

Hoping and coping: Understanding the experiences of people with glioma

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Declaration

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Summary

Overall median survival for malignant glioma or 'brain tumour' (hereafter glioma) is limited; few patients will survive longer than two years and many patients will live in a prolonged state of dependency with high attendant care needs, early cognitive failure, and prognostic uncertainty. Researchers have already undertaken specific studies identifying supportive care needs of glioma patients and caregivers, however little is currently known about people's experiences of living with a glioma diagnosis, from the point of diagnosis through the stages of treatment. The core aim of this study is to describe and explain how service-users come to terms with, adapt and cope with their illness from diagnosis through the initial stages of treatment. A related aim is to enhance best practice protocols in oncology services which are informed by service user perspectives.

Grounded Theory method was used to capture the experiences of people with glioma diagnosis across the treatment trajectory. Sixteen people with a recent diagnosis of glioma were sampled from a specialist radiation-oncology hospital upon referral to the hospital for treatment, approximately four weeks post-neurosurgery. Repeated in-depth qualitative interviews were conducted at the start of treatment, end of treatment and 3-4 months post-treatment with each participant regarding their experiences of their illness journey. All 43 interviews were transcribed. Data were collected and analysed in tandem, and emerging findings guided sampling. Data were analysed using initial, focused, and theoretical coding procedures. Reflexive and theoretical memos were compiled to guide sampling and to build substantive theory. NVivo12 was used as a tool to store coded data and memos, to link memos to codes and to develop the analysis.

The study illuminated the participants' experiences of becoming unwell, receiving their diagnosis and their introduction to the treatment process. It identified the sudden shock with which the unexpected and inexplicable illness arose, along with the speed at which medical interventions commenced. The subsequent uncertainty and loss of control was central to the early experiences of glioma patients. The study demonstrated the initial questions and thoughts of the participants as they sought to

come to terms with and make sense of the illness. Throughout their early experiences and interactions the participants displayed behaviours and engaged in actions which could enable them to locate and preserve their ability to have hope for their future, despite the troubling diagnosis being communicated to them.

This study is unique in its identification and exploration of the roles that embodiment and uncertainty had on the experiences of glioma patients. The uncertainty of their future and speed with which the illness occurred and treatment commenced caused difficulty coming to terms with the illness and integrating the reality of their circumstances into their understandings of their 'self'. Participants engaged in processes of monitoring their selves in order to gain insight into their body's response to treatment. This study highlighted the prominent role of embodiment in the illness experience as participants' emotional state and ability to cope was closely linked with how they felt physically. Feeling physically well engendered the ability to have hope for a positive outcome. Conversely, the arrival of symptoms of the disease and side effects of treatment prompted disappointment and disillusionment with treatment, challenging people's ability to have hope. As the implications of the illness began to manifest causing physical and social limitations, participants fought against the generalised identity of 'cancer patient' and sought to preserve their individuality by maintaining their dignity and independence.

The participants' aim during the time of the interviews was to achieve sufficient adaptation and adjustment to their illness so that they could make the most of daily life, while they had the ability to do so. Achieving this required coping with thoughts of the likely outcome of their illness. By exerting control over their thoughts, participants adapted a coping frame of mind allowing them to create a 'tolerable reality' which they occupied during everyday life.

The study found that hope, specifically hope for a better outcome, was the necessary element allowing people to cope with their illness despite their knowledge of their dismal future. Participants engaged in thoughts and behaviours which maintained their ability to hope for a better outcome, allowing them to cope with their illness,

resulting in their ability to make the most of everyday life. Conversely, people's ability to maintain hope was bolstered by their ability cope on a daily basis. People with glioma must maintain hope to cope, but also must perceive that they are able to cope, in order to maintain hope.

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Chapter One: Introduction

1.1 Introduction

As modern medicine has become increasingly proficient in managing malignancies and prolonging survival, issues related to quality of life in persons with cancer have become more prominent. Despite the attention given to quality of life in persons with cancer in general, very little is currently known about quality of life in persons with brain tumours, and how they experience their illness. Recent advances in the diagnosis and treatment of primary malignant brain tumours (glioma) have improved survival for those affected, and more people with glioma are living for longer periods of time (Lovely et al., 2013; Rock, Mcardle, Forde, & Faul, 2011; Steinbach et al., 2006). However, despite these advances in clinical treatment, patients with glioma diagnoses still experience high symptom burden and poor survival rates.

People with primary malignant brain tumour diagnoses also known as glioma are a heterogeneous group with unique needs which often differ from patients with other terminal malignancies. Those living with glioma must adapt to, and cope with, changes and losses to their physical, cognitive and emotional abilities. Their abilities may be further or continuously influenced by residual or recurrent tumour(s), or treatment-related complications (Russell et al., 2014). Researching this type of diagnosis encompasses a participant population with prognoses ranging from 8 months to 5 years, and includes patients who may be receiving radical (curative) and/or palliative treatment. Researching this patient group is different to researching other cancer diagnoses because this condition presents people with a cancer diagnosis, a terminal diagnosis, and a degenerative neurological condition.

1.2 Background and rationale

On average, about 290 malignant primary tumours of the brain are diagnosed in Ireland every year, representing just under 2% of all invasive cancers (NCRI, 2016). The total figure worldwide amounts to approximately 256,000 people and approximately 189,000 die as a result each year (Ferlay et al., 2013). Glioma are more commonly diagnosed in men than in women and the median age at diagnosis is 60 although onset can occur at any age. A further 40 non-malignant tumours of the brain are diagnosed annually in Ireland, on average, along with about 190 tumours (mainly benign) of other parts of the central nervous system and surrounding membranes (meninges) (NCRI, 2016). These, and secondary cancers of the brain originating from primary cancers elsewhere in the body, are not considered further in this study.

Astrocytic tumours are the most common subtype (about 67%) of all malignant brain cancers; of these, the majority (in adults) are high-grade glioblastomas (GBM). A further 15% of cases fall within other specific subtypes. Classification of brain tumours is complex, and almost 20% of Irish cases are not classified to subtype; largely as a result of some patients, particularly the elderly (over 70), not undergoing biopsy or surgery and being diagnosed through imaging or clinical assessment only (due to the greater potential for complications during treatment). There has, however, been an increase in the proportion of patients pathologically diagnosed over time (NCRI, 2016).

