 7.17: Stephen (son) - lines 301-302

St: Yeh but em .. she's still bad at reading and writing I don't think she's gotten across with that yet

Interview extract 7.18: Peter (brother) - lines 45-47

P: Well when she had her stroke at first say her reading ability was gone and her even her understanding about what was going on around her was quite gone

Interview extract 7.19: Peter (brother) - lines 503-504

P: Her speech was badly affected also her mobility's affected too and her right side is not what it was at all

Interview extract 7.20: Linda (OT) - lines 19-21

L: Really the only deficit that she has is in the area of communication she has a mild em incoordination and decreased strength in one hand

Both Suzanne (SLT) and Linda (OT) use the term "intervention"; such a term implies doing something to someone in order to modify and 'fix' behaviour. They refer to how she needs intervention to get well (or partially well) again.

Interview extract 7.21: Suzanne (SLT) – lines 298-300

S: She still needs quite a lot of kind of direct therapeutic intervention as in real direct treatment

Interview extract 7.22: Linda (OT) – lines 354-357

L: I mean of course everybody who comes through the door you know was em functioning at a higher level than they are at the moment that's why they're coming to us for rehab and we're trying to maximise that

A body as machine narrative was particularly strong in the health records to the exclusion of all other narratives except restitution. Throughout the records Anne is referred to in terms of her condition, functions and abilities, very little information (a couple of sentences only in the speech and language therapy report) is given about Anne as a person and one gets no sense of the actual impact of stroke on her both in terms of her day-to-day life and personally. Essentially she is reduced to a set of medical bodily facts.

Artefact extract 7.1: Health records

The bulk of the clinical psychologist's report is taken up with describing the assessments that were undertaken. These included the Wechsler Adult Intelligence Test, the Rivermead Behavioural Memory Test, the Rey Osterretch Complex Figure Test, the Trail Making Test, the Benton Visual Retention Test and the Draw A Clock Test. The report goes on to say that Anne's "overall non verbal intellectual function is in a low average range". It then states that on the Block Design and Matrix Reasoning she "performed at superior level" and so one "would assume that these performances most likely reflect her general intellectual capacity pre morbidly".

There was a strong view among participants that the body is like a machine that breaks down and that the role of "intervention" is, as far as possible, to fix it. This narrative of body as machine links closely to the following narrative of restitution where the focus is on making well and restoring function to those parts that have broken down.

7.2.5 Restitution Narrative

The narrative of *restitution* infers a sense that illness is transitory and that breakdowns can be fixed (Frank 1995). This narrative links to both the meta-narrative of western medicine and the narrative of *body as machine* in that they all align to the notion that the body breaks down and can be fixed (cured). Such narratives are very strong in western society (Kleinman, 1988; Stainton-Rogers, 1991; Frank, 1995).

In terms of use of metaphor there was a strong theme of 'recovery as a journey' from all participants and this fits well with a *restitution* narrative in that one is on a journey to be made well again. For example:

Interview extract 7.23: Anne - line 218

A: Slowly getting better ... but this time I am coming along

Interview extract 7.24: Peter (brother) – line 362

P: I see her coming back to the person that she was before

Interview extract 7.25: Suzanne (SLT) - lines 392-393

S: I don't know what kind of employment she'd really be what route she would go down

Interview extract 7.26: Linda (OT) – lines 375-376

L: They can improve in so many ways down the line

Both her son Stephen and her brother Peter's choice of pictures for 'now', together with Stephen's choice for the future, suggest a journey towards recovery. They both chose the 'Train tracks' picture.

Picture 7.4

Stephen (son) - now

"It's a long way to go"

Peter (brother) - now

"It's a long track ahead for her'

Stephen (son) - future

"This is for the future when she's fully better"

Similarly Suzanne's (SLT) choice of picture for this time infers a journey of some sort.

Picture 7.5



Suzanne (SLT)

"Getting better ... confidence improving ... hopeful ... changing ... going off somewhere a bit different ... so its hopeful"

Restitution is a very dominant narrative and comes through strongly in the interview with Anne and all her conversational partners. Anne herself seems to be particularly bound up in her quest to get better and in the belief that she will do so. For example, she frequently referred to her aphasia in temporary terms in that it was getting better albeit "slowly". There is an air of 'recovery' running throughout.

Interview extract 7.27: Anne – lines 171-180 [R = Rozanne]

A: All right but I could I had a stroke this I had a stroke this one [draws a line upwards as if plotting progress] ok and I come gradually better and then ... better [continues to draw progress on paper] and here which I come here [continues to draw]

R: So that's where you are now?

A: Yes and I come [laughs as points to high point in line]

R: And that's where you want to go?

A: Yes!

Interview extract 7.28: Anne – lines 353-354

A: Slowly getting better but not good enough

Anne feels that she will regain her speech three years after her stroke.

Ethnographic notes extract 7.1: Speech & Language Therapy session 16/02/2001

Anne says that she will get it [speech] back by three years and that she will "get some work as well". She draws a line going upwards, as if plotting progress, indicating the progress she has made at different times with the greatest progress being made recently since she started to attend the stroke clinic. Suzanne [SLT] acknowledges the progress that Anne has made and comments that it is due to "hard work".

A restitution narrative is also dominant in the language used by all other participants and one gets the sense that progress is still to be made. For example her son Stephen states that she is getting better, albeit slowly: "slowly slowly getting better". He goes on to refer to how she learns new words.

Interview extract 7.29: Stephen (son) - lines 369-371

St: The way she learns words is like she hears people saying them and she copies them and therefore she gradually learns them for herself

Like Anne and Stephen, her brother Peter alludes to the fact that there is progress but that it is slow.

Interview extract 7.30: Peter (brother) – lines 499-500

P: I think its just a very slow and long process em and she is slow to regain her speech faculty

The *restitution* narrative infers the goal of regaining past abilities or as near to them as possible and Suzanne's (SLT) main focus of therapy is on the impairment and remediating her speech and writing to be as near as possible to their pre-stroke state.

Ethnographic notes extract 7.2: Speech & Language Therapy session 16/02/2001 Suzanne highlights the errors that Anne makes in her writing and encourages her, and cues her where necessary, to correct them.

Suzanne is of the opinion that Anne still needs a lot of "direct therapeutic intervention"; from the context, this was inferred to mean impairment based therapy.

While the focus of Linda's (OT) intervention is on the disability, in terms of identifying how Anne is able to manage computer skills, the theme of restitution still emerges.

Interview extract 7.31: Linda (Occupational Therapist) – lines 129-132

L: My role then was really just to try and em show her the level of control she did have in that hand [the right hand] and try to encourage her to use it because obviously if she didn't use it it would be less and less functional

Ethnographic notes extract 7.3: Occupational Therapy session 14/02/2001

Linda explains how it is better to use the right hand (i.e. the hand that has been affected by the stroke) from "a stroke point of view". Linda encourages Anne to use her right hand when typing to "speed things up". Anne does not do so, though at Linda's request she tries to use the mouse with her right hand but says that it is slower and rejects this in favour of using the left hand.

There is an inference here that in order for something to be "functional" (i.e. of use) it needs to be used, even if it may be less efficient to do so. In terms of using her right hand to use the mouse, Anne stands her ground and opts to use her left hand which she finds easier and more effective.

A restitution narrative is also evident in a more public domain. When out shopping, Anne (participant observation 22/02/2001) explained to the cashier that she had had a stroke but that her speech was getting better slowly. The cashier responded by saying "as long as it's getting better that's the main thing", suggesting the public expectation

that people should be made well again and that being 'normal' is of more value than being different.

In addition to the strong restitution thread running through the interviews and as evidenced by the therapy sessions, the health records also tended to focus on the impairment and its remediation. Little was written about the disabling experience of aphasia in terms of how it affected Anne's day-to-day life. They referred almost exclusively to the assessment and treatment of the impairment, yet according to Suzanne (SLT), therapy also involved addressing issues of living with aphasia. No mention of this was made in the records. Kleinman (1988) and Mattingly (1998) note that the written record of an appointment can be quite different from the actual transcript of it. Recording into a health care chart is a ritual act in which illness experience and disability are transformed into disease. The difference between actual 'interview' and health record is the difference between disability as the person's problem and disease as the health professional's problem (Kleinman, 1988). It seems then that it is the health professional's problem that is the focus of the 'official' health record. It is as if the voice of the public narrative of biomedicine dominates at the expense of the voice of the 'patient' even though therapy may be concerned with the voice of the patient.

All participants draw on a *restitution* narrative in their understanding of acquired aphasia and disability, with a focus on regaining lost abilities. A *restitution* narrative infers that things are missing or not working properly and are in need of fixing. The next narrative to be presented focuses on the person with the impairment and how the presence of the impairment leads them to be *in need of care*.

7.2.6 In Need Of Care Narrative

This narrative infers that the person with the impairment is in need of care. This links to the cultural narrative of *philanthropy*, whereby one is 'good' and 'kind' to those less fortunate than oneself. This narrative does not feature in the language of Anne, and only a few comments by her son Stephen suggest it (e.g. "she depends on me more").

Anne herself strikes one as a very able, capable and independent woman. She is a successful homemaker, manages to get to and from clinic appointments independently, does the shopping, deals with bills and issues as they arise and is quick to ask for help should she require it. This is in sharp contrast to how her brother views her, whereby this narrative of *in need of care* is very dominant. Comments suggesting that she needs looking after in some way permeate the interview at regular intervals. For example:

Interview extract 7.32: Peter (brother) – lines 51-53

P: My main object I had at the time [of stroke] was that she remained in care for as long as possible

Interview extract 7.33: Peter (brother) - lines 266-269

P: Say in terms of the hospital and chasing after the doctors and making sure various things happened and keeping an eye on her mental progress and making sure that she wasn't discharged from hospital

Interview extract 7.34: Peter (brother) – lines 552-556

P: Yea he [GP] keeps an eye on her and I think well as often as possible for a doctor to do in that if she goes to see him he's aware of her condition and I suppose that if anything untoward he would ring me or somebody else but that it would be taken care of

Interview extract 7.35: Peter (brother) – lines 588-594

P: I suppose in a way you would have the concerns about Anne that you would have about an elderly person who an elderly person who was frail and living on their own . at the moment its good that Stephen's there he sort of in a way besides being her son he's become her sort of minder in many ways and he's very good at that

The narrative of *in need of care* also comes through in how Peter uses language. He frequently refers to Anne's need to be kept in care of some sort (e.g. "she remained in care", "she remained in the system [health care system]"). From his use of metaphor he seems to view care as 'protecting', 'shielding', and 'sheltering'; for example "she was under the care of Dr. Smith", "under the care of the doctor". While he maintains that one should not "call people vegetables these days", his language betrays him as he uses overwhelmingly passive and objectifying language when talking about Anne since she had her stroke, while he uses more active language when he talks about her before her stroke. For example:

Before stroke	After stroke
 "She was working extremely hard" (222) "She travelled a fair bit" (473) "She was always taking holidays" (474) 	 "She was kept in a private room" (55-56) Everyone was "very good to her" "It was very beneficial for her" (73-74) "A stroke victim" (218) "He always had a great interest in the case" (689) "She was transferred" (170) "I made sure that () she remained in care" (59-60) "They didn't sort of turn round and abuse her" (319-320)

To interpret some of these examples:

- Anne as passive object: "She was kept in a private room" infers that Anne was an
 object that could be "kept" in a particular place. There is no sense of agency.
 Similarly the comment "she was transferred" places Anne as a passive object.
- Anne as passive recipient: Comments such as everyone was "very good to her" and "they didn't sort of turn round and abuse her" place Anne in the position of being a passive recipient. (See also 6.2.9.)
- Anne as object worthy of scrutiny: "He [dr.] always had a great interest in the case" moves Anne away from being a person with agency to an object of scrutiny. Such language is frequently used in medical and other health settings (e.g. case conference where a particular person is discussed) and links to the pervasive metanarrative of modern medicine which guides our health service, whereby the primary role of health care is for the 'experts' to heal 'patients' and where the 'patient' is viewed as a passive recipient of care.
- Anne as stroke victim: This comment suggests that Anne was a passive recipient in that the stroke happened to her and she was the "victim" of it, implying a personal tragedy. The notion of personal tragedy underpins society's view of disability, in which to fit in with the norm is to be valued and deviance from the norm is to be pitied.

Anne, on the other hand views herself as having agency. Her language is very different from Peter's and it is dominated by use of active language (e.g. "I get myself driving again", "I can cook but not – cook slowly", "I am able to do things differently"). Also

Stephen's language use is more active in nature (e.g. "she can do a lot now", "[she] walks straight up to them and says like I had a stroke") suggesting that he still views his mother as an active agent rather than a passive object.

Linda (OT) at times uses language that, like Peter's, objectifies Anne, inferring that she is not an active agent but rather someone who needs things done for her. For example she says things like "trying to do something functional with her", "to help her to be placed in a course", "being easier to work with her being easier to treat". Suzanne (SLT), though not so pervasively, also uses language that places Anne in the passive role.

In summary, there is no evidence of the *in need of care* narrative with Anne or her son, Stephen. However it is apparent in the talk of her brother, Peter, who even two years post-onset thinks of Anne as someone needing some sort of care. There is some evidence of this narrative in the talk of both Linda (OT) and Suzanne (SLT).

Being in need of care infers some lack of control by the person. The following narrative implies control of a different sort, where the professionals hold a position of power and control the therapy proceedings. In both these narratives objectifying and passivising language is used when talking about Anne.

7.2.7 Professionals in Control Narrative

The way in which therapists are 'trained' and the dominant meta-narrative of modern medicine which guides our health service determines that the professional takes control and guides the course of treatment. How language was used in both the interviews and the therapy discourse sheds some light into how this narrative is central to the way in which 'rehabilitation' occurs in our society. Both the SLT, Suzanne, and the OT, Linda, use language in a way that suggests their position of power in the therapeutic relationship. One gets a sense that things are done to Anne and that she is not seen as an active agent in the process. The following are some examples.

• "I give her exercises" (Suzanne, line 71).

- "She is quite an easy person to treat" (Suzanne, lines 93-94).
- "See if we can make anything easier for her" (Suzanne, line 296).
- "She needs quite a lot of direct therapeutic intervention" (Suzanne, lines 298-299).
- "We are investigating work for her" (Suzanne, line 350).
- "Having looked back at what I had done with her" (Linda, lines 150-151).
- "Getting other agencies involved in helping Anne" (Linda, line 173).
- "Be able to help her to be placed in a course" (Linda, lines 201-202).
- "Her being easier to work with her being easier to treat" (Linda, lines 414-415).

There is much evidence of *professionals in control* in the therapy sessions observed (audio-taped discourse and ethnographic notes of observation of occupational therapy 14/02/2001 and speech and language therapy 16/02/2001). In both these sessions the therapist concerned directed activities, with only the occasional initiation from Anne – usually a request to do something again. This would be very different from Anne's experience prior to her stroke, when she was very much in control and active in decision making. In the therapy sessions Anne's expression is characterised by minimal turns in both the occupational therapy and speech and language therapy sessions. Such turns are shaped by the nature of the interaction in that the therapist in each situation is directing matters while at the same time checking out that they get agreement from Anne. For example:

Discourse extract 7.1: Speech & Language Therapy session – lines 491-507 [S = Suzanne]

S: (...) But extra time really helps Anne

A: Ok

S: Ok that's just there to remind you that when you're doing this at home

A: Ok

S: If the words aren't coming out quickly=26

A: Ok

S: =Enough I know its very frustrating

A: Ok

S: But getting frustrated you know getting impatient with it

A: Ok

S: Won't help it

A: Ok

S: So will you try that

A: Ok

S: When you take this out this week remember that's there [the post-it note to remind her to slow down]

²⁶ Shaded text denotes overlap.

A: Ok

<u>Discourse extract 7.2</u>: Speech & Language Therapy session – lines 877-887 [S = Suzanne]

- S: It's like that ok all right Anne em: I want to do a few more kind of sequences with you
- A: Ok
- S: All right?
- A: Ok
- S: So maybe we'll do one each time
- A: Ok
- S: Ok em: but I suppose I'll leave you with that one now and I'll do these ones cos I'm just looking at the time and we'll do another one the next time you're in
- A: Ok

Linda (OT) and Anne's discourse is also characterised by Anne's minimal turns. For example:

Discourse extract 7.3: Occupational Therapy session – lines 1167-1190 [L = Linda]

- L: Here let me show you-shall I show you right from the very beginning?
- A: Yes right from the beginning
- L: Ok I'll turn it [computer] off completely
- A: Ok
- L: Mine is probably a little bit different
- A: Ok
- L: Cos I have a few different things on=
- A: Ok
- L: =And its going to ask me do I want to turn things on but I'll show you ... so it'll turn itself off (6 secs) anytime you see the little egg timer ...
- A: Ok
- L: You know that its working=
- A: Ok
- L: =You just have to give it a few more minutes
- A: Ok ok
- L: So you come to your computer ... and yours might be a little different but you just turn on that button
- A: Ok
- L: Also you want to make sure that this is on
- A: Ok
- L: That its flashing
- A: Ok

There are times however (twice in the speech and language therapy session and once in the occupational therapy session) where there is a 'power flip' (Walsh-Brennan, 2001) and Anne takes control.

Discourse extract 7.4: Speech & Language Therapy session – lines 429-433 [S = Suzanne]

- S: Ok right now oh to see that [puts things back in folder 5 secs] its getting quite fat in there
- A: What?
- S: It's getting quite fat in there quite a lot
- A: Ok [takes the folder from Suzanne, removes the papers and puts them in the folder properly]

<u>Discourse extract 7.5</u>: Speech & Language Therapy session – lines 629-631 [S = Suzanne] S: Now [Anne corrects the shape of the 'P' that Suzanne has written] thank you Anne

A: [Laughs]

<u>Discourse extract 7.6</u>: Occupational Therapy session – lines 1266-1269 [L = Linda]

L: So even if you could try that

A: Ok what when will I see you again?

L: Ok lets go up to our diary and we'll have a look and

A: Thank you so much

In looking at the surface structure of the discourse it was noted that there is pervasive evidence of RRE (Request Response Evaluation) sequences, particularly in the speech and language therapy discourse. Such sequences are characteristic of therapeutic interactions and suggest that that the therapist is in the role of 'competent expert' and the person with aphasia is the 'incompetent patient/client' (Simmons-Mackie & Damico, 1999b). The following is an example of an RRE sequence.

<u>Discourse extract 7.7</u>: Speech & Language Therapy session – lines 208-210 [S = Suzanne] [Anne and Suzanne are doing a therapy task whereby Anne has to point to the letter that Suzanne says]

Request →

S: Show me B

Response →

A: B this one [points to the letter B]

Evaluation →

S: Good

On occasion there may be a delay in the correct response being given where Anne requires prompting and so there follows a 'help' sub sequence.

<u>Discourse extract 7.8</u>: Speech & Language Therapy session – lines 181-196 [S = Suzanne]

Request → S: [Show me] R

Response →

A: R .. R ... R

Help sequence

S: Hmmhmm

sequence S: Hmmhmm

A: ABCDEFG this one

S: What one did I ask you again . R

A: R

S: Try and say the alphabet

A: Ok

S: Now slowly

A: [Points to the letters as she says them aloud] ABCDEFGHIJKL.

S: M

A: MNO.P

S: P I'm looking for R . L M N

A: Yeh ok this one

Evaluation →

S: Yes that's it yes

Linda (OT) is more explicit in the language she uses when requesting Anne to do something. She frequently says "and I'll get you to ..." or "I'd like to let you try ...". Such language exposes the therapist as expert with an expectation that the

'patient/client' will fulfil what has been requested of her/him (Simmons-Mackie & Damico, 1999b).

In therapy encounters the 'patient/client' is bound to respond to a request by fulfilling or complying with it and this is then evaluated (as shown in the examples above). This differs from non-therapy encounters in which there are several possible responses to a request; the person receiving the request can choose to comply with the request, to refuse to comply with the request, or to derail the request (i.e. by asking for clarification, changing the topic) (Schiffrin, 1994). Therefore the role of the person who is the 'patient/client' is constrained in therapy encounters, in that they are expected only to comply with what is requested of them.

The narrative of *professionals in control* is also evident in the way the nurse dealt with Anne's complaint about her appointment times.

Ethnographic notes extract 7.4: Clinic Waiting Area 16/02/2001

Anne walks into the waiting area and we greet each other. She drops her bag on the chair beside me and goes to talk to the nurse at reception saying "ten o'clock no that's too much ten o'clock ten o'clock too much eleven o'clock twelve o'clock two o'clock yes ok but ten o'clock it's too much". The nurse responds by saying that no-one wants to come in at ten everyone wants an appointment at eleven, twelve or two and that she can't change the time. Anne responds to this by saying "it's too much it's too much". The nurse says she might be able to change it but that Anne must remember that there may not be the slots.

Anne has a long distance to travel to the clinic yet no allowance seems to be made for this.

Mattingly (1998) in her study of the practice of occupational therapy found that professionals rarely relinquished control of therapy sessions. She comments that a narrative is made by the combined efforts of both the therapist and the 'client', but that the therapist is very much in charge. She found that even casual social conversation is controlled by the professional. In Anne's work with therapists, both the content and the way in which language is used suggest that the professionals hold the power in the 'therapeutic' relationship.

The other narratives that emerged, but which were less dominant, were *philanthropic* and *quest*. These are now presented in turn.

7.2.8 Philanthropic Narrative

A *philanthropic* narrative infers being benevolent to others less fortunate than oneself. It is quite a dominant narrative in Ireland and no doubt in other western societies as is evidenced by the abundance of charities. Peter's narrative of *in need of care* directly links to this *philanthropic* narrative in that if one is ill or disabled, then one is in need of care so that others are good and kind to those in that situation.

In Ireland this *philanthropic* narrative may be particularly tied up with the dominance of the Christian church in Irish society and that the interpretation of what it is to be a good person is related with being good to people who are sick or disabled (Inglis, 1998). Peter frequently talks about how people have been "good" to Anne and not been 'abusive towards her'. For example:

Interview extract 7.36: Peter (brother) - lines 142-145

P: I think in general that people have been very good em there's nobody who's been abusive towards her or has treated her badly because she has had a stroke or because of her condition

This theme of people being "very good" to Anne despite her condition is reiterated throughout Peter's interview. Such comments suggest a particular attitude to disability. Explicitly stating that people have been "very good" to her infers that the expectation might be that people are not good to people who have an impairment and that it is a bonus when this expectation is not realised.

The following narrative is very different, in that it is about disability being incorporated fully into the person's life.

7.2.9 Quest Narrative

A quest narrative is when illness or disability is met head on and integrated into daily life (Frank, 1995). Anne herself has some awareness that she will not be able to return

to her previous employment and is keen to pursue other options. Suzanne (SLT) comments:

Interview extract 7.37: Suzanne (SLT) - lines 383-389

S: I think she wouldn't mind quite a different job in that she's said maybe she's come out and said maybe she'd like to be a librarian now which would be quite different from being an architect I would have my concerns about being a librarian myself given her literacy difficulties so I think a very different job wouldn't be a problem but a job that's not in her head at the moment

Her brother Peter remarks how he feels that she has accepted it now and that she is looking to the future. Suzanne (SLT) also feels that Anne is looking towards the future. The picture she chose to represent Anne in the future reflects a *quest* narrative in that she acknowledges that life is different from what it was before the stroke but that there is a sense of a future incorporating aphasia.

Picture 7.6



Suzanne (SLT)

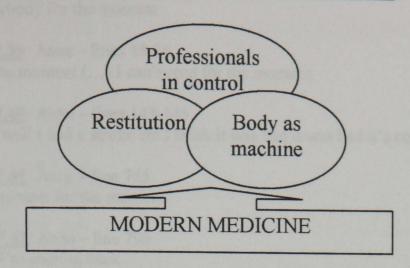
"Things changed, parts the same and parts different ... feel always compensating and living with the loss. The colour and brightness show that there is colour and a future that is bright but different. The essential person is there – essential and different."

There were only faint traces of a *quest* narrative in the talk of Anne and other participants. This may be because the onset of aphasia occurred only two years ago and there has not been sufficient time to adapt and incorporate it into everyday life. Rather a *restitution* narrative, among others, dominates.

7.2.10 Drawing Threads Together

As can be seen from what has been presented so far in this chapter people do not come with clear definite narratives, rather they are at times faint and are often overlapping as traced through the different methods. For example, in Suzanne (SLT) and Linda's (OT) discourse there is an overlap between *restitution*, *body as machine* and *professionals in control* all guided by the meta-narrative of modern medicine (Figure 7.7).

Figure 7.7: Overlapping narratives (Suzanne & Linda)



To summarise, there is a complex narrative tapestry surrounding Anne – of which she is a part – with different people presenting with different narratives; some in agreement others not, some faint others strong. For example, there are powerful threads of restitution with weaker threads of quest and philanthropy; Anne's brother Peter has a strong narrative of in need of care yet Anne does not. However all contribute to the overall picture of what it is like to live life with aphasia.

This section has presented the main narratives that emerged from the data. The following section summarises the overall theme that emerged in terms of the principle narrative type.

7.3 OVERALL THEME: PRINCIPAL NARRATIVE TYPE

Lieblich et al (1998) advocate undertaking holistic-form analysis which focuses on the overall plot or structure of the narrative. They identify four principal types: romance, comedy, tragedy and satire (see 5.3.2 for further detail). Out of these principal types, Anne's narrative seems to best fit with that of romance whereby the main theme is that the essence of the journey is the struggle itself in which the 'heroine' faces a series of challenges en route to the goal and eventual victory. Her language use communicates the temporary quality of her current situation, as she sees it. This links to a strong dominant theme of 'recovery as a journey' and a restitution narrative. The following are some examples of struggle and the temporary nature of the situation.

Interview extract 7.38: Anne - lines 03-04

A: I don't know anybody for the moment

Interview extract 7.39: Anne - lines 85-86

A: I can't talk for the moment (...) I can't read for the moment

Interview extract 7.40: Anne - lines 143-145

A: I can't speak so well I had a stroke em I think it was bad it was bad it's coming better slowly

Interview extract 7.41: Anne – line 765

A: No job for the moment for the moment

Interview extract 7.42: Anne - line 796

A: At the moment I'm coming back

Ethnographic notes extract 7.5: Speech & Language Therapy session 16/02/2001

Anne says that she will get it [speech] back by three years and that she will "get some work as well".

In addition to these accounts of the transitory nature of her current situation there is some evidence of when she has actually triumphed.

Interview extract 7.43: Anne – lines 229-230

A: I get myself driving again

Interview extract 7.44: Anne – lines 237-247 [R = Rozanne]

A: Because I ca- I go outside and em drive I drive em ...

R: And what has that given you?

A: A lot yes a lot of reason because this I get some em driving lesson driving lessons and I can walk ok I walk I go to Crazy Prices and I go to er Quinnsworth and I get ss em em I can't say the word em [writes "Xxx Xxx" – name of shopping centre] Xxx Xxx [name of shopping centre] (...)

R: It allows you to be able to do that the car?

A: Yes it allows me to be able to do that

<u>Interview extract 7.45</u>: Anne – lines 953-956 [R = Rozanne]

A: Yes its important ... a car this I get a car and er all right all right

R: All right so a car made a big difference

A: Yes a car was a big difference

Driving therefore was considered a significant achievement and provided her with the freedom to be more independent again and it gave her a sense of reclaimed autonomy.

The overall theme of Anne's narrative is one of *romance*, whereby she struggles to overcome adversity but anticipates triumphing in the end.

What is clear from what has been put forward so far is that Anne and those around her draw on a complex set of accounts in their interpretation of aphasia and disability. The

result is a rich tapestry of interweaving narratives that surround Anne and affect the way in which she manages threatened identity, aphasia and disability. This is the focus of the next section.

7.4 MANAGING THREATENED IDENTITY, APHASIA AND DISABILITY

While section 7.2 presented the emergent narratives as they were portrayed in the data, in this section I outline the role these narratives have to play in managing threatened identity, aphasia and disability. In addition I present how Anne is viewed both before and after her stroke.

7.4.1 Views of Anne

Anne's life has changed significantly since she had a stroke two years ago. This situation affects how she and others view her. The picture selection task revealed changes in how she is viewed now, compared with before her stroke. Anne herself selected two pictures to represent her before the stroke.

Picture 7.7



Both these have a similar feel to them – there is an air of unity and solidity though somewhat solitary. This contrasts with the pictures she chose for now which, though also solitary, have a sense of disintegration (i.e. lots of different parts trying to make a whole). However both pictures are quite different and one gets a sense that she is in two minds about how she wants to represent her current situation.

Picture 7.9



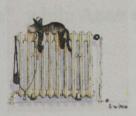
According to Newbury (1996), selection of images to reflect self and disability is a complex process and this is evident in Anne's insistence of selecting two pictures, rather than just one, to represent certain times. One gets a sense of this complexity when one views her choice of pictures (pictures 7.9 and 7.10) to represent her 'now'. One picture has a fragmented and distressed feel to it (picture 7.9: 'Weeping Woman'), while the other has more of a feel of parts coming together to form a cohesive whole (picture 7.10: 'Sunflowers'). This would relate to her experience of loss of many things (see 7.2.2) while at the same time not being as stressed as she was before, and even happier. This may link to Frank's (1991) claim that in western society illness is one of the few things that provides one with permission to slow down. Prior to her stroke, Anne worked extremely hard and was extremely stressed with never a moment to slow down, now she has that opportunity. This is illustrated by Stephen's remarks.

Interview extract 7.46: Stephen (son) – lines 192-194 St: She er . she more happy less stress on the job

<u>Interview extract 7.47</u>: Stephen (son) – line 218 **St**: She laughs more

Her brother Peter on the other hand sees Anne before the stroke as someone who enjoyed relaxing and taking it easy, as depicted by the picture he chose for her for this time (picture 7.11: 'Cat on radiator') and his accompanying remarks which are at odds with how Anne is described by her son, Stephen (as someone who was always stressed and working hard). While for now, Peter chose a picture suggesting a journey (picture 7.12: 'Train tracks') and that she still has a way to go.

Picture 7.11



Peter (brother) – before stroke
"Always liked cats and she'd be quite
fond of relaxing and taking it quite easy"

Picture 7.12



<u>Peter (brother) – now</u>
"It's a long track ahead for her"

The picture Suzanne (SLT) chose for now also had a sense of a journey about it. She sees Anne current situation as hopeful and looking to the future.

Picture 7.13

"Getting better ... confidence improving ... hopeful ... changing ... going off somewhere a bit different ... so its hopeful"

Linda, the OT, like Anne, chose the 'weeping woman' picture (picture 7.9) to represent her now, saying that for her this suggested that things are still missing in Anne's life: "starting to bring colour back as a bit but some areas still missing and so on".

7.4.2 Managing Threatened Identity

In terms of Breakwell's (1986) identity principles of continuity, distinctiveness and self-esteem, Anne defines herself in terms of what she can and cannot do, both before and after the stroke. For example she used to read a great deal, go on holidays and "work always". Now she is not able to do any of those things which potentially poses a threat to continuity, distinctiveness and self-esteem. Continuity is broken because Anne is no longer being able to do certain things in the way she had previously (i.e. working, reading, cooking). In addition, continuity is threatened by the fact that one friend does not treat her in the same way as he did prior to her stroke; if he bumps into her now he just says hello and walks away. Stephen says that this person is "uncomfortable", while Anne comments that this person is no longer the same towards her.

In terms of distinctiveness she is no longer distinctive in the way she once, was as she had a very strong identity as 'professional with a PhD' prior to her stroke and now she is no longer working as an architect. She is distinctive in a different way now, in that she is 'disabled' and a 'patient/client'.

In terms of self-esteem there is some evidence that she no longer has the confidence to do even those things that do not require speech. For example, in the first year post stroke she did not feel confident enough to drive on her own, but always requested her son Stephen to go with her. She is now quite comfortable driving on her own and it is evident that as she achieves more her confidence and self-esteem grow. However from the outset she has been confident enough to request help when she requires it.

Anne copes with these threats to her identity by her tendency to compartmentalise and isolate her aphasia into something separate from the rest of her self-definition and that, while it is a fact that she has aphasia, the situation is only temporary and she will do "all the things necessary" to get her speech back. One gets the sense that she feels that life will return to normal or near normal again sometime in the future. This is evidenced by her strong *restitution* narrative. This strategy corresponds to the intrapsychic acceptance strategy of 'compartmentalisation' in Breakwell's (1986) framework of coping with threatened identity in that one admits that something is wrong (e.g. "I can't talk") but adds that this is temporary (e.g. "for the moment").

7.4.3 Managing Aphasia and Disability

Effective management or coping with one's aphasia involves "maintaining a sense of value and meaning in life, in spite of symptoms and their effects" (Bury, 1991:461). Narrative enables one to do this. Anne, through the narratives she draws on and the way in which she compartmentalises her difficulties, has learnt to deal effectively with her aphasia without becoming overwhelmed by the situation in which she finds herself.

As stated earlier, Anne is a successful homemaker and manages most of the day-to-day tasks of living independently. In terms of her day-to-day practical management of aphasia, she uses a number of action strategies to help get her message across. For example, in each of my interactions with her, including the interview, she frequently used gesture, drawing, writing and her communication notebook, to augment what she was trying to say. These strategies were generally successful. However twice in my

company they were not and she had to resort to another strategy to enable her to get her message across. On both occasions she summonsed her son Stephen to act as 'translator', which he did. This strategy therefore was effective in that she was eventually able to get her message across.

Ethnographic notes extract 7.6: 31 January 2001

[We are talking about her ex-husband.] Anne shows me three fingers and says "three three" – I am not sure what she means and ask her whether they have been separated for three years or whether he has been living with someone else for three years. She responds by saying "no no" and continues to say "three" and show three fingers, raising her voice and using facial expression that conveys surprise while doing so. I continue to have difficulty understanding. She then goes to get Stephen from the study. He does not get what she wants to say straight away and Anne continues to say "three three" raising her three fingers. Stephen's face continues to show confusion and Anne responds to this by repeating "three three" while raising her voice and speaking in a more clipped way until he understands. Stephen says that his father has three more children, Anne then turns to me as if to confirm that this is what she wants to tell me.

Early on post-stroke Anne did not like to travel alone or make phone calls. For both these situations she would enlist the help of her son Stephen. She continues to request him to make phone calls for her, although she is happy to drive on her own.

<u>Interview extract 7.48</u>: Stephen (son) – lines 125-131

St: She doesn't feel that she's able to do the tasks like er drive down to Naul alone but she's getting used to now she can do a lot now but er earlier on she needed me to go down with her everywhere but she still feels unsafe ringing somebody she needs me to pick up the phone and ring som- a number and wait til the person answers before she'll talk

There are some things that Anne has found difficult to do because of her aphasia. These include dealing with her financial situation (this is quite complex and involves her exhusband), dealing with the police when she was burgled, buying a cat, and dealing with a complicated lawnmower service. For situations such as these she usually requests the help of others, generally from her brother or speech and language therapist. Anne is assertive, rather than reticent, in asking for help and in so doing manages her affairs effectively.

In addition to the above Anne uses a number of stock phrases such as "I've had a stroke I can't talk for the moment" or "I can't say the word but I can understand it" regularly in conversation. These repetitious comments can be viewed as strategies which seem to serve one of three functions.

- To alert her conversational partner as to why she is different. This is the opinion of her son Stephen. While out supermarket shopping she made the comment "I've had a stroke, I have trouble with words but I'm getting better slowly" to the cashier. This served to alert the cashier as to why her behaviour might seem odd or different and she couched it in socially acceptable terms (i.e. stroke may seem more socially acceptable than other conditions due to the work of such organisations of the Council on Stroke of the Irish Heart Foundation and the Volunteer Stroke Scheme).
- To act as a 'filler' to maintain social connection as she struggles to translate her thoughts into words. For example:

Interview extract 7.49: Anne - lines 860-861

A: Getting better if you if you working better but er slowly but I can't say ... better all the time but I can't say

 As a means to explain why she is having difficulty, she frequently says such comments to her speech and language therapist who knows why she is having difficulty.

<u>Discourse extract 7.9</u>: Speech & Language Therapy session – lines 194-198 [S = Suzanne] [Anne and Suzanne are doing a therapy task whereby Anne has to point to a letter that Suzanne says. Anne is experiencing particular difficulty with locating 'R' which she eventually gets.]

S: (...) P I'm looking for R . L M N

A: Yea ok this one

S: Yes that's it yes

A: This one ... I can't say the word I can understand it but I can't say the word

Other participants use a number of strategies to facilitate Anne to get her message across. For example Anne has a tendency to panic when she is not understood and Peter and others (e.g. the SLT) tell her to take her time. This usually helps, as according to Suzanne (SLT) her speech is much better when she is relaxed. Linda, the OT, on the other hand identifies a number of strategies that she employs when working with someone who has aphasia. These include using less language, demonstrating more what she wants the person to do, going slower, asking questions in a different way and using pen and paper more. In addition Linda would tend to get a family member involved so that she could gain details about the person's situation.

At times Anne is not understood. When this occurs her son Stephen explains the situation to the person and the person, according to Stephen, either gives her more time or walks away. Anne and Stephen both report that there is one friend of Anne's who does not seem to be able to cope. This friend no longer sees Anne and when he does bump into her he just says "hello" and walks off, while before he would have had a chat.

Interview extract 7.50: Stephen (son) – lines 176-181 [R = Rozanne]
[Talking about when Anne bumped into a work friend in the supermarket.]

St: I think he said a quick hello I think he said a quick hello and nothing and just walked

away

R: And how would it have been different before how would they have managed before?

St: I'm sure she would have kept in touch and they would have talked more

This particular friend "reacted very badly" according to Anne, while in general people have been "all right".

7.4.4 Overall Coping Strategy

In terms of the overall way in which Anne manages her situation, she seems to live very much in the present (focusing on working on her speech to make it better) and dealing with the day-to-day challenges as they come up. Anne does not seem overly distressed by her situation and frequently refers to how she "can't talk for the moment", implying that this is just a temporary condition. One of the therapists believes that one would expect Anne to be "devastated" when one takes into consideration the extent to which her life has been altered. However her son Stephen reports a different view and says that she is less stressed and even happier now that she was before her stroke. Indeed Anne does not appear to be "devastated" by her situation, but rather she comes across as someone living in the present with an expectation of regaining her speech. This ties in with the principal narrative of *romance* as well as *restitution*.

Stephen outwardly copes well as he manages in his day-to-day life. He successfully acts as interpreter for Anne when she requests it and deals with things effectively as they arise. However as we have seen, inwardly it is a different story as he presents with a *chaos* narrative (see 7.2.1), struggling to come to terms with what has happened and the loss of his previous mother/child relationship. Peter, on the other hand, admits to

having taken everything "in [his] stride" and has dealt and deals effectively with issues as they arise (e.g. if Anne phones him with something that she needs help with). He is a key support for Anne.

In this section I have outlined how Anne is viewed and how she and others manage her aphasia, disability and threatened identity. Her strong *restitution* narrative seems to be the primary means of coping, in that she lives very much in the present and focuses on working to get better. There seems to be an expectation that things will be all right in the end.

7.5 SUMMARY

I began this chapter by presenting the changes to Anne's lifestyle as a result of stroke. Prior to her stroke she held down a responsible, demanding, professional job and one of the major changes is that she has not been able to return to work. Her life now revolves around her children (as it did before her stroke) and attending therapy. She has moved from being someone early post-stroke who relied on her son, her brother and her SLT to do many things for her to being someone who is beginning to regain a real sense of autonomy and independence.

The narratives that Anne and her conversation partners draw on were then presented. Some narratives are shared across participants, others are not; some come through clearly, while there are only faint traces of others. What is apparent is that Anne is surrounded by, and is a part of, a complex tapestry of evolving narratives within which she lives her life. That being said, *restitution* came through as a particularly strong narrative; a narrative which seems to influence and guide the way she behaves and manages her aphasia. This strong *restitution* narrative links with her principal narrative type of *romance*, in which the storyline is one of struggle with eventual victory. Anne currently is struggling as she learns to adapt to living with aphasia, but she anticipates overcoming it in the end and works hard in her quest to do so. Her guiding principle seems to be: "slowly getting better but not good enough".

The chapter concluded by specifically outlining ways in which Anne and others manage aphasia, disability and threatened identity. I addressed how the identity principles of continuity, distinctiveness and self-esteem were threatened and managed. I then went on to present what participants do in a practical sense to overcome the effects of aphasia, as well as looking more broadly at the overall way in which Anne copes.

Tony experienced a similar life changing event to Anne and the following chapter explores his narratives and those of his conversational partners.

CHAPTER 8 TONY'S STORY

"It's a case where it's you had a stroke and er onwards"

Tony and some of his family and friends shared their stories of the aftermath of stroke freely with me. These data provide the basis for this chapter. Like the previous chapter, this one follows a similar format in its presentation of the data. Firstly, it addresses the lifestyle changes that have occurred since the stroke, it then presents the main narratives that emerged from the data as well as the overall theme that surfaced in terms of principle narrative type. Finally it presents how Tony and his conversational partners manage and deal with aphasia. Again an eclectic approach to data generation and analysis was undertaken.

Other participants included his partner Sue; family members Mary, his older sister, and Ciara, his younger sister; friends Fintan and Sarah; a work colleague Lorraine; and me (Rozanne) as researcher.

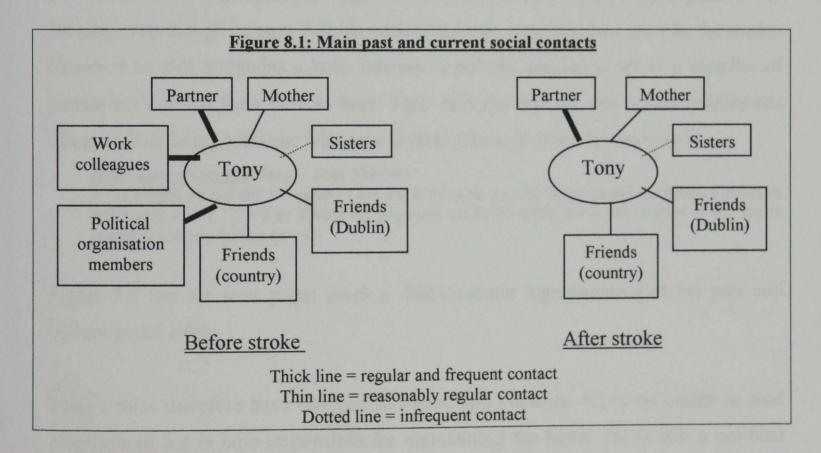
I begin Tony's story by placing him in the context of his lifestyle, with particular reference to changes that have been brought about by the onset of aphasia.

8.1 CHANGES IN LIFESTYLE

As outlined in 6.1.3, Tony is in his forties and is currently living with Sue, his partner of seventeen years. He had a stroke five years before recruitment to the study. Before that he worked in a clerical capacity in a large company. He is now retired on grounds of ill health. His aphasia was described as severe early on, but now he is able to get across much of what he wants to say through verbal expression, although there is evidence of word retrieval difficulty. Unlike Anne, Tony did not need someone to 'scaffold' his communication to the same extent in order to determine what it was that he was trying to say. In general he got across what he wished, although there were times when it was necessary to clarify and check out meaning.

8.1.1 Social Network

Tony's partner, family and friends feature strongly both before and after the stroke. The main changes since the stroke are that he no longer sees work colleagues or those members of the political organisation to which he was affiliated. In terms of this organisation, Tony says that he was reducing his involvement anyway just prior to the stroke. He admits to seeing more of Sue now – he meets her for lunch every day and this has been a positive development. Sue also welcomes this change. Friends remain a strong feature of their life and Sue goes so far as to say that you only "realise the value of friends" when something like a stroke happens. However following the stroke they did lose contact with one couple and Sue believes that this was due to their inability to deal with Tony's speech. He sees members of his family about as frequently as he had done prior to the stroke; he sees his mother every few weeks and his sisters about two or three times a year. However when he was in hospital, they were frequent visitors. Figure 8.1 provides a diagrammatic representation of his main past and current social contacts.



The only changes in Tony's social network concern the fact that he no longer sees work colleagues or members of the political organisation to which he was affiliated.

8.1.2 Social Roles

With regard to social roles the main change has been from that of 'worker' outside the home to that of homemaker or 'worker' inside the home. Tony now does most of the shopping, cooking and cleaning in the home. He reports that work had never been an important part of his life, other than 'bringing in the money'.

Interview extract 8.1: Tony – lines 264-266

T: It's a job you know it was a job and that's it really oh just er you know it wasn't great er it can be boring but it paid the money you know paid for the house

One of the things that irritated him when he was attending for rehabilitation and later when he attended the Stroke Clinic, was the assumption professionals made that he would want to return to some form of employment. Sue also took up this point in both her interview and in the article she wrote for the Stroke Newsletter. Returning to work was not an issue for Tony, as work was not a meaningful part of his life. He acknowledges feeling quite happy about being a "kept man".

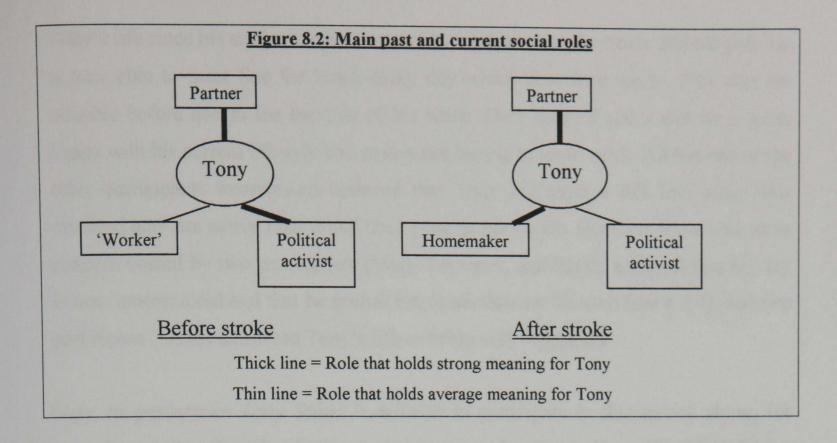
His involvement in the political organisation played a much more meaningful role in his life, even though he says that his connection was lessening just prior to the stroke. However he still maintains a keen interest in politics and helps out in a member of parliament's office from time to time. Tony remarks that his role within politics has changed from being someone who gave direction to someone who receives it.

Interview extract 8.2: Tony - lines 339-346

T: It's different but still the same I I not em er what do you call it em its still the issues I just do it differently now (...) It's as a what do you want me to do while previously a case of I'll say to people could you do this for me

Figure 8.2 (on the next page) gives a diagrammatic representation of his past and current social roles.

Tony's roles therefore have changed in nature and intensity. He is no longer in paid employment but is now responsible for maintaining the home. He is still a political activist, but not to the same extent that he was prior to his stroke.



8.1.3 Participation

In many respects Tony's life remains unchanged in terms of participation in that he meets friends and family from time to time, he continues to enjoy watching football on television, surfing the internet (particularly the club which he supports), going to the pub and visiting his cottage in the country.

The main differences are that he is no longer in employment and he does not spend time being involved in the political organisation to which he was affiliated, both of which took up a considerable amount of his time prior to the stroke. His involvement in the political organisation was extensive; he was both treasurer and general secretary at one time. As stated previously his activity within the organisation was reducing just prior to his stroke. However he still maintains an interest in politics and does some voluntary work in a member of parliament's office. This work takes the form of such things as photocopying and distributing leaflets. He admits that this would be very different from the type of responsibility he had before the stroke when he would have been the one to write the leaflets and give them to others to photocopy and distribute. In addition to these changes, Tony used to be an avid reader and now he is no longer able to enjoy this to the same extent, due to difficulties in reading as a result of aphasia.

Tony's life since his stroke revolves around his partner, Sue, the home and the pub. He is now able to meet Sue for lunch every day which they both enjoy. This was not possible before due to the location of his work. Tony himself states that he is quite happy with his current lifestyle and enjoys not having to go to work. All but one of the other participants interviewed believed that Tony led quite a full life, albeit less involved and less active than it had been prior to his stroke. However there was some concern voiced by two participants (Mary, his sister, and Sarah, a friend) that his day is now unstructured and that he spends too much time on his own (see 8.2.4), and one participant (Sarah) described Tony's life as being very "curtailed".

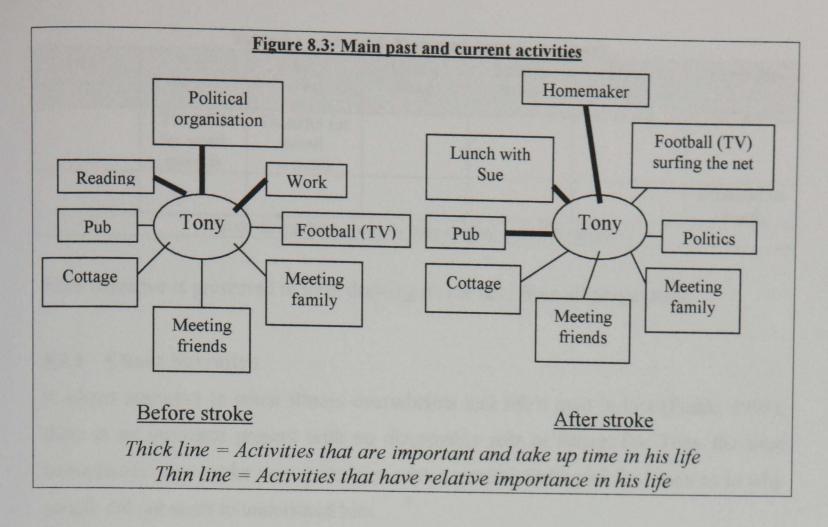
Early on post-stroke Tony found it difficult to participate in discussions about, for example, current affairs but he is now beginning to be able to do so. His friend Fintan comments:

Interview extract 8.3: Fintan (friend) - lines 106-114

F: Sue Tony and myself used to meet and discuss a number of things and em Tony and myself were the people doing the discussion and the talking because of his background in accountancy we were discussing financial stuff or whatever and Sue would be listening and chipping in the odd point making the odd comment but then when Tony had the stroke Sue and myself would talk and try to involve Tony in the thing I suddenly realise now Tony's sort of taking part in the conversation back again

Figure 8.3 (on the next page) gives a diagrammatic representation of the main 'activities' that Tony is involved in both before and after the stroke.

To summarise, Tony's life has changed in that he is now a home worker rather than a company worker, he is a television viewer rather than a reader, and he is political supporter rather than a political activist. He appears to be accepting of these changes except for some disappointment in no longer being able to read as he used to.



The following section outlines the main narratives that emerged from the data. They give some insight into how the effects of stroke have shaped Tony's life and the lives of those around him.

8.2 EMERGENT NARRATIVES

A number of narratives, some stronger than others, emerged from the data. These are summarised in Table 8.1.

Table 8.1: Emergent narratives (Tony) (continued overleaf)

60	Table 8.1: Emergent narratives (10ny) (communed overledy)							
Tony	Sue (partner)	Mary (sister)	Ciara (sister)	Fintan (friend)	Sarah (friend)	Lorraine (work colleague)		
Chaos	Chaos	Chaos	Chaos		Chaos			
Disability as less than whole	Disability as less than whole	Disability as less than whole	Disability as less than whole	Disability as less than whole	Disability as less than whole	Disability as less than whole		
Restitution	Restitution	Restitution	Restitution	Restitution	Restitution	Restitution		
		Importance of not being idle			Importance of not being idle			
Quest	Quest	Quest	Quest	Quest	Quest			
Fatalistic	Fatalistic	Fatalistic	Fatalistic			Fatalistic		
In need of care Philanthropic	In need of care		In need of care					
		Philanthropic			Philanthropic	Philanthropic		

Table 8.1 continued: Emergent narratives (Tony)

Tony	Sue (partner)	Mary (sister)	Ciara (sister)	Fintan (friend)	Sarah (friend)	Lorraine (work colleague)
	Thankful for small mercies	Thankful for small mercies				
						Disability as

Each narrative is presented in turn, drawing on the data from all participants.

Chaos Narrative 8.2.1

A chaos narrative is when illness overwhelms and life's map is lost (Frank, 1995), there is an incessant present with no discernable past or future. For Tony the time immediately post stroke was quite hazy with a general feeling of confusion as to why people did not seem to understand him.

Interview extract 8.4: Tony – lines 32-47 [R=Rozanne]

R: What about your stroke then can you tell me what happened then when you had your stroke?

T: I don't know basically

R: Don't know

T: Well as far as I was concerned I had a stroke and then about three weeks later say what's wrong but of course they believe me what I say was rubbish you know I said but what's wrong but they said oh what's he saying [whisper; shifting sideways glance] you know instead of (mumble) what's he saying I don't know [whisper] talking to each other as if (he) come on come on what what's wrong and so it was amazing co- er I was perf- I was perfect

R: oh right is that what it felt like?

T: yea in that what's the problem there you know but she Sue and the other people around what's he talking about you know I mean I don't know what its called but but er very em pissed off you know with the thing

A chaos narrative runs through some of the other participants' interviews in terms of how they talked about the time immediately post-stroke. Sue explains how she could only cope on a "day to day basis" and could not even consider what the future held.

Interview extract 8.5: Sue (partner) - lines 776-782

S: I could only take in so much information at one time you're coping on a sort of day to day basis and I couldn't even think what could be down the road what could possibly be down the road now maybe that's me being blinkered but I felt it was the only way I could cope with the situation at the time was on a day to day basis rather than on what might be or might not be you know

Sue and Tony's friend Sarah explains how Sue was at this time.

Interview extract 8.6: Sarah (friend) – lines 148-151

Sa: In the beginning she [Sue] just fell apart it was very sad and em she really went to pieces and er one or two of us had to kind of pick her up and do everything to the extent of driving her hither and yon

She later expands on this by saying:

Interview extract 8.7: Sarah (friend) - lines 284-291

Sa: I mean she [Sue] just sat and cried and she had to be scooped up and put in somebody else's house and totally totally minded I mean there was more minding of her than there was of I mean he [Tony] was obviously in hospital but I mean she just couldn't cope at all she couldn't drive she couldn't do anything she couldn't feed herself she couldn't do anything so it was a very good friend of theirs just scooped her up and kind of put her in her house and minded her

Sarah uses objectifying language in describing Sue (e.g. "had to pick her up", "she had to be scooped up and put in somebody else's house") at that time, clearly viewing her as a person, or object, to be cared for. One gets the impression that Sue was more in *chaos* than Tony was in those early days.

Both Mary and Ciara (sisters) state how "devastated" they were at that time. Ciara develops this by saying:

Interview extract 8.8: Ciara (sister) - lines 840-854

C: Yea I think at the time I was angry and em and just basically devastated you know really at the thought of going in seeing him in hooked up to tubes and on dialysis and just in em just being so sick you know and then wondering wondering first of all was he going to make it number one and then number two if he does make it what happens I mean he's only thirty-six thirty-seven he could live another thirty forty fifty sixty years you know and just the whole trying I think initially just trying to cope with everything I'd be one to try to cope with everything all at the same time instead of just taking it ok so he's fine he's going he's surviving now we take the next step then we take that step then that step and now we take the next one where initially I'd be one to go oh what are we going to do and I'd be thinking of every eventuality and sure half of them would never even happen you know

It is interesting to note how Ciara's way of dealing with the situation differs from Sue's. Sue can only take one day at a time and doesn't look into the future, while Ciara considers all possibilities and worries about them.

The picture Sarah (friend) chose to represent Tony at the time of stroke summarises how people around him felt then.

Picture 7.1



Sarah (friend)

"It's what I imagine what it would be like and a bit of what it felt like for us sort of just a jumble really ... we were confused and I'm sure he was very confused and it was a very confusing time"

Such feelings and reactions in the early days post stroke are probably not that different from how families and loved ones in general react when there is an emergency that entails admission to hospital. It is a worrying and uncertain time.

While Tony was extremely ill at the time of stroke he has made a reasonable recovery in that he is now able to walk and communicate quite effectively. However there remain some word retrieval difficulties and this affects how people view him. The following sub-section presents the narrative of *disability as less than whole* in relation to Tony.

8.2.2 Disability as Less Than Whole Narrative

As outlined previously in 7.2.3, this narrative infers that those with impairments are lacking something required to make them a fully participating member of the community (Phillips, 1990; Barton, 1993; Thomas, 1999b). For this reason then becoming disabled is viewed as a personal tragedy (Oliver, 1993a). Tony's interview is interspersed with comments that suggest this narrative. For example he refers to his reduced abilities in helping out in the political party's office.

Interview extract 8.9: Tony - lines 352-358

T: The issues are still I feel are important but now I let other people decide (...) yea we'd say why don't we do that or why don't we organise that but not a case of now er right you do it and I'm tell you- you just tell me when to call when you need me to stuff in envelopes

While before the stroke he would have been the one directing matters as he explains in interview extract 8.2.

Tony suggests that some people think that his intelligence has been affected and not just his speech. Ciara, his sister, also thinks that some people may think that he has a "learning difficulty" because of his speech. Tony explains.

Interview extract 8.10: Tony - lines 544-549

T: Well they feel that they're sort of saying now [looks down and sideways] oh (...) well as if your mental abilities or something as well you know mental rather than a stroke . that there's two pubs that I have refused and there right bye-bye

He goes on to talk about being refused in these pubs and that he attributes this to his speech.

Interview extract 8.11: Tony – lines 583-588 [R=Rozanne]

T: The feeling was that because of my er stroke you know from his point of view from the he was drunk or you know and I say right but as I say again right

R: What made you think it was- that he thought you were drunk?

T: I presume er just because er 'cos of my speech

He talks about other times when he has been treated differently.

Ethnographic notes extract 8.1: Tony's home 27/02/2001

[We are talking about the time of his stroke.] He relates how he didn't know he'd had a stroke and only knew when he heard the doctors telling Sue. He tells me how they [the doctors] used to talk over him to Sue and he eventually told them to talk to him. They did this but they spoke to him slowly enunciating each word very clearly and deliberately.

Sue does not always seem confident in Tony's abilities. She checks that he is clear about such things as what he needs to do in the bank (ethnographic notes 12/03/2001). She alludes to the things that Tony can no longer do since his stroke.

Interview extract 8.12: Sue (partner) - lines 423-429

S: Like for example one of the last things I remember him doing before the stroke is ringing up Vincent Brown [radio presenter] you remember Vincent Brown had a programme on radio ringing up and sort of saying abou- I don't know what the subject was but ring- and he actually got on air and was talking to Vincent there's no way he can do that sort of thing now so that side has stopped

Interview extract 8.13: Sue (partner) - lines 628-630

[Sue is talking about the time when her father was very ill and how vulnerable she felt at that time.]

S: Tony acted as a shield for that and he wouldn't have been able to obviously if he'd been ill himself

Later on in the interview Sue talks about how in the early days post-stroke people tended to avoid having political discussions with Tony. An indication of his

improvement is that these discussions are now a feature of Tony's meetings with friends again, as they were before his stroke.

Interview extract 8.14: Sue (partner) – lines 807-814

S: They'd [Tony and his friend Fintan] always have these deep philosophical discussions about the meaning of various peace treaties and things like that you know and it was Fintan was great 'cos he was actually chatting about the weather and the garden and stuff like that and now lately and I think this is what he means by Tony improving is that they're back to talking about politics and things that they're interested in you know

Similarly Tony's sisters talk about what gaps there are in his life now. For example Mary explains how articulate Tony was and how this is no longer the case.

<u>Interview extract 8.15</u>: Mary (sister) – lines 744-758

M: You feel like before that anybody could have come up and asked him an opinion [about politics] (...) and he would have been able to spout like mad about what he thinks and I said God you know he won't be able to do that now (...) maybe if he had a little bit of forewarning if he knew he was going to be asked he might be able to collect his thoughts a bit but I think if somebody just shoved a microphone in front of his nose I don't think so I think his brain wouldn't that's my opinion now I don't think his brain would be able to think on its feet do you know what I mean wouldn't be able to come out with something coherent

Threads of a *disability as less than whole* narrative run through the interviews with his friends, Fintan and Sarah. Fintan talks in terms of overcoming adversity when he says:

Interview extract 8.16: Fintan (friend) - lines 393-396

F: I'd be looking for or advising would be em to create conditions whereby the person can em feel fulfilled or do something in spite of the problem do something that's within their range of ability.

Tony's friend Sarah, who is a health professional, is more explicit in expressing this narrative.

Interview extract 8.17: Sarah (friend) - lines 64-71

Sa: He is particularly limited I think expressively at least that that's what I would- I think he's improved very much more than I thought he would since he had his stroke but I still think compared to the person he was I think he is very very limited em in being able to express what he would like to do I know I think he he's working em in a sort of office capacity with Tom Hewitt [a TD] but I really wonder what he actually does I don't know I can't quite get a handle on that

Lorraine who works full time in the office of Tony's friend, who is a politician, and where Tony sometimes helps out, has a particularly strong narrative of *disability as less than whole*. Lorraine has experience of working with "people with disabilities" and as a result she feels that she is more "tolerant" of them and feels that because of Tony's speech the general public would not react well to him (ethnographic notes 07/06/2001).

In my interview and conversations with her she frequently alluded to Tony's impairment in terms that suggested that he was missing something.

Interview extract 8.18: Lorraine (work colleague) - lines 51-53

L: We discussed it briefly and he seemed to be making sense despite his speech impairment

Interview extract 8.19: Lorraine (work colleague) - lines 111-118

L: I was more of a hindrance to him working talking to him because he would need all his capacity to do the job that he was doing I don't think he could separate the thought skills the mental skills and the speech skills that he would have to mentally use his brain each time to respond to me in a way that I wouldn't have to or he probably wouldn't have to before the stroke and would would sometimes not understand you know

Interview extract 8.20: Lorraine (work colleague) – lines 354-355 L: It's a terrible affliction dysphasia it really is it's degrading you know

It seems that Lorraine views aphasia as an impairment that makes one less than whole in that it reduces you in some way when she says that it is "degrading".

In terms of the way in which language was used, compared with Anne, Tony's conversational partners used mainly active language when talking about him; they rarely objectified him. This would link to their general view that he now leads a full and active life.

The pictures his friend Fintan chose and his accompanying commentary, to best represent Tony now and in the future, reflect the notion that his life has not quite returned or is unlikely to return to "completeness".



Fintan (friend) - now

"Partial view optimistic but perhaps not a complete recovery"

Picture 8.3



Fintan (friend) - future

"Hopeful but perhaps a question mark on completeness of it ... will the darkness completely clear ... no major storm brewing ... looks reliable and hopeful but still some question mark over completeness"

While this narrative is dominant there is evidence of a counter narrative whereby Tony is viewed as expert. This was apparent in the discourse that occurred during a pub lunch with Tony and Sue. Tony initiated as many topics as his conversation partners and his opinions were sought and listened to. For example:

Discourse extract 8.1: Pub lunch - lines 323-334

[T = Tony; S = Sue (partner); R = Rozanne (researcher)]

T: [Initiating topic] Oh yes the the Chinese are let go letting go

S: I beg your pardon

T: The Chinese have not the Yanks go [current news item] (...)

R: Oh they've been in captivity for a while now haven't they?

T: Seven days

R: Seven days yea

T: So they ok go ahead there was a letter from

S: Did they get their apology?

T: Yea I think so

A disability as less than whole narrative permeated the interviews and conversations I had with all participants. However there was also evidence of a counter narrative of Tony as expert. The next emergent narrative to be presented is restitution. This links to the disability as less than whole narrative in that the theme underpinning a restitution narrative is to be made whole again.

8.2.3 Restitution Narrative

A restitution narrative is one where the person is on a journey to recovery whereby she/he will regain lost abilities and will be made well again (Frank, 1995). While there is some evidence of this in Tony's discourse in that he thinks there has been "progression", it is much more apparent in the discourse of other participants. The

interview with his partner Sue reveals frequent references to progress and improvement, for example:

Interview extract 8.21: Sue (partner) - lines 201-205

S: It's funny there were times when you thought oh it's getting better it's improving (...) there were things that suddenly threw you like he couldn't say the days of the week in order he couldn't there was another one he couldn't count properly

Interview extract 8.22: Sue (partner) – lines 311-320

S: Ok he's got the word living spelt L I V B P instead of I N G at the end he's got a little bit of it right he didn't have that last week this is an improvement all the time I could see the improvement you know and I was encouraging him sort of saying you that you know when I think back to what you were two weeks ago this is great (...) in the beginning there was a huge progression and then gradually it slowed down it slowed down but there was always progression

Interview extract 8.23: Sue (partner) - lines 1200-1203

S: I can still see little improvements they might be small they might be minute but they are better and I think back a year ago and he wouldn't have done that couldn't have done it

There is some evidence that she believes that 'teaching' the person words will aid recovery. However there is some awareness that these methods may not work for Tony's particular set of circumstances.

Interview extract 8.24: Sue (partner) - lines 282-289

S: I always think that a lot of bad spelling is due to mispronunciation of words and I try and pronounce the word really you know exaggerate the pronunciation correctly and he still couldn't get he'd still be saying project and he'd be saying B S T no project you know pro pro B S no no S er you know and then it suddenly struck me this isn't working this isn't what's wrong with him

Also running through Sue's interview and other interactions with her is the notion that Tony should do things for himself as this would influence recovery and make him feel good about himself.

Interview extract 8.25: Sue (partner) – lines 588-593 [R = Rozanne]

S: Sometimes I'll chip in the word very very occasionally will I chip in the word 'cos I think that's wrong but if I chip if I chip

R: Why do you think that's wrong?

S: Because I feel he should try and get it himself I think it's good for him to feel that he can get it and find it

Ethnographic notes extract 8.2: Pub 12/02/2001

[We are talking about the Harry Potter books.] Tony says that he might get one [a Harry Potter book] at the airport. I tell them [Tony and Sue] that they should be read in order and that I can lend him my copies. Tony initially says yes and then thinks about it and says no because it would get "dirty" and then tries to explain why but gives up. Sue then asks him something like "well why do they get so dirty and scuffed?" and eventually Tony says it is because of keeping it in the rucksack.

I remember being struck at this point how Sue seemed to be encouraging Tony into giving exact details even when he was having difficulty in doing so. She did not help him out yet I had the feeling that she knew what he wanted to say, rather she looked at him waiting for him to say it for himself. This links in to the sense one gets that she feels that he needs to do things for himself which will help him to improve.

Just prior to this we were talking about reading generally and Sue made reference to the fact that it was good to practise.

Ethnographic notes extract 8.3: Pub 12/02/2001

We talk a bit about how it is more difficult for Tony to read and that while before he would persevere with a book even if it was "rubbish" now he doesn't he just puts it to one side. She [Sue] remarks how a few years ago it used to take him a month to read a book and now it is only a week. She tells him that she feels he ought to keep at reading as it is "important to practise". Tony looks at her, says nothing and smiles.

Tony's reaction gives the impression that he has heard this argument before and that it is easier to agree, but do his own thing anyway. This perhaps reflects wisdom on Tony's part in that he knows that practice may not be of that much help to him and that anyway he reads for enjoyment not for 'work'.

Sue makes a similar comment about the importance to "practise" in the article she wrote for the stroke newsletter.

Artefact extract 8.1: Sue's article

I keep telling him that he needs to practise and he tries to read some of his book (not a newspaper - psychologically, finishing a book is a terrific boost) every morning while I'm at work.

During the course of the interview Sue frequently returned to this theme of restitution and the progress that Tony has made even years following his stroke. Certainly one got the sense that the main goal following stroke was for him to regain his speech to as near to his pre-stroke abilities as possible. Both Tony and she feel quite strongly that doctors should not paint such a "bleak picture" in terms of recovery being limited to the first two years post stroke.

Interview extract 8.26: Tony - lines 814-817

T: Again to say to people that it would take a long time you know it's I know the school books or not the school books but whatever they are you know it is every year is gone but it's not it's for years and years you know (...) like now compared to last year ago you know there are

words I can say now but I couldn't get the words a year ago or two years ago you know it (takes) five years

Ethnographic notes extract 8.4: Telephone conversation with Sue 02/03/2001

She [Sue] talks about how wrong she feels it is that doctors and professionals give such a "bleak picture" of progress following a stroke. They seem to have a cut-off point of one to two years when the person supposedly "plateaus". She comments that she feels quite strongly that this is not the case and that professionals should not paint such a "bleak picture".

There were also threads of a *restitution* narrative running through the interviews of other participants particularly in terms of their remarks relating to the progress that Tony has made in his speech. For example:

Interview extract 8.27: Mary (sister) – lines 203-206

M: I noticed a huge improvement and I hadn't seen him now since before Christmas but I just noticed a huge improvement in his speech

Interview extract 8.28: Ciara (sister) – lines 274-275

C: I feel he's still actually improving that he's still getting better and better

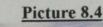
Interview extract 8.29: Fintan (friend) - lines 295-297

F: I may not have seen him for a month or something like that I was able to say well he's improved a lot since last time

Interview extract 8.30: Sarah (friend) - lines 363-365

Sa: And of course comparatively speaking he has made such enormous recovery from being so extremely ill that er that that's encouraging

The picture Ciara (sister) chose to reflect Tony 'now' represents the journey he has come and the improvement he has made.





Ciara (sister)

"The train track you know the long road that probably he's come along or whatever to get to where he is now"

It is interesting to note that Sarah (a health professional who is a friend) believes that Tony should have been "pushed" much harder in therapy, which in her opinion would have effected greater change. This links to the notion that one needs to work hard in order to improve and regain abilities and echoes the *professionals in control* narrative so evident in Anne's story (see 7.3.7).

Interview extract 8.31: Sarah (friend) - lines 427-442

Sa: Well push the person a bit harder [laughs] push them a lot harder em I think when they improve that is really the time that you can effect some change hopefully and I would think they should do their exercises religiously whatever it is they've been given to do and em do their homework (...) I mean if I had been their therapist boy oh boy would I have pushed them much harder

In addition to the strong *restitution* theme running through the interviews and interactions I had with participants, it was also very evident in the health records. The main focus of these was to restore 'function' again. A similar thread runs through Sue's article that she had written for a stroke newsletter entitled "Tony and me – and his Stroke". For example:

Artefact extract 8.2: Sue's article

I plagued all the therapists (but especially Speech and Language) for ways I could help Tony. I was aware that stimulation and help in the early stages after a stroke were vital and I was determined to play that part in helping Tony.

There is no evidence of a *restitution* narrative in Tony's diary which concentrates on relating what he does from day to day. However the diary he did at my request does talk about issues relating to his impairment in that he relates how long it takes him to write certain pieces.

Restitution was a strong narrative for all participants, except Tony. While he acknowledges the "progression" he does not dwell on the improvement he has made he remains very factual about what he can and cannot do. However all other participants refer frequently to the progress he has made and how this is a positive thing. Underpinning this theme is the sense that regaining pre-stroke abilities, or as near as possible to them, is the ultimate goal.

8.2.4 Importance of Not Being Idle Narrative

This narrative reflects the public's expectation that one should be a participating member of society and do something with one's time. While this was not expressed by most of the participants, it was a dominant narrative with two of them, his sister Mary and his friend Sarah. Both talk about how he now has no structure to his day and that this is of some concern.

Interview extract 8.32: Mary (sister) – lines 364-373

M: I feel myself now that if he had something to do everyday that would be a lot better for him (...) you know like for somebody so young to have another possibly twenty thirty years ahead of them and not have something structured everyday to do that's what I would worry about

Interview extract 8.33: Mary (sister) – lines 985-990

M: If he could get into something who knows I feel that he needs something I really do I said its not right for somebody of that age it's different if he was totally gaga you know an awful thing to say but you know what I mean that he couldn't cope but he's quite capable of doing a few hours a day or half a day

Interview extract 8.34: Sarah (friend) - lines 196-207

Sa: I would have loved to have seen him or even now trying just to to still be a participating member of society rather than just stepping back and just doing very very little he does very little in the house he does very little em in a sport I mean sport was never his thing he he watches it and is very interested but I don't think he participates but em I would just wonder I mean he's only in his early forties now and I mean it's a long long time if he er if he continues to be as good as he is or improves a little I would see an emptiness there but em he seems happy enough but whether they're just blotting things out or denying things or just trundling along from day to day I really wouldn't know

Interview extract 8.35: Sarah (friend) – lines 431-437

Sa: If they're as young as Tony just to try and put in some form of occupation because I mean particularly when he wasn't so well he was at home more the days must ha- must have been terribly terribly long and it seemed to me that he spent so much time watching television em it was a very very and still is in some ways a very passive existence

Sarah's attitude is also reflected in the picture she chose to represent Tony now.

Picture 8.5



Sarah (friend)

"A bit nasty but that's what I think he's like now ... it has it watching television sitting in a pub not really partaking participating a whole lot"

There are some links here with the *disability as less than whole* narrative in that Sarah does not view Tony as a 'full participating member of society' since he had his stroke.

The health records also reflect the importance that different professionals assign to going back to work. This belief that it is important to have structure to the day and not be idle is in contrast to how satisfied Tony is with life. Sue reports that he enjoys being a "kept man" and Tony agrees with this and says that work was never an important

feature in his life, other than that it brought in the money. He says that prior to his stroke he would have taken voluntary redundancy if a good enough package had been available. Ciara (sister) also refers to the fact that Tony does not miss the "nine-to-five type of situation" and that he is happy enough to "potter about". So there is some dissonance here with regard to how Tony spends his time. His sister Mary and his friend Sarah, who is a health professional, feel that his day should be more structured and that he should have some form of employment, while the other participants recognise that Tony is quite happy with the situation as it is. This leads on to the next narrative to be presented that of *quest* whereby illness and disability are incorporated into life.

8.2.5 Quest Narrative

A *quest* narrative speaks from the ill person's perspective, whereby illness is integrated into daily life (Frank, 1995). There were threads of a *quest* narrative running through the discourse of most participants though they were subtle. Tony himself refers to how one has to look to the future.

Interview extract 8.36: Tony - lines 846-847

T: It's a case where it's you had a stroke and er onwards

Tony has quite a pragmatic outlook when it comes to his difficulties in communication. If he is not understood and the other person refuses to listen then he just ignores it. He talks about the loss of one of his friends.

<u>Interview extract 8.37</u>: Tony – lines 516-522 [R=Rozanne]

R: And how does that make you feel?

T: Again . are for people things and that's bye-bye y'know

R: That's the way of it?

T: Yeh nothing because you can't (fall) everybody you can have y- so many people round who can talk to . to having them (kind) looking after a person who doesn't want you to talk with . y'see just ignore . y'know

He demonstrates how he has incorporated aphasia into his life by the way he manages certain situations. For example, he ensures that if he has to speak to someone about something in particular, he arranges it so that it is at a time when his speech is easier.

Interview extract 8.38: Tony - lines 742-747

T: What we need are you going to be talking to ya man ok so early in the morning or lunchtime rather than if you want to talk properly .. it's twelve o'clock rather than eight o'clock in the

afternoon or eight o'clock in the mor- in the night . y'know it would be a case of y'know being aware of that y'know

Sue alludes to the fact that Tony has "come to terms" with not being "perfect" anymore. Out of all the participants, however, it is Ciara (sister) who speaks most in terms of a *quest* narrative.

Interview extract 8.39: Ciara (sister) - lines 308-312

C: I feel he's adapted quite well with it and he's happy enough to potter about and to you know and I don't think he actually misses you know the nine to five type of situation so in that respect I'd say he's actually quite happier in the you know or happy now or as happy as he was beforehand

Interview extract 8.40: Ciara (sister) - lines 857-865

C: I think I've accepted I've accepted it now that it happened you know we'd all love to turn the clock back and say I should have done this I should have done that if only this had happened but at the end of the day you're just really eating away at yourself in that and what I'm happy about now is that he's happy and that Sue is happy and the pair of them you know are have their own lives and they're getting on with them and they're they're em from what I can see they're coping very well and they appear to be fine with it

The ethnographic notes as a whole reflect how integrated aphasia is in Tony's life. There is a real sense that he is quite content and living life as he would wish. The next narrative to be presented relates to this in that it is about accepting life as it is, with all its ups and downs.

8.2.6 Fatalistic Narrative

A fatalistic narrative implies accepting life with all its "slings and arrows". There is a sense that one has no control over one's destiny and that one must just take life as it comes and accept what it throws in front of you. It has spiritual undertones to it in that there is a sense that God has destined what will be. There is an implication of downplaying the event and a lack of agency in that the person is passive in the way in which she/he deals with the situation. This narrative permeated my interactions with Tony and others. For example, on one visit to Tony's house we talked about his adaptation to his stroke.

Ethnographic notes extract 8.5: Tony's home 27/03/2001

I remark how some people are quite distressed by their stroke but that he seems to be very well adjusted to his. He replies that from his point of view he "had a stroke – so?". (...) I ask does he feel the stroke has stopped him from doing things he initially says "no" but then follows this up by explaining how it may be that 'he just doesn't do it if he can't'. I ask does that bother him and he replies "no" and that he is quite content.

Other participants relate that the stroke happened and that you just have to get on with life. For example Sue relates:

Interview extract 8.41: Sue (partner) – lines 455-460

S: Tony's very practical you know ok this is the situation I'm presented with we go for it there's no point at looking at what might have been what if this is the situation that we're presented with make the best of it you know

Interview extract 8.42: Sue (partner) – lines 498-502

S: Well I think again it is like this has happened there's no point in saying if only I'd done this if only I'd done that (...) this has happened ok you know it's happened it could be worse

Tony's sisters make similar comments, for example:

<u>Interview extract 8.43</u>: Mary (sister) – lines 669-670

M: We've said look it happened it happened there's nothing you can do about it now

Interview extract 8.44: Ciara (sister) – lines 753-754

C: Yea if it happens it happens and sure to hell with it you know and there's not a lot you can do about it

Lorraine's (work colleague) discourse reveals her more pessimistic view of adapting to aphasia. This links in with her strong narrative of *disability as less than whole* whereby the person has to learn to live with imperfection.

Interview extract 8.45: Lorraine (work colleague) – lines 203-205

L: Sometimes it's a dead end you know for people to try and improve their speech after a stroke as you'd we know it's just something they have to learn to live with

On the surface this narrative may appear to have a quality of a *quest* narrative in that there is a general acceptance of living life with aphasia. However these narratives differ in that there is a sense of agency in a *quest* narrative and a sense of passivity in a *fatalistic* narrative.

The data also revealed traces of other narratives these included *body as machine*, in need of care, philanthropic, thankful for small mercies and disability as tragedy. These traces are tenuous and could be interpreted in many ways but my current interpretations are outlined below.

8.2.7 Body as Machine Narrative

As stated previously this narrative links in with a *restitution* narrative and is underpinned by the meta-narrative of modern medicine. Tony's health records illustrate a view of *body as machine* in that Tony is described in terms of bodily parts and the 'functioning' of these. There is a focus on the results of 'tests' and how he has 'performed' in them.

Artefact extract 8.3: Health records

An occupational therapy neurological examination was undertaken which outlines his functional balance, functional endurance, mobility, postural alignment, upper extremity status, sensation, lower extremity status, grip strength, functional status/quality of movement, co-ordination, cognition (he scored "27/30" on the Mini Mental State Evaluation), attention, carryover skills, activities of daily living (he scored "3" whereby he was deemed "independent with or without an aid").

There is little other evidence of this narrative in the discourse of participants except for the odd comment relating to Tony's impairment (e.g. "I can't remember the names", "his speech started slurring", "he had a very heavy limp", "he is particularly limited I think expressively").

The next narrative to be presented links to this *body as machine* narrative in that if the body is 'broken' then it needs care.