Average survival rates are poor and, for primary malignant brain cancers as a whole, five-year net survival remains unchanged at 19%. Glioblastoma and other high-grade astrocytic tumours have the poorest survival with just 4% of glioblastoma patients surviving five years post diagnosis. Glioblastoma (GBM) is the most common primary malignant brain tumour in adults. Regardless of ideal multidisciplinary treatment (including maximal surgical resection, followed by radiotherapy plus chemotherapy) almost all patients experience tumour progression with nearly universal mortality and a median survival of less than 15 months (Fernandes et al., 2017, Stupp et al., 2005), while those with low-grade glioma have a median survival of 6 to 13 years (Houillier et al., 2010). Glioblastoma patients not only have cancer, but also a progressive brain

disease, differentiating them from patients with other cancers or patients with cognitive impairment or dementia (Fritz et al., 2016).

Many patients will live in a prolonged state of dependency with high attendant care needs, early cognitive failure and prognostic uncertainty (Faithfull, Cook, & Lucas, 2005; Moore et al., 2013). Along with a poor prognosis, challenges faced by people with glioma may include declining cognition, limited or complete loss of mobility, loss or changes to memory and personality or the perception or fear of becoming a burden on their family. Fatigue, sleep disturbance and pain are the most frequent symptom complaints, but patients also have difficulties with other realms of quality of life including difficulties with cognitive and emotional dimensions (Liu, Page, Solheim, Fox, & Chang, 2009). Personality change, seizures, motor deficits, gait impairment and other disabling symptoms are each prevalent in 30-70% of patients with high-grade brain tumour at the end-of-life (Faithfull et al., 2005; Gofton, Graber, & Carver, 2012). Unsurprisingly, previous studies on the topic have reported that up to 63% of people with primary malignant brain tumours have reported feeling distressed (Keir, Guill, Carter, & Friedman, 2006) and the profound impact on caregivers and or family members has in recent years been recognised (Cavers et al., 2012; Flechl et al., 2013).

1.3 Understanding the patient experience

After receiving the diagnosis, the individual and their family must face the issues presented by a cancer diagnosis combined with a degenerative neurological condition. An Australian study into end-of-life experiences of people with glioma by Philip and colleagues (2014) characterized the patients' experiences as a pervasive loss of all that encompassed their former sense of self and a focus on immediate needs. Limited empirical knowledge exists to describe the needs of those directly affected by glioma (Moore et al., 2013), particularly patients and their carers (Faithful et al., 2005), thus the provision of supportive and palliative care services is ill-defined (Catt, Chalmers, & Fallowfield, 2008), and as a result frequently *ad hoc* (Faithful et al., 2005).

Salander et al. (1996) posit that the limited survival expectancy might be one of the reasons why the psychosocial condition of these patients is a neglected area in research. Fox and Lantz go as far as to label the lack of research into the experience of living with a brain tumour diagnosis as 'disturbing' (1998). At present, the evidence-base informing service provision and supportive interventions for people with glioma is limited, with this study being the first of its kind in Ireland focusing on this patient-group. Interventions by doctors and health and social care professionals can prompt a ripple effect across the illness experience. At a time when every day counts, we need to understand how people experience their illness journey, so that they can live daily life while they have the ability to do so. Interpretative research which focuses on the subjective experience of service users as they come to terms with, and engage with, the treatments and processes following diagnosis, has the capacity to ensure that best practice protocols are developed with a view to patient perspectives on what optimal services should be like.

1.4 Aims and objectives of the study

The purpose of this thesis is to develop a substantive framework describing how people with glioma experience their diagnosis and parts of their treatment journey. The overarching aim of the study is to inform service provision for those with glioma, by eliciting how people experience and understand their illness throughout the initial phases of treatment. This study employed the Grounded Theory method and qualitative interviews in order to explore, in great depth, the phenomenon of living with a glioma diagnosis, and to describe and theorise how individuals experience and attempt to adapt to, and cope with, a degenerative life-threatening illness - from diagnosis through different stages of treatment. Research questions focused on the person's understanding of the illness, their experience of its development over time, the impact of the diagnosis on daily living, their ability to cope with the transitions related to the disease trajectory, their engagement with medical and psychosocial support services, and the ways in which people make sense of this experience.

Most grounded theories are substantive theories because they address delimited

problems in specific substantive areas and contexts (Charmaz, 2006), in this case the experiences of people with glioma in Ireland. Substantive theory was developed during the research, and through a continuous interplay of data analysis and collection (Strauss & Corbin, 1994) and, as a result, the theorising presented in this thesis both describes and explains phenomena (Corbin & Strauss, 2008). The findings of this study were analysed, through conceptualisation of the key components of the participants' experiences, which in turn constituted (through examination and explanation of the relationships between concepts) a theory that explains how people with glioma experience their diagnosis. Generating abstract concepts and specifying relationships between them can mean it is possible to shed light on problems in multiple substantive areas with the help of a substantive theory (Charmaz, 2006). Therefore, it is hoped that the theory generated from this study will be of relevance not only to glioma patients, but to other forms of terminal or degenerative neurological illness.

1.5 Defining terms

1.5.1 Glioma/brain tumour

This study specifically focused on the experience of those with glioma. In this thesis, the term 'glioma' will be term used to refer to the various sub-categories of brain tumour experienced by the participants which prompted the commencement of their treatment journey. Gliomas are primary brain tumours originating from glial cells of the central nervous system, which rarely disseminate outside the nervous system but grow diffusely into the surrounding brain tissue (Fritz et al., 2016). This characteristic growth pattern attributes to the nearly always incurable nature of gliomas. Gliomas represent 74.6% of malignant brain tumours (Ostrom et al., 2017).

Although this study focuses on the specific type of brain tumour- 'glioma'- the broad term 'brain tumour' will be used in Chapter Two when discussing studies in which the exact tumour type is not explicit. A number of the studies discussed in Chapter Two included patients with glioma as well as alternative categories of brain tumours, benign tumours (noncancerous or precancerous) or secondary cancer of the brain (metastatic brain cancer/tumours) .