8.2.8 In Need of Care Narrative

This narrative infers that the person with aphasia is in need of care of some sort. There were traces of this in the interviews of Tony's sisters, Mary and Ciara, when talking about the early days post-stroke and now. For example:

Interview extract 8.46: Ciara (sister) – lines 704-706

C: I think initially you're inclined to rush in and do everything for him like don't lift the kettle you'll scald yourself I'll do it you know

The picture Ciara chose to reflect Tony at the time of stroke suggests that at that time he was dependent on others.

Picture 8.6



Ciara (sister)

"It's sort of depressing and very em the guy there seems to be sort of bound you know unable to do anything for himself very dependent on people"

Tony and Sue's friend Sarah on the other hand discusses how Sue was in need of care in the early days post-stroke, when she needed "minding" at the time to the extent of having to stay with a friend who could look after her (see interview extracts 8.6 and 8.7).

Participants no longer consider that either Tony or Sue is in need of care. However according to Tony's sisters his mother is still concerned that an eye needs to be kept on him. His sister Mary explains:

Interview extract 8.47: Mary (sister) – lines 647-659

M: Well she [Tony's mother] says that when she dies that we will be there that we'll keep an eye on him (...) always there's the worry worry worry and I think that's why she kind of pushes us along [to see Tony] like 'cos I think she's afraid that when she dies that you know if he looses contact or that there'll be nobody to kind of keep an eye on him for her

Both Tony and Sue therefore were perceived as needing care in the early days poststroke, but this is not longer the case with the exception that Tony's mother still worries about him.

An *in need of care* narrative stems from the cultural *philanthropic* narrative in that one needs to care for those less fortunate than oneself. There were faint traces of a *philanthropic* narrative and this is presented in the next sub-section.

8.2.9 Philanthropic Narrative

As outlined in 7.2.9, a *philanthropic* narrative permeates our society and infers a sense of 'feeling sorry for' people with disabilities and others deemed to be in need, and

therefore one must be kind to them. There is some evidence of this narrative when his sister Mary speaks about people with disabilities.

Interview extract 8.48: Mary (sister) - lines 319-326

M: Now I think most people are very good I really do I think people now accept you know people be it a learning disability or physical disability now much more than they would have a few years ago you know it's much better now (...) I think people are much more accepting now of disabilities

Lorraine (working colleague) also refers to this theme of accepting people with disabilities. However she is of the opinion that she is more "tolerant" of them than others because of her experience of working for a disability organisation.

Interview extract 8.49: Lorraine (working colleague) – lines 218-220

L: You know I would be quite tolerant of Tony more so than other people would

People are generally tolerant and good to people with disabilities to the extent that they are "very good" or "brilliant" to them. This notion of being "good" to someone with a disability has a patronising undertone, giving a sense of the non-disabled person being in the position of power and caring for those less fortunate than her/himself. As stated previously this narrative gives rise to the *in need of care* narrative and also links with the *disability as less than whole* narrative. The next narrative to be presented also intertwines with the *philanthropic* narrative in that things could have been worse and that one is grateful that they are not so.

8.2.10 Thankful for Small Mercies Narrative

This narrative has a theme that one should be thankful that things are not worse. In addition to linking with the *philanthropic* narrative it connects with the *fatalistic* narrative in that one has to accept what life throws at one. However it is underpinned by a sense that one is lucky. It is only really evident in Sue's discourse which is permeated with comments about how lucky they were that the stroke was not more severe. For example:

Interview extract 8.50: Sue (partner) - lines 464-465

S: The stroke happened things could be a million times worse they really could

Interview extract 8.51: Sue (partner) - lines 617-618

S: Things could be worse there's never anything as bad that couldn't be worse

Interview extract 8.52: Sue (partner) – lines 842-843

S: Sometimes you have to make a whole complete set of new friends I thought oh well we've been lucky [as only lost one couple as friends]

His sister Mary also alludes to the fact that Tony has been lucky.

Ethnographic notes extract 8.6: Mary's home 30/05/2001

She [Mary] comments that it is as if he takes each day as it comes and is thankful to be still alive and that things could be worse.

The following narrative to be presented links with this narrative in that disability is viewed as a personal tragedy and that one is thankful that one is not worse because to be worse would be even more tragic.

8.2.11 Disability as Tragedy Narrative

This narrative infers a belief that to be disabled is extremely undesirable and to be avoided at all costs. Therefore becoming disabled is viewed as a personal tragedy (Hevey, 1993; Oliver, 1993b). It links with the narrative of disability as less than whole. Lorraine, Tony's work colleague, is the only participant who portrays this narrative. She is of the opinion that to have aphasia is a "terrible affliction" that is "degrading". She talks about Tony being "knocked down in life" and uses words like "dreadful" when referring to his difficulties.

8.2.12 Drawing Threads Together

As in Anne's situation, Tony contributes to and is surrounded by a wide variety of narratives; some are faint while others are stronger, there is agreement with some and dissonance with others, some relate to each other while others do not. However they all interweave to form a complex tapestry of how the participants understand and make sense of aphasia and disability and how they draw on cultural resources in doing so. Such narratives give insight into the lived experience of aphasia from the perspective of the 'stories we live by'.

This section has presented the main narratives that emerged from the data. The next section puts forward the overall narrative theme as advocated by Lieblich et al (1998).

8.3 OVERALL THEME: PRINCIPAL NARRATIVE TYPE

Tony's principal narrative type shows elements of both *comedy* and *satire*. *Comedy* is when the goal is restoration of social order whereby the 'hero' must have the skills to overcome the hazards that threaten that order. *Satire* on the other hand is when the theme taken is one of cynicism on social hegemony. There are faint traces in Tony's interview of both, though *comedy* dominates.

In terms of the *comedy* theme, Tony's life has a sense of order to it; there is a daily routine of getting up, tidying, meeting Sue for lunch and doing chores like shopping. In terms of overcoming hazards he does not allow the impairment of aphasia to stand in his way. For example he uses a variety of strategies to make order out of disorder. He explains how he remembers my name.

<u>Interview extract 8.53</u>: Tony – lines 78-85 [R = Rozanne]

- T: I can't remember the names I can't remember the names
- R: Oh yes
- T: Because can't can't remember like I know your name is Rozanna 'cos now I've almost written if I've a R O S A N N E
- R: Yes that's right
- T: And I think also because I er Anne is A N N its not A N N E: and so right so its Rose Anna

In other instances when he is unable to get across what he wants he is happy to rely on his partner, Sue, to speak for him and in this way he maintains order. The penalty for this however is that he is aware that when this happens the other person may view him as "sick".

Interview extract 8.54: Tony – lines 529-540 [R = Rozanne]

- **R**: What about if you're trying to say something and you can't get understood? (...)
- T: You can just say sort of excuse me or Sue will say er could you do that please you know and I say thank you very much you know
- R: So does she say it for you then?
- T: Yea yea
- R: And is that something you like her to do or not like her to do?
- T: I don't mind basically it's ok you know
- R: Then how does the other person react?
- T: Well he's sick

Interview extract 8.55: Tony – lines 618-625 [R = Rozanne]

R: What about other times when you've gone to say something and you're having difficulty with your speech and there's been other people about how have you dealt with that? Say if Sue hasn't been there

T: I'd (be saying) em ok [looks down and thumps thigh] ere r wha- wha- [sighs] sorry can't see so what's the problem the and that way I'll try it again and see oh fu- [whisper] and I'll say hey listen Sue will tal- er in here soon she'll tell you properly you know

Another way in which he establishes order is by telling people that he has had a stroke and by ignoring those who treat him differently because of it.

Later on he describes how he is gradually overcoming other 'hazards' more effectively as his word retrieval abilities improve.

Interview extract 8.56: Tony – lines 627-641

T: I used to say to people I have been I had a stroke you know my language and my speech is wrong but I think I want a pint of Guinness and a packet of [audible in breath] tea coffee

R: So then you get stuck

T: Yea I'd say tea coffee you know Pringles you know you know and that would be or I'd say (egg) pint of Guinness and a pint of Guinness please and a (4 seconds) [taps arm of sofa] a and any er crisps er no (Jesus) peanuts you know you know but like previously I'd say there is a problem I'd say apples oranges tea but now its getting round it crisps you know cheese no (5 seconds) peanuts you know

R: So you're getting sort of closer to it

T: Closer yea yea rather than prior to that it was er God knows where it comes from you know

While *comedy* seems to be the overall theme, there are traces of *satire*, whereby Tony's cynical perspective on social hegemony seeps through at times in the narrative of the interview. For example at a couple of points in the interview he explains how he was asked to leave two pubs for no apparent reason, but which he attributed to his speech and the fact that he is a little unsteady on his feet. He describes his attitude.

Interview extract 8.57: Tony – lines 216-218

T: Oh fine oh (as in) er fuck off you know if you spend worry about worry about people said Jesus finally realise that don't need people

He later explains how he no longer sees one particular friend and he attributes this to the stroke. His attitude appears cynical in that he is of the opinion that one should not bother with people like that as they are only one person out of many. A Dublin saying is brought to mind "the people who mind don't matter and the people who matter don't mind".

Interview extract 8.58: Tony - lines 519-522

T: yea nothing because you can't (fall) everybody you can have y- so many people round who can't talk to to having them (kind) looking after a person who doesn't want you to talk with you see just ignore you know

On balance Tony reports that things have returned to some sense of social order in that much of his life has returned to the pre-stroke pattern. He sees many of the same people as he did prior to the stroke and life revolves around being with Sue. In terms of principal narrative type this return to social order reflects a *comedy* narrative, though there is some evidence of *satire* as discussed above.

Tony presents with many interweaving narratives that contribute to the experience of aphasia. The next section addresses how Tony and other participants manage and deal with his aphasia.

8.4 MANAGING THREATENED IDENTITY, APHASIA AND DISABILITY

Section 8.2 presented the narratives that emerged from the data. In contrast this section identifies how these narratives have a role to play in managing threatened identity, aphasia and disability. I first outline how Tony is viewed both before and after the stroke.

8.4.1 Views of Tony

Tony's life has changed since he had a stroke over five years ago. However as outlined previously, he is happy and content with his current lifestyle. In terms of identity, participants and Tony himself use similar words to describe him which include "easygoing", "placid", "quiet" and someone who is deeply committed to the peace movement. In addition his sister Mary says that he was and still is a "non-conformist". There is also agreement amongst participants in the pictures they chose for Tony to reflect what he was like before and what he is like now; they all have a peaceful, easygoing feel to them. They either reflect his easygoing attitude or his commitment to the peace movement. For example, Tony and both his sisters chose the 'cat on the radiator' to represent Tony before the stroke.

Picture 8.7



Tony
No comment made
Mary (sister)

"That definitely sums up Tony ... look at the cat that would be him now totally very placid very easygoing but I'd say if you gave him a poke he'd attack you"

Ciara (sister)

"He always struck me as being lazy even though he was running around but he was lazy in his own way"

Mary's comment that "if you gave him a poke he'd attack you" may echo back to her remarks about how Tony was very "individual" as a child and would be very determined about certain things and would stand his ground and not be pushed around (see 8.4.1).

His partner Sue and their friend Sarah chose the picture of the 'doves' to reflect Tony's commitment to the peace movement.

Picture 8.8



"Xxx [a political organisation] and the peace movement"

Sarah (friend)

"That's how I would see how he was ... well I suppose it's the symbolism of the Xxx [political organisation] thing ... and also the business of up and away and out and very articulate I have this vision of him always in my mind just talking to a crowd and so passionate and sincere and believing in what he was conveying"

All participants who knew Tony before the stroke agree that his "personality" has not changed. The choice of pictures to represent Tony 'now' reflects this, in that they have

a very similar feel of him being easygoing and peaceful. Indeed when Sue was asked to choose a picture to represent Tony now, she chose the 'Yellow Chair' (picture 8.9) but insisted that this reflected Tony both before and now. Tony selected the same picture to define him now, as did Mary his sister.

Picture 8.9



Tony No comment made Sue (partner)

"Reminds me of when on holidays and things like that ... before and now" Mary (sister)

"He still is very placid and easygoing and the stroke hasn't as far as I'm aware upset his personality at all ... his actual personality Tony himself hasn't changed and that is just a lovely view of peace and you know sitting by the chair looking at the view and a lovely scene"

Tony's friend Fintan also chose this picture to represent Tony now, but for different reasons. His accompanying commentary inferred that there has not been a complete recovery (see 8.2.2 and Picture 8.2).

8.4.2 **Managing Threatened Identity**

In terms of threats to the identity principles of continuity, distinctiveness and selfesteem (Breakwell, 1986), continuity is primarily maintained, as participants describe Tony in much the same way for both before and after the stroke. All say that he has not changed and that he is still as easygoing as he always has been. Continuity is also reflected in many other domains of Tony's life. For example, he still has the same group of friends, he still maintains the same interests (i.e. politics, current affairs, football), he still keeps up the same amount of contact with family members, and the strength of his relationship with Sue remains constant. However there are some areas of his life where there is evidence of discontinuity. Prior to his stroke he had the routine of getting up and going to work, this is no longer the case and he now works within the home. In addition while he still maintains an active interest in politics he is now more

of the backroom supporter than an activist. Tony reports that he does not miss going out to work or being a political activist and indeed his sister Ciara feels that he is even happier now than he was before the stroke.

In terms of distinctiveness, Tony himself says that he has always been considered 'different' when he says:

<u>Interview extract 8.59</u>: Tony – lines 437-440 [R = Rozanne]

T: When I was in [company he worked for] I was er the third spare car from the west sort of thing you know

R: The third what?!

T: Spare character in the left

His sister Mary's comments suggest something similar in that she describes him as being a "non conformist" and standing by what he believes in. She gives an example from his childhood.

Interview extract 8.60: Mary (sister) - lines 488-507

M: Very placid very quiet eh would have opinions very strong opinions and wouldn't be swayed from them oh no (...) I remember my mother said that when he was making his confirmation he didn't want to make it like that was a stand up fight that he was making a decision and that was it and my mother was mortified and what would the Christian Brothers say if he didn't but my father of course er you know couldn't believe it at all and then he decided that he would make his confirmation but that he wasn't going to wear a tie (...) so I think after much to do in the household he would he did make his confirmation he went to the church and I think just for my mother's sake and then the minute he came out of the church he took the tie off and she hasn't seen him in a tie since

In addition to being distinctive in this way, Tony is now distinctive in other ways – he is seen as somebody with a stroke who has speech difficulties. Tony explains:

Interview extract 8.61: Tony – lines 199-204

T: Its er I don't know like some people were er very strange you know basically Tony has a stroke be very careful 'cos it could be contagious as far as we know (...) not that actual word but a case of er Sue Sue do you think do you think Tony wants a pint of Guinness I said fuck you you know

In terms of how he copes with these threats to continuity and distinctiveness, he views his loss of work in terms of having time to spend on things that he enjoys doing (e.g. having a lie-in in the morning, meeting Sue for lunch, 'surfing the net', being a homemaker) rather than a loss of income and status. It may be that in order to minimise the effects of no longer being employed on continuity, distinctiveness and self-esteem Tony has elevated the status of being 'retired' and devalued the important role that

work played in his life. In terms of Breakwell's (1986) framework of coping with threatened identity, Tony's way of coping corresponds with her 'salience of principles', in that he shifts the emphasis from the threatened to the unthreatened.

One gets a real sense that Tony has incorporated aphasia into his life (*quest* narrative); all participants remark how happy he is and how he has accepted what happened, and Tony himself admits to being content. Tony is very politically aware and it could have been predicted that he would draw on narratives that were political in nature, yet this is not the case.

8.4.3 Managing Aphasia and Disability

In terms of managing his aphasia in day-to-day life, Tony is effectively able to run the home – doing such things as shopping, banking, tidying and cooking. He has even developed strategies to place people at their ease. For example, at times Tony realises that some people are uncomfortable around acknowledging that he has had a stroke as if there was some stigma attached to it. In these instances he finds it helpful to tell them that he has had a stroke in an effort to dispel their discomfort.

Ethnographic notes extract 8.7: Tony's home 27/02/2001

Tony says how some people can't say the word 'stroke' and it 'could be cancer' or I don't know but rather it is 'I have this problem'. He tells me that he finds it helps to say something like "hey I've had a stroke so what".

However Tony was not always such an effective communicator as early post stroke he experienced significant difficulties in verbal communication. At that time he tended to avoid situations and let Sue do all the talking for him. The situation is different now in that there are only one or two situations which he avoids (e.g. talking to strangers on the telephone).

Tony now tends to use strategies to help him navigate his way through his word retrieval difficulties. When he does get stuck he spontaneously stops and starts again.

Discourse extract 8.2: Pub lunch - lines 548-550

T: [Name of a vocational training centre] I saw him on the er bri- ge- the er it er the post office ho post office you know er <u>start again</u> I was going in to Mount Pleasant in post office in James Street and that's why the er [name of vocational training centre]

His awareness and insight into what helps and what does not help his communication has led Tony to use strategies to successfully navigate his way round difficult speaking situations. For example, he is aware that fatigue has a detrimental effect on his speech, and he plans things accordingly.

<u>Interview extract 8.62</u>: Tony – lines 730-747 [R = Rozanne]

T: Like if at eleven o'clock at night my speech would be woegeous

R: Would it be?

T: Yea yea you know it would be a case of er [sighs] you know like it's two or three o'clock you know or it's you know that would be ok

R: Eleven o'clock at night

T: Eleven at night it would be woegeous

R: So that would be something you wouldn't so you wouldn't arrange it for that time so you would tend to arrange things then when your speech is?

T: When I think its ok you know you know could be you know just basically right what we need are you going to be talking to yer man ok so early in the morning or lunchtime rather than if you want to talk properly its twelve o'clock rather than eight o'clock in the afternoon or eight o'clock in the mor- in the night you know it would be a case of you know being aware of that you know

Tony is quite persistent in ensuring that he gets his voice heard and will persevere in this. The discourse reveals that when there is overlap between Tony and Sue, it is Sue who ends up holding the floor. However Tony makes certain that his point of view is heard in that at the earliest opportunity he states what it is he was going to say. For example:

Discourse extract 8.3: Pub lunch – lines 394-400 [S = Sue; R = Rozanne]

[We are talking about the possible developments that were going to occur in Alaska and how this might impact on the environment.]

R: Alaska is meant to be beautiful

T: Yea

S: I'd love to go there actually=

T: Snow

S: =We should go there before they ruin it

→ T: Snow there

S: I know there's snow there but still I like snow

In terms of writing Tony elects to use the computer wherever possible as he believes his handwriting is "woegeous". For example when I asked him to keep a diary of what he did he requested that he be able to do this on the computer, rather than writing it by hand. He will spontaneously use things in his environment to help him. On one of my visits to his house (27/02/2001) he suggested that he email me his diary extracts, but he had great difficulty with the spelling of my email address. I spelt it aloud for him, but

he still had difficulty. He got up to get the explanation sheet about the study which had my email address on it, and he copy typed it from that.

Tony makes good use of strategies to get across what he wants to say. He is aware of the times when his speech is more difficult and he avoids speaking at those times. In general he manages to get himself understood.

8.4.4 Overall Coping Strategy

Tony and Sue have adopted a 'laissez-faire' style and tend to take things as they come. Their attitude is one of acceptance, whereby what has happened has happened and one needs to get on with life. His sisters, while "devastated" at the beginning, have adopted a similar style. According to them, however, his mother still becomes quite distressed by his condition and the fact that the stroke happened. They wish that she could just "accept" it, like they have. Aphasia seems to have successfully become incorporated into his life which reflects his *quest* narrative.

8.5 SUMMARY

This chapter began by outlining the changes in Tony's lifestyle since the onset of aphasia. The main differences are that he is no longer in paid employment and he is no longer involved in the political organisation to which he was affiliated. He misses neither of these; he maintains that he is quite content with his life. He sees his friends and family about as regularly as he did prior to his stroke. He continues his interest in politics, but not with the same intensity.

The narratives that Tony and others draw on were then presented. The tapestry emerging from the interweaving narratives allow for glimpses of beliefs, attitudes and ways of thinking about aphasia that contribute to the experience of it. He and those close to him have moved from the *chaos* and *in need of care* of the early days post-stroke, through a strong *restitution* narrative in the first couple of years, to a *quest* and *fatalistic* narrative of the present time. While *quest* and *fatalism* dominate now, *restitution* remains a background voice as further progress is hoped for. Similarly other

narratives such as disability as less than whole and the importance of not being idle are evident.

In terms of managing threatened identity and aphasia, Tony and most of his conversation partners have a 'laissez-faire' type approach, in that they accept what has happened and have incorporated aphasia into their lives. Continuity is maintained in many spheres of his life, and those which are not he does not miss. Similarly Tony remains distinctive in the same way as before his stroke; he still is laid back and easygoing while holding strong opinions. He admits, and others agree, that he is quite content with his life.

The narratives explored provided rich insight into the lived experience of aphasia from the point of view of Tony and some of his family and friends. It allowed me to view the resources they draw on to manage aphasia and make sense of it in day-to-day life.

Like Anne and Tony, May suffered a stroke which was to change her life significantly. The following chapter explores the narratives that surround her and how these enable her to make sense of aphasia and physical disability and to manage them in day-to-day life.

CHAPTER 9 MAY'S STORY

"Just get up and get going keep going you know because if you cry you're left there (...) when if you laugh they went hello hello you know that's why I don't cry you know if I all cry I be on my own"

May, and a number of others who were significant in her life, shared in what it was like to live with aphasia and physical disability. May was the principal participant, but other participants included a number of her family members: Yvonne, her daughter; Bridie, her sister; Maeve, another sister; and Michael, her son-in-law. Also involved in the study were some care workers: Bríd, the day centre manager; Sinéad, May's key worker in the day centre; and Eleanor, the stroke club organiser. In addition I (Rozanne) was there as researcher.

As in the previous two chapters the data in terms of changes in lifestyle since stroke is presented first. I then present the narratives that emerged in the course of the fieldwork before going on to outline the overall theme in terms of principle narrative type. Finally I present how May and others manage threatened identity, aphasia and physical disability. An eclectic approach to data generation and analysis was undertaken.

I begin May's story by placing her in context of her overall lifestyle and in particular how this has been affected by aphasia and physical disability.

9.1 CHANGES IN LIFESTYLE

To recap May is in her sixties and lives with her daughter, son-in-law and granddaughter. She had a stroke approximately six years prior to inclusion in the study. The stroke left her with a right-hemiparesis (she is a wheelchair user) and aphasia. Before the stroke May worked part-time as a cleaner and was a homemaker, she was responsible for running the family home. One of her sons lived with her up until the time of her stroke. However following her stroke he moved out and May's daughter and son-in-law moved in. The house was renovated to allow May freedom of movement downstairs, upstairs remains inaccessible to her. In terms of aphasia she has

excellent social and stereotypical speech which allows her to connect socially with others effectively. Initially her aphasia was severe in that she described her speech as "gone", but she is now able to get across much of what she wants to say. However most of May's verbal expression, in the situations in which she was observed, is limited to social type speech and she rarely gets the opportunity to converse in more depth. Further information about May is provided in 6.1.3. Like with Anne, but not to the same extent, May benefited from conversation partners who would 'scaffold' communication. Therefore from time to time it was necessary to ask questions about what I thought May was telling me, to clarify and check out meaning.

9.1.1 Social Network

May's children and sisters form the basis of her social network, both before and after the stroke. She has always been very close to her sisters and has regular nights out with them. However one sister has much less contact with May than she did before the stroke. May's daughter, Yvonne, reports that this is because that sister can't handle the stroke. She explains:

Interview extract 9.1: Yvonne (daughter) – lines 529-539 [R = Rozanne]

Y: Well em a lot of people were afraid by it you know because they didn't because me mam couldn't talk that em and awf- it did make an awful lot of people nervous you know and em and it made me ma nervous 'cos me ma couldn't it was ok when me ma was with me or with Bridie [sister] or she was with Maeve [sister] but in particular Emma the other sister couldn't handle it at all

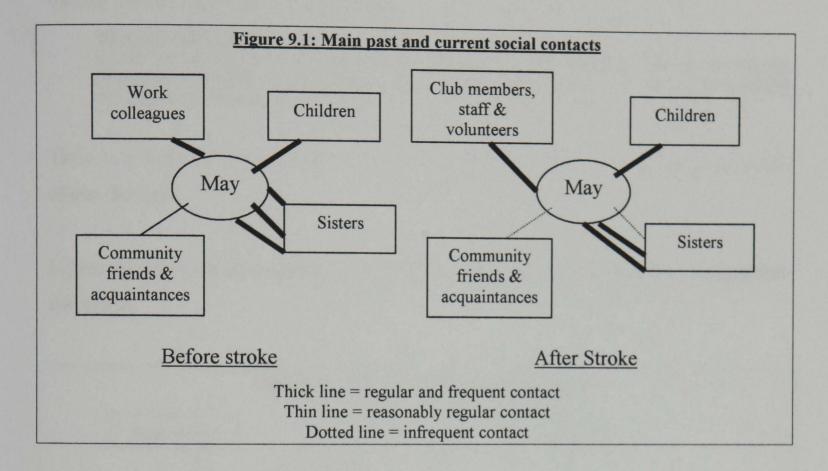
R: Really

Y: No no like she barely ever sees me mam now and er you know she'd be down in the area and she just for some reason you know she she just couldn't handle it you know

In addition to not seeing one of her sisters as frequently as she did before the stroke, the rest of her social network has also changed. Before, she enjoyed the company of her work colleagues and would see and chat to many acquaintances as she did her daily shopping on her bicycle. These social contacts have virtually ceased to exist since she had the stroke. Her week is now filled with attending her clubs (e.g. the day centre, the stroke club, the community centre club) and with this has come a completely different set of contacts. Her daughter Yvonne refers to these new social contacts as her mother's new set of "friends". May now also has less contact with the neighbours.

When she first arrived home after her stroke the neighbours visited quite regularly, but Yvonne reports that this soon faded and now they rarely visit.

May's current social network consists of her family together with the members, staff and volunteers of the various clubs she attends. Figure 9.1 gives a diagrammatic representation of her main past and current social contacts.



9.1.2 Social Roles

Prior to her stroke May worked as a cleaner, she was a homemaker, a 'socialiser' and 'advisor' to her family and friends. In addition she was a carer of people close to her, for example she looked after and cared for her family. Some of her roles in life have not altered – she still enjoys socialising and gives advice and support to her family and club members. She continues to care for those around her by behaving in such a way as not to cause them distress (see 9.2.10). However there are also changes, the most significant ones being that she no longer works outside the home and she is no longer the principal homemaker. May's work as a cleaner was something she really enjoyed and now misses; she feels that she should still be working. In relation to her role as homemaker, prior to her stroke she was very much in charge of her own household. This is no longer the case because her daughter and son-in-law have taken on this key

role, although May does anything she can to help around the house (e.g. doing the ironing) and cooks her own meals in the microwave.

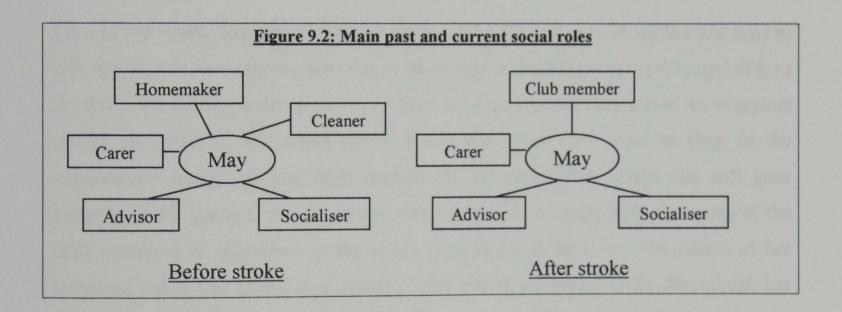
One of her main new roles is that of 'club member' and participants report that she is an extremely active member in the clubs, getting involved in lots of activities and outings. She is described as someone who "uplifts" others and helps to motivate them. Eleanor (stroke club organiser) explains:

Interview extract 9.2: Eleanor (stroke club organiser) – lines 313-317

E: She tries to er what will I say er be part of the club and er create like uplift you know to uplift other people she tries to uplift other people and not to bring people down like by her problems that's the kind of person she is you know

There is a sense of caring in this in that she behaves in such a way so as not to cause others distress.

Figure 9.2 gives a diagrammatic representation of her main social roles before and after the stroke.



9.1.3 Participation

May's life has changed considerably as a result of the stroke and many of her past activities are no longer accessible to her. She retains her active nature in that she is always out doing things, albeit different things to those she did prior to the stroke. She is an active member of her clubs and has developed new pastimes as a result; for example, she has painted a number of pictures which she has had framed, and she

practises yoga with a yoga teacher. Sinéad, May's key worker, outlines May's participation in the day centre.

Interview extract 9.3: Sinéad (key worker) – lines 549-558

S: Em let me see Mondays now there's a lady that comes in and does art creative art like em art therapy is what it's called and May would get into that and then em Monday afternoon there's a lady that comes in and does clay work with them and she would get involved in that as well now em and she does the yoga when the girl comes in about the yoga now she would do that em the paintings now and the drawings she's doing down there em dominoes scrabble anything at all if you ask her to come over and join in she'll come over and join in no bother like

She will even participate in things that she finds difficult to do.

Interview extract 9.4: Brid (day centre manager) - lines 270-274

Br: She'll partake in the quizzes in the afternoon not that she can get the answer out (...) someone else would say something and she would say hhh hhh yea yea yea [laughs] that's the way she interacts you know

May is eager to go on any of the club outings and frequently does so and she is described as loving an old sing-song. She has been away on club holidays, which she has really enjoyed. In addition, for the past three years she has done the mini marathon with Eleanor (stroke club organiser) about which she is very proud.

Prior to her stroke different things took up her time. She was a keen cyclist and used to ride her bicycle everywhere, now due to her physical disability she is no longer able to do this. Her cycling used to be a key link to people in the community as everyone would say hello to her when she was out and about. She used to shop in the supermarket every day and then prepare the evening meal. While she still goes shopping when she is at the day centre, she does not do so independently as one of the staff members or volunteers at the centre goes along to help her. The nature of her shopping before the stroke was crucial to the effective running of the household; her shopping now does not have this vital role as she just gets a few bits and pieces for herself; Yvonne, her daughter, does the main shop. She rarely goes out shopping any other time except occasionally her son or her sister bring her to the local shopping centre, which she enjoys. She still sees two of her sisters as frequently as she did before and about once every two weeks she goes to the pub with them. However before her stroke outings like this were much more frequent.

Prior to her stroke May was an avid reader and really enjoyed novels. Now due to her aphasia she is no longer able to read and this she misses terribly. While reading is not possible she is able to watch the television as much as she did before; she has always enjoyed the soaps and continues to watch them eagerly.

The clubs take up a significant amount of her time and she enjoys going to them as they get her out of the house. When in the house she spends most of her time in her room which has been specially converted for her. She reports that she always hated this room before her stroke and now finds it quite ironic that this is the room in which she spends most time. In May's words:

Interview extract 9.5: May – lines 1541-1553 [R = Rozanne]

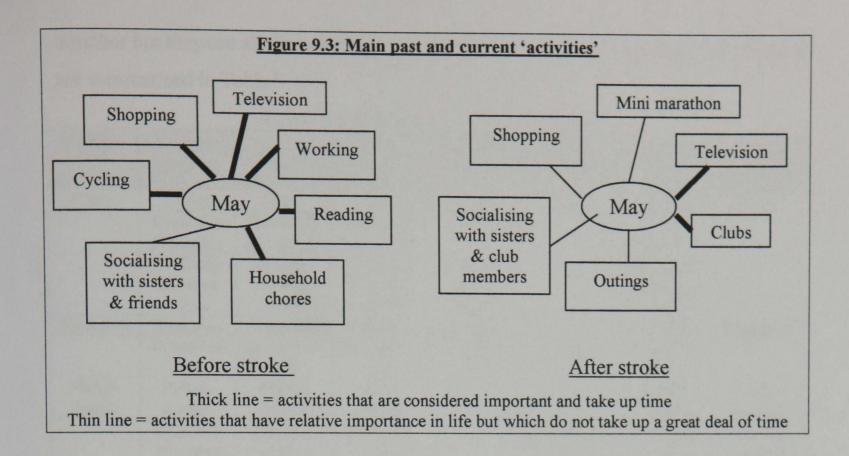
M: In here this house this this room I hate i- I always when I had the stroke see this room I was lovely you know I used to go in I used to come in here never never now I never I used to (gloss) the wash the the be like children the young ones used the young ones er talking in here and that was that was my room [points to living room next door] in there and up there and that's different you know and I couldn't I hated the room I hated and the big tree sat there you know but I used to say o:h I hate going in that room I hate it I hate it

R: And do you still hate it?

M: Ah yea well not exactly not exactly you know but I say Gaw just imagine I'd always hated this room and I ended up you know yea

She rarely joins her daughter and son-in-law in the living room as she feels that they need space on their own. So when May is home she spends most of the time in her room watching television.

To summarise, before her stroke May's day used to revolve round shopping, doing the house, preparing meals, going out to work, seeing her sisters, reading and watching television. Now it consists of going to her clubs, having a rest, seeing her sisters and watching television. Her family help her out with the things that she can no longer do—for example her sister Maeve does her washing for her and collects her tablets. Figure 9.3 gives a diagrammatic representation of her main past and current activities.



In this section I outlined how May's lifestyle has changed since she had a stroke. Before her stroke May's life revolved round issues surrounding household management and going out to work. In her free time she read, watched television or went out with her sisters and friends. She gave advice to family and friends when they needed it. She still gives advice to family and friends and helps out wherever she can, but otherwise her life since her stroke has changed; much time is taken up with going to clubs and in the evening she watches television and occasionally goes out with her sisters. May says she misses her "old life".

The following section explores the main narratives which surround May that emerged from the data. They provide a window from which to view how the stroke has affected May and her conversational partners and the resources they draw on to make sense of it and manage it in day to day life.

9.2 EMERGENT NARRATIVES

There are a number of narratives that emerged from the data in relation to how participants thought about and experienced aphasia and physical disability. As with Anne and Tony, they present as an intricate tapestry of meanings that interweave

together but they are all discernible narratives nonetheless. The narratives that emerged are summarised in Table 9.1

Table 9.1: Emergent narratives (May)

		Table).	1. Linei ge	nt narrativ	ves (May)		
May	Yvonne (daughter)	Maeve (sister)	Bridie (sister)	Michael (son-in-law)	Sinéad (key worker)	Bríd (day centre manager)	Eleanor (stroke club organiser)
Chaos	Chaos	Chaos	Chaos	Chaos	Chaos	Chaos	Chaos
	Disability	Disability	Disability			Disability	
	as tragedy	as tragedy	as tragedy	D' 1'''		as tragedy	
	Disability less than whole	Disability less than whole	Disability less than whole	Disability less than whole		Disability less than whole	
Restitution	Restitution	Restitution	Restitution	Restitution		Restitution	Restitution
	In need of care	In need of care	In need of care	In need of care	In need of care	In need of care	
Philan- thropic	Philan- thropic	Philan- thropic	Philan- thropic			Philan- thropic	Philan- thropic
	Beholden to others	Beholden to others	Beholden to others		Beholden to others	Beholden to others	Beholden to others
		Good patient			Good patient	Good patient	Good patient
Putting on a happy face	Putting on a happy face	Putting on a happy face	Putting on a happy face		Putting on a happy face	Putting on a happy face	Putting on a happy face
Quest	Quest	Quest			Quest		Quest
	Thankful for small mercies	Thankful for small mercies	Thankful for small mercies		Thankful for small mercies	Thankful for small mercies	
	Others in control	Others in control		Others in control		Others in control	Others in control
	Body	as machine -	mainly only	evidence from	n day centre r	ecords	

Each narrative is presented in turn, drawing on the data from all participants.

9.2.1 Chaos Narrative

A *chaos* narrative is when illness engulfs the person and the experience is too great to tell (Frank, 1995). This narrative was dominant when participants were talking about the time immediately post-stroke. May relates her experience of that time.

Interview extract 9.6: May – lines 51-58 [R = Rozanne]

M: I just don't know what happened just yea just fe- felt her in me neck [holds back of neck] and it just went out and I brought down to [name of hospital] and I think I told you that I was asleep no wait now [whisper] oh er asleep asleep three weeks [shows three fingers] yea yea

R: So quite a long time

M: yea yea I didn't know what had happened I didn't know what happened you know

Interview extract 9.7: May – lines 72-75 [R = Rozanne]

R: And how did you manage then when you were in hospital?

M: Em I don't know like I don't know I used to see em I was frightened I was frightened you know kind of in the in ther [name of hospital] real frightened you know made me very frightened yea

Yvonne, May's daughter, talks similarly about her mother at the time when May had just returned home after being in hospital for some time.

Interview extract 9.8: Yvonne (daughter) – 108-116

Y: Em at nights like she'd just I'd just be in here and I'd go in and she'd be crying em she er em she kind of di- em want you around all the time and if you were around she became like a child again like you because she was so frightened probably because she thought like ourself that she was I mean you can imagine like she couldn't even look that way her brain was totally devastated at that stage her- she couldn't move she couldn't get up and walk and she was sitting like I mean in the chair and all she could do was look out the window

Clearly those early days post stroke were a distressing time for May as can be evidenced from the many comments made by her family. For example, her sister Bridie remarks:

Interview extract 9.9: Bridie (sister) – lines 262-265

B: Well the least little thing like now she'd start crying like ah I wish I was dead you know the usual thing yea she felt she couldn't cope like it took so long like for her to come out of all that yea

Some of the pictures chosen to represent May at the time of stroke, with their accompanying commentary, give this sense of a *chaos* narrative around that time.



Michael (son-in-law)

"Basically looking at her in the bed in the hospital and her being unaware of her condition at the time and em like the darkness that she would have been in at the time"

The pictures chosen by Bríd, the day centre manager, and Sinéad, May's key worker, to represent how they imagined May to be at the time of stroke also suggest a *chaos* narrative.

Picture 9.2



Brid (day centre manager)
"Shattered"

Picture 9.3



Sinéad (key worker)

"That looks a bit drastic but I was gong to say for confusion or not really knowing what was gong to happen next ... but it looks a bit drastic but there's colour in it and you can kind of see her going well look this has happened but I can go on with the future sort of thing you know"

A *chaos* narrative therefore was evident at the time immediately following the stroke when life was in turmoil and before adaptation had begun. It is characteristic of the early days and other people who experience an emergency admission to hospital would probably go through something similar.

Next I explore how participants viewed such a significant life event.

9.2.2 Disability as Tragedy Narrative

This narrative implies that becoming disabled is viewed as a personal tragedy (Oliver, 1993b). It links strongly to the narrative of *disability as less than whole*. Some of the comments participants make suggest that they are of the belief that to become disabled is a tragic event.

Interview extract 9.10: Yvonne (daughter) – lines 49-51
Y: When the stroke happened her like it was totally devastation like for her

Interview extract 9.11: Yvonne (daughter) – lines 1035-1036 Y: And it's a terrible thing for a person to be in a wheelchair Interview extract 9.12: Maeve (sister) – lines 318-320

Mv: You have to have patience with them [people who've had a stroke] God help them 'cos it is an awful blow to a person

Interview extract 9.13: Brid (day centre manager) - lines 505-509

Br: Because it is an awful an awful thing to happen to a family (...) I mean it just upheavals the whole family situation and especially if their speech is gone as well

The idea of a stroke being a "blow" to a person and an "upheaval" suggests that having a stroke is viewed as an aggressive force. A force that is undesirable and difficult to cope with.

Also running through the interviews and my interactions with participants is the sense that May is "marvellous" in the way in which she overcomes this tragedy. She is viewed as the heroine of the tragedy. Her sisters, particularly, comment about how "marvellous" she is. For example:

Interview extract 9.14: Bridie (sister) – line 200

B: I think she's [May] marvellous

Interview extract 9.15: Bridie (sister) – line 198-199

B: I think she's [May] great when I do see her like getting herself ready there in the morning like washing herself

Interview extract 9.16: Maeve (sister) – lines 135-137

Mv: You want to see the paintings and all she does with her left hand you know what I mean she's a marvel

One of the reasons why disability is viewed as a personal tragedy is that the person is considered to be missing something that is crucial to leading a full life. This notion leads onto the next narrative to be presented: disability as less than whole.

9.2.3 Disability as Less Than Whole Narrative

As outlined previously, this narrative suggests that the person with a disability is missing some essential element and so is not 'whole'. This links closely to the view that to become disabled is a personal tragedy. The *disability as less than whole* narrative is not evident in May's discourse, but it is apparent from what Yvonne, her daughter, and Maeve, her sister, say that she felt this way at some stage.

Interview extract 9.17: Yvonne (daughter) – lines 356-359

Y: I mean she was very frustrated I mean when she'd talk about it we'd have to talk her through it but like I mean but she'd be hitting herself [thumps thigh] and all and going ooh you know I'm stupid I'm stupid

Interview extract 9.18: Maeve (sister) – lines 399-402

Mv: When you bring her out she be thanking ah sure May no problem like this was in the beginning now she used to feel she was kind of a hindrance on people naturally enough you would

While this narrative is not evident in May's talk, it is in the discourse of her conversational partners. They frequently talk in such a way that infers that they view disability as less than whole. For example:

Interview extract 9.19: Yvonne (daughter) – lines 509-510

Y: Not that she's normal or anything but like but she's a hell of a lot stronger than what she was you know

Interview extract 9.20: Yvonne (daughter) – lines 1055-1058

Y: The doctor said you'll have to give up the smokes that's what makes my ma happy do you know what I mean I mean you can't take away everything you know Jesus she's bad enough

Interview extract 9.21: Maeve (sister) – lines 297-299

Mv: And all them clubs them people and she's out among people like herself people in wheelchairs

Interview extract 9.22: Bridie (sister) – lines 212-213

B: Like you feel you have to give her you know her own little bit of independence

Interview extract 9.23: Michael (son-in-law) - lines 600-603

Mi: She's stuck in a wheelchair she's not able to read her speech wasn't yea? Em she would have been real nervous and the speech thing would have come across really bad

Bridie, May's sister, is of the opinion that May is not capable of writing birthday cards without assistance.

Interview extract 9.24: Bridie (sister) – lines 166-171

B: Now if I buy a card now for nieces and nephews I always put May's name on it and I'd say to her look don't worry I've got the card and your name's down or if I bring the card over with me to May I get her to put her name down on it to let her know like she's still in the circle you know that's the way it has to go like

The discourse of one of the day care workers reveals this narrative of *disability as less* than whole. Much of what she says when she talks about the people in the day centre suggests it. For example:

Interview extract 9.25: Brid (day centre manager) - lines 50-51

Br: All the other members have a disability so she doesn't feel any way out

Interview extract 9.26: Brid (day centre manager) - lines 275-279

Br: But sure they all enjoy the auld quizzes sure it's the staff that do answer most of them [laughs] but you know the staff might say is it this or is it that or there might be a show of hands for the first answer or the second answer and then one is written down

Interview extract 9.27: Brid (day centre manager) - lines 528-533

Br: I don't think people bother bother with an individual who can't speak as much as an individual who can speak no matter how disabled they are if a person can speak people will communicate more with them and will have more interaction with them so that's why I think when speech goes it's a hu:ge thing gone

Ethnographic notes extract 9.1: Day centre 08/08/2001

One of the care workers talks about the holidays that the day centre organises for members. She remarks how some places are not prepared for a "bunch of crocks like what we've got".

Ethnographic notes extract 9.2: Day centre 15/08/2001

One of the care workers and I talk about the general lack of services in the community for people with disabilities. She tells me that they are about to advertise for a part-time physiotherapist, occupational therapist, speech & language therapist and social worker but she is not sure about whether or not they will be able to get the right personnel because this group of people are so "difficult" and it might be like working with a "brick wall".

This narrative is supported by how May is treated in the centre. For example, one day I notice that one of the care workers asks May to sign something, but does not tell her what it is about (ethnographic notes 08/08/2001). It is as if because May is disabled she does not need to know what it is that needs her signature. It may be that this had been discussed with May previously when I was not there. Nonetheless if this was the case she did not remind May about what it was that she was signing.

This narrative of *disability as less than whole* also permeates my conversations with other care workers not interviewed. For example:

Ethnographic notes extract 9.3: Day centre 01/08/2001

The care worker says that May will "put her hand to anything" that she can though there are some activities that she cannot do with "only one hand". She then explains about the things that they do in the centre and points out some of the things that the members have made. She says how at one time they made dolls – she shows me the big doll that they made which is sitting on a chair beside May. May comments how "gorgeous" it is and says that she bought one each for her three sisters. The care worker cuts across May and says "yes you bought some for your two sisters". May points out the cup and saucer that she made which is on a shelf along with some others. The care worker explains that they do pottery once a week on a Monday and that May has been doing that even with her one hand.

<u>Interpretative note</u>: The care worker keeps referring to May's one hand; May has two hands it's just that one of them is paralysed.

Thus it seems that those around May have a narrative in which they explain disability in terms of being less than whole. This is a prevalent narrative in our society (Phillips,

1990; Barton, 1993; Thomas 1999b) and links to the next narrative to be presented: a *restitution* narrative whereby there is a strong drive to try and regain lost abilities so that one can return to being 'whole' again.

9.2.4 Restitution Narrative

As outlined previously a *restitution* narrative is where the focus of attention is to 'get better' and to strive to return to one's previous non-disabled state (Frank, 1995). Even though there is some acceptance that May will not get 'better' (see 9.2.11), *restitution* was a strong theme in all my dealings with participants in that in their view the desirable state was for May to return to her previous abilities and that one has to "fight" to do so. May explains how in the early days, she worked to try and get her speech back.

Interview extract 9.28: May – lines 183-192 [R = Rozanne]

M: She bring me a knife a fork you know er buttons you know and I used to oh ve- oh I very didn't know but then I er I found out yea a button a button you know yea

R: You knew how to say it or what to do with it?

M: I say it I say it

R: So she would bring you things for you to tell her what they were

M: Yea yea all the pend er pencils and biro loads of things loads of things yea yea

R: And did you find that helpful?

M: Yes I did oh yea yea yea

Others explain how she had to work towards recovery.

Interview extract 9.29: Yvonne (daughter) – lines 125-131

Y: Then the physio me mam was to get certain physio but at that stage me mam was too bad even to to take physio but the physio did come just to move hands and we had to do exercises with her as well but slowly like I mean she started to get into the physio and we we'd have her in here and say every evening we'd walk her stand her up and she'd hobble like holding on to us

Interview extract 9.30: Maeve (sister) – lines 603-606

Mv: He'd [Maeve's husband] say to her now May if you don't get out of that bed and try moving a bit you're going to be left there 'cos what you're go- and he was great but it did help and she idolises him

Interview extract 9.31: Brid (day centre manager) - lines 497-499

Br: Do whatever exercises are recommended at home for your hand your leg em whatever speech do your activities

Interview extract 9.32: Eleanor (stroke club organiser) - lines 757-763

E: You have to start from the very beginning again and and to learn how to speak now to er basic words you know you have to relearn how to say them again and how to communicate communicate again and that's er the speech therapy is so crucial like I find it is like for for somebody especially especially with dysphasia

The picture Michael, May's son-in-law, chose to represent her when she first came out of hospital reflects this journey of recovery.



"This one to me the hope the colour the shapes sort of even steps in a sense of climbing her up climbing up it"

Similarly the picture he chose to represent May now mirrors this journey of recovery and that there is still a way to go.



Michael [son-in-law]

"It's a long long road or should I say train track it really is it hasn't been easy for anybody and it's not over yet it really isn't"

May's daughter Yvonne likens recovery to a battle in that it is necessary to "fight" to get well again.

Interview extract 9.33: Yvonne (daughter) - lines 916-920

Y: Everything is worth fighting for like you know and never say die like you know what I mean em you know if you put a lot of effort in like me ma did which she did an awful lot of effort in you know and she pulled through so much like

Similarly Maeve, her sister, comments:

Interview extract 9.34: Maeve (sister) – lines 636-638

Mv: So you never give up do you no matter how bad a thing is once there's life there's hope

There is a theme and expectation running through that therapy helps to restore or maintain abilities. For example Michael, son-in-law, comments that if May had more therapy her speech would improve.

Interview extract 9.35: Michael (son-in-law) – lines 174-178

Mi: To change it [her speech] you looking at going away to Xxx [name of a hospital] for six months therapy speech bom intense yea that's the only way and that's not going to happen you know what I mean she'll never get a place

Ethnographic notes extract 9.4: Eleanor's (stroke club organiser) house 27/04/2001 Eleanor tells me that she and a volunteer went out to [name of a hospital] to see May with the speech and language therapist. She explains that the volunteer was going to visit May at home to

do some work with her but that it fell through.

There is also an expectation that if one does things for oneself, it helps towards recovery.

Interview extract 9.36: Michael (son-in-law) lines - 730-733

Mi: All of them coming in oh I'll have a cup of tea make us a cup of tea like it's probably her tenth cup of tea that morning but who cares like it's you know out of the wheelchair ten times the circulation you know yeh?

Ethnographic notes extract 9.5: May's house 25/04/2001

Michael [son-in-law] tells me that he feels it is important that May do things for herself and says how her sister Bridie tends to make the tea and coffee when she is here and that he tells her that May should do it as she is "well able to". He says that the exercise of standing up out of the chair is "good for her".

Ethnographic notes extract 9.6: Maeve's (sister) house 04/11/2001

Matthew [Maeve's husband] tells me that it is important not to do everything for the person [with the impairment] but that one should make them do things for themselves as this helps them to become more independent.

There is a strong thread of a *restitution* narrative running throughout the discourse of all participants. Recovery is desirable though it may not be possible but there is a sense that one ought to strive to regain as many former abilities as possible.

A restitution narrative implies that the expectation is to regain past abilities or as near as possible to this and this permeated my interactions with participants. The next narrative to be presented focuses on the person who has not yet gained their past abilities as being in need of care.

9.2.5 In Need Of Care Narrative

This narrative implies that the person with the impairment is in need of care. As stated previously in 7.2.6, it links with the cultural narrative of *philanthropy* in that one is good and kind to those less fortunate than oneself. An *in need of care* narrative features in the discourse of all participants except for May's. Yvonne, her daughter, makes

reference to the fact that she and Michael, May's son-in-law, had to move back to the family home (i.e. May's house) to "look after" her. There is a sense of duty in this decision to take care of May. They are now held responsible for May as Michael says.

Interview extract 9.37: Michael [son-in-law] - lines 608-609

Mi: We [Yvonne & Michael] ourselves as a family unit as two people who are held responsible for her

While May is able to stay in the house on her own now this was not always the case and Michael explains how the clubs played their role in looking after her.

Interview extract 9.38: Michael (son-in-law) – lines 590-593

Mi: If she went out [to the clubs] that meant that three days at the time three days nearly three and a half days a week we didn't have to worry about her we didn't have to make sure that there was somebody at home with her

In the early days post-stroke Yvonne found that many things had changed in her relationship with her mother. She explains how their roles were reversed in that she was now caring for her mother in the same way as her mother had cared for her when she was a child in that she had to "spoon feed" her and change her "nappies".

Interview extract 9.39: Yvonne (daughter) - lines 941-951

Y: For the first time in me life me ma depended on me and I was feeding me mam I was changing her nappy em that was the thing with me that em I think for the second year I got annoyed with that like you know that me mam wasn't normal and why it wasn't fair (...) the first year was like once me ma's alive that was grand the second year I I did get very annoyed and very down on meself 'cos looking at me mam like that you know em and change her nappy and doing this like things that she used to do for me like and now I was doing it for her

In the early days the family strove to protect May. While now she is back to giving advice to others when they seek it, this was not always the case.

Interview extract 9.40: Yvonne (daughter) - lines 898-901

Y: It [giving advice] did stop for years like you know but em everybody was afraid to say anything to me ma that was worrying or anything you don't tell your ma that

There are other areas where May's family take care of and look after her. For example they will get her tablets, do her washing, write her cards and help her choose her clothes if she is going on an outing.

The care workers also allude to the need to care for someone with disabilities. Sinéad, May's key worker at the day centre, refers to the importance of ensuring that May gets a decent meal every day.

Interview extract 9.41: Sinéad (key worker) - lines 355-360

S: She's getting a good decent meal into her some of our members now like May who her I know her family live with her but they eat at different times or because they're working so she's kind of by herself so just to make sure that she does eat properly it's a decent meal that she gets here

Bríd, the day centre manager, is more general in her comments about people with disabilities needing care.

Interview extract 9.42: Brid (day centre manager) - lines 591-595

Br: I mean they're very isolated the families are doing massive work really and truly they are to maintain some of the people that come in here into the centre in the community and I would I would think that planned respite is what is needed

Bríd goes on to talk about the holidays that members go on that are organised by the day centre. Again there is a theme of the members needing care.

Interview extract 9.43: Brid (day care manager) - lines 688-691

Br: They don't have to worry someone reminds them to take their medication that's a huge thing when you're on holidays as well because they are out of routine they forget to take their medication themselves you know

Interview extract 9.44: Brid (day centre manager) - lines 698-704

Br: So there's five staff trying to get people up in the morning into their wheelchair showered and all that like it's damn hard work and we're used to them coming in for a couple of hours in the centre and you can say goodbye to them at five o'clock and go home to your own but on holidays you're with them twenty four hours you're on call basically twenty four hours

Michael, May's son-in-law, puts a different complexion on matters when he explains that they, Yvonne and himself, are also entitled to care.

Interview extract 9.45: Michael (son-in-law) - lines 610-619

Mi: Basically nobody really has come round really and sat down and talked to us yea? They really haven't (...) not at home not in the house no em about the (house cleans) or anything like that like people have come and it's always sort of been directed at May which is fair enough em but at the end of the day as well we live the situation you know what I mean we're the ones that are yea? living with it and paying as well you get no money help whatsoever that's a joke as well

At times there is an element of 'childlikeness' in this *in need of care* narrative. For example May's sister, Bridie, says that May can only go shopping if she is "good". The ethnographic notes explain.

Ethnographic notes extract 9.7: May's house 10/06/2001 [May's two sisters (Bridie and Maeve), May and I are talking about how May may have to leave the day centre she's at and she is concerned about this particularly with regard to the fact that she

may not be able to shop in a new day centre.] May then mentions about shopping and is concerned that she won't be able to go shopping in the new place. Maeve looks at me and explains that there is a Supervalu store right beside the day centre which May attends and that May used to do her shopping there. She then explains to May that Superquinn is across the road from the new centre and that she is sure that somebody would take her shopping there. Bridie then comments that she would be able to shop there but only if she was "very good". She laughs at this as do Maeve and May.

Another thread of 'childlikeness' is weaved into the way one of the care workers refers to May.

Ethnographic notes extract 9.8: Day centre 01/08/2001

[A care worker and I are talking to May.] The care worker explains how May enjoys doing everything "don't you pet". When she is addressing May she refers to her as "pet" most of the time. May responds to this by laughing and agreeing to whatever has been said.

Interpretative note: 'Pet' is a common term of endearment in Ireland and is particularly used with children. In this instance I feel it marks the different roles both the care worker and May have: the care worker being the care-giver and May the recipient of that care. I wonder how it would be taken if May referred to the care worker as 'pet'?

There is a very strong narrative of *in need of care* for May early post stroke. This is evident in the talk of May's conversation partners, but not of May's discourse. In addition, participants tend to use objectifying language when they talk about May, particularly in the early days post-stroke. For example comments include: "we'd walk her stand her up", "they put mammy to bed", "I had to spoon feed her", "wheel her around", "they came to the house to wash her and dress her". Such remarks place May as the object receiving care. However objectifying language is less pervasive when the participants talk about May now. Therefore while this narrative was strong early on post-stroke, it is now less evident.

The next narrative to be presented is a *philanthropic* narrative from which *in need of care* stems and therefore they are closely linked.

9.2.6 Philanthropic narrative

A *philanthropic* narrative implies that one should be good and kind to those who are less fortunate than oneself. As stated previously, it is a dominant and prevalent narrative in our society. May has a very strong *philanthropic* narrative permeating her discourse. She frequently alludes to the fact that people are very good to her, it is as if she does not expect people to be good to her and is pleasantly surprised when they are.

Interview extract 9.46: May - lines 579-581

M: Because I can't speak you know yea but they all very ni- very good very good on the road they're terrible nice now you know really nice and they wave to you you know

Interview extract 9.47: May - lines 753-756

M: They're [Yvonne and Michael] very good they're great and they're goo- they're really great because they needn't have come and lived with here they th- they gan they they were going to be married and they come here and live here

Interview extract 9.48: May - lines 1690-1692

M: I can't talk you know and they [the neighbours] feel awful but they're very good they're very good yea yea but I can't talk to them you know

Others also talk about people being "good" to her. For example:

Interview extract 9.49: Yvonne (daughter) - lines 546-547

Y: The two neighbours now next door are very good and Paul across the road

Interview extract 9.50: Maeve (sister) – lines 18-20

Mv: As I often say only for them people [those who run the clubs] I don't know what they'd do because I mean they're so good the way they look after them

Yvonne, May's daughter, expands on this theme when she says:

Interview extract 9.51: Yvonne (daughter) - lines 472-477

Y: Eleanor now at the stroke club she was- that woman is a saint like you know they'd only have they'd only have the club on a Thursday but em Eleanor would take me mam off and they'd go shopping and they'd have their chat you know and a cup of coffee and their cake or whatever and then come home she has an awful lot of time for my mam

The function of the stroke organisation as seen through Eleanor's (stroke club organiser) eyes is underpinned by a *philanthropic* narrative.

Interview extract 9.52: Eleanor (stroke club organiser) – lines 818-820

E: Well as I say the [stroke organisation] I suppose we're we try to help everybody that we can but em you can't help everybody

Later she expands:

Interview extract 9.53: Eleanor (stroke club organiser) – lines 830-832

E: Our role really just for the people that are referred to to help them in whatever way if it's just to give them information or to refer them on to something else

While a *philanthropic* narrative is not particularly strong it does permeate the discourse at regular points particularly with regard to how "good" people are to May. In the normal course of events one expects people to be "good" to one another and such regular explicit statements about people being "good" to May infers that the expectation is that she is not entitled to such 'goodness' and that receiving it is a bonus.

With a *philanthropic* narrative comes the notion that others take control of the lives of those 'less fortunate'. The next narrative to be presented is *others in control* and so links in with this view.

9.2.7 Others in Control Narrative

May's story shows an underlying theme of others taking control of her life since she had the stroke. This links to the *professionals in control* narrative presented in Anne's story (7.2.7). For example May had always been mistress in control of her house and home, however following the stroke this role was taken over by her daughter and son-in-law who came to live with her; they now live in the body of the house while May is mainly confined to her room. Attendance at clubs was organised for her, initially she was very reluctant to attend but now participates fully.

Even the amount she drinks is controlled now; her daughter, Yvonne, explains.

Interview extract 9.54: Yvonne (daughter) - lines 281-291

Y: Eddie [son] is the only one that gets it [beer] nobody else gets her any cans or if anybody asks can my mam have a drink like they have to ask me you know (...) vodka would be a thing now that I might let her have one small one and I I'd have to make it like myself

In addition there are other times in the way in which people spoke about May that suggested that they were in control. In these instances they tended to speak in language that objectified May more.

Interview extract 9.55: Maeve (sister) - lines 75-76

Mv: But I'd let people talk to her instead of me talking for her

Interview extract 9.56: Maeve (sister) - lines 599-604

Mv: I was too soft with her he [Maeve's husband] was great with her he was great with her he went down and made her get out of the bed and he had her on a br- brush (...) and he'd say to her em now May if you don't get out of that bed and try moving a bit you're going to be left there

Similarly Michael's comment objectifies May but infers that he and Yvonne want to absolve responsibility for May and hand her over to the social services.

Interview extract 9.57: Michael (son-in-law) - lines 290-294

Mi: Myself and my wife has made a new year's resolution em it's going to be Michael and Yvonne Walker's year end of story and she [person from social services] was looking at me what you mean by that and I say May is all yours for the rest of the year I says anything that needs to be organised you organise it

Like the professionals in Anne's story, there is some evidence of care workers and volunteers taking control over members' behaviour. For example:

Interview extract 9.58: Brid (day centre manager) - lines 675-676

Br: [We are talking about the holidays that the day centre organises.] They can have their two drinks that's all I ever allow them on holidays

Ethnographic notes extract 9.9: Stroke club 26/04/2001

The group is being led in a quiz by a man who Eleanor tells me is a volunteer, he is reading questions out of a quiz book for the members to answer. I notice that just after he has said the question he tends to look down at the book and does not always acknowledge the answers that some of the members are giving. One of the women complains to me that he never listens as on one or two occasions she said an answer that was right and he didn't acknowledge it. (...) At one time the answer to a question is 'skip' and this leads to a lively discussion about skips amongst the group about how much they cost, how good they are at being taken away, etc. For a time the 'quiz-master' is involved in this discussion but he then puts his eyes down and looks at the book however the discussion continues without him. He then looks up from his book and says "now let's leave the skips" and goes on to ask the next question. The members stop talking and listen to the next question.

Interpretative note: This was a lively discussion which was still in full flow yet members stopped and listened to the next question. The 'quiz-master' seems to be the one who orchestrates the turns and when others start chatting amongst themselves he tries to regain control by asking another quiz question. The group members were so much livelier during the skip discussion as compared to when they were just routinely answering the quiz questions. The quiz-master clearly took his role seriously and would continue on regardless.

May was a woman who was very much in control of her life prior to her stroke but now there is evidence of others taking control and doing things for her. May is grateful for what others do for her and this links to the next narrative of being beholden to others.

Beholden To Others Narrative 9.2.8

A narrative of being beholden to others suggests that the person with the impairment is in someone's debt. There is a sense of unworthiness in that one is thankful that someone is taking the time out to be good to one. May is constantly thankful for anything that is done for her and this pervades the discourse of the participants who seem to view this as a very positive attribute.

Interview extract 9.59: Maeve (sister) - lines 519-525

Mv: Even if I bring her down her few clothes pressed and she says ah thanks very much I only throw them in and I make her think that it's only a matter- well it is only a matter I say she's no problem I say ah sure I'll throw them in the machine no problem but she appreciates what you do for her she really appreciates what you do for her

Interview extract 9.60: Bridie (sister) - lines 288-290

B: And then she keeps saying oh thanks very much and you only hand her a drink of water and she's thanking you

The care workers echo May's tendency to be thankful for the least little thing.

Interview extract 9.61: Sinéad (key worker) – lines 122-124

S: I mean it's a joy now to work with May she's one of my favourites em she's always so grateful for everything you do to her

Interview extract 9.62: Sinéad (key worker) – lines 515-519

S: But then of course the minute you had finished talking to her and everything all of a sudden then she'd be so grateful to you for listening to her and she'd be around the shop buying you chocolates and you know and she's so nice like

Interview extract 9.63: Brid (day centre manager) – lines 24-27

Br: She's just so pleasant she's very very thankful for anything you ever do for her loves going on outings poses no problems here whatsoever

Such thankfulness seems to give the impression that May feels, being disabled, that she is not entitled to time and so when others give her time she is grateful. She tends not to ask anything of people as Eleanor explains.

Interview extract 9.64: Eleanor (stroke club organiser) – lines 536-550 [R = Rozanne]

E: Now sometimes though I notice she will em she'll be too nice to to maybe ask for something she wants done you know she sometimes she's too nice and she wouldn't like to ask maybe one of the volunteers or to to you know if you tell her if you tell her like that she's free to do it you know to ask say a volunteer maybe to bring her somewhere or you know to that she can't get out to the Wheelchair Association to go on a holiday you know

R: She would tend not to ask?

E: She would tend not to ask sometimes you know like she wouldn't like to em she'd feel she was being too em not demanding but er er

R: Imposing?

E: Imposing yea so she'd be imposing on somebody she'd be like that as well like she wouldn't like to impose on people you know

This narrative of being beholden to others links to the next narrative of being a good patient in that she does everything that is asked of her and is grateful for what everyone does for her.

9.2.9 Good Patient Narrative

This narrative suggests May fits in with what is considered to be a good patient someone who is compliant with what others want them to do and who does so in a good-humoured way.

Interview extract 9.65: May - lines 1960-1963

M: 'Cos nobody will er crying nobody will you know they haven't got time ye make me feel you know but no I never laugh I I un- to I never cry you know

There is much evidence of this narrative in the talk of Maeve, her sister, and the day care workers, for example:

Interview extract 9.66: Maeve (sister) – lines 272-273

Mv: [May] doesn't keep anybody waiting and doesn't give them any problems you know she's ready and waiting for them [the transport people]

Interview extract 9.67: Maeve (sister) - line 672

Mv: She [May] doesn't really moan

Interview extract 9.68: Maeve (sister) – lines 676-682

Mv: Even on holidays the girl that was minding her [May] the girl that was in her hotel room with May em she she'd have she'd be in bed and then the next morning she'd [the carer] go down for a swim or something and when she'd come back May would be having a bit of a lie on and when she come back May would be dressed and everything and she'd say jeez what am I going to do with you ain't you great

The 'care workers' talk a great deal about how May is "no bother". The following are some examples of the way in which they speak about May.

Interview extract 9.69: Sinéad (key worker) – lines 131-133

S: I'm very fond of her she's a lovely woman now it's a joy to work with her not a bother at all on her she's no problem at all you know

Interview extract 9.70: Sinéad (key worker) – lines 556-558

S: Anything at all you ask her to come over and join in she'll come over and join in no bother like

Interview extract 9.71: Brid (day centre manager) - lines 39-42

Br: She loves any activity she'll never turn her nose up to anything so she's just very pleasant and very easy to manage and I never have a staff coming in complaining about May

Interview extract 9.72: Brid (day centre manager) – lines 127-134

Br: I wouldn't have that much interaction with May because she's no problem [laughs] but that's basically it I mean I'd have more pro- more interaction er with members that have a lot of problems (...) I mean May doesn't she comes in and she's happy happy go lucky she'll eat what's put in front of her she will go on any outing that's going

Interview extract 9.73: Brid (day centre manager) – lines 243-251

Br: Now if she was a devill I'd be reducing her days I mean I'm meant to be reducing her days but I you know I can't because she doesn't pose any problems she doesn't you know she very rarely needs assistance of to the toilet she gets her shower here I mean staff don't mind showering her she's very light very thankful so staff don't mind showering her and I mean she only needs her food cutting up it's not as if she needs to be fed so she doesn't draw on the staff that much

Comments like she is "very easy to manage" (interview extract 9.71) objectifies May placing her as a passive recipient of care; a 'patient' who gives no trouble and who is compliant. There is a sense that to be a good patient the person must not be demanding.

Ethnographic notes extract 9.10: Day centre 01/08/2001

[I am talking with Sinéad, May's key worker.] I ask about the system with care workers and she explains that they operate a system of key workers whereby each care worker has particular

responsibility for about eight members. She tells me that she has only been here since April and that May is "one of the easiest" and "least demanding" out of her group members.

Clearly May presents as being someone who is thankful for everything and who is compliant and will go with the flow. This links into the next narrative whereby May feels that she needs to *put on a happy face* so that people will talk to her and it is this happy face that so endears her to her family and care workers.

9.2.10 Putting On a Happy Face Narrative

This narrative infers that one needs to present a face to the world that is happy and coping, otherwise there is a risk of rejection. This is a particularly dominant narrative with May and it is a narrative that makes others feel good about themselves; in this way May cares for her conversation partners. She explains why it is important to put on a happy face.

Interview extract 9.74: May – lines 1780-1784

M: Just get up and get going keep going you know because if you cry you're left there you don't you don't I don't lau- they don't you know when if you laugh they went ho hello hello you know that's why I don't cry you know if I all cry I be on my own you know but I don't cry often you know

Ethnographic notes extract 9.11: Stroke club 26/04/2001

May and I are talking about the interview and I tell her that it gave me some insight into what it is like to live with stroke. She says "it's horrible horrible". I ask her if it is still horrible and she says "yes" but that it is important to "keep laughing and keep going" otherwise you will be left on your own.

May's only previous experience of stroke was that her grandmother had one and was "locked up in her room". She explains further.

Interview extract 9.75: May – lines 1921-1923

M: Do you know years ago you be er stroke you bes locked up in the room and or maybe throw away em home and nobody come near them

It is as if that by *putting on a happy face* May will avoid this situation from occurring. There are some grounds for being afraid of being "locked up" in her room and left isolated. For example her main living area is her room which functions as a bedroom, living room, toilet and wash room. She spends most of her time in here and only rarely seems to join her family for meals, to watch television or to entertain guests. The only

regular times that she leaves the room is when she attends her clubs or when she goes into the kitchen/living room to microwave her food.

Participants remark how May is always in a good mood.

Interview extract 9.76: Yvonne (daughter) – lines 448-454

Y: I mean you you'll rarely find her in bad form (...) she doesn't really get upset about the stroke any more gets annoyed with her speech still the odd time

Interview extract 9.77: Bridie (sister) – line 291

B: And it's very seldom that she's in bad humour

Interview extract 9.78: Sinéad (key worker) – lines 127-128

S: She's a:lways in a good mood always I don't think I've ever met May when she's in a bad mood

The pictures that both Maeve, her sister, and Sinéad, her key worker, chose to represent May in the future maintain this theme of *happy face*.



Maeve (sister)
"Again it's brightness happy you know that kind of way it's happy you know"

Picture 9.7

Sinéad (key worker)

"May loves flowers and again there's plenty of colour in this plenty of brightness always cheerful and the watering can's on the frog kind of still has room to grow I don't think she gets very down ... she may want to stay the way she is but she may want to do something else grow a little more

However there is some awareness among the care workers that May does get down at times.

Ethnographic notes extract 9.12: Day centre 01/08/2001

Sinéad says how May is always chatty and never seems to let things "get on top of her" even though she may feel down she keeps it hidden.

However Sinéad does report that there are times when May looks "a bit down" but that one has to draw what the matter is out of her.

Interview extract 9.79: Sinéad (key worker) – lines 504-512

S: You'd have to ask her about something she wouldn't tell you you know she wouldn't come out straight now and kind of say oh I'm missing so and so she'd kind of sit there and you'd say oh May are you all right you know you look a bit down and you're a little bit tired tut I kind of miss Yvonne or do you know the way and you'd have to kind of draw it out of her she's not the kind of person that you'd look at them and eroh and start bawling crying you know this kind of way

Eleanor, the stroke club organiser, remarks how May hides how she may be feeling.

Interview extract 9.80: Eleanor (stroke club organiser) - lines 90-92

E: And her smile you know she always smiled no matter how she felt inside she smiled

Later when talking about depression, Eleanor speculates:

Interview extract 9.81: Eleanor (stroke club organiser) – lines 311-317

E: I'd say she still goes through it [depression] she doesn't show it though she does not show it in the club she she's that type that she em she tries to em she tries to er what will I say er be part of the club and er create like uplift you know to uplift other people and not to bring people down like by her problems that's the kind of person she is you know

May did not always *put on a happy face*, there was a time early post stroke when she would cry a great deal and say that she wished she were dead. Maeve explains.

Interview extract 9.82: Maeve (sister) - lines 610-624

Mv: But one day I was down there this was in the beginning I was down there and she had a bit of a cold and er she was really feeling sorry for herself and she started this business ah I wish I was dead and then ah- I don't know what came over me and I let her roar and I said May I said if youand I was kind of crying- and I said if you keep that up I'm not coming down any more and then she started (laughing) and she said I won't sure I won't say it any more (...) like you have to be that bit stern as well for their own good for their own good 'cos they'd only die of self pity

According to Maeve, since that time May has never cried or said that she wanted to die.

May experiences word retrieval difficulties and the care workers state that she has difficulty the "odd time". However May's family feel that there is no real problem with her speech and that "the only thing that is wrong with May is that she's in a wheelchair". Such an opinion may be based on the notion that by *putting on a happy face* May just uses speech that she knows she succeeds in and for which she receives positive feedback (i.e. use of her fluent social and stereotypical speech) in this way she

gives the impression that all is well. She rarely seems to have the opportunity to have a deeper conversation. May herself is not satisfied with her speech and one thing that she wishes for is that her speech will come back.

Interview extract 9.83: May – lines 1998-2000

M: If I could only speak I'd love to be able to speak I would really I know its coming on little by little but if I c- could just sp- speak I'd be delighted I'd be delighted yea

The picture she chose to represent her in the future echoes this wish to be able to speak again.

Picture 9.8

May
"The future I can speak I can speak the future"

This is at odds with how satisfied her family feel she is with her speech. For example her sister Maeve comments.

Interview extract 9.84: Maeve (sister) - lines 282-283

Mv: No it [speech] doesn't seem to bother her now because she's really great Rozanne as I say she can have a conversation with you

There seems to be some dissonance here in that her family feel that her speech is fine yet May, herself, feels it is not.

May has a very dominant narrative of *putting on a happy face* and every time I met her she was always cheerful and pleased to see me. It is as if she has found a way of living life with aphasia and physical disability. This leads on to the next narrative to be presented: *quest* narrative.

9.2.11 Quest Narrative

A quest narrative is when disability is incorporated into daily life, it is as if life's map has been redrawn (Frank, 1995). Most of the participants spoke of how May has now

adapted to her stroke. May herself says that you have to "just get up and keep going". The following comments are some examples of talk that reflect a *quest* narrative.

Interview extract 9.85: Yvonne (daughter) – line 406 Y: She's totally like I mean back to herself now

Interview extract 9.86: Yvonne (daughter) – lines 724-729

Y: As I said like if she hadn't had the stroke I know it's a mad way of putting it sh- all her friends now wouldn't be her friends and she wouldn't have the lifestyle so I'm not saying that she's happy that she had the stroke but I don't think she really dwells on that any more she she's totally accepted the way she is

Interview extract 9.87: Maeve (sister) - lines 254-256

Mv: As far as I can see she has adjusted to it you know what I mean she has really adjusted to it now and she has accepted it

Interview extract 9.88: Sinéad (key worker) – lines 138-145

S: My impression of her now since I started and that she has a stroke and everything she just gets on with things it's happened you know there's no going back like May will tell you there's no point in dwelling over it there's no way you can go back and change the past you know just get on with the future her attitude is I'm here now I'm lucky to be here she takes every day as it comes

Interview extract 9.89: Eleanor (stroke club organiser) – lines 822-826

E: With May I feel she was one of the em I suppose one of the success stories in a sense that em she's able to get on with her life reasonably well you know she has her problems but she still you know is able to cope pretty well with them

Others seem to have also integrated the stroke into their day to day life. For example her daughter Yvonne comments:

<u>Interview extract 9.90</u>: Yvonne (daughter) – lines 968-981 [R = Rozanne]

Y: She's very like I said a totally different person you know what I mean and er a brilliant person like you know but er as I said if you had been interviewing me now probably three years ago I probably wouldn't be.

R: It would be different?

Y: It would be a different story altogether I I'd probably be breaking down as I was talking to you you know what I mean but I can definitely sit here and tell you that like time- they say about death time is a great healer but with sickness time is a great healer because your whole lifestyle just changes you know what I mean and you have to adapt and obviously the person that's sick has to adapt but on the whole it affects everybody

The accompanying commentary to the picture that Eleanor, the stroke club organiser, chose has a *quest* narrative feel to it.

Picture 9.9



Eleanor (stroke club organiser)

"Travel the world she'd be confident enough to travel and that's something you know I can see her travelling again abroad and going off on a plane and going to other countries and that"

While the initial couple of years post-stroke were difficult for May, according to participants she now seems to have adapted to it and has incorporated her disabilities into her life.

Other less dominant narratives which emerged from the data include *thankful for small* mercies and *body as machine*.

9.2.12 Thankful For Small Mercies Narrative

The premise of this narrative is that one should be thankful that things are not worse. There are a number of comments that permeate the discourse that suggeste this narrative.

Interview extract 9.91: Yvonne (daughter) - lines 883-884

Y: Well that woman [a member at one of May's clubs] has got problems you know what I mean oh Jesus me ma is blessed

Interview extract 9.92: Bridie (sister) – lines 131-132

B: But thank God she's as well as she is now you know

Interview extract 9.93: Sinéad (key worker) - lines 149-154

S: The way she [May] looks upon it is she still has other (powers) like she's still alive she still can talk she can still feed herself go to the toilet on her own you know she is quite independent you know compared to other people other members now that she would see here she would kind of consider herself quite lucky

The picture her sister Bridie selected to represent May now together with her commentary suggests this narrative.

Picture 9.10



Bridie (sister)

"Take each day as it comes like I don't kinda say next year or anything I just sort of take each day as it comes and I thank God for being able to go out"

There is a general feeling then that May is lucky not to have been worse. However May herself makes no comment that she is thankful about this.

The next narrative to be presented is *body as machine* which links in with the metanarrative of modern bio-medicine.

9.2.13 Body As Machine Narrative

This narrative treats the body as a machine in which breakdowns occur but that they can be fixed (Stainton Rogers, 1991). This metaphor is evident in some of the talk of participants with comments such as "me leg you know wouldn't work", "the physio did come just to move hands", "we'd walk her stand her up", and "it's [speech] coming along little by little". However it is most apparent in the day centre records whereby the main record reduces May to a set of abilities and disabilities. For example:

Artefact notes extract 9.1

The case history form gives the name and address of the GP and this is followed by a checklist to identify her current abilities. It includes things like 'mobility', 'limb function', 'swallow', 'toileting', 'vision', 'hearing', etc.

Similarly the application form for the centre is centred around issues surrounding her functional abilities and there is no mention of the impact on May of aphasia and physical disability in terms of both her day to day life and personally.

However the Cardex which comprises short notes made on each day that May attends the centre, gives more of a sense of May as a person in terms of how she is feeling and the impact of her situation on her life.

9.2.14 Drawing Threads Together

To summarise, May is surrounded by a complex and intricate tapestry of narratives, some narratives are shared others are not, some are strong while others are less so. All, however, contribute to participants' experience of aphasia and disability.

While May is surrounded by a complex tapestry of narratives, there is an underlying theme relevant to the experience of disability and this is presented in the next section.

9.3 OVERALL THEME: PRINCIPAL NARRATIVE TYPE

Lieblich et al (1998) advocate identifying the person's principal narrative type, that is the type of narrative that best represents the way the person lives her/his life as a whole (see 5.3.2). May's narrative type reflects that of *comedy* whereby the goal is restoration of social order and the 'heroine' must have the skills to overcome the obstacles that threaten that order. However this narrative interweaves with *tragedy* where the heroine is defeated by forces of evil and isolated from society (Lieblich et al, 1998).

There is a sense of return to social order running throughout May's narrative in that she now has structure and a routine to her day, albeit very different from her routine prior to her stroke. May outlines her week:

Interview extract 9.94: May – lines 479-515 [R = Rozanne]

M: Well that's Monday Tuesday and Wednesday is er [name of day centre] and when I get back f- at home at four you be tired and you might look at the television or you might on the bed and then we wake up f- for the soaps

R: Oh right yes of course

M: [laughs] And then I get back into bed you know that's Monday Tuesday Wednesday Thursday's skro- the s- the stroke Thursday

R: Oh right the stroke club

M: And then the other one St. Andrews you know St. Andrews?

R: No I don't

M: In the school up here

R: Oh right what do they have there?

M: Oh it be great d- great they have em the Bingo they have to and em they have raffles they're great it's great up there it's terrific yea

R: And when do you go there?M: On Thursday afternoon yea

R: So Thursday morning you have the stroke club and Thursday afternoon you go to St. Andrews?

M: Yea yea

R: Oh right

M: It's great yea the amblance we come in amblance you know yea

R: So they come and pick you up?