1.5.2 Treatment: the participants' illness journey

Treatment for a primary malignant brain tumour can take the form of either radical treatment (intent to cure) or palliative treatment (symptom and pain management). The typical pathway for people in receipt of radical treatment for glioma usually consists of neurosurgery followed by a four-week recovery period followed by 6 weeks intensive radiotherapy and either combined with, or followed, by 6 months chemotherapy. In comparison, palliative treatment usually consists of a biopsy or an attempt at removing the tumour through neurosurgery followed by between 5 to 10 days of radiotherapy with the aim of managing symptoms and promoting comfort. The decision to adopt either a radical or a palliative approach is made by the team of surgeons, oncologists and radiation oncologists involved in the patient's care, while considering the patient's and his or her family members' wishes.

All participants recruited for this study were undergoing radical radiotherapy based on the fact that it best supported the longitudinal element of the study. Only those receiving radical radiotherapy (6 weeks) were recruited for the study, as opposed to palliative radiotherapy (10 days), in order to allow for a full examination of the journey (i.e. less likely they would become very unwell, have severe cognitive impairment, or drop out of the study).

This study was a single-site study and was conducted in a specialist radiation-oncology centre in Dublin. The participants in this study underwent neurosurgery in an acute hospital elsewhere, and were referred to the radiation oncology study in which the study took place on a geographical basis or having been identified or requiring support throughout treatment (i.e. those likely to become unwell/deteriorate during treatment or those with identified emotional or social supportive needs).

Participants attended the radiation oncology centre for six weeks during which they received chemotherapy which was taken orally in the form of a tablet. Upon completion of this phase of treatment the participants had a four week break before

commencing chemotherapy again as outpatients for an additional 6-8 months. This treatment phase only required monthly attendance at follow-up clinics to monitor the person's response to chemotherapy.

In this thesis the term 'treatment' is used to denote the 6 week course of radiotherapy and combined chemotherapy undertaken by the participants, during which the initial two interviews were conducted. The final interview was conducted when the participant returned to the hospital for follow-up.

1.6 Context and the researcher

Reflexive research refers to consideration of the researcher's role, and her or his impact on the construction of knowledge throughout the research process. The reflexive researcher maintains that knowledge is co-constructed by both the researcher and participants and is informed by both the researchers and the participants positioning (both personal and social) and their biases (Charmaz 2014). My initial interest in undertaking this study was influenced by my experiences working with people undergoing treatment for glioma towards the end of my Medical Social Work training. During my training I became curious as to how people with glioma seemed to cope, despite their unimaginable situation. Upon trying to inform my practice as a social worker, I realised there was very little research available to provide guidance on how best to support this patient group. Therefore, I undertook this study so that I, and others, could understand how people with glioma experienced their illness.

By acknowledging that qualitative research can never be objective, I must consider my role in co-constructing the experiences reported in this thesis. This study and its findings are shaped by my own experience as social worker, along with the many personal elements which make me, me. However, my experience of glioma is grounded in the provision of health and social care only, and not from personal contexts. I undertook this study in the context of a social and healthcare professional with the view to enhancing my abilities as a researcher and my ability to make a

difference in the lives of people experiencing serious illness. Chapter Three provides a detailed account of my understanding and undertaking of reflexive practice throughout the conduct of this study. It is with consideration of these properties and attributes that I locate myself in this study.

1.7 Locating the research in an Irish context

This study seeks to capture the experiences of people with a recent glioma diagnosis in the Republic of Ireland. There is little to no policy or practice guidelines informing the provision of psychosocial care of this patient group in Ireland. Even though this study is focused on the experiences of people in Ireland, their experiences can be compared to people with glioma (and indeed a range of other cancers and neurodegenerative diseases, both terminal and curative) outside of Ireland. The existing research conducted in Ireland is solely scientific/medical in nature and focused on extending and/or improving survival of people with glioma (particularly those with glioblastoma multiforme).

As previously mentioned, the underrepresentation of glioma patients in research potentially stems from the incurable nature of the disease and the limited survival of those afflicted. The last 5 years have seen a marginal increase in interest in the provision of support to glioma patients in Ireland. However, an evidence-based approach to care involving a coordinated and integrated pathway within formal care settings is still lacking. A study of this kind has not been conducted in Ireland to date. Given the unique experience of those with glioma, best practice will only be possible when a broad understanding of the subjective experience of living with a glioma is developed.

1.8 Structure of the thesis

The thesis comprises of seven chapters. This chapter (Chapter One) has explained the rationale for undertaking the study, outlined the aim and objectives of the study, explained the diagnosis of glioma and the processes involved in treatment while situating and making explicit my own context within the study.

Chapter Two outlines the literature pertaining to the topic of investigation. It documents a detailed review of existing studies that have sought to detail the experiences of people with glioma, experiences of the onset of the disease, as well as literature identifying the information and supportive care needs of people with glioma and palliative care and awareness of dying within the context of glioma. The chapter also reviews relevant literature on grief, loss and bereavement, post-traumatic growth and adaptation to cancer and terminal illness.

Chapter Three outlines the methods used in the conduct of this study. In this chapter I outline my own ontological viewpoint and the potential impact of this viewpoint on the study and my interpretations of the patient experience. The chapter provides a detailed account of the steps taken throughout the research and the methods which allowed the development of a substantive and explanatory theory.

The findings of this study are presented over the course of three chapters (Chapters Four, Five and Six). The progression of the findings chapters reflects, to a degree, the chronological progression of the experiences as captured by the repeated interviews throughout the treatment journey. Chapter Four is primarily descriptive in nature and serves to introduce the participants and provide insight into their early experiences of becoming unwell and their initial responses upon receiving their diagnosis. It also seeks to lay the groundwork for the more abstract and conceptualised discussions in the later chapters. Chapter Five centres around the internal and private thoughts of the participants as they attempt to come to terms with their diagnosis and its implications for their body, sense of self and independence. It examines the relationships between the physical experiences and the emotional experiences of illness and how these relationships impacted the participants' understanding of their diagnosis. Chapter Six provides an insight into how participants create and maintain a 'tolerable reality', allowing them to cope on a daily basis. The chapter develops on the preceding findings and offers a more conceptual and abstract rendering of the motivations behind the participants' behaviours and thoughts.

Chapter Seven (Conclusions) synthesizes the findings portrayed in the earlier chapters, and in doing so reveals the central storyline of the experiences of the participants in this study. The analytic rendering of the central storyline offers a substantive theory that explains how people with glioma experience their illness across the initial treatment trajectory. Importantly, the theory gives an account of what influences the behaviours of people with glioma, and why they experience the illness as they do. This chapter situates this study and its findings within the existing knowledge base and offers recommendations for practice which were based on the understandings and descriptions that emerged from the study.

Chapter Two: A review of the literature relevant to the experience of glioma patients

2.1 Introduction

Glioma is a severe disease with little chance of recovery. It causes cognitive and physical deterioration affecting all facets of a person's life and identity, with a significant resulting impact on family life and work. Although prognosis is poor, recent medical advances have managed to begin to improve survival outcomes in Ireland (Rock et al., 2011). Due to these advances in treatment, people with glioma may be

able to live for longer, albeit with significant impairments. Lovely et al., (2013) examined the experiences of those who had survived a high-grade glioma for three years or more and found that they experienced profound change and loss in their lives.

The experiences of glioma patients are unique. While this patient population somewhat resembles those with neurodegenerative disorders, the nature of the illness can be progressive with a rapid cognitive decline uncommon in other malignancies and in most neurodegenerative disorders. Frequently the diagnosis is made following a sudden emergent event such as a seizure, and the patient may never return to normalcy in terms of functioning or cognition. The deleterious psychosocial effects of a malignant brain tumour and its treatments on patients and their family are profound (Catt et al., 2008).

2.2 Method of literature review

A systematic review of the literature was conducted in order to integrate, evaluate and interpret the findings of the existing research on the topic of glioma and relevant theoretical frameworks informing living with illness. As the first study of its kind in the Irish context, and with very limited information available internationally regarding the processes informing the study of this experience, this approach was selected to allow for a multi-focal exploration to begin the construction and combination of themes and theories in order to develop a body of knowledge for this Grounded Theory study.

An ongoing search of the relevant literature took place between September 2015 and June 2016 prior to fieldwork, and again between June 2017 and September 2018 during the later stages of data analysis and theorizing. The key aspects of the journey of those with glioma available in the existing research, pertinent to the topic of investigation are provided below.

By way of more systematic searches that followed, databases searched in order to conduct this review included PubMed, TARA, NCBI, CINAHL, Trinity College Dublin's library database, Web of Science, ScienceDirect, PsychoInfo and Google Scholar.

Particularly relevant journals include the Journal of Neuro-Oncology, the Journal of Psychosocial Oncology, the Journal of Death Studies, the Clinical Journal of Oncology Nursing, the European Journal of Oncology Nursing, the Journal of Social Science and Medicine, the Journal of Neuropsychological Rehabilitation, the Journal of Neuroscience Nursing, the Journal of Palliative Medicine, the Journal of Medical Humanities, the Psycho-Oncology Journal, and Qualitative Health Research. The search terms used included; *'glioma'*, *'brain tumour'*, *'cancer'*, *'patient experience'*, *'psychosocial'*, *'palliative care'*, *'end-of-life care'* *'experience'*, *'understanding'*, *'communication'*, *'adjustment'* and *'coping'*. The search covered a time span of the last 10 and subsequently 20 years. The literature review that is presented below is a narrative review.

The approach taken for this review was chosen in order to provide the reader with an overview of the phenomenon of glioma and the many difficulties afflicted patients face. This review examines the available literature pertaining to the aims and findings of this study, and identifies gaps in the research which require further investigation. These will be discussed in Section 2.8. This chapter will first detail the experiences of the onset of glioma using the literature available. It will then outline the existing literature exploring the experiences of people with glioma, including their experiences of palliative care and dying. The review will then provide an overview of the concepts of adaptation, coping and adjustment within the broader illness experience, followed by the research specific to glioma.

2.3 Onset of glioma and brain tumours

Gliomas are primary brain tumours originating from glial cells of the central nervous system, which rarely disseminate outside the nervous system but grow diffusely into the surrounding brain tissue; this characteristic growth pattern attributes to the nearly always incurable nature of gliomas (Fritz et al., 2016). Previously, the classification of these tumours was mainly based on histological features (Louis et al., 2007) resulting in low-grade and high-grade gliomas, with a higher grade being more malignant. This is reflected in the median survival of patients: low-grade glioma patients have a

median survival of 6 to 13 years (Houillier et al., 2010), while patients with glioblastoma have a median survival of only 15 months (Stupp et al., 2005). Recently, the WHO classification has been revised, now including molecular parameters in addition to histology to define tumour entities (Louis et al., 2016). These new criteria allow better prediction of response to treatment and prognosis. Other prognostic factors for survival are age, performance status, tumour location, and extent of surgical resection (Davis, 2016).

The onset of glioma can present in a variety of manners, meaning diagnosis may be not be immediately recognisable by General Practitioners (GPs). This can cause a delay in the person seeking medical attention, and/or a delay in formal diagnosis and care due to the difficulty in recognising subtle symptoms. Ozawa et al. (2018) conducted a secondary analysis of brain tumour cases from a national data source in the UK in order to establish how different symptoms predict variations in time to brain tumour diagnosis and found the most common presentation was focal neurology (difficulty with brain/nerve/muscle function), followed by 'fits, faints and falls' combined with headaches. The study found that people presenting to primary care services (GP) with headaches or memory problems (in isolation) experienced potentially avoidable delays in referral leading to a longer pathway to diagnosis and treatment. Salander, Bergenheim, Hamberg, & Henriksson, (1999) suggested this could be a result of 'reasonable alternative diagnoses', the doctors' reluctance to change their initial diagnosis, or the doctors' personal values regarding the efficacy of treatment. Other than delays on the part of primary care providers, Salander et al. (1999) identified the obstacles on the pathway to medical care on behalf of the patient themselves. These delays were imposed by the presence of symptoms that were not perceived to be abnormal (such as headache), personality changes caused by the presence of the tumour and avoidance. The authors also identified spouses' passivity or adaptation to the presence of the symptoms in their lives as obstacles to diagnosis.