M: Yea yea and we have a cup of tea a cup of tea and er em not cake it's like cake you know yea

R: Brack or?

M: Yes brack yea

R: Is that it brack?

M: Yea yea (...)

R: What about the rest of the week what about Friday Saturday and Sunday?

M: Nothing nothing sometimes the boy th- jum th- er lats last last Saturday Joe not Joe Eddie [son] took me down to [name of a shopping centre]

The order and routine to her week revolves mainly around her clubs. In addition May was always someone who helped others and this is now returning in that she helps out in the house whenever she can and when her daughter "lets" her. However unlike Anne and Tony, there is no sense that she is mistress of her own house as she once used to be.

One gets the impression that initially, following her return home after stroke, there was a lack of social order in the household. Michael, her son-in-law, explains how they were nearly "killing one another" at that time. Now social order has been re-established and they are able to live in harmony.

While *comedy* is evident in the narrative there are also strong traces of *tragedy* whereby May is isolated from society. She rarely lives life out in the community as she is either in the house or at her clubs, where according to her sister Maeve, "she's out among people like herself". May explains how she used to "frighten" people off.

Interview extract 9.95: May - lines 225-229

M: The sometime the use er k- er some the nei- neighbours they wouldn't come near me they- I frightened everyone off you know [laughs] you know you know bu- you can't blame them 'cos I couldn't talk right you know

She rarely ventures out into the community where in the past prior to her stroke she spent a great deal of time. She does go to the pub once a fortnight with her sisters and to Mass once a month, other than this she seems confined to either her room in the house, the clubs or outings organised by the clubs. I got a real sense of this isolation on one of my visits to May.

Ethnographic notes extract 9.13: May's home 10/06/2001

viewing the happy family scene from the isolation of her room.

[Just prior to this May, her sisters Bridie and Maeve, and I had been chatting in May's room. Maeve had just left and Bridie had gone into the front garden to join Yvonne [daughter] and Michael [son-in-law].] I take my leave of May telling her that I will probably see her at the day centre in a few weeks. I thank her for her time and go out into the garden. Bridie gets up off the wall where she has been sitting and says that she will get the gate for me. As she opens the gate she comments how "marvellous" May is in the way she manages. I say goodbye to her and wave to Yvonne and Michael. May is looking out the window and I wave goodbye to her as well. Interpretative note: Everyone is outside and May seems stuck indoors on her own looking out yet she loves the sunshine – she doesn't have the freedom to move about as the others do. My lasting impression is one of May being isolated in the house while the others are enjoying the sun in the garden outside. Maybe she will come out and down the path later as it is wheelchair friendly but I wonder how easy or confident May feels about making her own way as it is quite a slope. I

wonder will one of them go in to ask her to join them outside or do they even realise that May is

The narrative reveals that May no longer feels that she is free to roam her house as she used to. For example, Michael, May's son-in-law, has put a toilet in May's bedroom and she admits to finding this very useful as it means that she does not disturb Yvonne and Michael by going through the living room if she wants to go to the bathroom.

Interview extract 9.96: May – lines 1578-1583

M: Honest to God no matter what he get he he de- de- get get at them get at them the toilet and all it's handy 'cos I don't have to go out down at the end if anyone sitting in there there er you know friends I'd have to go right through and I be a:wful you'd feel awful you know scuse me say scuse me and go and you know

While this gives her a sense of comfort in that it allows her not to disturb others, one also gets a sense that she is being isolated away from the family as a whole and that she is confined to her room. My impression of her being confined to her room was confirmed when on a previous visit (ethnographic notes 25/04/2001) to her house I was waiting in the living room talking to Michael, her son-in-law, when May arrived back from the club. She greeted me, but rather than come into the living room to join us she called me in to her room for a chat. It was as if the living room was no longer her territory and as if she felt that that she needed to be invited into it.

One gets the sense of both *comedy* and *tragedy* permeating the interviews and the ethnographic notes. These principal narratives interweave together giving a sense of overcoming the hazards with a return to social order of some sort on one hand while at the same time one gets a strong sense that May is isolated from society and that she is living in a world alongside rather than within society at large.

As stated earlier, May is surrounded by a tapestry of many different and subtle narratives that influence her experience of aphasia and disability as well as contributing to how she and others view her as a person. The following section focuses on how she manages threatened identity, aphasia and physical disability.

9.4 MANAGING THREATENED IDENTITY, APHASIA AND DISABILITY

This section outlines how the emergent narratives described in section 9.2 have a role to play in managing threatened identity, aphasia and disability. I begin by presenting how May is viewed both before and after her stroke.

9.4.1 Views of May

May's life has altered significantly due to both her aphasia and physical disability. It is something she has to learn to live with in the long term. As discussed previously, prior to her stroke May was an active person in charge of her home and who worked as a cleaner. The pictures chosen to represent May prior to her stroke are various; most portray a sense of relaxation, for example:

Picture 9.11



Bridie (sister)
"That there would have been May just relaxing"

Picture 9.12



Michael (son-in-law)

"Many a night I came I with Yvonne and she'd be over there in her chair after having a few drinks and basically just totally looked relaxed in the chair"

However this is at odds with how May views herself before, which is that she was "always out working" and doing "anything anything". Her daughter, Yvonne, comments that her mother was much more serious and more of a worrier prior to her stroke and the picture she chose to represent May before the stroke and her accompanying commentary reflects this.

Picture 9.13

Yvonne (daughter)

"It just reminds me just she was kind of a lot more serious then and her outlook on life was a lot more serious and em she would have been probably much more of a worrier then so it's more of a serious kind of a picture than she is now"

May has a different perception as she says that she was never one to worry. Her sister, Maeve, is also of the opinion that May was not one to worry prior to her stroke.

Most of the pictures chosen to represent May now suggest that she is happy and content. May herself chose a picture to signify a scene she loves.



May "The trees the trees and I love that"

Others chose similar pictures that reflect colour and happiness which mirror the *putting* on a happy face narrative.



Maeve (sister)

"That would be her now too 'cos she's into lovely colours she loves colours when she's doing her paintings"



Sinéad (key worker)

"There's plenty of colour in the card so it's bright and cheerful and the dolphins (...) they're free angelic peaceful kind of animals but they also have a people say they kind of help with others they kind of draw different things out of each other and I would look at May like that you know she's always there to have a chat she's very affectionate and dolphins are very affectionate kind of animals"

9.4.2 Managing Threatened Identity

With regard to Breakwell's (1986) identity principles of continuity, distinctiveness and self-esteem, there is some continuity between most of the pictures chosen to represent May before the stroke (pictures 9.11 and 9.12) and those chosen to represent her now

(pictures 9.14, 9.15 and 9.16). They have a sense of contentment about them. May herself describes herself as being "ordinary now again" and her family say that she is now back to herself. However while there is some evidence of continuity in May's life in that she reports that her sisters talk to her in the same way as they did before the stroke and her family still play a big part in her life, there is some break in continuity in that she is no longer in charge of her own household and is not able to do many of the things that made her distinctive (e.g. cycling, being an avid reader, working as a cleaner). New things now make her distinctive and this constitutes a break in continuity. Some of the things that make her distinctive now include that she has become a painter, she goes to clubs, she is a wheelchair user and she has aphasia. May enjoys going to her clubs and gains great satisfaction from doing her paintings, some of which she has had framed. This new-found interest in painting and the fact that it makes her distinctive is reflected in some of the pictures people chose to represent May now. For example the accompanying commentary to Maeve's choice suggests this interest in painting (see picture 9.15). Similarly the picture chosen by Bríd, day centre manager, and Eleanor, stroke club organiser, signifies this interest.



Brid (day centre manager)

"Now because she's so good at her art and she loves drawing her little flowers I'd imagine this"

Eleanor (stroke club organiser)

"Oh yea that describes May well I know she paints sunflowers and she loves flowers that's a painting like and she's developed a sort of an interest in painting now and maybe the art that's something now she's able to access"

However while she enjoys going to her clubs and painting she does say that a stroke is a "horrible horrible feeling" and that she misses the old life. She has learned to manage her aphasia and physical disability in a variety of ways. One of the main coping strategies she employs is to *put on a happy face* in order to ensure that people will talk to her and not isolate her. This is very effective in that people enjoy May's company and tell me that she is "no trouble". Part of this strategy's effectiveness is that it makes

others feel good about themselves and they do not get disturbed by the times when May feels down as she successfully masks such feelings.

9.4.3 Managing Aphasia

In terms of how May deals directly with her aphasia, she employs a number of active strategies. May is an excellent social communicator and listens attentively to what people have to say. However she breaks down when she tries to get specific or complex information across. In these instances when she runs into trouble she needs to take her time and she tends to slow herself down by saying "I can tell you in a minute", this she finds is usually effective. Her family discuss how at times they have to tell her to slow down and take her time. Another effective strategy is her use of a notebook to convey key bits of information. This notebook contains people's names and contact details, places she goes to and general biographical information. She made use of this on a number of occasions during my interactions with her.

9.4.4 Overall Coping Strategy

May's overall coping strategy is one of compliance, which links in with the *putting on a happy face* narrative. She agrees with what people say and complies with everything that people want her to do. For example, she goes on all the outings that the clubs organise and she sets her hand to any activity that is requested of her. Another example of compliance is that a few years ago May used to spend more time in the living room watching television with the family; however her son-in-law requested that she should give him and Yvonne, May's daughter, more time on their own. May complied with this request to the extent that she now rarely watches television with the family and instead spends most of her time in her room. This type of strategy corresponds to Breakwell's (1986) framework of coping with threatened identity which identifies a key interpersonal coping strategy as that of compliance whereby the threatened person, in this case May, gains social approval by complying and so does not disrupt status or power hierarchies.

9.5 SUMMARY

This chapter began by presenting the changes in May's lifestyle since she had a stroke six years ago. She has always been, and continues to be, an active person. Before her life revolved around her family, her work and being mistress in charge of her own home. While her life still revolves around her family, attendance at her clubs is now a major focus. She relies on others to bring her out due to her physical disability.

The narratives that May and her conversation partners draw on are numerous, leading to an intricate tapestry with some threads strong and vibrant while others weaker. All contribute to the experience of living with aphasia and physical disability. She primarily copes by adopting a *happy face* narrative whereby she presents as a happy, compliant person willing to do anything and everything. This has been successful in that people talk fondly of May, refer to her as a "marvel", and say that she is "no trouble". Due to her compliant and sunny nature, May has been allowed to stay on longer at the day centre than she is entitled to as she is now past the age band for that particular centre. May therefore, is using a particular means of coping that allows her to keep in contact with others in a way that maintains the status quo.

There is a break in the identity principles of continuity and distinctiveness. She is no longer able to do many of the things that she used to. However there is some maintenance in continuity whereby she remains active as is evident from the way she participates fully in the clubs and goes out at every opportunity. May is distinctive now in different ways than she was before her stroke. Before she was a homemaker, cleaner and cyclist, while now she is a club member, wheelchair user and someone who has aphasia. She manages her aphasia well by employing a number of strategies to compensate.

In conclusion, May and the other participants draw on numerous narratives to make sense of aphasia and physical disability. She has been a key weaver of this narrative tapestry, but others have contributed to it resulting in an overall picture, with numerous authors, that has provided me with insight into the lived experience of aphasia and physical disability.

The following chapter will present my story in the research process. In it I outline how the way I felt may have affected the shape of the study.

CHAPTER 10 MY STORY

Kleinman (1988) advises that how we listen to accounts will affect the telling and the hearing of them. He believes that clinicians need to "unpack their own interpretive schemes, which are portmanteaus filled with personal and cultural biases" (p.53) if they are to ensure that they do not delegitimatise the illness experience, and so impact on effective care. Researchers also bring with them their portmanteaus filled with their personal and cultural biases that affect the way in which data are generated, analysed and written about. Therefore in this chapter I address my role in undertaking this study. I explore the range of emotions, feelings, doubts and questions I experienced on finding myself immersed in the research process. I am more familiar, comfortable and confident with the role of therapist and I found this new role of researcher much more challenging, on a personal level, than I had anticipated. There were many times I felt overwhelmed with the data, the data generation methods and the data analysis. This may have been compounded by the fact that I was working as a full-time clinician and manager at the same time. At times I felt I was in a *chaos* narrative.

This chapter is written with the benefit of distance. I reflect on the data generation and analysis methods and how they affected me personally, as well as the effect they had on participants, before going on to discuss the impact that I, a practising speech and language therapist, may have had on the research process. I begin by outlining how the study's direction was shaped by the data.

10.1 SHAPING THE STUDY'S DIRECTION

The focus of the study was shaped by a mixture of what emerged from the data and the feasibility of some of the data generation methods. At the very beginning of this project I had the notion of discovering the influence narratives had on behaviour. However I soon realised that exploring and identifying narratives was a study in itself. In addition it was difficult to gain consent to video-record interactions in structured environments (e.g. therapy sessions) as well as in public places, and lack of video-recorded data

would have made it difficult to analyse behaviour. This also contributed to the decision to explore narratives of aphasia only. It was felt that comparing narratives with behaviour was beyond the scope of the present study.

The data itself tended to shape the direction of the study in that it was this that guided the narratives identified. Initially I approached the data intending to find particular illness and disability narratives as outlined by people like Frank (1995), Stainton Rogers (1991) and Crossley (2000). However the data did not confine itself to just these narratives; rather other more personal narratives emerged, many of which were connected to the more public narratives. In this way the study was data-driven.

The feasibility of data generation methods as well as the data itself guided the shape of this study. The next section reflects specifically on the data generation methods and the challenge these posed for me.

10.2 REFLECTIONS ON DATA GENERATION METHODS

This study used a number of data generation methods which included in-depth interviews, picture selection, participant observation, audio-recording, use of artefacts and my personal research journal. Some of these I found easier to deal with than others.

10.2.1 In-Depth Interviews

At the beginning of the research process I considered I had reasonable experience in undertaking in-depth interviews as part of my role as a practising speech and language therapist and from attending a course on in-depth interviewing. So at the outset I was quite confident that I would get the depth I was striving for and was not unduly concerned about my abilities or role as interviewer. However a different tale emerged that was to affect my confidence for the remainder of the study. I found it unexpectedly difficult to get a balance between listening and being guided by the participant's story and ensuring that everything was covered in the topic guide. I find therapy initial interviews much easier, as in these I feel free to follow the person's story wherever that may lead and do not feel constrained by a list of topics to cover. Therapy interviews

seem to flow much more naturally than did the in-depth interviews of the study. This could be linked to my confidence as therapist and my lack of confidence as researcher. The following is an excerpt from my research journal which conveys my lack of confidence and comfort in the research interview process.

Personal research journal²⁷ extract 10.1: 02/12/2000

Have recently completed two interviews one a pilot interview and the other with someone who is to be part of the main study. Following both interviews I felt quite down and did not feel I had done a particularly good job. I felt I was unable to get the depth that I had hoped. General feeling is that I seem to get much more depth and in a more relaxed way in a more open ended therapeutic initial interview when I start with a looser agenda and am guided by what the person brings up and what seems to be a priority to them.

I felt the topic guide constrained me and in retrospect I wonder whether I would have been more comfortable with a life-story interview design. Such a format would probably access similar narratives as what emerged in the topic-guided interview. Indeed pre-aphasia narratives may be elicited more easily in a life-story interview, albeit sifted through their current aphasia story.

There was one particular interview that I was very concerned about and that was the interview with Stephen, Anne's fourteen-year-old son. I was anxious that he was vulnerable and that the interview would be upsetting for him (as it proved to be) yet it seemed important that I interview him as he was the person with whom Anne spent most time and who was her greatest support, so his perspective was an important one. In the end I interviewed Stephen, following guidelines set out by Ward (1997) in her book about involving children in research. Prior to the interview I ensured that there was 'back-up' for Stephen; a psychologist had agreed to see him for counselling should he request it or agree to it. Stephen ended up being very upset at interview, but he refused to go to talk to anyone about it. I wrote in my research journal at the time:

Personal research journal extract 10.2: 26/04/2001

Have interviewed Anne's son. I found it very difficult. He was quite quiet and also tearful but when I asked if he wanted to stop he said he wanted to continue. I asked him a few times as I was very concerned that it might have been too upsetting for him. It was the first time he had ever really talked about it as even at the time the stroke happened he did not talk about it with any of the family. (...) I saw Anne after the interview and stated that the interview was difficult for Stephen but did not go into depth as I did not want to break confidentiality. I feel very worried about him particularly as he refused to see anyone. I wonder also whether I should have said more to Anne. What I have done is sent Stephen a card to thank him and to give him my phone number

²⁷ Personal research journal extracts are in note form and as they appear in the journal.

again inviting him to contact me if he wanted to talk or if he changed his mind about seeing someone.

I never heard from Stephen and he did not seem at all upset on subsequent meetings.

10.2.2 Picture Selection

The picture selection task involved participants selecting a picture to best represent the person with aphasia before the stroke, at the time of stroke, now and in the future. They had to choose from a range of forty greeting cards. I felt quite comfortable asking participants to do this task. All it required was the occasional prompt to request them to talk about the reason for their selection. I felt I could just follow their lead. The task facilitated the person to talk in a different way about the person with aphasia and thus added a different dimension to the study. For example Tony's friend Fintan spoke extensively about the pictures. I note in my research journal.

Personal research journal extract 10.3: 06/04/2001

I interviewed Fintan and found him quite stiff and measured. I felt he was responding more as he felt he should, he seemed to be minding his words all the time. I met him again so that he would select the pictures that best represented Tony at various times and he was much more relaxed. He said he was glad the tape recorder was not on as he found it inhibiting. I thought he might be quite suspicious about selecting cards but as it happened he seemed to throw himself into the task and said that he had learned something from the process. He found he could see meaning in some of the more abstract modern art pictures that he had never seen before. He gave quite a lot of information as to why he did and did not select certain pictures.

The picture selection task then facilitated people to talk about the person with aphasia in quite a focused way. I felt quite comfortable requesting participants to do it.

10.2.3 Participant Observation

My role of participant observer ranged from entering into quite structured situations (e.g. therapy sessions, stroke club) to quite unstructured ones (e.g. visiting Anne in her home). In some I was a passive observer (e.g. therapy sessions), while in others I was an active observer (e.g. visiting May with her sisters). With the exception of the therapy sessions I was always an active observer. In general I was uncomfortable in my role of participant observer, particularly in those situations where I was an active participant, as I felt I intruded on the privacy of the persons concerned. I felt more comfortable in the formal structured situations such as the therapy sessions or attending

the day centre, as there seemed to be particular 'things' to observe. It was more familiar as it was something I did as part of my role of clinical supervisor of students. However the majority of instances I was an active participant taking an equal part in the conversation.

I found taking notes during the observation period extremely difficult unless I was a very passive observer as in the therapy sessions. I felt that the taking of notes intruded upon the natural flow of the interaction and that it would highlight to the participants that they were being observed and so affect behaviour. I note this in my research journal.

Personal research journal extract 10.4: 14/03/2001

I recently had lunch with Tony and Sue. There was plenty in it and I am kicking myself that I did not tape it. I am not sure how much I was able to capture in the ethnographic notes. I find it very difficult to get out the notebook when I am quite a full participant in the interaction – it would seem unnatural.

For this reason notes were only taken during those observation periods in which I was a passive observer. Therefore in the majority of situations condensed notes were taken immediately after the observation period and these acted as a memory aid for the expanded notes which were written as soon as possible after withdrawal from the situation.

My discomfort with observation may have led to fewer observation periods than would have been ideal though this was not done consciously. At times my request to observe was refused and my discomfort with this role meant that I did not push the request further.

10.2.4 Audio-Recording of Interactions

Initially it was hoped to video-record interviews and interactions, but this was refused on a number of occasions, so it was abandoned in favour of audio-recording which participants were more open to. Perhaps my discomfort with the intrusiveness of video-recording may have influenced my decision not to push it in all situations. While all interviews were recorded, there are only a few samples of audio-recorded interactions.

This, in part, is due to it not being possible to record certain situations – for example, the noisy environment of the day centre and stroke club was not conducive to audio-recording. However the few samples may also be due to my feeling uncomfortable with requesting this of participants who were giving so much of themselves already. I remember a particular time I had intended to audio-record when I was with May and her sisters, but when the time came it seemed inappropriate and invasive to get the tape recorder out. I felt it would have made the interaction more artificial.

10.2.5 Artefacts

A number of artefacts were sourced and these included the health records, Tony's diary, an article written by Tony's partner and literature pertaining to stroke and aphasia that is readily available to the public. This was a relatively straightforward process. Permission was readily given to source health records, Tony offered a copy of his diary and agreed to write a diary for me for one week and Sue, Tony's partner, offered and gave me a copy of her article.

With regard to the health records I was struck by how impersonal they were. I wrote in the personal research journal:

Personal research journal extract 10.5: 14/03/2001

Since I last wrote I have been into the stroke clinic and looked through both Anne and Tony's notes. What is quite striking is the fact that they are so impersonal and you get no real sense of the person behind the stroke or impairment. Yet I know from talking to the speech and language therapist that she did tackle quite a few "traumas" with Anne, traumas that Anne would bring up at the beginning of a session. Yet there is no mention of this in the notes and I wonder why this is so as they were generally to do with disabling barriers. Similarly the speech and language therapist says that she worked on the disabling experience of aphasia yet this is not mentioned. The notes only record work done on the impairment. It is as if such work (i.e. on the disabling experience) is not relevant to the type of information required for the formal chart. There seems to be a contradiction in the flavour you get of the person when talking to the professionals and how the person is depicted in the health records – one personal and one impersonal.

I felt saddened that the person became so lost in the public record. No mention was made of the impact in personal terms of aphasia on the person or others close to her/him. I wondered how issues surrounding communication could become so depersonalised.

10.2.6 Personal Research Journal

The personal research journal provided me with the opportunity to document my thoughts and feelings about the whole research project in quite a free way on a personal level. At times I found recording these feelings and thoughts quite liberating, while at other times I found it quite difficult particularly when my feelings were in turmoil and I knew only that I felt uncomfortable. At those times I found it hard to articulate and write down the reasons for this discomfort. It was as if I was in a *chaos* narrative and did not have the words to express myself. However the very act of trying to write down my thoughts helped to clarify meaning for me. The research journal has acted as a source and resource for this chapter.

This section has described some of the issues that the data generation methods threw up for me personally. One of the overriding feelings I had during the data generation phase was one of concern that I was exploiting participants. This is addressed in the next section.

10.3 FEELINGS REGARDING EXPLOITATION

I felt throughout the study that I was exploiting participants, particularly with regard to the in-depth interviews and participant observation. I explain in my research journal.

Personal research journal extract 10.6: 10/01/2001

Come to the conclusion that one of the things that is different about a research interview is that I feel that I am taking everything and not giving anything in return. In a therapy interview I am facilitating the person and giving something while in a research interview I am only taking – or that is what it feels like. Need to remember that people also enjoy and get something from telling their stories so it is not just a one sided affair.

The feeling that I was intruding on the privacy of the participants never left me. I felt that I was the sole beneficiary of the process and they got little in return yet they were so generous in the way they welcomed me into their lives. I am aware that people gain something from having their story listened to (Atkinson, 1998) and that it is their opportunity to contribute to the understanding of aphasia on a wider stage, rather than just a personal one. Indeed Sue, Tony's partner, explicitly stated that she felt she was giving something back to a system that had been 'very good' to Tony and her. However

even given this I still felt that I was exploiting the participants. This is very different from the therapist role where I feel not only that I am gaining something, but that I am also giving something back.

One way to 'give back' to participants in a research project is to involve them in the process as much as possible and to ensure that consent is sought at all stages. This was done on all occasions. Also each participant will receive a written summary of the study at the end of the process. I see this only as one small way of giving back to them who have given so much. I still need to reconcile myself with the long term value of the research in terms of its contribution to our understanding of aphasia and of balancing the value of this with the intrusion into participants' lives. I wrote in my personal research journal:

Personal research journal extract 10.7: 31/01/2001

Last Saturday I had a really useful meeting with SP. The main focus was on discussing some of the practical issues of participant observation and my feelings and fears surrounding it. I still have this fear of intrusion and the feeling that I am the one getting everything and the participants I am observing are getting very little from the process. SP said that she had similar fears but can now justify it in terms of the more long term value for people with aphasia.

With the benefit of distance I am now better able to see the value of the research process for participants, so my feelings of exploitation have lessened with time.

This section addressed some of my concerns about the exploitation of participants. The next section outlines some reflections on data analysis.

10.4 REFLECTIONS ON DATA ANALYSIS

Data analysis began during data generation as I tried to transcribe interviews as I went along. I soon found that I got bogged down in all the detail and was living life through the participants' eyes and so was having difficulty in gaining objectivity. I noted in my personal research journal.

Personal research journal extract 10.8: 06/04/2001

SP and I went through ways or possible ways that I could analyse the data. We talked of how I tend to get bogged down in the detail and how I find it difficult to rise above it and see the themes. I still feel that I am searching for something to grasp a hold of, it is like being submersed in a sea of information in which I am inextricably bound and from which I cannot gain distance to look at it as a whole.

As time went by I was better able to identify the themes emerging from the data.

This study aspired to being data-driven but with that came a feeling of being lost. At times I felt completely directionless.

Personal research journal extract 10.9: 16/04/2001

SP says that this stage is about plodding along which is what I am doing but I can't help wondering plodding to where!

Personal research journal extract 10.10: 05/09/2001

I don't think I am clear on what I am doing. Am I trying to link public and private narratives and to see the effects this has on the individual concerned?

As time went by and I gained some distance from the data, I found a story emerging of how people lead their lives guided by public and personal narratives.

This section touched on some of the issues that were of concern to me during the time I was analysing data and, in particular, my difficulty in rising above the data to identify emergent themes. The next section explores issues surrounding how my role affected data generation and interpretation.

10.5 ISSUES SURROUNDING DATA GENERATION & INTERPRETATION

The nature of qualitative research determines that it is not an entirely objective enterprise. Therefore I am aware of a number of particular issues that may have affected the generation and interpretation of the data. They include the influence that knowledge that the observer/interviewer is a speech and language therapist has on participants, other issues surrounding observation, the danger of asking leading questions particularly with those interviewees who have aphasia, and the blurring of roles of researcher and therapist.

10.5.1 Speech and Language Therapist as Observer/Interviewer

In these narratives it is difficult to determine the degree of influence I, the observer and interviewer who was known to be a speech and language therapist, had on proceedings. For example in one of the participant observation sessions Sue, Tony's partner, waited expectedly for Tony to respond and I wonder whether she would have done this if I had

not been there. Did my presence and her knowledge that I was a speech and language therapist shape her behaviour in that she acted in such a way that she thought would gain my approval, i.e. by allowing him time to respond rather than speak for him? Similarly I wondered whether awareness of my profession led to a comment she made during the interview about the fact that she thought it was important not to give the word to the person with aphasia when they were struggling to say it, but rather one should wait until they had succeeded in saying it.

<u>Interview extract 10.1</u>: Sue (Tony's partner) – lines 588-593 [R = Rozanne]

S: Sometimes I'll chip in the word very very occasionally will I chip in the word 'cos I think that's wrong but if I chip if I chip

R: Why do you think that's wrong?

S: Because I feel he should try and get it himself I think it's good for him to feel that he can get it and find it

I wonder did knowledge of my profession influence this remark. Similarly at one time towards the end of my interview with May I did speculate whether knowledge that I was a speech and language therapist influenced her response to a question.

Interview extract 10.2: May – lines 1994-2002 [R = Rozanne]

R: Is there anything else that you would like to add at all just before we finish?

M: Em:

R: That you think that maybe I should know about

M: If I could only speak I'd love to be able to speak I would really I know it's coming on little by little but if I c- could just sp- speak I'd be delighted I'd be delighted yea

R: Is that one of the things that you find most difficult for you?

M: Yea yea

With regard to May, Bríd (day centre manager) talks about what an "upheaval" it is for the family if someone has a stroke, "especially if their speech is gone". Perhaps the knowledge that I was a speech and language therapist made her think to add "especially if their speech was gone" or perhaps it was something she genuinely believed. Similarly Eleanor, May's stroke club organiser, spoke of needing more people to be trained in the field of speech and language therapy and that one needed guidelines from a speech and language therapist on how to help the person with aphasia. Again I speculated whether the focus on the speech and language therapy aspect of stroke and not others was a result of her knowledge of my profession.

It is not possible to determine the actual influence that knowledge of my profession had on what people said or how they behaved, but it needs to be taken into consideration when interpreting the data.

10.5.2 Other Issues Surrounding Observation

In my role as observer I found it strange to be a passive observer, except in the formal situations of the therapy sessions; in those I could act in the more familiar role of student or clinical supervisor observing a student working. I felt I needed to be part of what I was observing. So in most situations I am very much a participant observer. For this reason as mentioned earlier I found it difficult, except in the more formal situations, to take notes during the participant observer situations. I felt that if I was to do so it would set me apart as researcher and make them too aware that they were being observed. I felt that it would have marked those I observed as different and may have affected the way in which they behaved. I outlined my concerns about how representative the behaviour is that I observe in my research journal.

Personal research journal extract 10.11:11/06/2001

The only other bit of fieldwork I have done recently is some participant observation with May and two of her sisters. Again before I went I was a little anxious wondering how it would pan out. I was hoping that I may be able to tape it but didn't as it didn't feel right to get out the tape recorder. During these times conversation tends to be directed at me as I am the 'guest' so I wonder what sort of representation I get of how they interact together. They certainly seemed to have quite an easy relationship with each other, particularly May and Maeve.

However there were times when I felt I did get a true reflection of what life was like.

Personal research journal extract 10.12: 16/03/2001

[Prior to this visit I had asked Anne if I could visit her one evening at home to see how she and Stephen interacted.] I went to Anne's house on Wednesday night (14th) and it didn't really go as I expected. I don't know what she had told Stephen about the visit. Anyway it mainly consisted of Anne and I chatting together in the sitting room while Stephen was in the study watching a video. From what I can gather this would be a reflection of how they would spend their evenings so nothing was put on especially for me. (...) They seem to lead quite interactionally autonomous lives yet Anne does rely on Stephen in lots of ways. Stephen did come in a few times when he heard Anne's voice raised [Anne tends to raise her voice when she is excited about something] – he seemed to be coming in as 'rescuer'. I had wanted to see how Anne and Stephen interacted at home and I didn't see this, but I do think it is a true reflection as to how they live their lives in the same house – Anne in the sitting room watching television and Stephen in the study watching a video or doing homework.

I found my role in the observation periods strange; I knew what I was there for and why, but it felt odd and very far removed from my more familiar and comfortable

therapist role. While I had observed people with aphasia in different situations as part of my working life as a therapist, it always felt as if it had more purpose and that I could do something with those observations that would ultimately benefit, or so I hoped, the life of the person with aphasia. So I felt observer as therapist and observer as researcher were different. Again the researcher role felt very much more like an intruder than the therapist role. In the therapist role, the aims and objectives of the observation would have been carefully negotiated and discussed, while in the researcher role it was less clear-cut, and it was more a case of seeing what emerged. This I found difficult to explain to participants.

10.5.3 Asking Leading Questions

While all conversations, including interviews, are co-constructed there is always the danger in interviews that the interviewer might phrase things in such a fashion that leads the interviewee to respond in a particular way. There is perhaps more of a risk of this when interviewing people with aphasia, as at times one has to 'scaffold' communication and check out and clarify meaning. The person may end up agreeing to something that is not quite what they meant, in order to expedite matters. The following is an extract where there was potential for putting words in Anne's mouth.

Interview extract 10.3: Anne – lines 185-187 [R = Rozanne]

R: What do you mean by grey? ... very down? Or very ...

A: No em I can't I had a stroke but I I can't read em a long time this one was em hhh I can't say

In the following extract it could be argued that I did determine what Anne was going to say.

Interview extract 10.4: Anne – lines 404-412 [R = Rozanne]

- R: And you used to work with him is that right?
- A: Yes I worked with him all the time
- → R: So was he a very good friend of yours or ...
 - A: Yes a very good friend er until em I this I had a stroke
- → R: And then things changed
 - A: Changed [laughs] no yes
- → R: Big time
 - A: Yes big time

Similarly in the next extract from Tony's interview, I could have presumed that something was too difficult, when in fact this may not have been the reason but it was easier (and more polite) to agree with me.

<u>Interview extract 10.5</u>: Tony – lines 693-701 [R = Rozanne]

T: Right I would get Sue and me together and go into town rather than go in meself

R: And why why would that have been?

T: Because basically getting if Sue wanted to Sue er talk to Sue and say that em say do you want coffee or tea and she say right ok coffee and tea rather than like- pr- prior to that I'd say I don't want coffee and tea just home and ..

→ R: And is that because it would have been too difficult?

T: Yea yea

It is possible that there were times when the questions I asked were leading and had I asked them in a different way I may have got a different answer. It is impossible to determine exactly the degree of influence many of my questions and comments had, but it is important to be aware of the possible effect of them when interpreting the data.

10.5.4 Therapist as Researcher

I found the switch from therapist to researcher a difficult one. I felt I was intruding on the personal lives of those I observed and that they were doing all the giving and I was doing all the taking. As mentioned earlier I wondered what they got in return for the intrusion of a researcher upon their life. It took me some time to reconcile that part of what they got out of it was the opportunity to participate in research that may help others in the future. I was so used to my role as therapist, where I feel I am giving as much as taking, that I found the role of researcher a difficult one to take on as one is so much more remote.

There was one particular interview where I discarded my researcher's hat for the more familiar hat of therapist. This was the interview with Stephen, Anne's fourteen-year-old son. While I may have started out with the intention of wearing my researcher's hat, it soon changed when Stephen became upset and I responded to him the way a therapist would by trying to reflect, hold and contain his distress. I will give the example I gave in Anne's story (interview extract 7.3) again.

Interview extract 10.6: Stephen (Anne's son) – lines 52-75 [R = Rozanne]

R: Right so when you went to visit her what was it like visiting her?

St: Sad [choked up]

R: Was it sad ok Stephen . was it very different

St: [Attempts to withhold sobbing]

R: Ok would you prefer do you want me to stop it [indicates tape recorder]

St: No [shakes head still trying to withhold sobbing]

R: Are you sure? I think it is a very sad time .. is it still very sad?

St: Not as much [choked up] no

R: Right it must have been a very big shock for you?

St: [Controlled sobs] (6secs)

R: Do you not talk about it much

St: Not really

R: Is there maybe someone you would like to talk to about it

St: No just feel uncomfortable [choked up]

R: You just feel uncomfortable ok do you want us to move on thinking about now

St: I'll talk about whatever is in discussion [choked up]

R: Are you sure Stephen?

St: Yeh

R: Cos I know that was a really difficult time for you . did you fee- you felt very very sad what wa-

St: And confused

I behaved as a therapist would, as evidenced by the way in which I reflect what he is feeling and by trying to hold things together. Concern for his well-being also guided my decision not to seek feedback from him about the interview, as I felt it would upset him further and as he was not prepared to access help, I felt it was unethical to make him revisit something that was so upsetting. I wrote in my research journal.

Personal research journal extract 10.13: 21/11/2001

I am in a real dilemma with regard to feeding back to Stephen as he was so upset during the interview. I feel it is best not to and feel that it would be unethical to do so as it may open up wounds that he is not yet ready to deal with.

Personal research journal extract 10.14: 05/12/2001

I feel that if I go back to Stephen it would be for my benefit only and would do him no good at all as it would only make him upset again. I am not happy to do that, with him unwilling to avail of back-up. Indeed I think it would be unethical to do so.

In this section I have outlined how I feel I influenced participants' responses and behaviour. I did this by discussing the possible role that the fact that I was a practising speech and language therapist had on proceedings, and by outlining the risk of asking leading questions, particularly with participants with aphasia.

10.6 SUMMARY

In this chapter I have discussed some of the issues surrounding my role in the research process including some of my expectations, disappointments and fears. It began by

describing how the study was shaped by the data and issues surrounding data generation methods. I then outlined how some of the specific data generation methods affected me and how I dealt with this, before going on to discuss data analysis methods. I then went on to present how I, in my various roles (i.e. researcher, speech and language therapist, observer), affected the research findings.

One of the key issues is that I found the role of researcher challenging as compared to my more comfortable role of therapist. However on reflection, there are many similarities between the two. Both delve into the personal lives of people with aphasia and their conversation partners; both aim to gain insight into the experience of aphasia from that person's perspective; and in both the direction of therapy or area of study is shaped by what emerges from the data. Where they differ is in what one does with the data. In research the data are used to expand knowledge, while in therapy the data are used to target therapy for a particular individual with the aim of maximising feelings of well-being. In this way what participants get out of the process is clearer cut in therapy than it is in the research process (i.e. in therapy the individual benefits directly, while in research the benefit to the individual is less obvious). It was this notion that participants were gaining little from the process that bothered me the most. It is only with passing time that I have been able to fully recognise that participants could gain something from just being involved in research and having their story heard; it is their opportunity to contribute to the expansion of knowledge through their unique experience and expertise.

While much of the research process has been a painful and overwhelming experience for me, compounded by the fact that I was in full-time employment, I have learned an enormous amount and so have gained much as a result.

The following two chapters discuss what emerged from the study in light of the prevailing public narratives, current theory and what the implications are for future practice. The first one draws together the stories of Anne, Tony and May identifying common threads and exploring the relationship of their personal narratives with the

public narratives that are so pervasive in our society. The final chapter then discusses more general issues surrounding narratives of aphasia.

CHAPTER 11 THE COLLECTIVE STORY: DRAWING THREADS TOGETHER

Chapters Seven, Eight and Nine presented the fieldwork data centred on the stories concerning the key participants, Anne, Tony and May. This chapter draws together these stories to explore what threads they have in common and in what ways they differ. In doing this it also draws on data outside of the immediate fieldwork, in the form of samples of literature available to the public about stroke and aphasia. These are from an Irish stroke association, a UK charity specifically for people with aphasia and their relatives and friends, aphasia sites on the internet and articles from newspapers (see Appendix 15 for a summary of the literature sourced). The aim was to obtain samples from which I could compare the more public face of aphasia and disability, with the more private face as generated through the ethnographic study. The literature sampled was that which was considered to be easily accessible to people who have had a stroke and their conversation partners. The internet sites sourced were accessed through a search on the word *aphasia*. However this is not an exhaustive study of public narratives. The chapter explores whether or not personal narratives of aphasia reflect public narratives.

11.1 SIMILARITIES AND DIFFERENCES BETWEEN PARTICIPANTS

The lives and circumstances of the main participants all differ significantly from each other, but are linked by the onset of aphasia. To recap, Anne is in her forties, lives with her teenage son and attends therapy. Tony, also in his forties, lives with his partner of many years and does some voluntary work in a politician's office. May, on the other hand, is in her sixties, lives with her daughter, son-in-law and granddaughter; she is a wheelchair user and attends clubs every day. Anne and Tony are more independent than May in that they are able to walk and drive and carry out the business of daily life effectively and efficiently. Due to her physical disability, May relies on others to take her about and rarely goes out except to her clubs. Although Anne and Tony are able to go out when they wish, they are involved in fewer activities than they were prior to the stroke. Tony does, however, maintain similar interests, while Anne and May do not.

Anne's focus is on her therapy and much of her life revolves around therapy appointments, she has few other interests at present other than watching television. May's focus since her stroke is on her family and her clubs.

Just as their experiences of now differ so did their experiences in the acute stage differ. Anne spent the first couple of weeks in a small hospital in which her brother reports nothing was done, before being transferred to a large teaching hospital. Tony was treated homeopathically for the first eight days before being admitted to a teaching hospital. May, on the other hand, was admitted to a large teaching hospital where she remained for a number of months. All attended rehabilitation staff during their stay in hospital.