Despite multimodal treatment with surgery, radiotherapy and chemotherapy, most gliomas are still incurable. Patients may present with various symptoms and signs such as increased intracranial pressure, resulting from a rapidly growing tumour, or the

condition can manifest itself in progressive headache, nausea, vomiting, drowsiness, and visual abnormalities. Other symptoms are partial or generalized seizures, progressive focal neurologic deficits and cognitive decline (Fritz et al., 2016). The diagnosis of glioma brings about shock and a recognition of death for both the patient and the caregiver (Sterckx et al, 2013).

2.3 The experiences of glioma patients

In a study on the quality of life of glioma patients and their caregivers, Fox and Lantz, (1998) found that the stigma of the mind-body illness, the loss of self - caused by the loss of memory and previous abilities - the colossal impact of the illness on the family, the issues navigating the medical system, and the need to live were identified as key elements of the experience. The significance of the body in the experiences of those with glioma is also discussed by Salander, Bergenheim, and Henriksson (1996). Here, the authors examined how the patient constructs a new sense of reality when confronted with a malignant brain tumour diagnosis and found that feeling healthy makes it easier to suppress knowledge about the disease, makes intimidating information less credible, and promotes a general confidence for the future based on perceptions of having sound bodies.

In a longitudinal, exploratory study with nine people (yielding 21 interviews), Molassiotis et al. (2010) found that people with (a range of different types of) brain tumours identified key challenges as ongoing fatigue, memory loss and inability to drive. In a review of the literature concerning patient and caregiver perspectives, Sterckx et al. (2013) found patients struggled most with coping with restrictions as a result of the loss of autonomy.

Although those with low-grade gliomas do not face as short a prognosis as those with high grade tumours, their diagnosis is nonetheless irreversible, meaning that they may live for longer but with increasing cognitive, physical and emotional deficits. In response to a paucity in qualitative research on the experiences of people with low-grade glioma, Edvardsson and Ahlström (2005) sought to explore the challenges faced

by this patient group. The authors found that those with low-grade glioma faced cognitive issues such as deteriorated concentration, emotional problems dominated by sadness, difficulties with communication and difficulties with perception, primarily sight and hearing. They also struggled with problems concerning employment, education, driving a car and leisure activities.

Fox and Lantz (1998), amongst others, included participants with a variety of tumour types who were at various points of the disease and treatment journey. They also included those with metastatic disease of the brain¹. Similarly in their study on how people with brain tumours make sense of their diagnosis Ownsworth, Chambers, Hawkes, Walker, and Shum (2011) included people with both benign and malignant tumours. For the purpose of informing psychosocial service provision, it can be assumed that the experiences associated with brain metastases differ from that of primary brain tumours (given that the person with metastatic disease would also be dealing with a primary tumour elsewhere in their body). Although these studies provide a broad understanding of the experiences of those with various forms of brain cancer, more insight is needed specifically regarding how people with glioma experience their illness in order to improve the provision of services.

2.3.1 Loss and 'loss of self'

Loss is a universal concept and is closely associated with the experience of illness (Foley, Timonen, & Hardiman, 2014; Parkes & Prigerson, 2013). Further, dying persons experience multiple, accumulating, and profound losses of functions, abilities, roles, and relationships and are therefore forced to adjust and adapt (Knight & Emanuel, 2007). In a recent Irish study that explored the topic of adapting to loss in amyotrophic lateral sclerosis, Foley et al. (2014) found that losing hope and 'losing out on the future' were two primary dimensions to participant's experience of loss. As a neurodegenerative disorder, there can be some close comparisons drawn between amyotrophic lateral sclerosis and a primary malignant brain tumour diagnosis;

¹ Secondary cancer of the brain. When the cancer does not originate in the brain, rather, it travels there from a primary cancer elsewhere in the body, most commonly lung or breast.

however Fox & Lantz (1998) suggest that the 'loss of self' is unique to the brain tumour experience. In the context of living with a brain tumour diagnosis, Philip and colleagues (2014) described an impending sense of loss and decline combined with feelings of vulnerability.

One of the core themes arising from the grounded theory study conducted by Fox & Lantz (1998) includes the impact of the tumour on the 'self'. Participants experiencing memory loss described it as 'losing track of who you really are'; the participants equated their loss of memory with a 'loss of self'. It is also important to remember that this loss of memory and perceived loss of self often takes place within the context of a gradual or sudden loss of mobility, senses and/or bodily/motor functions. Echoing this, Philip et al. (2014) in Australia reported that the patient experience of living and dying with a primary malignant brain tumour is characterized by a pervasive loss of all that encompassed their former sense of self, while (Foley, Timonen, & Hardiman, 2014; Parkes & Prigerson, 2013) summarised that from the point of diagnosis onwards, the patient's life was marked by loss.

Philip et al. (2014) found that the phenomenon of 'loss of self' was closely linked to physical deterioration and restriction of their ability to undertake everyday tasks, while (Adelbratt & Strang, 2000) furthered that the gradual loss of autonomy became a metaphor for dying in the lives of brain tumour patients. This in turn was enhanced by a feeling of loneliness and isolation caused by changed relationships, misunderstandings, a lack of appreciation regarding changes and difficulties, and physical limitations inhibiting social life. Similarly, relatives report feelings of powerlessness, helplessness, and isolation, and their own health and wellbeing often suffer (Catt et al., 2008).

2.3.2 Hope in illness

Cavers et al. (2012), Molassiotis et al. (2010) and Salander et al. (1996) conducted repeat interviews throughout the treatment/disease trajectory of people with glioma. Cavers et al. (2012) described the distress experienced by patients leading up to and

after formal diagnosis but despite their declining health, found both patients and caregivers worked hard to foster a sense of hope and well-being, although they often fluctuated between that and despair throughout their experience. Salander et al. (1996) found hope to be a positive coping response to a diagnosis of glioma, a response which may mediate helplessness, powerlessness and hopelessness. Acquaye et al. (2016) maintain that the ambiguity of defining hope impacts the abilities of healthcare professionals working with glioma patients, given its unpredictable nature. In their study Acquaye and colleagues (2016) found a correlation between hope and mood, suggesting that interventions targeting hope may have an impact on negative mood states and facilitate positive coping strategies.