While Anne, Tony and May have all adapted, or are in the process of adapting, to their altered lifestyle brought about by their strokes, they all have different overall themes to their story in terms of principal narrative type. Anne's principal narrative type is that of *romance*, whereby the essence of the journey is the struggle itself en route to eventual victory, in this case recovery, or as near as possible to this. Tony's principal narrative type on the other hand is that of *comedy* where the goal is the restoration of social order. He also had some elements of *satire* whereby the theme is one of cynicism on social hegemony. While May has a different combination of *comedy* and *tragedy* so in part there is return to social order but there is also the essence of being isolated from society.

Each of them uses different strategies to cope with the challenges of living with aphasia and disability. Anne copes by compartmentalising the aphasia into something separate from the rest of her self-definition; she tends to live in the present seemingly assuming that things will return to some sense of 'normality' again. She copes primarily through a *restitution* narrative. Tony, on the other hand, copes by putting a positive slant on the changes that have occurred in his life. For example, he says that he enjoys not working and that if he had had the opportunity to take voluntary redundancy prior to his stroke he would have done so. He takes things as they come and has quite a pragmatic

approach to any difficulties he might encounter. He has more of a *quest* narrative. May differs again, in that she uses more of an interpersonal coping strategy whereby she complies with what people want and 'puts on a happy face' while doing so. She uses to *put on a happy face* narrative to cope. She is of the belief that if she does not put on a happy face, no-one will talk to her. Therefore the way in which she ensures that she has social contact is by fitting in with what others want and being seen to be happy to do so.

While they share some traits, each participant is highly individual enjoying different things and coping in different ways. The individual nature of the participants' lives as presented in their stories and the above notes are illustrated in Table 11.1.

Table 11.1: Summary of main similarities and differences between participants

	Anne	Tony	May
Age	40's	40's	60's
Onset of aphasia	2 years ago	5 years ago	6 years ago
Physical disability	Mild right hand weakness	Mild right sided weakness	Wheelchair user
Aphasia	Moderate-severe	Mild-moderate	Mild-moderate
Therapy/clubs/work	Therapy twice a week	Occasional voluntary work	Clubs 5 days a week
Family role	Single parent of teenage children	Partner	Single parent of grown-up children
Home role	Homemaker	Homemaker	Daughter & son-in- law principal homemakers
Interests	Therapy and television	Politics, current affairs, environment	Clubs and television
Coping strategy	Compartmentalisation and living in the present (restitution narrative)	Seeing the positive side and taking things as they come (quest narrative)	Compliance and putting on a happy face (happy face narrative)
Principal narrative type	Romance	Comedy and satire	Comedy and tragedy

Participants also included many conversation partners of the key participants. These ranged from family members and friends to professional and care staff. Like Anne,

Tony and May, they draw on many narratives to make sense of aphasia and disability. Some of these narratives were shared with the main participants, others were not, but all contributed to the overall experience of aphasia.

The next section discusses some of the issues surrounding these narratives. Firstly, it presents an overview of all the narratives and then outlines and discusses those that were shared and those that were not.

11.2 EMERGENT NARRATIVES

To set the scene, Table 11.2 presents all the narratives that emerged from the data which have been outlined in Chapters Seven, Eight and Nine. Those narratives written in bold reflect strong narratives, while those that are written in regular font are weaker narratives. Strong narratives were those narratives which were evident or repeated throughout the data and which were characteristic of a number of participants. Therefore I interpreted some narratives as strong when participants placed emphasis on them in terms of frequency and intensity. They underpinned much of what the participants talked about and how they behaved. A narrative was classified as a weak narrative when there was only a faint trace of it in the data. Therefore weak narratives included those narratives which were referred to on only one or two occasions in the data or which were only evident with one or two participants. However these weak narratives could have stronger resonance at other times depending on the person's emotional and personal state at the time.

As is evident from the table, some narratives are shared and others not, some are weak and others stronger. Together they provide insight into the lived experience of aphasia and disability.

Table 11.2: Narratives of participants

Anne	Tony	May
Chaos	Chaos	Chaos
Loss		
Disability as less than	Disability as less than	Disability as less than
whole	whole	whole
Body as machine	Body as machine	Body as machine
Restitution Restitution		Restitution
In need of care	In need of care	In need of care
Professionals in control		Others in control
Quest	Quest	Quest
Philanthropic	Philanthropic	Philanthropic
	Importance of not being	
	idle	
	Fatalistic	
	Thankful for small mercies	Thankful for small mercies
	Disability as tragedy	Disability as tragedy
		Beholden to others
		Good patient
		Putting on a happy face

Bold font = Strong narratives

Regular font = weaker narratives

The next section takes each narrative in turn and discusses it in the light of the three key participants and the artefacts outside of the direct fieldwork (i.e. literature about stroke and aphasia available to the public). Many of these narratives interweave but are distinctive nonetheless. The section starts with those narratives that are shared amongst the key participants.

11.2.1 Chaos Narrative

A 'living' chaos narrative has a fragmented quality to it with an incessant present, no discernable future and a lack of reflection. To be true narratives, they demand a reflective grasp in order to tell them (Frank, 1995). A chaos narrative was evident across participants, particularly when they spoke about the time in the early days post-stroke. Such a response to the sudden onset of illness may be common with any emergency admission to hospital.

All the participants, except Anne's son, viewed *chaos* from a distance. Stephen was 'living' a *chaos* narrative; in his interview he presented in *chaos* as he struggled to make sense of what had happened. The interview had a fragmented and incoherent feel to it, so characteristic of a 'living' *chaos* narrative when the teller finds it difficult to put into words what they are feeling.

The interview with Stephen and the chaos he was in raises a number of issues. While he admitted it was the first time he had really talked about his mother's stroke and what it meant for him, he had in the past spoken to the speech and language therapist about issues surrounding communication on a practical level though this meeting, according to the speech and language therapist, did not address issues at a personal level. Stephen was still coming to terms with the loss of his 'normal functioning' mother. It seemed as if he was still grieving for this loss two years on. This highlights the need for counselling for young people to help them deal with such a situation. However Stephen refused to take up the offer of counselling when I suggested it to him. Therefore he remains relatively isolated in terms of having someone to talk things over with. He reported that he had not discussed, and did not want to discuss, it with his father, his siblings, his uncle or his friends. What transpired at interview, therefore, highlights the importance of giving time to young people affected by stroke in order to explore what it means to them from a personal perspective. This may result in the recognition that supports need to be put in place to facilitate their ability to deal with such a life changing event. However despite this current chaos narrative, outwardly Stephen appears to cope well with the day-to-day challenges of living with a mother who has aphasia and for whom at times he has to act as 'interpreter'. He manages to deal with things on a practical level but not on an emotional one. The reason why he presented with this chaos narrative, which told the story of a young person struggling to come to terms with having a disabled mother, may be due to his young age and the fact that he had never previously spoken to anyone on a personal level about his mother's stroke, and so found it particularly difficult to articulate. Such a situation led me to conclude that Stephen, while outwardly coping, was in fact in chaos in terms of how he was still experiencing life with a mother who has aphasia. Therefore Stephen's interview highlighted for me how isolated a young person can be in their struggle to deal with life changing circumstances. Services need to take their particular needs more fully into account.

While *chaos* was evident in the early days following stroke and in some cases, as with Stephen, a few years on, there is only a hint that *chaos* narratives exist in the literature and they suggest that *chaos* only occurs in the confusion of the early days. One of the Speakability (2001a, p.2) booklets states:

Extract from Speakability booklet 'How to help a person with aphasia in the early stages' In the early days following a stroke or brain injury all the problems are at their most severe. People are almost always confused. Often they will not understand what has happened to them or its implications.

The next narrative that was shared amongst participants was the public narrative of disability as less than whole.

11.2.2 Disability as Less Than Whole Narrative

The storyline of this narrative is that becoming disabled is a tragedy that makes you less than whole and prevents you from leading a full life. The person with the impairment is perceived as missing some essential element in order to be able to participate fully in the community (Phillips, 1990; Barton, 1993; Thomas 1999b). It is underpinned by the public narrative of *disability as tragedy*, which in turn is underpinned by the meta-narrative of modern medicine (see Figure 11.1 later in the chapter).

This is a strong narrative surrounding all three participants; indeed, with the exception of May, it is a narrative the participants with aphasia hold about themselves. As described in the preceding chapters participants talked about the person with aphasia in terms that suggested that they thought that being disabled meant being less than whole. This narrative also pervades the information on stroke and aphasia that is available to the public, for example:

Extract from Tesarta internet site (n.d.)

Barring magical intervention, there is very little a person can do to recover from aphasia. The result will usually be a loss of language and/or reading skills (for skill-based systems), charisma and possibility intelligence (for systems without skills).

Extract from Serendip internet site (Xiong, 2002)

It is crucial to say that aphasia completely changes a person as a normal functioning human being. Although his physical attributes are present, depending on the severity of the disorder his mind may be lost

In addition the narrative of disability as less than whole was suggested in the press.

Extract from newspaper article (Sweeney, 2003, p.22)

A disabled teenager is furious at his local council for erecting a stile that has stopped him from walking his dog in the public park close to his home. (...) Colm's dad Joe Jennings said the stile where it did (sic) because of restricting what little freedom his son has. "It's awful to deprive him of his little bit of social life" he said. "He likes to watch football but his real love is the dogs".

Extract from newspaper article (Baker, 2003, p.35)

Sick thugs sabotaged a disabled woman's electric wheelchair by ripping the wires out for a LAUGH. The twisted teenagers' stupid stunt left 71 year old Maureen Cooling stranded in the middle of a shopping centre.

Both quotes infer that once stripped of their means of access, people who are disabled are unable to lead a full life.

Disability as less than whole is present in both private and public domains. Thomas (1999b) is of the opinion that this is a strong public narrative and certainly evidence was found for it in the information available to the public. It was also evident in the talk of professionals and care staff. Therefore people with aphasia are surrounded by this narrative, so it is not unusual that their personal narratives are influenced by it.

11.2.3 Body as Machine Narrative

This narrative suggests that the body is like a machine that is broken up into parts, any of which may break down. The meta-narrative of modern medicine underpins this narrative, being based in objective and rational science with a focus to diagnose the breakdown and then use scientific methods to cure it (Stainton Rogers, 1991). Body as machine is a particularly Western view of illness that is rooted in Greek and Roman culture. It is not so evident in other cultures, where the body is viewed as an open system linking social relations to the self and so has more of a holistic approach, e.g. the Chinese (Kleinman, 1988), Hmong (Fadiman, 1997) and Navajo (Connors &

Donnellan, 1993) cultures. In the West this narrative enables us to understand illness in terms of something in a system that has broken down and which medicine, hopefully, can fix. It generates a dependency on medicine and therapy, which are seen as responsible for bringing about cure.

All participants indicated objectification of body parts or functions, but *body as machine* is a particularly strong narrative with Anne. She constantly refers to aspects of her abilities that have broken down. It is less strong with Tony and May. Because Tony and May have lived longer with aphasia and disability and so have incorporated it more into daily life, they may not view it so much in terms of breakdowns. With the passing of time they may have come to realise that medicine and therapy have no more to offer them and so they no longer see the breakdown as something to be fixed.

All the health care records had a very strong narrative of *body as machine*, whereby the participants were recorded as a set of medical facts and functions suggesting the value health professionals and care workers assign to this area of care. The day centre records, however, did include more personal detail than the stroke clinic records. Nonetheless the records never really considered the actual impact of aphasia and disability had on the person emotionally and in their day-to-day lives. Clearly the role of the professional and care worker is viewed from a purely medical standpoint – they are the experts pronouncing on the abilities of the 'patient', 'client' or 'member'.

The body as machine narrative is also strong in the public domain, in that the majority of the stroke and aphasia literature available to the public that I analysed had this as a very strong theme. Descriptions of stroke and aphasia were fragmented into parts of the whole that had broken down. A similar theme ran through the newspaper articles examined. Therefore there is a clear public narrative of aphasia and disability being viewed as body as machine as they are represented as breakdowns in the bodily system. It is hardly surprising that this narrative is so strong in the literature when one considers the image most commonly portrayed of medicine in the media is one which stresses its

scientific base and ability to fix breakdowns (Kristiansen, 1985, cited in Stainton Rogers 1991). For example:

Extract from newspaper article (Marsh G., 2003, p.19)

Toddler Suzanne Mawbey who had a kidney removed by pioneering keyhole surgery has made an "incredible" recovery.

However the press is no longer completely dominated by such stories, as more stories highlighting the right to equal participation are beginning to appear in the media (e.g. Kelly, A., 2003). Nonetheless *body as machine* remains a strong narrative in our society and may account for participants aligning to it.

The next narrative of *restitution* links very strongly to this narrative of *body as machine*.

11.2.4 Restitution Narrative

A restitution narrative infers that breakdowns can be fixed (cured). The basic storyline is that "yesterday I was healthy, today I'm sick, but tomorrow I will be healthy again" (Frank, 1995). It reflects the natural optimism of the human race, capitalised on by marketing and media, as well as the natural desire to get well again and have life return to normal. It is the preferred narrative of institutional medicine. This narrative is underpinned by the modernist expectation that there is a remedy or solution to all suffering. There is the expectation that the expertise of others or some external agent (e.g. medication, technology) will bring about change. It allows the self to be dissociated from the body in that "I am well, it is just my body needs fixing".

Restitution is very much in evidence with all participants, as well as in the stroke and aphasia literature. Clearly participants' expectation was that one attends therapy to be made well again and that the aim of it was to restore lost function. It is difficult to determine the influence I had on their views, as each participant was aware that I was a speech and language therapist. However even allowing for that, restitution was a very strong narrative and all participants spoke in terms of "getting better", "improving" and "progress" towards a goal of returning to pre-stroke abilities, or as near as possible to

these. Anne particularly talked about how her current state was only temporary and that she is "getting better slowly", she talked about it very much in the present. While on the other hand, Tony, May and their conversational partners' restitution talk focused more on the early years when one had to work at and "fight" to improve. The difference between the restitution focus in the present for Anne and in the past for Tony and May may be the length of time post-stroke. Anne had her stroke just two years ago, while Tony and May had their strokes five and six years ago respectively and have had a longer time to adapt to living with aphasia in the long term.

The way in which therapists worked and wrote in the health records very much reflected a *restitution* narrative. The focus was on bringing about change in the impairment with the aim of regaining past abilities. The strength of this narrative with professionals gives the impression that there is a wish to eradicate aphasia in that it is essentially something undesirable. This would link in with the meta-narrative of modern medicine with its scientific base to cure sickness and disease.

Similarly the focus of the literature, other than the newsletters, is that therapy is about working with the impairment to bring about change in language abilities. All the Speakability booklets about helping with different aspects of aphasia focus on exercises that one can do with the person with aphasia. They infer that one needs to work hard to improve.

Extract from the Speakability booklet 'Lost for words' (2001b, p.5)

With practice and support even people with severe aphasia can continue to communicate. (...) A person with aphasia has to work hard to improve communication skills and the will to succeed is essential.

The majority of internet sites accessed talked in terms of recovery.

Extract from the NIDCD internet site (n.d.)

In some instances an individual will completely recover from aphasia without treatment. (...) For most cases of aphasia, however, language recovery is not as quick or as complete. (...) In these cases speech-language therapy is often helpful. (...) Aphasia therapy strives to improve an individual's ability to communicate by helping the person to use remaining abilities, to restore language abilities as much as possible, to compensate for language problems, and to learn other methods of communication.

Extract from the Tavistock Trust for Aphasia internet site (n.d.)

With the help of intensive speech therapy he slowly began to recover, although even now he experiences difficulty accessing the words he needs or wants to use.

The Aphasia Hope Foundation internet site emphasises the importance of therapy as one of the "ten commandments for stroke survivors":

Extract from Aphasia Hope Foundation internet site (Day, 2002)

Thou shall put all thine heart into thine therapy and honor thy therapist.

Similarly newspaper articles tended to focus on people getting better or requiring services in order to get better, for example:

Extract from newspaper article (Kelly O., 2003, p.3)

Three years after his accident and well on the road to recovery, Mr. John Costello was placed in the Learning Disabilities Unit of Peamount Hospital because there was no longer room at the National Rehabilitation Hospital, and his family home was not yet equipped to meet his needs. "Peamount was just the wrong place for John", Ms. Annette Costello said. "People are looked after, but it's not for rehabilitation. I had to fight to get physio for John". After 16 months in Peamount Hospital, Ms. Costello brought her son home. "I had to take him out. He was going downhill. With brain injury, if you sit back and do nothing the brain won't develop. You have to constantly work the brain, and it will start to heal itself."

The focus of the newsletters, on the other hand, was on outings, activities, personal experience, and reports back from group meetings. They did not address issues surrounding the treatment of the impairment.

A very strong *restitution* narrative is evident with all participants, as well as in the information available to the public. It is the preferred narrative of the early years post-stroke and demonstrates the pervasiveness of the meta-narrative of modern medicine in our society. Such a medical rendering of disability, which believes that the impairment is the cause of whatever is wrong in the disabled person's life, leads to the powerful force behind the aim of therapy being to repair the impairment.

11.2.5 Disability as Tragedy Narrative

This narrative implies that being disabled is a personal tragedy (Hevey, 1993; Oliver, 1993b). The strength of this narrative in our society is reflected in the ways that disability is portrayed in the media, usually in the form of 'pathetic victims' of circumstance. However this is beginning to change with disabled people taking more

control and fulfilling more of an active role on television and film. They are no longer just being portrayed as helpless tragic victims and a more positive face of disability is beginning to emerge.

While this is a strong narrative in the public domain there is not a great deal of evidence for it in participants' talk. Only some of May's conversational partners and only one of Tony's spoke in these terms. It is not evident with Anne or her conversational partners. While there was not much explicit evidence of *disability as tragedy* in participants' narratives, it could be inferred in some of the pictures participants chose to reflect the time of stroke. For example:

Picture 11.1: Peter (Anne's brother)



"I suppose that would be quite a good one for when the stroke happened"

Picture 11.2: Suzanne (Anne's speech & language therapist)



"Shock and shattered"

Picture 11.3: Linda (Anne's occupational therapist) & Bríd (day centre manager for May)



"Shattered"

Picture 11.4: Ciara (Tony's sister)



"It's sort of depressing and very em the guy there seems to be sort of bound you know unable to do anything for himself very dependent on people"

Picture 11.5: Eleanor (stroke club organiser - May)



"Dark you know dark"

There is some evidence of a *disability as tragedy* narrative in some of the stroke literature. There was a tendency to refer to the stroke as being "devastating", inferring that a tragedy had led to the laying waste of abilities. For example:

Extract from the 'Friends of Speakability Application' form

Aphasia is a *devastating* communication disorder in which the person's ability to use and understand words is *damaged*. [My emphasis]

Extract from Irish Heart Foundation report on Stroke Care (2000, p.1)

This report arose from the realisation of the many groups (patient-advocacy and professional) on the IHF Council on Stroke that strategies for prevention and treatment for this *devastating* disease are randomly organised, incomplete and under-funded. (...) Focussed prevention and treatment strategies for stroke can reduce the *burden* of death and disability associated with stroke. [My emphasis]

While the narratives of body as machine and restitution dominated the internet sites visited, there was some evidence of aphasia as tragedy.

Extract from the Stroke Support internet site (n.d.)

Aphasia can have a devastating effect, isolating the sufferer from the very people who want to help.

Extract from Serendip internet site (Xiong, 2002)

Aphasia attacks an intricate part of a person's daily life – the simple act of communication and sharing. The disbursement of such a tool deprives an individual of education learned through their life, often leaving the ill fated feeling hopeless and alone.

In addition to the above, the term stroke "survivor" is mentioned a great deal in the literature. This infers that you are a 'survivor' of tragedy.

Extract from Irish Heart Foundation report on Stroke Care (2000, p.2)

The social impact is well captured by one stroke survivor who ...

Extract from Aphasia Hope Foundation internet site (Stradinger, 2001)

Tips from a spouse of an aphasia survivor.

Similarly the term "stroke victim" is used, implying that one is a victim of tragedy which has an aggressive force. For example:

Extract from VSS News (2001, p.4)

The Bray and North Wicklow Stroke Club was started in March 2000 by Michael Whelan who is a stroke victim himself.

Extract from VSS News (Byrne, 2001, p.13)

My name is Jim Byrne, and I suffered a stroke in October 1998 and this will be my account of how I have found it being a stroke victim and the difficulties I have found to date.

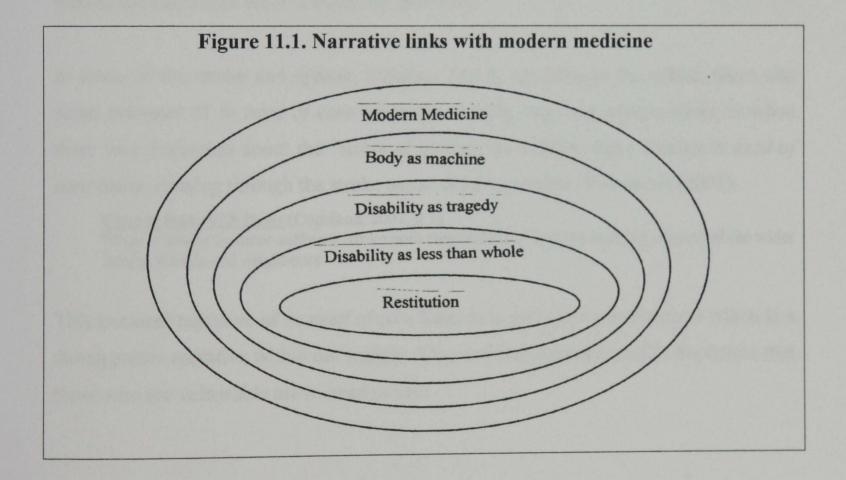
Extract from Stroke Recovery Association of Ontario internet site (n.d.)

For a stroke victim, at a time when he or she is already disoriented and afraid, the loss or impairment of language is a cruel blow.

There seems to be some dissonance between what emerged from the literature and what participants expressed. There were only threads of *disability as tragedy* with participants, yet this narrative permeated much of the literature. This perhaps suggests a strong public view that having a stroke or becoming disabled is a tragedy. However on a personal level it is viewed as less so. This may be because the passing of time takes away from the feeling of tragedy, as reality steps in. The theme of tragedy therefore may be more evident in the early days post-stroke.

The narratives of body as machine, disability as tragedy, disability as less than whole and restitution are all strong narratives in the public domain. With the exception of disability as tragedy, all are also dominant narratives with the individual participants and their conversational partners suggesting perhaps that individuals are influenced by narratives portrayed in the literature available to the public. However equally individuals' narratives affect what is reported, as is evidenced by the personal stories depicted in the media. In addition two internet sites visited provide personalised stories of the experience of living with aphasia (aphasiahelp.org; ukconnect.org). In them people with aphasia have the opportunity, in their own words, to express what it is like to live with aphasia. So the relationship of public and personal narratives is cyclic in nature, each influencing the other.

All these narratives link together and are underpinned by the meta-narrative of biomedicine. For example the body is treated as a machine that breaks down which is tragic; when this occurs it is less than whole and therefore one needs to fix it to make it whole again. The links are represented diagrammatically in Figure 11.1.



11.2.6 In Need Of Care Narrative

This narrative infers that the person with the impairment is in need of care. The storyline is that people who are disabled are in need of care, you provide that care and the person will not do themselves further injury. It suggests that care is needed before cure. It links with the narrative of disability as less than whole whereby because the person is not whole they need to be cared for.

The narrative of *in need of care* only really permeated the discourse when participants talked about the person with aphasia in the early days post-stroke when they were physically more vulnerable. What is interesting to note is that none of the participants with aphasia spoke in terms of being in need of care. Only their conversation partners did. Other than the way in which Anne's brother, Peter, talked about Anne, this narrative was much less in evidence when participants spoke about the person with aphasia now. Again the difference in time post-stroke may be a factor. However *in need of care* was a very strong narrative with Anne's brother, Peter, to the extent that he thought Anne should have bought a bungalow "because of her condition", even though she can climb stairs without any difficulty.

In terms of the stroke and aphasia literature that is available to the public, there was some evidence of *in need of care* when the nursing role was written about or when there was discussion about the "stress of caring". In addition there was an *in need of care* theme running through the stroke association newsletter, VSS News (2001).

Extract from VSS News (Copeland, 2001, p.1)
When a family member suffers a stroke both they and their families need the support of the wider family, friends and neighbours.

This personal narrative of *in need of care* links to a *philanthropic* narrative which is a strong public narrative within our society. They are both underpinned by the notion that those who are vulnerable are in need of care.

11.2.7 Philanthropic Narrative

This narrative implies that one should be good and kind to those less fortunate than oneself. This is a dominant narrative in western society as can be evidenced by the many charities that are in operation.

There is evidence of a *philanthropic* narrative with all three key participants although it is strongest with May. May herself constantly referred to how people are "very good" to her; it was as if she did not feel entitled to time, and when people gave her time she tended to thank them and say how "good" they were. In addition others in her family reported how "good" people were to May. Similarly Peter, Anne's brother, remarked how "there's nobody who's been abusive towards [Anne]" and that on the whole "people have been very good".

As mentioned in 7.2.8, a philanthropic narrative may be particularly linked to the dominance of Christian teaching in our society which focuses on what is meant by being a good person and that one needs to be good and kind to those less fortunate than oneself (Inglis, 1998). Although Marx rejected the church, this notion of caring for those 'less fortunate' is also a feature of his philosophy.

The religious influence is evident in the "Ten commandments for the Family, Friends, and Caregivers of Stroke Survivors" (Day, 2002). Two of the 'commandments' have a distinctly philanthropic feel to them. They are:

Extract from Aphasia Hope Foundation Internet site (Day, 2002)

Thou shall smile at thine Stroke Survivor when they are in their tantrum.

Thou shall love thy Stroke Survivor with all thine heart, even when they are crotchety.

The lead article of the stroke association's newsletter, VSS News, is entitled "Volunteers Giving and Receiving" and has strong *philanthropic* threads running through it. While it is acknowledged that volunteers receive much from members, the thrust of the article is on the volunteer as giver and active agent, while the person with the stroke is depicted as the passive recipient of care. To take an extract:

Extract from VSS News (Copeland, 2001, p.1)

We rely on our volunteers to drive our stroke club members to and from our stroke clubs every week. We also rely on them to provide all the activities in the club. (...) The frequent outings and annual holidays could not happen but for the support of our volunteers.

The Speakability Newsletter does not have the same *philanthropic* undertone to it, rather it is more focused on how people have overcome the effects of stroke.

There are many disability charities in our society, usually depicting the person with the disability as in need of care and support. A *philanthropic* narrative generally suggests that well-meaning others, usually non-disabled people, are in control of disabled people's physical and social environment and quality of life. There was evidence of *others in control* in both Anne and May's stories.

11.2.8 Others/Professionals in Control Narrative

As just stated, this narrative was evident in both Anne and May's stories, but not in Tony's. In this narrative there is an underlying theme of others taking control in certain aspects of the life of the person with aphasia. The basic storyline is that because of disability the person is unable to take control of some or all aspects of their life and that expert others are needed to take control and restore order. Mattingly (1998) notes that even when people with disabilities are in a rehabilitation context and participating in ordinary conversation with the therapist, the therapist rarely relinquishes control of the interchange.

With Anne it is the professionals that take control of the course and direction of therapy. While with May it is members of her family and care staff who try to take control of different elements of her life (e.g. making her get out of bed to exercise, getting her to sign something without telling her what it is). Both Anne and May were very much in control of their lives prior to the stroke, so this situation constitutes a change. There is no evidence on the other hand of others taking control of aspects of Tony's life rather he seems to go about his business with very little interference.

It is difficult to postulate as to why others have taken control in Anne and May's life, but not in Tony's. With Anne the only people who take control are the therapists and Tony is not attending for therapy. Traditionally in our health care system underpinned by the meta-narrative of modern medicine, professionals take the lead in the direction and course of 'intervention'. They are viewed as expert in charge of diminishing or eradicating the impairment, which traditionally within a medical rendering of disability is viewed as the cause of disability. It is interesting to note that Tony's friend Sarah, a health professional, talks in terms of taking control. For example:

Interview extract 11.1: Sarah (Tony's friend) - lines 441-445

S: I mean if I had been their therapist boy oh boy would I have pushed them much harder but when you're a friend it's a different thing altogether

This provides an example of the personal rendering of a public narrative.

Anne and Tony are physically independent, while May is a wheelchair user, and it is difficult to determine whether or not this is a defining quality that leads others to take control of her life.

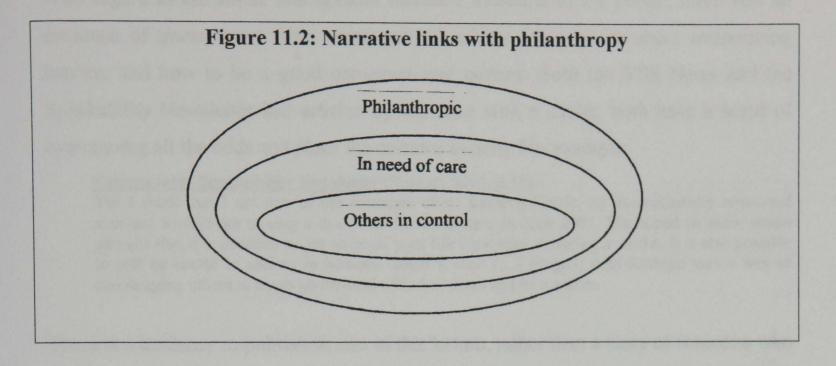
There are threads of *professionals in control* running through the stroke literature, particularly those that relate to 'stroke care'. They outline the role of each profession and what they do in the 'rehabilitation' process. There is an inference that the person with the stroke is guided by the experts in order to 'rehabilitate' themselves. This is exemplified by Clear (2002) who had a stroke, when she says:

Extract from newspaper article (Clear, 2002, p.56)

My speech therapist would ask me questions and encourage me to use my brain. The daily sessions with her were very tiring; it's not easy learning to speak all over again. I was also made to read out loud and play simple games.

Traditionally this is the role that professionals take when working with people with disabilities. However this is beginning to change with people with aphasia beginning to guide the direction of therapy (e.g. Barrow, 2000; Pound *et al*, 2000).

The narratives of *in need of care* and *others in control* are underpinned by a *philanthropic* narrative. Figure 11.2 provides a diagrammatic representation of the links between these narratives.



The next narrative to be discussed is *quest* which is about taking control of one's life again and incorporating aphasia and disability into it.

11.2.9 Quest Narrative

A quest narrative is when illness and disability are integrated into daily life. Suffering is met head on, illness or disability is accepted and there is a belief that something is to be gained through the experience; losses are to be mourned but the emphasis is on what has been gained (Frank, 1995). It speaks from the disabled or ill person's perspective.

All participants have evidence of *quest*, but there is stronger evidence for Tony and May. This may be because Anne's stroke is more recent and there has not yet been a chance for aphasia to be incorporated into daily life and the fact that she is still very bound up in a *restitution* narrative. Tony's is the strongest *quest* narrative and comes in the form of a 'memoir' (Frank, 1995) whereby trials are not minimised, but are told in a resigned way and without flourish. No special insight is claimed other than the insight gained with the incorporation of aphasia into his life. Tony relates how aphasia affected

and affects his life in a very practical way. He reports that he is quite content with his lifestyle as it is, indicating how aphasia has been integrated into his way of life.

With regard to the stroke and aphasia literature available to the public, there was no evidence of *quest*, apart from some general advice being given about overcoming barriers and how to be a good conversational partner. Both the VSS News and the Speakability Newsletter had articles by someone with a stroke, both have a sense of overcoming all the odds and place the narrator as hero. For example:

Extract from Speakability Newsletter (Stewart, 2001, p.10)

Yet I think that I am one of the fortunate ones! Kathryn Harris, an internationally renowned soprano, invited me to sing a duet with her in Bolton, in June 2001. We hoped to show stroke patients that it is possible to get some of your life back after suffering a stroke. It is also possible to still be useful in society in however small a way. (...) Singing with Kathryn was a way of encouraging others to try to go forward with their lives and be positive.

There is a tendency to publish stories of this nature, rather than a story of someone who has incorporated aphasia into their life without flourish as is the case with Tony. The only exception is one or two of the internet sites present stories of living with aphasia which does not necessarily cast the teller as hero (e.g. aphasiahelp.org).

11.2.10 Thankful For Small Mercies Narrative

This narrative has a theme that one should be thankful that things are not worse. It links with *disability as tragedy* in that one is thankful that one's situation is not more tragic.

This narrative was not evident in Anne's story, except for one comment made by her brother Peter, but there were faint threads of it running through both Tony and May's stories. With Tony it is only really evident in his partner Sue's discourse, while with May it is evident with a number of participants who related how lucky she was and that it could have been worse. There is little evidence of this narrative in the stroke and aphasia literature. However there was a thread of being *thankful for small mercies* running through one of the internet sites visited.

Extract from Stroke Support internet site (Marsh P., n.d.)

Sitting in their living room, surrounded by pictures of their children and grandchildren, this inspiring couple continue to count their blessings. As Jayne puts it: "We have so much to be grateful for – first the surgeons and therapists, and now the computer as well".

This narrative while evident in the private face of aphasia, it was not so within the public rendering of aphasia except when telling a personal story.

11.2.11 Loss Narrative

The underpinning theme of this narrative is the loss of previous abilities and lifestyle that accompanies illness and disability. For many people aphasia brings with it loss (e.g. Brumfitt, 1993; Herrmann, Johannsen-Horbach & Wallesch, 1993; Ireland, 1995).

While all participants experienced loss, the *loss* narrative is only really evident in Anne's story, in that participants and Anne herself spoke a great deal in terms of what abilities she had lost. It is much less in evidence in Tony and May's stories. The reason for this may be that Anne's stroke occurred more recently and so her past abilities are fresher in people's minds and feelings of loss may diminish with time.

This narrative was evident in the literature, particularly that literature which pertained to giving information about stroke. It frequently referred to the loss of certain abilities as a result of stroke. For example:

Extract from the stroke association's guide to stroke (Irish Heart Foundation, 1994, p.5) Loss of sensation on one side of the body: This can be more than just loss of feeling in the skin. It can mean that the patient, without looking, will not know where an arm or leg is positioned. In the most severe cases, this loss of sensation can result in complete neglect of one side of the body.

The way in which loss is written about here links with the narrative of *body as machine* in terms of fragmenting the body into working parts that have gone wrong. Similarly all the internet sites accessed describe aphasia as the loss of, or difficulty with, understanding and expressing language.

11.2.12 Importance Of Not Being Idle Narrative

This narrative reflects the public's expectation that one should be a participating member of society and not be idle. It is only evident in Tony's story, whereby two participants were concerned that there was not enough structure to his day and both felt that he should be in some form of work. It is not evident in either Anne or May's stories. Perhaps Anne is seen as being busy with her therapy and May with her clubs.

Conversely it may be that as Tony is a man in the prime of life (being only in his forties), he should be working and keeping occupied as that is what is expected and valued in our society.

There was no overt evidence of this narrative in the public literature reviewed pertaining to stroke and aphasia.

11.2.13 Fatalistic Narrative

This narrative implies that one accepts life's blows; there is a sense that there is no control over one's destiny. It is underpinned by a spiritual narrative that is particularly dominant in Irish culture (Inglis, 1998) whereby there is an implication that our destiny is tied up with God's will and that one must accept this and make the most of life. Parr's (1994) study of coping with aphasia found that just under half of her sample of people with aphasia and their partners employed fatalism as a coping strategy. Tony is the only participant who portrayed a *fatalistic* narrative. This may link to the fact that he was brought up within a religious family whereby it was believed that God's will guided one's destiny.

This narrative was not evident in the literature available to the public on stroke and aphasia which was accessed as part of this study. However the term stroke itself has a fatalistic flavour to it.

11.2.14 Putting On A Happy Face Narrative

This narrative implies that one must present a cheerful and happy face to the world, otherwise one risks rejection. May reports the importance to keep laughing:

Interview extract 11.2: May - lines 1780-1784

M: Just get up and get going keep going you know because if you cry you're left there (...) when if you laugh they went hello hello you know that's why I don't cry you know if I cry I be on my own you know

This narrative is a coping narrative for May. She copes with her disability and fear of isolation by complying and *putting on a happy face*. In this way she ensures that others will pay her attention. This narrative is not a feature of either Anne or Tony's stories.

There was some of evidence of this narrative in the literature. One was in the form of one of the 'ten commandments for the stroke survivor'.

Extract from Aphasia Hope Foundation internet site (Day, 2002)

Thou shalt smile all thine day, whether thou feel like it or not.

This is reinforced by the happy faces portrayed in the VSS News and the Speakability Newsletter.

This narrative links into the next two narratives: beholden to others and good patient narratives.

11.2.15 Beholden To Others Narrative

This narrative suggests that if you have a disability, others will help you and therefore you are in their debt. It is only evident in May's story, whereby she was constantly thankful for anything that was done for her and this was viewed positively by her conversation partners. This narrative may be linked with her to *put on a happy face* narrative which emphasises the putting on of a happy face otherwise people will not talk to you and one is thankful that people give you that attention.

There was some evidence of this narrative in the stroke literature in one of the articles written by someone who had a stroke.

Extract from VSS News (Byrne, 2001, p.13)

I am also lucky that I have a wonderful wife who helps and supports me every day. Without her loving support life for me would have been very different and for that I'm eternally grateful.

However such a comment also conveys the natural supporting and enabling role that people take for each other.

Traditionally people with disabilities are seen to be dependent on others and a key focus of rehabilitation is towards 'functional independence'. With this dependency comes the necessity of being beholden to others and others expect to be thanked for their help. It is an asymmetrical relationship with one side being viewed as the giver

and the other as the receiver. It does not take into account the many things that disabled people give to others.

This narrative links with the next one, *good patient*, in that a 'good patient' is seen also as a thankful 'patient'.

11.2.16 Good Patient Narrative

This narrative suggests someone who is compliant and does what the health professionals want of them, and in a good humoured way, while at the same time being thankful for the care that they are receiving. It is only evident in May's story and not in the other two. May will always go along with anything that others want her to do and will do so in a cheerful way. This again links in with her *put on a happy face* narrative, as she feels she has to present a cheerful compliant face to social care staff as well as others.

There was some evidence of this narrative in the literature in the form of one of the 'ten commandments for the stroke survivor'.

Extract from Aphasia Hope Foundation internet site (Day, 2002)
Thou shall put all thine heart into thine therapy and honor thy therapist

Being a good patient entails being compliant and not creating a fuss about anything. It ensures that you get positive attention. If on the other hand you are seen as a troublesome 'patient' attention may not be so favourable. With her *happy face* and compliant nature May fits in with the former category.

The good patient narrative links with professionals in control. There is an asymmetrical relationship whereby the 'patient' is expected to comply with the expert professional or care staff, but professionals or care staff are not expected to comply with what the patient wants except for requests for help.

This section has summarised and discussed the narratives that emerged from the fieldwork data in the context of narratives that emerged from the publicly available

information on disability and illness. The following section identifies the guiding narratives for each participant and how these are influenced by public narratives.

11.3 GUIDING NARRATIVES

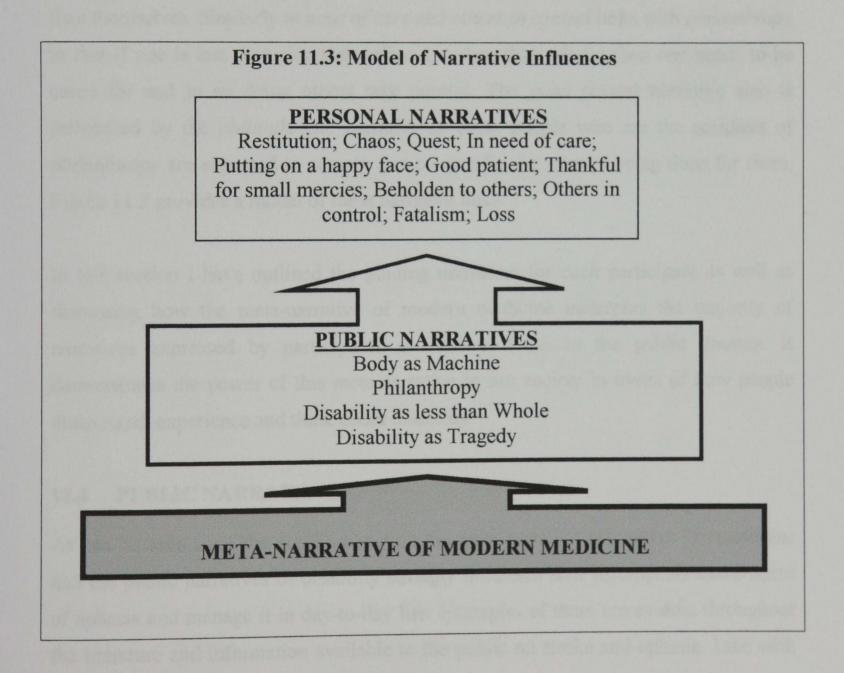
While each participant is surrounded by an intricate tapestry of narratives which affect the lived experience of aphasia, each participant has a different guiding narrative (i.e. those narratives that seem to guide how the person lives their life overall) although the others remain background voices. For Anne *restitution* is the guiding force as she focuses on "getting better" and does all in her power to do so. On the other hand Tony's guiding narrative is that of *quest*, where his aphasia is incorporated into his social and life world to the extent that he is reported to be even happier now than he was before his stroke. May's guiding narrative is that of *putting on a happy face* as this is how she copes on a day to day basis with her aphasia and physical disability. According to Frank (1995) restitution is the generally preferred narrative as it is natural that people want to get well again. However when this is not possible other stories need to be created and lived; both Tony and May effectively do this.

In general the guiding narratives of the other participants are in agreement with the key participants although there are some exceptions. For example Peter, Anne's brother, has a strong narrative of *in need of care* while Anne's guiding narrative is *restitution*. Anne sees herself as being an active agent in the process of regaining language abilities while Peter views her as a passive recipient of care. However this does not cause friction between the two, as generally Peter fits in with what Anne wants him to do. If on the other hand, such a clash of narratives interfered with their relationship, then this may suggest a focus of therapy (i.e. to bring narratives back into harmony).

In summary, the narratives unmasked show convergent and divergent themes. Some narratives were shared, others were not. The most dominant narratives across participants were those that related to the narratives portrayed in the public literature. However different participants had different things in common reflecting the individuality of each person's story. Some of the narratives are strong while others are

more subtle; some reflect public narratives while others are more personal, but all interweave to form a complex narrative tapestry.

Figure 11.3 illustrates how the majority of narratives that people draw on to make sense of aphasia and disability stem from the meta-narrative of modern medicine. What is interesting to note is the fact that Tony elected to be treated homeopathically initially. This would suggest that he would draw on narratives of health and illness that were not aligned to the meta-narrative of modern medicine. Yet this is not the case, what emerged from the data was that the narratives he drew on to make sense of aphasia and stroke were, like with Anne and May, underpinned by this meta-narrative. The only narrative that is not influenced by this is the *importance of not being idle*. This narrative links more with the work ethic of our society and the public expectation that one should be a contributing member of society.



The meta-narrative of modern medicine gives rise to the public narratives of body as machine, disability as less than whole, disability as tragedy and philanthropy. All of these are evident in the narrative tapestries of participants. These in turn influence many of the personal narratives that participants draw on. For example to put on a happy face is one way of dealing with the belief that disability is less than whole and disability as tragedy. Similarly the quest and fatalistic narratives are other ways of managing a body that has broken down, while chaos is the immediate response to breakdown. Restitution stems directly from body as machine and disability as less than whole whereby the body has broken down and one's quest is to restore it to being whole again. Thankful for small mercies also stems from body as machine, in that one is thankful that the bodily breakdown was not more severe. Being beholden to others on the other hand, is influenced by the public narrative of philanthropy where the person with the impairment is beholden to people who are good to those less fortunate than themselves. Similarly in need of care and others in control links with philanthropy in that if one is less fortunate than others (i.e. less than whole) then one needs to be cared for and in so doing others take control. The good patient narrative also is influenced by the philanthropic narrative as those people who are the recipient of philanthropy are expected to comply and be grateful for what is being done for them. Figure 11.3 provides a model of these narrative links.

In this section I have outlined the guiding narratives for each participant as well as discussing how the meta-narrative of modern medicine underpins the majority of narratives expressed by participants as well as those in the public domain. It demonstrates the power of this meta-narrative in our society in terms of how people understand, experience and think about disability.

11.4 PUBLIC NARRATIVES

As can be seen from the previous section the meta-narrative of modern bio-medicine and the public narratives of disability strongly influence how participants make sense of aphasia and manage it in day-to-day life. Examples of them are evident throughout the literature and information available to the public on stroke and aphasia. Like with

metaphor, narrative provides a medium within which people can make sense of a situation by attaching what they are experiencing to something that is already known, and in this way they demystify aphasia and disability. The following is a summary of what emerged from the publicly available information in terms of public narratives.

As stated at the beginning of the chapter, a sample of the literature that is available to the public giving information about stroke and aphasia was gathered, as well as a selection of articles on disability that appeared in the press. Information from a stroke association, an aphasia association and a number of aphasia internet sites were sourced; these are detailed in Appendix 15. Surface analysis revealed very strong themes of body as machine and restitution running through them. Such a focus is underpinned by the meta-narrative of modern medicine. This is exemplified in the following extract.

Extract from Stroke Information internet site (n.d.)

Global aphasia is an acquired language disorder involving severe impairments in both comprehension and production. It is caused by injuries to language-processing areas of the brain, notably Wernicke's and Broca's areas. The symptoms of global aphasia reflect processing difficulties in Wernicke's and Broca's areas. These areas would ordinarily assign words and meanings, string words together, and complete other word-based tasks. Thus, the symptoms of global aphasia are impairments in all aspects of word-based communication – reading, writing, speaking and understanding speech. [Emphasis in the original]

In this extract global aphasia is fragmented into parts of a system that has broken down, thus revealing the *body as machine* narrative.

In terms of models of disability, the public literature is entrenched in the individual or bio-medical model of disability. An impairment is viewed as the breaking down of a particular bodily function, the locus of the problem rests with the individual with the impairment, and it is their responsibility to do something about it. The following extract illustrates how it is important to work at improving the impairment.

Extract from Stroke Support internet site (Marsh P., n.d.)

"I remember the first time he heard the computer applaud his efforts he lit up like a Christmas tree. Now he can easily spend an hour working on his own" – Jayne Quigley.

The social model of disability on the other hand locates the problem as being externally imposed social barriers that prevent the person with the impairment from participating as fully as they would wish in the life of the community. Out of the

internet sites sourced only three were designed in an aphasia-friendly format (aphasiahelp.org; ukconnect.org; Queensland University Aphasia Groups). Similarly only one of the leaflets on aphasia and stroke was written in such a way as to make it accessible to people with aphasia (Speakability, 2000). However there are in addition two resource manuals (Kagan *et al*, 1996; Parr *et al*, 1999) which are presented in an aphasia-friendly format.

While the majority of the literature available to the public that was accessed was dominated by narratives underpinned by modern bio-medicine (e.g. body as machine, restitution) there were some examples of more of a social model philosophy. In one, barriers to living at home are overcome by the use of technology and in the other there is the coming together of a group of women with the aim of increasing participation.

Extract from newspaper article (Sunday Independent, 2002)

A pilot project using assistive technology to help older people with disabilities to live independently at home has been launched in the Northern Area Health Board (NAHB) region. (...) Following some high-tech adaptations to his house, Lawlor has been able to return home.

Extract from newspaper article (Kelly A., 2003, p.24)

The women, who come from all corners of Ireland, have been chosen to form the core group for the first National Network for women with disabilities. This network will seek to increase participation in public decision-making in areas of education, training and employment.

Even given these examples, the meta-narrative of modern medicine which underpins the individual model of disability, is the narrative that the general public is most exposed to and may account for these strong themes coming through in the personal narratives of individual participants. For example, in general participants revealed strong restitution and disability as less than whole narratives, both of which link in with the individual model of disability. However body as machine was less in evidence with participants, except for Anne whose stroke is of more recent onset. It did on the other hand permeate the health records. There is some dissonance here, whereby the public face reveals a strong body as machine narrative yet the private face, particularly after a number of years post stroke, does not. This may be because after a number of years a quest or other narrative becomes the guiding narrative as aphasia becomes incorporated into the person's life world; it is no longer seen as the breaking down of a system. This certainly seems the case where quest is stronger with both Tony and May,

while restitution remains the guiding narrative with Anne whose aphasia is of more recent onset.

There is further evidence in the literature sourced of a social model of disability where the locus of the problem is viewed as societal barriers to full participation, whereby others have to change their behaviour to facilitate the person with the impairment. A number of internet sites give examples of how conversation partners can alter the way in which they communicate in order to facilitate communication when talking with someone with aphasia. For example the main focus of the 'Aphasia Hope Foundation' "Talking with individuals with aphasia: maximising communication effectiveness" is on overcoming barriers to conversation. A similar theme is evident in some of the booklets about aphasia and stroke, though it would not be the main focus. For example:

Extract from Speakability booklet "Lost for words" (Speakability, 2001b, p.6)

When you are talking to a person with aphasia

- Talk normally but slightly slower than usual. Do not patronise the person or talk as if he or she is a child.
- Use clear, short sentences and avoid difficult words.
- Give only one piece of information at a time and allow the person plenty of time to absorb what you have said.
- Find a quiet place to talk. Turn off the television and radio.
- Don't shout.
- Use familiar names and phrases.
- Use gesture and facial expression to help get your message across.
- Ask questions with a "Yes" or "No" answer. For example, "Do you want a cup of tea?" rather than "What would you like to drink?".
- Do not talk about the person as if he [sic] is not there.

While this illustrates the advice given, there is no sense of partnership in the conversational endeavour.

In general the main thrust of the literature overall was on *restitution* and *body as machine*, rather than on overcoming barriers to communication. This is reflected in the language used whereby the person with aphasia is objectified and frequently referred to as "an aphasic".

Extract from National Aphasia Association internet site (n.d.)
There is a need for public education – the aphasic is the same person as before and should be treated as such. [My emphasis]

Extract from Tavistock Trust for Aphasia internet site (n.d.)

Virtually no help is available for aphasics and minimal speech and language therapy is offered. [My emphasis]

Rarely is the actual illness experience recorded except for some examples in the stroke association newsletter, VSS News, and the Speakability Newsletter, where people who have had a stroke relate their experience. These articles are written in terms of overcoming the odds. Two of the internet sites visited (aphasiahelp.org; ukconnect.org) had stories of people who have aphasia, written in their own words of the experience of living with aphasia. These were written with a matter-of-fact style generally outlining how aphasia has become incorporated into life. They did not have the theme of hero overcoming the odds, as did the newsletter articles.

Both the Aphasiahelp (aphasiahelp.org) and the Connect (ukconnect.org) internet sites differed from other aphasia internet sites visited in the way in which people with aphasia told their story in their own words albeit many achieving this through the techniques of supported conversation. The Aphasiahelp internet site is unique in that it is specifically designed for people with aphasia. It gives extensive information about stroke and aphasia in a format that is accessible for those who experience difficulties in language processing. It provides practical information about the challenges of actually living with aphasia as well as providing a medium, through their 'pen pal' scheme, by which people with aphasia can contact others. While the Connect internet site is not specifically designed for people with aphasia their web pages on aphasia are aphasia-friendly in the way that they are written and designed. Like the Aphasiahelp site, the Connect site provides the opportunity for visitors to meet other people with aphasia. Out of all the aphasia sites visited this 'pen pal' initiative is unique to these two internet sites. Only one other site (Queensland University Aphasia Groups) visited made any attempt to design their pages in such a way as to be accessible to people with aphasia.

The majority of newspaper articles accessed were generally about people who were experiencing some specific difficulty that affected their ability to lead a fulfilling life. One or two of the articles did outline the person's illness experience, but again these

generally emphasised the bio-medical aspects of stroke rather than societal disabling barriers or the emotional impact.

Extract newspaper article (O'Kelly, 2003)

Time passed slowly. Three weeks into my recovery I wheeled to the gym for physiotherapy. Although you may think early intensive therapy is essential after a stroke, I was assigned just one session a week initially. It wasn't until a close friend got angry enough to demand more attention that my allocation was bumped up to four times a week.

The strong body as machine and restitution narratives are also reflected in what is advertised as ongoing research into aphasia. For example the National Aphasia Association (NAA) Newsletter gives a 'research update'. In this the focus is very much on restoration of language abilities and very little to do with the challenge of living with aphasia in the long term. For example;

Extract from NAA Newsletter (Lundgren & Albert, 2002)

Two other studies used a different neurotransmitter, bromocriptine (a dopaminergic agent) to improve verbal output in chronic nonfluent aphasic subjects. (...) In the field of biotechnology, repetitive transcranial magnetic stimulation has been used on a small group of patients with nonfluent aphasia to improve naming skills.

With regard to the health records it is interesting to note that no mention of the experience of illness and disability is mentioned in them, yet Suzanne, Anne's speech and language therapist, stated that she addressed some issues of living with aphasia with Anne. The focus of the records of the participants in general was on describing the person in terms of their functional abilities and in particular their disabilities. Gillman, Swain and Heyman (1997) state that health records marginalise the voice of the person which is drowned out by expert talk and opinion. Goode (1984) also highlights how clinical records rarely describe the person in terms of their competence and human value.

Overall the public literature accessed and the health records record only bodily facts and what one can do to overcome them; it is as if there is no language in the biomedical discourse to write about the actual illness experience (Mattingly, 1998). Narratives in the public domain are heavily influenced by the meta-narrative of modern medicine. There are, however, some exceptions where the experience of aphasia is written about in personal terms.

11.5 SUMMARY

This chapter has drawn together the stories of Anne, Tony and May and discussed them in relation to the public face of aphasia and disability. Each participant is highly individual, each making use of different resources in order to cope and make sense of aphasia and disability. Participants draw on a wide array of narratives - some shared others not - but all interweave to form a complex narrative tapestry. Many of those narratives drawn on are directly linked to the prevailing narratives of the publicly available literature on stroke and aphasia as well as media reports. The most prevalent public narratives are body as machine, restitution and disability as less than whole. Even those narratives with no obvious links can be traced back to many of the public narratives. For example to put on a happy face can be traced back to what constitutes a good patient in the world of modern medicine and the western narrative of putting on a brave face (e.g. the English stiff upper lip). Therefore the public face of stroke and aphasia tended to favour more of an individual or medical model than a social model of disability, as did the private face. However there is evidence of social model thinking beginning to appear within the public domain. Nonetheless the meta-narrative of modern medicine with its scientific base remains the dominant force in our society with regard to disability.

The following chapter moves on to discuss the emergent themes of the study in a more general way linking it to current literature before going on to discuss the implications for speech and language therapy practice.

CHAPTER 12 DISCUSSION, CONCLUSIONS & THE WAY FORWARD

In this chapter I discuss what emerges from the data and how this relates to current literature and thinking. I start by discussing the complexity of the narrative tapestry that participants weave and the implications of this for our understanding of aphasia and disability. I go on to present the implications this study has on speech and language therapy practice. I then outline the advantages, disadvantages and limitations of using multiple methods in accessing narratives. Finally I conclude by presenting ideas for future research.

12.1 NARRATIVE TAPESTRY

The themes that emerged from the data highlight the individuality in the way in which individuals experience and manage aphasia and disability. Each person lives by a unique tapestry of narratives, drawn from the public narratives of disability and illness, which they use to make sense of aphasia and live with it in day-to-day life. Participants did not draw on just one narrative but many, thus the reality of living with aphasia is a complex, messy and elusive picture with some threads strong and vibrant while others weaker and more subtle, but all contributing to the overall picture.

This section discusses this complexity in light of the current narrative frameworks as outlined in Chapter Four, before going on to outline how narrative shapes behaviour, the relationship of narrative to disability and the role of public narratives.

12.1.1 Current Narrative Frameworks

This study found many narratives that people draw on to make sense of disability. Some link to narratives found in previous studies and these are outlined below.

a) Disability narratives

Phillips (1990) found only three cultural notions which dominated the narratives of participants in her study. These notions are also reflected in the current study. Firstly,

Phillips found that society perceived disabled people to be damaged. In the current study this is illustrated by the disability as less than whole narrative evident with all participants. In addition Phillips suggested that loss of friends was an indication that disabled people are damaged. In the present study all participants with aphasia lost friends since the acquisition of aphasia. The second notion that emerged from Phillips' study is that disabled people should try harder to overcome obstacles. In the current study this is reflected in the strong restitution narrative of participants in the first few years post-stroke, whereby they felt they needed to work hard to recover and overcome the obstacles of the impairment of aphasia. This view still persists a number of years post-stroke. For example Tony's partner, Sue, remarks about how Tony should practise and work at his reading in order to overcome the difficulties he experiences. Anne is currently in a strong restitution narrative and has every expectation of "getting better" and overcoming her difficulties, albeit "slowly". Thirdly, Phillips found that society assumed that disabled people want to be with other disabled people. This notion did not come across strongly in the narratives of participants in the current study; only one comment made by May's sister suggests it, when she said that May was happy in her clubs because she was with "her own kind". The current study paints a much more complex picture of disability with many narratives making up the experience of disability.

b) Illness narratives

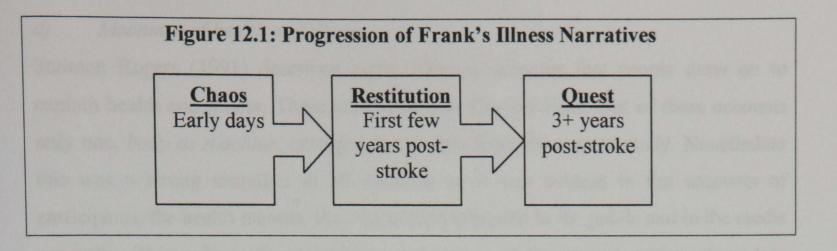
As with Phillips' (1990) disability narratives, Frank's (1995) illness narratives do not go far enough to illustrate the complexity of living with disability. As outlined in Chapter Four, he proposes three main illness narratives that people may or may not experience in the course of their illness. These are *restitution* where illness is viewed as transitory with a focus on remedy; *chaos* where illness is so overwhelming that the voice of the teller is lost; and *quest* where illness is met head on and incorporated into daily life. While Frank refers to these narratives in terms of experiencing illness, they are equally applicable to those experiencing acquired disability. All of Frank's narratives were present with each of the participants, however many other stories were told.

When participants – those with aphasia and their relatives and friends – spoke about the early days post-stroke, they reflected how confused they were at that time. This suggests that they were in a *chaos* narrative during this period and such a narrative may be a common response to a traumatising event such as stroke. Therefore it may also be a common thread in other acute illness narratives.

While a *chaos* narrative was evident in the early days post-stroke, a *restitution* narrative was evident in the initial few years post-stroke. However the strength of the *restitution* narrative passed with time as for example, it did not feature strongly when people spoke about Tony or May now, five or six years since the onset of aphasia. The *restitution* narrative dominates the literature available to the public about stroke and aphasia, and so it is not surprising that it is so strong amongst participants in the early years following stroke.

A quest narrative was not evident when participants spoke about stroke early on; rather it only became evident when they talked about the person with aphasia in the present. This narrative was strongest with Tony and May, both of whom had their stroke five and six years previously. It was least strong with Anne where restitution dominated; her stroke was of more recent onset and she was still attending therapy which was focusing on restoration of language abilities.

Findings from this study therefore suggest that people go through Frank's illness narratives at different stages. For example, none (except Anne's son, Stephen) are in a chaos narrative now, but all were in the early days following stroke. Restitution was a strong narrative in the first two to three years following stroke, but only Anne is in a restitution narrative at present though it remains a background voice with Tony and May. The strongest quest narratives were lived by Tony and May who had their strokes five and six years respectively. Figure 12.1 illustrates this progression diagrammatically.



However if one just views narrative from this simplistic viewpoint, there is a risk that the complexity of living with aphasia will be overlooked. Individuals draw on many other narratives to make sense of aphasia and live with it in day-to-day life. For example, while May has a strong *quest* narrative it is not as strong as her *happy face* narrative that really guides the way in which she manages aphasia and disability. Frank acknowledges that there are other narratives, but he gives most credence to the narratives he proposes and fails to highlight the complexity of the narrative tapestry that constitutes living with aphasia and disability.

c) HIV narratives

Crossley (2000), in her study of narratives of people who were diagnosed with HIV positive, outlined three main narrative types (see Chapter Four) that according to her, closely align to Frank's (1995) illness narratives. She says that

Although it is important to recognize the specific problems introduced into a person's existence with the advent of HIV infection, particularly their increased psychological vulnerability, it is also important to recognize that people develop various ways of thinking and dealing with their situation which enable them to adjust with varying degrees of effectiveness. (p.142-143)

While Crossley's (2000) narratives supposedly closely align to Frank's (1995) narratives of *chaos*, *restitution* and *quest*, they were not evident in the data of this study. This may be because participants in the current study all have a normal life expectancy, while the participants in Crossley's study did not and her narratives make direct reference to the way in which they think about and deal with a limited life expectancy.

d) Meanings of health and illness

Stainton Rogers (1991) described eight different accounts that people draw on to explain health and illness. These are outlined in Chapter Four. Out of these accounts only one, body as machine, emerged in the data from the current study. Nonetheless this was a strong narrative in all domains as it was evident in the accounts of participants, the health records, the information available to the public and in the media generally. This reflects the dominance and power of the meta-narrative of modern medicine in our society, whereby the body is viewed as a machine which can be fixed when it breaks down. Stainton Rogers highlights the role of such things as culture, ideology and sense of self play in the way one thinks about health and illness, when she says:

The accounts which each of us, as individuals, draw on to 'make sense of' health and illness will also be influenced by other broader aspects of our strivings to explain the world, such as our political ideology, our religious beliefs (or lack of them), our constructions of authentic personhood and how we see ourselves, how we see our relations with other people; these in turn are mediated by our experiences, up bringing, stage in the life-cycle, access to media and so on. (p.228-229)

However in this study the influence of the meta-narrative of modern medicine was the strongest factor in the development of the narratives of participants though other influences were clearly at work. For example, how one should behave in the face of disability is evident in May's happy face narrative, though this also aligns to the meta-narrative of modern medicine as it links with what it means to be a good patient. The fact that this was such a strong influence on nearly all the narratives that emerged from the data suggests the power of this meta-narrative and how this is the 'common sense' view of illness and disability in our society leaving little room for other ways of thinking about it. However other influences were at work such as the individual's life experience. For example May's previous experience of stroke was of a grandparent who had had a stroke but who was kept in a room upstairs. Therefore May does everything in her power to ensure social contact, which her grandparent lacked, and does this by maintaining a happy face.

e) Current changes in medical practice policy

Most narratives in the publicly available literature align to the meta-narrative of modern medicine, so this narrative is the one that people are most exposed to. Yet it has been noted that people are increasingly demanding to play a fuller part in the decision making process about their illness and treatment (Department of Health, 2001) and this would suggest the emergence of a different public narrative. Recent health policies reflect this increased emphasis on user involvement (see 12.2.3b) and these may in turn influence and develop this public narrative. However such narratives were not evident in this study.

To summarise, in terms of the published narrative frameworks, participants in this study drew on a number of these narratives, but in addition they drew on many more, suggesting a highly complex picture. However the common theme running throughout is the underpinning meta-narrative of modern medicine which guides the narratives that emerged. Burck (1997) comments:

The cultural stories available and the way we are positioned in the dominant discourses will powerfully shape the personal stories we develop in interaction with those around us. (p.65)

12.1.2 Narratives Shaping Behaviour

Aphasia results, in the majority of cases, from an acute event such as stroke or head injury whereby the person is usually hospitalised and therefore viewed as sick. Brody (1987) drawing on the work of Parsons (1951, 1958), outlines four features of the sick role. They are:

- The person is unable to perform socially approved roles and cannot be held responsible for them.
- Sickness is a legitimate excuse for not performing role responsibilities.
- The person shares the same basic value assumptions as the rest of society with regard to sickness.
- The person seeks help from a socially identified authority on sickness.

These notions adhere to the meta-narrative of modern medicine and are still in operation today, as can be evidenced by the way in which participants are viewed and

behave at any given time. For example all participants conformed to the sick role when they first developed aphasia. At that time they were in hospital, unable to work and were seeking help from an appropriate authority (i.e. medicine, nursing care and therapy); they were all in a *restitution* narrative. Both Anne and May are still viewed in this sick role, as is suggested by the narratives surrounding them of being *in need of care* and *others in control*, and the fact that neither is expected to work. In addition Anne continues to attend a 'socially identified authority' for therapy, and May attends a day activity centre. Tony, on the other hand, no longer conforms to the sick role in that he does not attend any 'socially identified authority' for his aphasia and there is an expectation from some participants that he should be in some form of employment. Therefore there is an expectation that people who are disabled should conform and behave in particular ways; for example, by attending therapy to seek restoration of abilities (*restitution* narrative) or by being in employment if no longer viewed as sick (*importance of not being idle* narrative).

According to Becker (1999) and Crossley (2000), the narratives we live by are a means of making coherence and order out of possible chaos. *Chaos* was clearly evident with all participants in the early days post-stroke and with some of their close family, but it diminished with time. This highlights that an unexpected and traumatic event throws one's sense of order in life and chaos comes in its place. As stated previously, after some time the *chaos* narrative tended to be replaced by other narratives. For example, a *restitution* narrative shaped the way in which participants behaved in that they did what medical, nursing and therapy staff asked of them. Similarly May's *happy face* narrative shapes the way in which she behaves. Dale and Altschuler (1997) comment:

Society and health care professionals support the idea that portraying a positive mental attitude can be seen as the way to achieve victory over illness, and thus essential in the battle for health. (p.128)

Therefore May's happy face narrative links in to society's public narrative of having a positive mental attitude. Such a narrative infers that unless one can maintain a positive attitude then the person is in some way to blame (Dale & Altschuler, 1997). Representations such as these play a role in how people experience illness and

disability, as well as affecting the way a person relates to others and how others relate to the person. This is clearly the case with May who explains that if she does not maintain a happy face no-one will speak to her. In this way May's happy face narrative affects how she behaves and how others behave towards her; she ensures that she is always cheerful and compliant and this leads others to respond to her in a positive manner.

Similarly the narratives of Anne and Tony shape the way in which they behave. Anne's attention is constantly focused on getting better. She attends therapy regularly, rarely cancelling appointments and does all that the speech and language therapist asks of her both in the therapy sessions and in terms of completing homework. Tony, on the other hand, is much more laid back and is accepting of his aphasia and lives life as if aphasia is a minor nuisance.

12.1.3 Narrative and Dealing with Aphasia and Disability

The individual or medical model of disability locates the problem of disability with the individual, while the social model of disability asserts that disability is a consequence of social oppression (i.e. restrictions imposed by a disabling society). The social model now acknowledges that some impairments may have disabling consequences in their own right, as in the case of aphasia (e.g. no longer being able to enjoy reading). The participants in this study are more closely aligned to the individual model of disability than the social model. This is perhaps because of the strong prevailing meta-narrative of modern medicine in our society and the public narratives that stem from this (e.g. body as machine, disability as less than whole, etc.). For example, the individual model is evident in the expectation that it is up to the individual to adapt. Anne is working hard at therapy to get her speech back; it is assumed by Sue, Tony's partner, that if Tony practises reading he will improve; and if May takes her time it is assumed that her speech will be easier. Little is said about others adapting to facilitate communication. Anderson (1988), in his study of quality of life of people who had a stroke and their spouses, found that they were preoccupied with improving their abilities.

Becker (1999) highlights that after disruption, as in the case of the onset of aphasia, people experience a time of "living in limbo" before they can restore order to their life once more. This "limbo-like" condition is when one is in an in-between state with a feeling of being trapped in the present. One enters as one sort of person and emerges altered in some essential way. Both Tony and May give the impression of having been through this "limbo-like" state and have emerged dealing with their aphasia and disability in a particular way in the form of living by specific dominant narratives. Becker (1999) comments that:

Those who interpret their efforts as reflecting normalcy and at the same time acknowledge difference are the ones who view the disruption as transformed and the task of recreating order as nearing completion. (p.199)

This is the case with both Tony and May as they have adapted to their situation, albeit in different ways, and have emerged from the experience altered in some essential way. Anne, on the other hand, lives very much in the present in which a *restitution* narrative dominates; she has not yet come through the "limbo-like" state, as other stories need to be told if she is to live life with aphasia in the long term. According to her speech and language therapist, Anne is unlikely to regain all of her communication abilities so a dominant *restitution* narrative may not be conducive to healthy living with aphasia in the long term; she will need to come through this "limbo-like" state and develop other narratives in order to live healthily with aphasia.

Depression has been cited as a common reaction to aphasia (Währborg, 1991). While no specific assessment was undertaken to determine the presence or absence of depression, none of the participants seemed depressed. Both Tony and May seem to have adapted to the changes brought about by stroke as is evidenced by their *quest* narratives. Anne, on the other hand, is bound up in a *restitution* narrative and it is a possibility that she may experience depression once the realisation dawns that she is not going to regain her language abilities.

In terms of dealing with disability, French (1993b), who has a visual impairment, admits that she denied her disability for years by avoiding other people's anxiety,

distress, disappointment and frustration, as well as living up to other people's ideas of normality. May also does this to some extent in the way she cares for others by being cheerful and compliant (i.e. her *putting on a happy face* and *good patient* narratives), giving the impression that all is well so that her conversation partners will feel comfortable and forget she has aphasia. The conversations I observed in which May participated were characterised by her fluent social speech. She successfully masks her impairment by this strategy as she rarely seems to converse in any depth about things. At interview, however, her word retrieval difficulties became apparent. Anne and Tony, on the other hand, do not mask their impairment; indeed Anne will state explicitly to strangers that she has had a stroke and that her speech is affected.

As discussed in the participant stories chapters, each participant dealt with their aphasia in different ways highlighting the individuality of coping with acquired disability. Anne still predominantly deals and manages her aphasia by drawing on a restitution narrative. Tony and May have moved on to develop other dominant narratives in their quest to live healthily with aphasia and disability. Just as the key participants deal with aphasia differently, so do those who encounter people with aphasia. Some are, to quote Anne, "very good", while others are not. The participants had mixed reactions from people, some positive and some less so. Thomas (1999a) and Reeve (2002) outline how a person with a disability can come under scrutiny from other people in such a way as to leave the person feeling ashamed, vulnerable and invalidated. Tony describes how, early on, people would give him a sideways glance indicating, from his perception, that he was "mental rather than a stroke". In addition to this there were two occasions when he was refused service in a pub with no explanation given. All participants report having lost friends in that some friends have not been able to cope with their difficulties in communication and subsequently avoided contact with them. According to Reeve (2002) this particular form of disablism can prevent people from participating within society as much as the presence of physical barriers. Such barriers to participation are what Thomas (1999a) refers to as the psycho-emotional dimension of disability which should be taken into account when considering the disability

experience. While losing friends, all participants do participate in life and do not seem to avoid many situations because of their aphasia.

People develop various ways of thinking and dealing with their situation that enable them to adjust with varying degrees of effectiveness (Crossley, 2000). Each of the participants in the current study has a different way of thinking about their situation. All employ numerous narratives to make sense of their condition in order to live life as fully as possible.

12.1.4 The Role of Public Narratives

As previously described, people with acquired aphasia have to incorporate this alien event into their life and they do this by drawing on available public narratives. Most narratives that emerged from the data link in some way to public narratives of illness and disability. This would be in line with much of the literature (e.g. Kleinman, 1988; Nettleton, 1995; Banja, 1996; Thomas, 1999b). This was discussed in Chapter Eleven.

As stated earlier the meta-narrative of modern medicine is a dominant force in the development of both personal and public narratives (see Figure 11.3). Modern medicine weaves power over people in that one is expected to comply with what its practitioners recommend. This is evident in this study from the narratives of both the professionals and care staff. With regard to therapy, Anne is expected to comply with impairment based therapy which casts the therapist as expert. On the other hand, when Tony was attending therapy he was expected to comply with professionals in their recommendation that he seek vocational training with the aim of regaining entry into the workforce. This was not a priority for Tony and in the end he told the doctors and therapists that he had found work for himself to "keep them quiet". Rather than stating that their aim was of no interest to him, he felt compelled to comply with the therapists' wishes and recommendations. This focus on returning to the workforce without due consultation with Tony, frustrated and annoyed both Tony and his partner, Sue; they found their own way of dealing with it that would not cause offence to the professional staff. Care staff similarly expect members to comply with the activities of the club. In

the rehabilitation and care culture that we live in, the person with the impairment is placed in the role of recipient of care/therapy/treatment. In this study the focus of therapy was on *restitution* as the aims of the therapists were to minimise the impairment and maximise function.

This study reveals that public narratives of disability and the meta-narrative of modern medicine in particular, are important sources of influence in the way people (disabled people, their loved ones and health care staff alike) think about and experience aphasia and disability. Thomas (1999b) also found that personal narratives were bound up with public and meta-narratives. Difficulty in coming to terms with disability was entwined in long-standing acceptance of implicit messages in some of the public narratives about the impaired body and person (i.e. disability as less than whole). Thomas (1999b) contends that finding counter narratives can help reconstruct personal narratives and that without counter narratives the person may become trapped within the storylines of the prevailing public narratives. Anne and May particularly are bound up in public narratives of disability. Anne is trapped in the prevailing narrative of restitution while May is trapped in the prevailing narrative of being a good patient and so is compliant and puts on a happy face. Tony, on the other hand, is much more self assured and lives life very much as he wants to, successfully incorporating aphasia. All participants rely on public narratives to make sense of aphasia and disability. None seem to have accessed counter narratives of disability and I wonder what different stories they would have to tell had they been influenced by such narratives. Counter narratives of disability are most prevalent in the disability rights movement where disability is viewed as a social creation rather than an individual problem (e.g. Swain et al, 1993; Barton, 1996b; Hales, 1996; Corker & French, 1999b).

12.1.5 Developing Counter Narratives

As already mentioned, the social model of disability provides a counter narrative to the prevailing public narratives of disability, by reframing disability in terms of societal responsibility and in the celebration of difference. However such counter narratives were not expressed by any of the participants in the study. This highlights the strength

of the public narratives that relate to the individual model of disability in our society and they are the most common narratives that people are exposed to. The social model of disability in the main remains trapped inside specialist literature and so is not easily accessible to many disabled people. Clearly such counter narratives need to be told and should be accessible to the general public so that they are exposed to alternative views of thinking about and experiencing disability. Phillips' (1990) study highlighted the fact that disabled people felt liberated when made aware of narratives of disability that valued their minority status. Making counter narratives easily accessible would entail a major shift in focus away from the individual model and the meta-narrative of modern medicine for those writers who contribute, for example, to daily newspapers, many of the aphasia internet sites and information leaflets about stroke. Even writers with an impairment fall into the individual model trap of viewing disability as less than whole. For example, Diamond (1999) who had cancer of the tongue remarks:

I suddenly heard how I sound nowadays. It turns out I have the gravelly and meaningless grunt of a major stroke victim. (p.85)

Such a comment particularly casts the person who has had a stroke in a negative light. Cant (1997) who actually had a stroke, makes a similarly disparaging comment about difficulty in speech. He links it in with intelligence in that if clarity of speech is affected then the perceived value of what one says is reduced. This is how John, introduced in Chapter One, viewed his dysarthria.

Making counter narratives of disability accessible means writing about disability in a different way. Some internet sites are beginning to do this (e.g. aphasiahelp.org, ukconnect.org). While counter narratives are beginning to become evident in the public domain, this study suggests that the meta-narrative of modern medicine remains a dominant force in our culture. We need to develop in consultation with people with aphasia, specific counter narratives of aphasia that are not underpinned by modern medicine, but rather a public narrative that values difference. This is beginning to occur. For example, Chris Ireland, a poet with aphasia, celebrates her difference whereby rather than correcting her language errors she capitalises on them in order to entertain and challenge her audiences (Ireland & Pound, 2003). Such a celebration of

difference is a direct challenge to public narratives such as disability as tragedy and disability as less than whole.

Nonetheless to date there are few other examples of social model thinking in the public domain that are readily accessible to people with aphasia and their families and friends. The situation is improving, however, with the occasional newspaper article being written about increased participation for disabled people and ways to facilitate this (e.g. Kelly A., 2003), as well as an increase in the number of aphasia-friendly internet sites. (Accessing counter narratives is discussed in more depth under 'Change in Role' – 12.2.3 (e).)

This section has addressed issues surrounding the narrative tapestries that emerged from the data in terms of the current narrative frameworks, how narrative shapes behaviour, narrative as a way of dealing with aphasia and disability, and the role of public and counter narratives. This study contributes to the narrative, disability and aphasia literature by highlighting the complexity with which people experience and manage aphasia and disability in day-to-day life. It draws attention to the fact that people live by a variety of narratives in their quest to make sense of their situation. The personal narratives that participants live by draw on the dominant public narratives in our society, particularly the meta-narrative of modern medicine. It highlights the power of such narratives in our culture in terms of how they determine how people, those with aphasia and their conversation partners, respond to and behave when they are faced with an impairment.

The following section will address the implications of this study for speech and language therapy practice.

12.2 NARRATIVE REFRAMING OF APHASIA THERAPY

This study has provided a depth of understanding as to what it is like to live with aphasia that has not been realised before. What therefore are the implications of this depth of understanding for clinical practice? Is it necessary to go into such depth to bring about positive change in well-being? Is it our role? These issues are now addressed.

12.2.1 Healing Power of Narrative

Storytelling increases our working knowledge of ourselves and helps make our lives coherent, understandable and meaningful (Atkinson, 1998; Becker, 1999). Telling stories is healing in its own right, as they help the teller to reorder her/his life story (Brody, 1987; Kleinman, 1988; Booth, 1996; Greenhalgh & Hurwitz, 1998). Therefore the very act of having the opportunity to tell their story through in-depth interview can have a therapeutic effect as it attaches meaning to the aphasia experience. This alone is sufficient reason to include an in-depth interview, exploring what it means to have aphasia, in one's overall 'assessment'. This can be a challenging process with someone who has aphasia and it is important that the therapist, through supported conversation (Kagan, 1998), facilitates the telling of the story. It may be useful to include some nonverbal means (e.g. picture selection task, 'tree of life'28) to help access the insider perspective. Such non-verbal methods gives one a platform from which to probe the person's perspective on what it is like to live with aphasia. The importance of life story work, utilising both verbal and non-verbal means of communication, has been acknowledged in working with people with learning difficulties. Life story work with this group of people offers a means of allowing the person to make sense of their past and to explore the feelings associated with the recording of such personally relevant information (Hamilton & McKenzie, 1999). Opening up the opportunity for people with learning difficulties to talk about and make sense of their past can influence the way in which they think about themselves; frequently making them more confident with a stronger sense of themselves (Gray & Ridden, 1999).

²⁸ This is described in Footnote 8, p.33.

Rather than just focusing on exploring the nature of the impairment and the way this affects day to day living from a functional perspective, as is the traditional way of working, one should also explore the narratives the person draws on to make sense of aphasia. This could be done via a life story interview as advocated by Price-Lackey and Cashman (1996), Atkinson (1998) and Clouston (2003). According to Price-Lackey and Cashman (1996), a life story interview can increase one's understanding of how people experience and adapt to major life events. They suggest that a life story interview can enhance practice in a number of ways. Firstly, it can improve rapport between the person with the impairment and the therapist as it acknowledges the 'patient' as a person. Secondly, the therapist can learn about adaptive patterns and strategies that the person has used in the past that could be capitalised on in the current situation. Thirdly, the stories the person tells about the self in the past and present can help the therapist to understand the meaning the person attaches to their current situation. And fourthly, storytelling can facilitate collaborative goal setting. I would add a fifth function of life story interview in clinical practice: that it can provide insight into the way in which the person thinks about and deals with their situation in terms of the narratives she/he draws on to make sense of their condition. Thus, not only is storytelling healing in its own right, but it also provides the means for the therapist and the person to work collaboratively towards an agreed goal that is meaningful to the person concerned and that will enhance feelings of well-being.