The theme of hope emerges in the empirical literature as an important method of coping and making sense of the cancer and/or glioma diagnosis (Catt et al., 2008; O'Connor, Wicker, & Germino, 1990). Snyder et al. (1991) define hope as goal-directed thinking, in which people appraise their capability to produce workable routes to goals, pathways thinking, along with their potential to initiate and sustain movement via a pathway (agency thinking). Pathways thinking refers to thoughts that one can generate for attaining goals; agentic thinking refers to the perceptions involving one's capacity to initiate and sustain movement along the chosen pathways.

Hope within the context of glioma was generally fuelled by the expectation of achieving future good; thoughts of others; treatments; religious faith; and expectation of a positive outcome (Ford, Catt, Chalmers, & Fallowfield, 2012). Rosenblum et al. (2009) found that participants believed hope helped them to live longer because of its positive impact on stress, leading to better strength and ability to fight the disease. Treatment then offers a positive shift from despair to hope, particularly the prospect of positive post-treatment scan results (Adelbratt & Strang, 2000, Rosenblum et al., 2009). The receipt of good news from imaging tests is a time of great hope (Sterckx et al., 2013). However, the existing research explains that hope is vulnerable and easily undermined, while hearing the prognosis or that the disease is 'terminal' takes all hope away (Lobb, Halkett, & Nowak, 2011; Rosenblum et al., 2009). Piil et al. (2015) and Clayton et al. (2005) reported the unmet need of being supported by healthcare

professionals concerning hope. Such a concern did not feature in the experiences of the participants of this PhD study, who rather than depend on hope from external sources, strengthened and protected themselves by creating and maintaining hope for their future (see Chapters Four, Five and Six).

2.4 Information and support needs of glioma patients

Most notable throughout the literature is patients' dissatisfaction with communication surrounding their diagnosis between healthcare professionals (Ford et al., 2012). Information provision and awareness of the serious implications of a glioma diagnosis are vital elements in the provision of support to this patient group given the life-threatening and often terminal nature of the illness. Existing studies found that patients were dissatisfied with health care provider communication and information provision (Fox & Lantz, 1998, Halkett, Lobb, Oldham, & Nowak, 2010, Lobb, Halkett, & Nowak, 2011, Sterckx et al., 2015). Fox & Lantz, (1998) found that patients and caregivers believed doctors were not forthcoming with information and they struggled to obtain any pertinent information, often resorting to having to find out for themselves. From a nursing perspective O'Donnell (2005) found that informational support by nurses was essential to enhancing glioma patients' ability to cope with their diagnosis. The author called for greater accuracy in the information given to patients during their time in hospital (O'Donnell, 2005).

Despite the available research highlighting the difficulties glioma patients face in accessing information, there are gaps in the evidence base surrounding how much patients want to know and how best to disclose diagnosis and prognosis (Ford et al., 2012; Taillibert, Laigle-Donadey, & Sanson, 2004). A quantitative study by Díaz et al. (2009) found that patients' information preferences varied between wanting to know everything and wanting to know nothing, and that those who wanted to know more information about their prognosis expressed less anxiety. Patients in the study by Molassiotis et al. (2010) expressed anger and dissatisfaction about the way the diagnosis is delivered. Some patients reported having misunderstood the terminal

nature of the condition. Halkett et al. (2010b) found that medical jargon and/or the shock of the diagnosis hindered the correct registration of information.

Tension surrounding the provision of prognostic information stems from the fear of removing the person's ability to hope, however, in a study by Clayton, Butow, Arnold, & Tattersall (2005) patients identified ways in which health care professionals could foster hope when communicating prognostic information. These approaches involved emphasising what could be done, exploring realistic goals and discussing day-to-day living.

In their seminal work, Glaser and Strauss (1966) found that the terminally ill maintained different contexts of awareness with those caring for them relating to the fact that they were dying, namely; closed awareness, suspected awareness, mutual pretence awareness and open awareness. The authors found that the impact of each type of awareness context upon interactions between patient and professional was profound, and that the manner in which people communicated was mediated around what it was assumed the other person knew. In their study into death anxiety in brain tumour patients, Adelbratt and Strang (2000) reported that Glaser and Strauss' (1966) findings were still applicable. However, these contexts were challenged by Salander and Spetz, (2002) in their work within the context of glioma patients and their spouses. They proposed that rather than 'mutual pretence awareness', 'mutual acknowledgement' better described the process of a shared understanding of the serious facts of the situation, but doing so in a way which promotes the ability to continue living daily life.

Owensworth, Chambers, Hawkes, Walker and Shum (2011) highlighted the importance of the period leading up to diagnosis as having integral influence on long-term emotional adjustment. A greater understanding of how glioma patients approach information provision and the impact of varying styles of prognostic communication on the illness journey would help determine how best to approach this sensitive area of work. Sterckx et al. (2015) identified that patients' pivotal professional care needs concerned information, communication and accessibility, while Cavers et al. (2013)

suggest that offering suitable information about what to expect early on in the process, and frequently in a supportive way, is much appreciated by patients.

Within the limited research conducted on the subjective experiences of glioma patients, most of the empirical evidence focuses on the identification of patients information and supportive care needs and as a result the other aspects of care for those with glioma must rely on very little evidence. This can often mean that patients and caregivers feel unprepared for aspects of the illness journey such as what to expect after treatment, especially the ongoing side-effects of treatment and its implications in their lives (Ownsworth et al., 2011).

The results of this literature review support the argument that the benefits of adequate information provision can include improved adjustment and adaptation to the illness, which in turn can enhance one's ability to cope. One of the premises of 'hope theory' is that high - as compared to low - hope people are more knowledgeable about matters in their surrounding environment and that such knowledge is helpful in related goal pursuits (Snyder, 1994). In a study where participants were tasked with addressing an imagined cancer diagnosis, Irving, Snyder and Crowson Jr. (1998) found a correlation between high hope individuals and a demonstration of greater knowledge of cancer even after controlling for academic achievement and experiences of cancer among family and friends. These high hope women in turn generated a wider variety of potential coping responses thus providing preliminary empirical support for the relationship between hopeful thinking and responding to cancer. The authors suggest that those who have good medical information, who demonstrate a hopeful, active coping style are likely to deal more effectively with adversity. Taylor (1990) clarifies that examination of the correlation between the ability to produce coping responses and the extent to which people know the facts pertaining to cancer, could illuminate processes most commonly related to beneficial health practices.

2.5 Unmet care needs

Using a cross-sectional survey, Janda et al., (2008) reported on the unmet supportive care needs of people with brain tumours. Participants required assistance due to physical implications of the tumour and treatment (primarily fatigue and limitations to one's ability to perform normal everyday tasks), psychological issues, and practical problems (parking at hospital, financial difficulty). The study found that patients were unsupported in the physical adverse effects of the tumour and treatment, changes in their cognitive abilities, feeling that they are no longer the same person, receiving information on clinical trials and latest treatment options, and limitations on their ability to work.

2.5.1 Uncertainty and glioma

Hilton (1992) defined uncertainty as a cognitive state that emerges when an event cannot be adequately defined or categorized due to a lack of information. Through the reconceptualization of the 'uncertainty in illness theory' Mishel (1990) explains that uncertainty experienced at the early/acute phase of illness, or one with a downward illness trajectory, is quite different to the experience of constant uncertainty in an illness with a treatable acute phase and possible eventual recurrence. Mishel (1990) found that while uncertainty experienced early on in the illness was the source of fluctuation and disruption, later on in the illness experience (if persistent) the uncertainty can become the foundation on which the new sense of order is constructed. Such a process echoes contemporary research on responses to the distressing experience of loss where positive changes can also occur, in a phenomenon termed post-traumatic growth; responding to one's loss in adaptive ways (Tedeschi, Park & Calhoun 1998, Janoff-Bulman, 2010, Neimeyer, 2001).

Within the context of cancer, Sherman and colleagues (2012) highlight that some studies have reported that women with breast cancer seek to find a sense of personal meaning, growth and hope through the experience. In the case of advanced gastrointestinal cancer people expressed thoughts about personal learning initiated by the struggle of living with an uncertain future despite their efforts to live in the

present; their personal learning was experienced through a changed life for themselves and having to confront their own pending death and develop self-insight regarding finality of life (Karlsson, Friberg, Wallengren, & Öhlén, 2014). In the study by Adelbratt and Strang (2000), proximity to death, for those with glioma and their caregivers, gave new zest and values for life. However, there were a few patients who felt a lack of meaning and resignation; a wish for death was characteristic of these.

The uncertainty involved in the life of someone with glioma is considered in some of the previous literature (O' Connor et al., 1990, Catt et al. 2011, Ownsworth et al., 2011). Difficulty with uncertainty resulting from a lack of information about the cancer journey arises in matters relating to the future (O' Connor et al., 1990), and treatment, and the 'limbo' between when treatment finishes and palliative care begins (Catt et al. 2011). In studies by Halkett et al. (2010) and by Wideheim, Edvardsson, Pahlson and Ahlstrom, (2002) patients described uncertainty about what effect the diagnosis would have on their lives and how it would impact family and friends. Uncertainty was prompted by treatment decisions and schedules, disease progression and the presence of symptoms such as seizures, loss of vision or memory, speech difficulties, motor deficit, the inability to return to work and not being able to do what they used to do (Halkett et al., 2010b, Newton & Mateo, 1994). The inability for doctors to determine prognosis and survival time furthered the uncertainty experienced and impacted patients' ability to plan their life (Halkett et al., 2010b).

Philip et al. (2013) emphasized the constant sense of waiting that characterised the glioma patient's journey. From the time of diagnosis, patients and their family are in a situation characterised by many confounding feelings, such as uncertainty, fear and hope (Khalili, 2007). The ambiguity of the progression of the brain tumour and treatment protocol makes it difficult for the patient and family to cope with rapid changes in lifestyle (Newton & Maeto, 1994). However, Newton and Maeto (1994) reported that the uncertainty experienced in circumstances such as awaiting scan results or follow-up appointments with their medical team can foster hope (e.g. that the tumour has stabilized or responded to treatment) which can give strength to the patient and their family at that period of time, whereas the patients included in the

study by Ownsworth et al., (2011) described the phenomenon as akin to being on 'death row', albeit, without any certainty as to what lies ahead.

2.6 Palliative care and dying with glioma

In light of the inconsistent approaches to communicating the prognosis of glioma, the terminal nature of the majority of glioma diagnoses means that consideration must be given to the palliative care and end-of-life experiences of glioma patients. Faithfull, Cook and Lucas (2005), Pace et al. (2009) and Sizoo et al. (2013) retrospectively documented the palliative care needs of people with glioma during the end-of-life stage of the disease. Drowsiness and loss of consciousness were most common symptoms experienced in the final week/s. The physical experience also includes weakness, seizures, dysphagia, headache and fatigue. Despite the lack of advance directives about end-of-life treatment, 82% of the patients in Pace et al. (2009) had a peaceful death.

For patients with incurable disease, consideration of advanced care planning is warranted. Advanced care planning (ACP) is a process aimed at timely involvement of patients and their relatives in decision-making on future (palliative) care, including end-of-life care (Andreassen, Neergaard, Brogaard, Skorstengaard, & Jensen, 2017). Early implementation of ACP may be particularly warranted for glioblastoma patients, because these patients have an incurable disease and most of them will at some point no longer be able to participate in ACP discussions due to the rapid cognitive decline that may occur as the disease progresses (Fritz et al., 2016). However, in light of the abovementioned tension surrounding prognostic communication with glioma patients, whether to introduce ACP, and indeed when, can be difficult for health care providers. In a review of the literature focusing on palliative care, hospice care and end of life care, Walbert (2014) found that despite the high symptom burden experienced by glioma patients, many do not receive the same level of palliative care, and have fewer interactions with palliative care services than other cancer populations. The author suggests that early palliative care interventions and structured advance care planning might improve symptom control and quality of life for brain tumour patients.

Although Walbert's (2014) study was conducted within the context of care in the United States, my own experience of working with this patient group in Ireland reflects these reported findings. To the best of my knowledge, no research on this topic exists in the Irish context.

In Ireland, concurrent access to tumour-directed therapies and palliative care management is available for those with a life-threatening diagnosis. However, access and referral to palliative care services is sporadic across the primary malignant brain tumour patient population. Taillibert et al. (2004) argue that neuro-oncologists devote most of their efforts to seeking active treatment against the tumour, while dedicating very little time to what happens to patients who have progressive disease and whose treatment has ended. In an Australian study exploring the experience of dying with glioma, Philip et al. (2013) found that patients perceived acute care providers to be reluctant to provide information about palliative care particularly if they were still receiving treatment. Those who were receiving palliative care noted that some acute doctors seemed uncomfortable talking about death and palliative care, and that given the inevitability of the disease trajectory, the involvement of palliative care at an earlier point would have been helpful (Philip et al., 2013). The study also found that those in an earlier stage of their illness were unaware of what palliative care offered.