Being exposed to and having access to counter narratives of aphasia and disability may also have a healing effect and this is discussed in 12.2.3 (e).

12.2.2 Narrative as a Way of Listening

The type of social relationship one has with a person can determine the impression one has of that person and the identity one assigns to her/him (Goode, 1984). For example a doctor or therapist may define a person in diagnostic (frequently negative) terms while a family member or carer, who has a more intimate relationship with the person, may define her/him in terms of her/his competence and abilities. Indeed their intimate knowledge of the person sees competence where the professional may only see

disability – "fault-finding procedures are almost always employed by non-intimates" (Goode, 1984, p.245). A narrative way of working emphasises really listening to and valuing the perspective of the person with aphasia and those who have a more intimate relationship with her/him. In this way the therapist is exposed to ways of viewing the person as someone who lives in a social world rather than a view that is bound up with the technical aspects of the impairment.

Pound (1999) highlights the importance of really listening to the person's story, otherwise one risks a "clash" of narratives. The health professional may be influenced by the predominant medical narrative of impairment and abnormality, coping, rehabilitation and adjustment and this may be at odds with the person's struggle to develop a new narrative incorporating aphasia. The evidence from this study suggests however that the first couple of years following the onset of aphasia participants' narratives were at one with the health professionals, in that there was a strong restitution narrative which would fit with the aims and objectives of therapy (i.e. to enable the person to regain as many of their language abilities as possible). Therapists in this study clearly saw their role as working with the person to help them to improve language and physical functioning. They rarely spoke of working with people with impairments to address how they might deal with the challenge of living life with disability in the long term. Certainly they never spoke in terms of what narratives the person came with to therapy; there was a presumption that the person attends therapy to get better. This again highlights how entrenched rehabilitation professionals are in the individual or medical model of disability.

This study emphasises the importance of listening to the person's story and to the complexity of narratives the person draws on in order to target therapy appropriately. For example, listening to David's story (Barrow, 2000) allowed me to gain insight into how he was living with aphasia. He was living by the narrative *striving to be normal* and it was changing this that became the focus of therapy. Therefore therapy may focus on facilitating change in the person's narrative to meet the aim of living life healthily with aphasia. Mattingly (1998) suggests:

Healers may draw upon narrative to encourage powerful reframings of illness that actively change the sufferer's perception of his own body and personal experience. (p.14)

Without intelligible narratives one is lost and Donald (1998) is of the opinion that one needs language to help one to navigate one's way through experiences and disruption. However people with aphasia may not have the language with which to tell their story coherently, therefore one needs to explore alternative methods to access narratives with this group of people. This study used two particular methods to do this. Firstly, participant observation was an integral part of the study and it allowed me to access narratives through action as well as words. Also it used a picture selection task which allowed participants to convey the experience of life with and without aphasia through imagery where words were not necessarily necessary. This method is used by Pound *et al* (2000) in their work with people with aphasia.

Further opportunities for exploring the inner experience are offered in the endless range of visual material provided by the greetings card industry – a rich source of easily accessible imagery. We use a range of photographs, cartoons, landscapes, abstract, impressionistic, romantic, classical and modern art images when working with our clients to help them find a point of reference for their inner state. Such activities support expression of feelings, experiences and dreams where words may not be available or adequate to the complexity of the task. (p.233)

Other non-verbal methods could also be used (e.g. 'tree of life', VASES²⁹). Such methods can be used to clarify narratives and help to ensure that the therapist is aware of the insider perspective. The information gained will help ensure that the therapist does not just view aphasia as an impairment, but rather as a person living with an impairment and all that that entails. Donald (1998) comments:

One type of conflict arises from an ontological mismatch between the sufferer's actual experience of illness and the health professional's reformulation of it as disease. (...) Illness is a realm that the ill person *inhabits*, whereas disease categories are often quite crude maps that health professionals use to interpret the ill person's experience, from the other side of the wellness-illness divide. (p.23, emphasis in the original)

Sensitive in-depth listening and watching help to ensure that the therapist views the situation from the individual's perspective. Welch (1996) remarks:

A disabled person's personal circumstances, including individual experiences of life and people, will influence the disabled person's attitude and response to any intervention from professionals. (...) From the outset of the relationship and in any subsequent interactions it is vital that a clear understanding of roles, responsibilities and expectations is established between practitioner and client. (p.23)

²⁹ Visual Analogue Self-Esteem Scales (Brumfitt & Sheeran, 1999)

Many people come to the therapy encounter expecting 'treatment' for their impairment, therefore it is important to clarify for them that one's role is broader than this and entails listening to their perspective of their situation and working from that.

A narrative way of working entails listening with the story that the person comes with, rather than taking a case history. One lets the person guide the telling of the story using non-verbal methods and supported conversation to facilitate the process if indicated. In this way one gains insight into the private face of aphasia rather than the professional's. Clouston (2003), an occupational therapist, advocates using a life story approach to provide information that would otherwise remain outside the professional relationship.

There is a focus on how the story is told as well as what is said, in that one analyses for submerged stories (Atkinson, 1998) as well as the content. It is often the submerged stories that open the door to determining what narratives the person lives by. For example, as mentioned in Chapter Four, one person I worked with stated that "you can run the country from a wheelchair"; this was said in the context that you could not run the country if you had something wrong with your speech. Such a submerged story suggests a narrative of, for example, 'communication is power' or 'communication disability is less than whole'. A submerged story of this nature may influence, and indeed in this case did, the way one lives one's life. For this man this submerged story or narrative had a negative impact on his feelings of self-esteem, self-worth and self confidence.

Listening with the story is a key skill in gaining insight into narratives of aphasia and disability. One wants to explore the meaning of the narratives to the individual concerned. Atkinson (1998) acknowledges the challenge of really listening when he says:

Listening well produces a safe place built on the twin pillars of trust and acceptance. There can be no room for making judgements of any kind at all. Listening well means caring for, respecting, and honouring the other person's life and story. Listening well is both an art to be learned and a gift to be given. (p.35)

12.2.3 Change in Role

Such a way of listening with the person's story and where it may lead the therapist calls for a reflection on our role as speech and language therapist. The traditional role of a health care professional, as guided by the meta-narrative of modern medicine and the many public narratives of disability, is one of 'making things better' and 'fixing' the problem (Simmons-Mackie & Damico, 1996). The therapists in this study conformed to that role and it is what other participants expected of them.

The sociological perspective to aphasia explores the insider view of the aphasia experience. It takes a social model stance and focuses on dismantling barriers as well as the disabling experience of the impairment itself. As advocated by Simmons-Mackie (1998), we are currently in the process of a philosophical shift in the way aphasia is viewed. There is a move away from the traditional focus on linguistic impairment and functional communication towards assisting the person with aphasia to integrate into a communicating society. This does not mean that the impairment and issues surrounding functional communication are now ignored; rather that they are incorporated into a more holistic way of working with the person which takes into account the person's insider perspective. However what does remain a requirement of good working practice is for the speech and language therapist to listen to the story the person brings to the therapeutic encounter. Otherwise there may be a risk of a clash of narratives (e.g. the therapist being firmly entrenched in a *restitution* narrative while the person with aphasia is seeking to develop a narrative that would enable them to live healthily *with* aphasia). Being aware of where the person is at is crucial at all stages.

a) Traditional way of working

The traditional role of the speech and language therapist is underpinned and guided by the meta-narrative of modern medicine and the many public narratives of disability (e.g. body as machine, disability as less than whole) with their focus on cure and restoring to 'normal' or as near normal as possible. Generally therapists work within traditional health care settings such as hospitals and clinics. Such institutions exist to cure and care for those who are ill, the overriding aim being to restore the person to

past abilities so that she/he can participate fully in society once more. For this reason it is hardly surprising that speech and language therapists conform to this *restitution* type role, as the very environment in which they work demands it. Discharge from therapy usually occurs when recovery is complete or, if incomplete, when there is no further progress envisaged. As outlined in Chapter One it was at this point that I negotiated discharge from therapy for John who in my opinion had reached his maximum potential as far as the impairment was concerned. It was not until I really listened to his narrative of disability that I realised that therapy was far from over and that I had a role to play in enabling him to think about his impairment differently that would allow him to live life healthily with dysarthria. Therefore in general therapy does not extend to issues surrounding living with the impairment. There are however a few notable exceptions in the work undertaken by Connect and the LPAA Project Group (see Chapter Two). Because working from a narrative perspective focuses on living life healthily with aphasia, it is best suited for those people who have to live with aphasia in the long term (i.e. those people who are not going to regain all their language abilities).

b) Person with aphasia as expert

A narrative way of working entails among other things exploring the personal narratives of the person concerned, it demands that one is guided by the person with aphasia rather than the therapist guiding the process. The person with aphasia is considered the expert on their aphasia. The therapist works with the person's narratives rather than from a narrative of her/his making. It demands a power shift away from the therapist to the person with aphasia. It moves away from just a 'fix-it' role to encompass a role that involves working with the person in such a way that acknowledges her/him as expert. It moves away from working within the therapist's explanatory model of aphasia towards working from the person's explanatory model. Kleinman (1988) describes explanatory models as "notions that patients, families, and practitioners have about a specific illness episode" (p.121). A traditional focus on aphasia therapy tends to operate with the therapist's explanatory model which is usually guided by the meta-narrative of modern medicine (i.e. that brain injury causes aphasia and that it is the impairment of aphasia that leads to disability). In contrast a

narrative way of working operates with the individual's, and those close to her/him, explanatory models of their condition and these can be various. Focusing on the individual's explanatory model helps to ensure a more person-centred approach to therapy. In the traditional way of working therapy tends to be guided by professional theories and so the public face of aphasia dominates the therapeutic stance taken. A narrative focus, on the other hand, privileges the subjective experience of living with aphasia and it is this that guides therapy. There is a focus on abilities and achievements, whilst taking into account the difficulties and changes the individual may face.

Traditionally the person with aphasia is the passive recipient of care, whereby the therapist does the guiding and directing of the therapy process. This is evident in Anne's story where both the speech and language therapist and occupational therapist took the lead. A narrative way of working promotes the person with aphasia to be an active agent in guiding therapy.

This stance of acknowledging the person as expert is in line with the UK Department of Health's recommendation of the development of "Expert Patient Programmes" or "self-management programmes" (Department of Health, 2001). Health professionals in general have long been aware that people with chronic conditions frequently know more about their condition than they do. Unfortunately this knowledge of the 'patient' being an expert in their own condition has for a long time been an untapped resource. It is only recently that their expertise has become recognised as a resource that might have a positive effect on quality of life. It was this recognition that led the UK government to set up a task force to implement the establishment of Expert Patient Programmes in the UK. This awareness of the patient as expert involves listening to their narrative.

The UK Department of Health (2001) and Donaldson (2003) cite the seminal work of Lorig at Stanford University in California. She equipped people with chronic diseases with the skills to manage their own condition. She found that expert patients improved their self-rated health status and were better able to cope with the many factors

associated with a chronic condition (i.e. fatigue) thus reducing their dependence on hospital care. Research evidence of Expert Patient Programmes (or self-management programmes) in general has shown positive benefits in a number of areas (e.g. reduced severity of symptoms, decrease in pain, improved resourcefulness and life satisfaction). This recognition of the benefits of Expert Patient Programmes led the UK Department of Health task force to recommend the introduction of user-led self-management training programmes. Initially this is to be on a pilot basis with the aim of establishing them throughout the UK between 2004 and 2007. The proposal of the development of such programmes acknowledges that people with chronic conditions need not be mere recipients of care but can become key decision makers in the treatment process.

Patient self-management programmes, or Expert Patients Programmes, are not simply about educating or instructing patients about their condition and then measuring success on the basis of patient compliance. They are based on developing the confidence and motivation of patients to use their own skills and knowledge to take effective control over life with a chronic illness. (Department of Health, 2001, p.6)

Therefore user-led programmes help people with long-term conditions to take responsibility for their own lives. The whole person is the focus rather that just the illness or disability.

The era of the passive patient is changing and is being replaced by an equal partnership between patient and health professional in which the best solution to the patient's problem is collaboratively sought. While recognising the emergence of this shift in emphasis the UK Department of Health's Report on the Expert Patient suggests that "a cultural change is needed so that user-led self-management can be fully valued and understood by health care professionals" (p.31). The findings of this study on narratives of stroke and aphasia highlight the importance of recognising the person as expert and active agent in the therapy process.

c) Role in supporting expression of narratives

Narratives are rarely articulated in such a way that makes them readily accessible both to the teller and the audience. Rather they are frequently incoherent and messy demanding a collaborative approach to disentangling them to make them coherent. Not

only does the therapist have to really listen to the person's story as previously discussed, she/he has a role in supporting the telling of aphasia and disability narratives through supported conversations techniques (Kagan, 1995, 1998). The narrative needs to be teased out and recorded in a way that makes it accessible and coherent. In so doing it can be agreed with, discussed and challenged. This process also entails exploration of the basis for the narratives. Do they stem from the dominant public narratives of disability? If so, are they perpetuated by the attitudes of health professionals, other care staff and volunteers? Or are they internalised oppressive narratives? Are they guided by the strong narratives of family and friends? Do these narratives contribute to feelings of well-being or do they enhance feelings of oppression, depression, anxiety and worthlessness? So firstly, one needs, through supported conversation, to identify, clarify and record the narratives the person, and those close to her/him, live by. Secondly, one needs to establish whether or not these narratives contribute to feelings of well-being. Thirdly, one needs to explore the origins of those narratives that do not contribute to healthy living with aphasia with the aim of providing access to counter narratives of disability that will promote feelings of wellbeing.

Therefore what this study suggests is that one of the aims of therapy should be to explore what narratives the person, and those close to her/him, uses to make sense of aphasia and manage it in day to day life. The focus here would be to determine whether or not the narratives they are living by contribute to a sense of well-being. If they do not, then therapy would entail exposing the person to alternative ways of thinking and experiencing aphasia. Therapy would be about the re-construction of change brought about by the onset and persistence of aphasia. Brody (1987) advocates that therapy should be about changing a negative narrative or metaphor to a positive one in order to alter the meaning the person attaches to her/his condition. Barrow (1999, 2000), in conjunction with a social worker, worked in this way with someone with aphasia who came to therapy with a narrative of *striving to be normal*. The aim of therapy was to change this narrative to more of a *quest* narrative so that the man could live healthily with aphasia, rather than constantly experiencing failure in his attempts to appear

normal which was having a negative effect on his self-esteem. Therapy strategies included exploration of what was involved in communication, validation of his abilities and ways in which he could influence his conversation partners to communicate in such a way that would enhance rather than negate his abilities. He attended for therapy for one hour every week for a period of ten weeks. At the end of this time his feelings of self-esteem (as measured on a visual analogue scale of "feeling well within myself") moved from 24% to 88%, and maintained at 72% three months after the completion of therapy (Barrow, 1999). This demonstrates that such work is possible and change can be brought about in a relatively short period of time. Pound *et al* (2000) advocate working in a similar way with the aim of healthy living with aphasia.

While narratives are important to consider at all stages of therapy in order to ascertain how the person is making sense of and managing aphasia, the therapeutic focus on accessing counter narratives may be more appropriate after a couple of years when most of the language recovery has occurred. This is because the aim of bringing about change in narrative construction is for the person to live healthily with aphasia in the long term and during the first couple of years the person is usually seeking restitution, as was the case with the participants in this study. However being aware of the narratives the person draws on throughout therapy may help to prevent the development of narratives that do not enhance feelings of well-being.

d) Counselling role

Such a change in therapy emphasis as described by Barrow (1999, 2000) and Pound et al (2000) would demand a move away from the therapist's role of 'fixer' to that of facilitator and collaborator. The very nature of the work would demand more of a counselling approach and for this reason there are implications for the profession. Currently many therapists do counsel 'clients' as part of their overall work but, with a few exceptions, not in the depth that would be required to affect a change in narratives. Therefore there are implications with regard to training both at under-graduate and post-graduate levels, as increased emphasis on counselling would be required. A narrative way of working may also entail closer collaboration with colleagues from

other disciplines (e.g. psychiatry, clinical psychology, social work) whereby one could work together with the person with aphasia and the other professional to facilitate change in narratives. This was done successfully by Barrow (1999). It demands an understanding of the role of all participants with the central focus being the perspective of the person with aphasia.

If emotions dominate the therapy process then it may be necessary to refer the person on to someone skilled in counselling. However they would need to be aware of the particular needs of people with aphasia in terms of the implications of living life with compromised language abilities, as well as an understanding of the many obstacles that people with aphasia face in their day-to-day life. In addition they would need to be skilful conversation partners, with training in supported conversation techniques (Kagan, 1998). Together with the person with aphasia, the speech and language therapist has a major role to play in providing such training. It remains the case that, in general, speech and language therapy is the profession which has greatest understanding of aphasia and the implications of living life with aphasia and therefore has a key role in working with the person to manage their aphasia effectively. However that does not mean that speech and language therapists are the best at communicating with and listening to people particularly if the therapist has a strong restitution narrative which guides the way in which she/he works with its focus on fixing the breakdown. A change in the therapists' narrative is required to allow them to change their role of 'fixer' to facilitator which would be necessary if the focus of therapy is to re-construct change in the face of ongoing aphasia. One needs to listen at a deep level to both what is said and how it is told to be able to access the narratives the individual draws on to make sense of their aphasia; this requires a move away from restitution towards a narrative that allows one to really listen to the person's story and work from her/his perspective. With a traditional focus on therapy, the therapist's personal, social, vocational and cultural history as well as her/his accompanying beliefs, attitudes and narratives are not necessarily taken into consideration. This is not the case with a narrative focus on therapy, where the therapist's history, attitudes, beliefs and narratives are taken into account in terms of the role that they play in the therapy process and how they influence the way in what the therapist works.

e) Accessing counter narratives

People make sense of their lives through stories, both the cultural narratives they are born into and the personal narratives they construct in relation to the cultural narratives. In any culture, certain narratives will come to be dominant over other narratives. These dominant narratives will specify the preferred and customary ways of believing and behaving within the particular culture. (Freedman & Combs, 1996, p.32)

We tend to internalise the dominant narratives believing that they speak the truth; they tend to blind us to the possibilities that other narratives might offer. This study suggests that the meta-narrative of modern medicine shapes the majority of public and personal narratives of disability that participants drew on. Therefore most narratives of disability view disability as less than whole and as tragedy. They do not value difference. If a person is to live healthily with aphasia then she/he may need to access counter narratives of disability; narratives that value difference.

One way to make a person aware of counter narratives is to identify those aspects of their story that do not support or sustain the dominant narratives that do not promote feelings of well-being. In the narrative therapy literature such counter narratives are referred to as "unique outcomes" (Freedman & Combs, 1996; Payne, 2000). They go against the guiding narrative. Expanding and thickening these counter narratives constitutes a narrative reframing of the problem. However it is not enough to simply recite a new story, rather it needs to be lifted and experienced outside of the individual therapy context in order to make a difference. The following are some ideas to do this:

- Group therapy may provide a means for the person not only to be exposed to alternative narratives, but to have their 'new' narratives heard and validated.
- Inviting family and friends to a therapy session so that they can observe a
 discussion about the alternative counter narratives identified. In this way family and
 friends are more likely to witness the counter narratives outside of the therapy
 context and so validate them thus thickening the alternative story.

 The individual could discuss the alternative view with family and friends, perhaps supported by written documentation, encouraging them to recognise and witness this new preferred way of thinking and behaving.

In addition part of the therapy role is to provide contexts and opportunities for the person to be exposed to counter narratives. For example, the 'Connect for a day' days that Connect run expose those who attend to alternative narratives of disability as well as the prevailing public narratives. So participants on these days have the opportunity to be exposed to narratives that are underpinned by a social model of disability as well as those underpinned by an individual or medical model of disability (Pound, personal communication). Such days therefore have the potential to open up ways for people to view aphasia and disability differently; ways that value and celebrate difference. Similarly the sharing of personal portfolios (described in Footnote 6, p.26) provides another method of exposing a person to alternative ways of thinking about aphasia.

Therapists need to consider ways to develop an atmosphere and a context that fosters the development of these less dominant narratives (i.e. narratives that are underpinned by a social model of disability). At present there are few opportunities for people with aphasia to be exposed to non medical model narratives. Perhaps part of the speech and language therapist's role is to explore ways that facilitates the introduction of counter narratives of disability so that the individual has the opportunity to consider alternative ways of thinking about and experiencing aphasia.

f) Role of supervision

Working in ways as described above with people with aphasia and those close to them entails getting closer to the psycho-emotional dimension of living with aphasia. Thomas (1999a) highlights the importance of taking the psycho-emotional dimension into account when considering the experience of living with disability. Dealing with the psycho-emotional consequences of aphasia can have ramifications with regard to the necessity of supervision for the therapist concerned. At present formal supervision is not part of the overall way of working in speech and language therapy, particularly for

senior therapists. Those professions (e.g. clinical psychology, social work) who work extensively in this area have a more formal supervision process that allows them to reflect on their work. If the speech and language therapy profession is to encompass a narrative way of working then regular formal supervision is recommended.

To summarise taking narratives into consideration extends our role with people with aphasia. It moves away from solely working on the impairment, or the disabling barriers that increase the experience of disability, towards a way of working that incorporates the exploration and identification of those narratives that contribute to or negate feelings of well-being. In so doing the speech and language therapist provides a context to support the expression of narratives and an environment to absorb counter narratives of aphasia and disability so as to promote healthy living with aphasia. Such a way of working demands a revised definition of aphasia. Definitions of aphasia were presented in Chapter Two but none incorporated the issue of living with aphasia in the long term. The following definition is suggested:

Aphasia is an acquired language impairment which affects, among other things, the person's ability to socially interact. The impairment together with the narratives of aphasia and disability that the person draws on and by which she/he is surrounded, affects the way aphasia is experienced and managed in day-to-day life the consequences of which may affect feelings of well-being.

Table 12.1 summarises what is involved in a narrative reframing of aphasia therapy when compared with a traditional way of working.

Table 12.1: Reframing of aphasia therapy

'Traditional' focus	Narrative focus
Take a case history with its emphasis on	Hear the story with the emphasis on
expert talk and opinion, marginalising the	ensuring that the voice of the person is
voice of the person.	more dominant than that of the health
• Documentation of facts.	professional.
	 Documentation of facts-as-experience from the individual's perspective.
Listening to and interpreting.	Listening with their interpretation.
Focus on what said.	Focus on <i>how</i> the story is told (i.e. submerged stories) as well as what said.
Health professional's explanatory models of aphasia dominate. Therapist as expert.	Individual's explanatory model of aphasia frames therapy. Person with aphasia as expert.
Public face of aphasia (i.e. the impairment and how the person 'functions' in day to	Private face of aphasia (i.e. the unique, personal and subjective experience of
day life). Tendency to view behaviour through the glasses of professional	living life with aphasia). Aims to look behind the mask of aphasia to the lived
theories with the risk of overlooking other possible reasons to account for behaviour.	experience of it in the context of their life story.
Focus on deviance from the norm in terms of identifying deficits, problems and needs.	Focus on abilities and achievements while taking into account the changes brought about by aphasia.
Aligns to the meta-narrative of modern medicine. Takes an individual model perspective.	Develops and aligns to counter narratives of disability (i.e. those that value difference). Takes a social model perspective.
Risk of person being a passive recipient in the therapy process.	Promotes person being an active agent in the therapy process.
Celebrates the objective.	Celebrates the subjective.
The therapist's personal, social, vocational and cultural background together with the accompanying narratives, are not necessarily considered significant.	An awareness of the possible role of the therapist's personal, social, vocational and cultural background with the accompanying narratives, have on the therapy process.

This section has discussed the implications that the results of the study have on the practice of speech and language therapy. It highlights the therapeutic role of telling one's story, as well as the need for active listening to gain insight into narratives of aphasia. It challenges our traditional role of 'fixer' and advocates the role of facilitator and collaborator in the quest to healthy living with aphasia. In so doing it outlines our role in supporting the expression of narratives and in accessing counter narratives. It

sums up by proposing a narrative way of working and contrasts this with the more traditional way of working. The following section outlines the advantages, disadvantages and limitations of using multiple methods.

12.3 ACCESSING NARRATIVES

The purpose of the study was to investigate the resources people draw on to make sense of aphasia and manage it in day to day life and unlike other studies on narrative it used a variety of methods to gain insight into this. Most other studies have used the interview method alone to gain access to the insider view of aphasia (e.g. Parr et al, 1997; Simpson, 2000). However there is one study in progress that uses a similar eclectic approach in order to explore what it is like to live with severe aphasia (Parr et al, 2001). Also Simmons-Mackie and Damico (1996) advocate using both interview and participant observation in their Communication Profiling System (CPS). That being said, the current study is unusual in the range of methods used to explore narratives of aphasia. In collecting and analysing the data the following were used: indepth interviews, informal conversations, participant observations and the selection of pictures to reflect certain times in the person's life. In addition, artefacts such as health records were sourced. A personal research journal was kept throughout the study so that I could determine the filter through which I was collecting and analysing the data.

There are a number of advantages, disadvantages to using such an eclectic approach and these are outlined here.

12.3.1 Advantages of Using Multiple Methods

The use of ethnographic techniques has been found to enhance assessment procedures of children with language delay allowing the therapist or teacher to understand patterns of communicative interaction that cannot be realised by other means (Haas, 1994). Similarly in this study I found that using multiple methods allowed me to view the person's situation from a number of different angles which all contributed to gaining a fuller and more complete composite picture of the inner experience of aphasia. For example, the interview method allowed the person to talk freely about their life both

before and after aphasia and the picture selection task allowed the person to convey what it was like at different times without relying on the spoken word. Even for those people without aphasia the picture selection task facilitated them to look at the situation from a different perspective and triggered a commentary different from that which was elicited at interview. The participant observation enabled me to view how the individual and significant others managed in more naturalistic situations, not relying solely on what was told and reported. It allowed me to verify narratives that emerged at interview. The exploration of artefacts such as the health records provided me with insight as to how the person was viewed in more of a public domain. Invariably the person was portrayed through the narratives of body as machine and restitution indicating the focus of the health care professionals and other day care staff. Documenting in this manner is understandable if one is working from an individual or medical model perspective as many health care workers are. However, a social model perspective would demand that other factors are documented (e.g. the experience of disability, how she/he and others view aphasia) in order to reflect the insider view of aphasia.

In addition to the above methods, artefacts from the public domain were sourced. These included any literature that it was felt was easily accessible to those who had a stroke and their family and friends. The aim of this was to compare the personal narratives of participants to those narratives evident in the public arena. In the main this exercise highlighted the influence that the meta-narrative of modern medicine has on people and the way in which they think about and deal with disability. This information, like the health records, viewed the disabled person as a machine which had broken down and who should seek appropriate help in order to restore to full functioning. There were, however, exceptions which took more of a social model perspective in that they focused on dismantling barriers and in portraying the inside experience of aphasia. This method allowed me to view aphasia and disability from more of a public perspective from which I could compare the private and personal perspective. This could not have been done in any other way.

The combination of these methods had the advantage of allowing me to get multiple views of the narratives that were drawn on by the person and which surrounded her/him. It allowed me to explore how these contributed to making sense of aphasia and managing it in day-to-day life. Such multiple views provided me with the opportunity to gather narratives from a variety of perspectives. It therefore provides a depth of understanding of the complexity of living with aphasia that has not been realised before.

12.3.2 Disadvantages of Using Multiple Methods

Employing multiple methods is time consuming both in terms of gathering the data and in terms of analysis. However I felt it was warranted in order to get the depth achieved. That being said it may not be necessary to go to such lengths to access narratives in day to day clinical practice. I would suggest that in-depth interviews with the person with aphasia and important others, together with the picture selection task, would allow one sufficient depth to ascertain what narratives they are drawing on to make sense of aphasia and how they manage it in day to day life.

This study was a small in-depth qualitative study exploring narratives of aphasia in three people with aphasia and some of their conversation partners. Due to the small numbers it is impossible to generalise results to the wider population, but it is likely that others also may live by numerous narratives, albeit different ones – just as Anne, Tony and May draw on numerous but different narratives to make sense of aphasia. A much larger study would be necessary before any definitive conclusions could be drawn. However this study has provided rich insight into the narratives of a number of people.

This section has outlined the advantages and disadvantages of the study. Overall it was worth undertaking as it provided an in-depth insight into how people make sense of aphasia and manage it in day to day life.

12.4 LIMITATIONS OF THE STUDY

No study is without its limitations and this study is no exception. The following provides a summary of the limitations of the study.

12.4.1 Assessing the impairment

This study involved the participation of three people with aphasia. Narratives of aphasia providing a general description of their individual aphasias were collected through conversations. Some historical data in terms of the nature of the impairment were provided from health records. The main motivation of the study was to explore narratives of stroke, aphasia and disability regardless of the type or severity of aphasia. Therefore no impairment based assessments were undertaken by the researcher as part of the study. This decision was taken because assuming the role of ethnographer places one in the role of learner, not expert and undertaking impairment based assessment places one in the role of expert. Also assessment and management of the impairment, which had been the focus of previous/current therapy experience, may have implied another attempt to provide further therapy along these lines. This was not my intention. It was for this reason that the impairment of aphasia was not formally assessed.

However it is clear that more information on the impairment would have provided insight into the nature and degree of difficulty in language processing the person was experiencing. Impairment based assessment highlights such difficulties experienced as a result of aphasia. It does not however provide a complete picture of communication abilities. For example, it would have provided only limited information about how May communicates in context. May experiences difficulties in word retrieval but she masks this with her excellent use of social communication. It is her skill in social communication that leads her family to comment that they do not feel May has any problem with her speech yet May herself complains of difficulties and these were evident at interview and in other conversations with her. While assessing the impairment of aphasia would have provided specific information about the individual's language processing it would have only provided limited information about how she/he communicates in context. Therefore formal language assessment would have provided

the opportunity to compare profiles and this would have added another dimension to the study regarding how degree and type of aphasia influence narrative. However this was not the central concern here.

12.4.2 Other non-verbal means of assessing feelings and attitudes

The study would have benefited from the use of other non-verbal means of eliciting feelings about stroke and aphasia. For example, the Visual Analogue Self-Esteem Scales (VASES) (Brumfitt & Sheeran, 1999) would have added a more quantitative view of how the person felt and the results could have been compared with the other verbal and non-verbal accounts. The VASES is a means of assessing the individual's emotional state which the authors contend is linked to self-esteem. It comprises ten bipolar visual analogue scales which depict a variety of emotional states and the person has to indicate the point on the scale which best reflects their current state. This would have added a further dimension to the study as it would have been interesting if participants had completed the VASES to indicate, like in the picture selection task, how they felt at different times – both before and after the onset of aphasia. One could then contrast and compare findings between different methods.

Another non-verbal means of eliciting what it is like to live with aphasia is the 'tree of life'. In this the person plots her/himself on the tree indicating a figure that best reflects how she/he feels at a given time. This method would have provided further insight into participants' insider views which may not be so readily accessible through the spoken word. Both the 'tree of life' and the VASES have been used with people with aphasia; indeed the VASES were designed specifically with people with aphasia in mind. Inclusion of such additional methods of accessing the insider view would have enriched the study.

12.4.3 Gender, age and social situation

The study did not specifically take into account issues surrounding gender, age and social situation. While differences were alluded to they were not considered in depth in the sampling procedure and in the analysis. The possible role they may have played in

determining the narratives different individuals drew on was not explored in detail. For example Anne's comparatively young age and her professional background which demanded precision and accuracy, may have influenced her focus on regaining her speech. Also the fact that she was a woman essentially living alone without another adult may have had a bearing on her brother Peter's strong narrative of *in need of care*. However the cultural representations of age, gender and social situation were not explored in this study yet they were relevant to its focus. The consideration of aspects such as these would have added further depth.

12.4.4 Time since stroke

While time since stroke was referred to in terms of how it might have influenced the narratives participants drew on, it was not considered in depth. However the findings of this study do suggest that narratives evolve over time. For example *chaos* was reported in the early days following stroke in all participants but not currently. Similarly *quest* was not evident when participants talked about the early days and only really began to emerge a number of years following stroke. Also time since stroke was proposed as a possible explanation for why Anne drew on a strong restitution narrative and why Tony and May no longer did. A study exploring how narratives evolve over time following a stroke would help to determine the influence that time since stroke has on the narratives people draw on to make sense of stroke and aphasia.

12.4.5 Acute phase post stroke

As alluded to in Chapter Eleven each participant's experience of the time immediately post stroke was slightly different. Anne moved hospitals in the first couple of weeks; Tony was treated homeopathically for the first week; while May remained in the one hospital. Their differing experiences were not explored in great depth, had I done so different elements in narratives may have been revealed that reflected experience at this time. Also previous experiences of illness, hospital, traditional and alternative medicine were not explored. Such information may have shed some light on the influence these experiences had on the narratives that were drawn on to make sense of stroke and

aphasia. For example, the fact that Tony opted to be treated homeopathically was not explored in depth, had I done so different narratives may have emerged.

12.4.6 Narratives of aphasia vs. narratives of stroke

Most of the narratives which emerged are narratives of stroke within which aphasia is incorporated. More could have been done in the data generation phase to explore the specific impact of aphasia as opposed to stroke in general. However that being said some narratives reflect the specific impact of aphasia. For example, Anne's body as machine and restitution narratives mainly relate to aspects of her communication that have broken down. Similarly with Tony the narratives of disability as less than whole and restitution reflect issues surrounding the impairment in language processing. With May it is more difficult to extrapolate what specifically influenced her narratives as, unlike Anne and Tony where aphasia is the main effect of stroke, May also experiences significant physical disability and is a wheelchair user. In the data generation phase attempts to explore what related to aphasia and what related to her physical disability were superficial only. It is recommended that a future study should make a specific effort to extrapolate and define what are narratives of aphasia as opposed to stroke in general.

12.4.7 Identity

The issue of identity has been raised a number of times but it has not been addressed in detail. For example moving from an individual or medical model perception of disability with its focus on disability as tragedy, to a social model perspective, which celebrates difference, involves a change in identity. Also Tony's *fatalistic* narrative has a sense that one accepts one's destiny. This links with how religion plays a strong role in Irish life (Inglis, 1998) particularly in the way in which children are reared. Tony was brought up in a religious environment in which things were explained in terms of God's will. While no longer a practising Roman Catholic these spiritual links may account for his *fatalistic* narrative. The way in which one is brought up contributes to the development of one's identity. While some tenuous links with identity are made, it

was felt that to address the issue of identity in depth was outside the scope of this study, but rather it is an area for further research.

12.4.8 Experience in qualitative research

Another limitation of this study was my inexperience in carrying out such research. A more experienced researcher may have elicited more in-depth information at interview and have been able to see things while observing that I did not. While two pilot interviews were conducted with people with aphasia in order to refine the topic guide and gain experience in in-depth interviewing none were undertaken with relatives, care staff or professionals. In hindsight it would have been advantageous to undertake such pilot interviews. Other limitations associated with my personal background and lack of experience in qualitative research methods are discussed in Chapter Ten which presents 'my story' in the research process. However, despite these conditions, a great deal of depth was achieved, and much was learnt in the process.

This section has outlined the limitations of the study. However despite these a depth of insight into what it is like to live with aphasia was acquired which has not been realised before. In addition a great deal was learnt in the process of undertaking this study.

The following section goes on to contemplate the way forward with regard to other research implications.

12.5 FUTURE DIRECTIONS

This study has extended the work of such people as Simmons-Mackie and Damico (1996), Parr et al (1997), Byng et al (2000), Pound et al (2000) and Simmons-Mackie (2001) in the way in which it emphasises the insider perspective. It particularly explored narratives of aphasia as a means of gaining insight into how people make sense of and manage aphasia in day to day life. However it posed more questions than answers. I have identified six key areas on which one could base future research:

- i. Are the narratives elicited in this study typical of people with acquired communication impairment? What about type and severity of impairment? Does this influence narrative?
- ii. Do people with physical impairment draw on similar narratives?
- iii. Do people with developmental communication impairments draw on similar narratives?
- iv. How do narratives change over time? What is the influence of time since stroke on narrative construction?
- v. How does one determine from the person's perspective whether a narrative contributes to overall feelings of well-being?
- vi. What methods are most effective in bringing about change in narrative (re)construction?

These are just some of the questions that arose during the course of this study. It is recommended that further research should address some of these issues if knowledge of the role of narrative in the process of living life healthily with disability is to be established. This study is only an initial foray into the subject.

12.6 FINAL COMMENT

This study reveals the complex tapestry of narratives that surrounds a person with aphasia in the process of making sense of it and managing it in day to day life. However while each participant drew on many narratives, each had one or two particularly strong narratives that seemed to dominate the way in which they managed and lived life with aphasia. In general public narratives of disability, particularly those guided by the meta-narrative of modern medicine, influenced how the person experienced and managed aphasia. In this study public narratives underpinned personal narratives; they determined how the person with aphasia behaved and how others behaved towards her/him.

If we are to work with the person with aphasia collaboratively towards the goal of living life healthily with aphasia, then the narratives that people live by have to be

taken into consideration in all their tangled mess. We need to expand our role beyond working with the impairment alone. Lyon (1999) highlights the necessity of working closely with the person with aphasia and other people in her/his context when he says:

It means that we can no longer devote the lion's share of therapeutic time and resources to the repair of linguistic and/or communicative breakdown in the injured party. It means that we must broaden our therapeutic contexts to include the dynamics of family and community and to rejuvenate disrupted life processes that seemingly stand in the way. As such, aphasia treatment should not be a process of a person, but of people. It should not be a process of 'just' language and communication repair, but of facilitating purpose and meaning in life and strengthening ties with others in those natural life contexts that matter the most. (p.689)

In working with the person with aphasia and their important others one may find that they are living by a narrative (or narratives) that does not contribute to feelings of well-being. This was the case of John discussed in Chapter One whereby his narrative of difficulty in speech means you're learning disabled and less than whole inhibited him from going out and mixing with people much more than his actual impairment did. Working with narratives can open up different ways of thinking about and experiencing aphasia that may enhance healthy living.

While generating and analysing narratives is a lengthy and complex task, taking account of narratives of aphasia is a powerful way of gaining insight into the aphasia experience and is time well spent. It enables one to view aphasia from the individual's perspective and facilitates one to work collaboratively with the individual towards the goal of healthy living. Awareness of narratives that do not enhance feelings of well-being may guide therapy towards narrative reconstruction and so may make a positive difference to the way the person lives her/his life.

While the individual model dominates in the way in which people with aphasia and their significant others think about aphasia and how aphasia is treated, the past few years have seen a surge of interest in applying a social model perspective to aphasia therapy (e.g. Penman, 1998; Pound *et al*, 2000; Simmons-Mackie, 2000, 2001; Stirling, 2003). Such work as undertaken by these authors demands reflection on the part of practitioners as to the role of the speech and language therapist. The aims, methods and findings of this study contribute to this body of literature in that the study addresses the

insider perspectives of those with aphasia and a number of their significant others. It is about exploring what it is like to live with aphasia or to know someone with aphasia. This study is innovative in that it provides insight into narratives that both surround people with aphasia and are created and experienced by them; such work has not been undertaken before. It reveals the complexity of living with aphasia in the form of the many narratives that emerged from the participants with aphasia and those around them. There was agreement with some narratives and not others. All narratives were influenced by public narratives and in particular the meta-narrative of modern medicine. Up until this time one could only assume that there were many influences on the person with aphasia and some of those close to her/him in making sense of it in day-to-day life. This study adds to our understanding of the complexity of living life with aphasia in a way that has not been done before.

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