There is, as of yet, no consensus regarding when the end-of-life stage begins in a brain tumour journey (Flechl et al. 2013). This is possibly because the disease is incurable and ultimately terminal from onset and therefore no point has been established where end-of-life supports are introduced, but may also be attributed to the uncertain trajectory of the disease, perceptions of palliative care, and the importance of hope.

Given that most glioma diagnoses are ultimately terminal, there is an argument to be made that end-of-life care should be offered from the point of diagnosis, despite the person both looking and feeling well. In comparison, Foley et al. (2013) highlight that from the point of diagnosis, the care approach for individuals with Motor Neuron Disease (ALS) is a palliative one. Flechl et al. (2013) suggest that for glioma patients,

the end-of-life stage may occur at the point of symptomatic tumour recurrence² when the symptom burden increases and the focus of the goals of care shifts to supportive. In the last stage of the disease, patients present with severe symptoms due to the growing tumour or to treatment side-effects, which require adequate palliative management and supportive therapy. Despite this, studies specifically addressing palliative care and end-of-life issues in brain tumour patients are lacking (Pace et al, 2009).

Albratt and Strang (2000) explored whether and to what extent patients with glioma and their next of kin experienced death anxiety and in what way these experiences were expressed. Their study found that both patients and their next of kin were preoccupied with existential thoughts and death anxiety (Albratt & Strang, 2000). The study also reported that a fear of the unknown and an existential anxiety underpinned the experience. With the threat to life underlying most individuals' anxiety related to the diagnosis (Strang & Strang, 2001) it might be possible that there is a role for the timely involvement of a specialist support service focused on issues related to the life-threatening/terminal element of the disease available to the patient and their family/caregivers from the point of initial diagnosis.

2.6.1 The Irish context

In the Irish context, The Ombudsman (2014) issued a report compiled of the complaints received regarding end-of-life care in hospitals in Ireland noting that Irish people need to improve their ability to talk about our end-of-life care preferences in order to create the best chance of having a good death. The Irish Hospice Foundation and the Forum on End of Life (2009) are currently working to promote openness about the issues of where we die, how we die and how we should plan for it. They have highlighted the need to talk, plan and act in order to ensure a dignified death for as

² When the tumour that had been either removed or 'debulked' through surgery, or treated with radiotherapy to reduce its size or palliate symptoms, returns. When a tumour recurs the person can present with a myriad of symptoms including changes to personality and mobility, increased seizures, loss of sight or loss of speech. There is usually little that can be done to treat the tumour at this stage and hence the person begins to receive a palliative approach to care.

many people as possible and a peaceful life for those who are bereaved . This is echoed by Philip et al. (2014) who found that the patients in their study wished for another dimension to their care, namely care that recognised them in all their humanity and acknowledge them as a valued, active member in the provision of their care.

The report (IHF, 2009) found that each year, 29,000 people die in Ireland and as many as 290,000 people are left bereaved. Research carried out for the Irish Hospice Foundation has found that most people, 67%, would prefer to die at home. In reality, only 26% of people in Ireland will die at home, 43% will die in an acute hospital, 25% in a long stay setting and 6% in a hospice (McKeown, 2014). In the context of glioma Sizoo and co-authors (2013) found that end-of-life practices such as stating and recording end-of life care preferences are common in the Netherlands. Flechl et al. (2013) undertook a study to compare the findings of the Dutch study by Sizoo et al. (2012) to that of the experiences of Austrian brain tumour patients and their caregivers. Sizoo et al. (2012) revealed that in the Netherlands 42% of participants had advance directives, and 66% of the participants were able to die at home, compared with no one in the Austrian study having advanced directives, half of the participants dying in hospital and only 40% managing to die at home (Flechl et al., 2013).

2.7 Adjustment and coping

Viktor Frankl (1985) identified the search for meaning as a primary motivational force in human kind, unique and specific to the individual, and defined the desire to give life purpose as the 'will to meaning'. The existing literature strongly supports the concept that being faced with a life-threatening circumstance can bring a heightened awareness of personal mortality and prompt questions about the personal significance of this circumstance in order to give the experience purpose, and to place it in the context of a total life pattern (Fife, 1994, Janoff-Bulman, 2010).

This existential search for meaning has been identified as important in situations that involve loss: in the grief process of bereaved parents (Miles & Crandall 1983) and in the dying process of hospice patients (Lewis et al. 1986). In this same study by Lewis

et al. (1986), hospice patients were found to impart meaning or purpose on their situation, thereby creating a world in which they had control. One method of engaging with meaning is through causal attributions. The relevance of attributions within the context of this study stems from its frequent inclusion in past empirical research surrounding coping with negative life events (Janoff-Bulman, 1989). Attribution theory was developed by Heider (1958; Taylor 1983) and a decade later furthered by Kelly (1967; Cramer 2000). Attribution theory maintains that by understanding the cause of an event one may be able to understand its significance and what it symbolizes about one's life. In Taylor's (1983) important study regarding adapting to a life threatening diagnosis, 95% of the participants offered some explanation for why their cancer occurred, despite there not being a known cause. Becker, (2007) purports that creating or finding meaning and purpose in one's life, or as he terms it; 'heroism', is a response to a need to believe we can transcend death. He suggests we do this by participating in or 'sacrificing' ourselves or our pleasure to the creation of something we believe is of lasting worth or value.

Antonovsky (1987) developed the model of coping from a health policy perspective, 'a sense of coherence', in order to attempt to explain why some people become ill under stress and others stay healthy. The crucial component of Antonovsky's model is meaningfulness, namely that individuals who experience a high level of coherence despite a difficult situation can still experience a good quality of life when they understand what is happening to them (comprehensibility), believe they possess resources to manage the demands of the situation (manageability) and can find meaning in their life situation (meaningfulness). This model holds similarities with the concept of coping on a broader scale, and specifically in relation to the experience of living with a brain tumour diagnosis; effective coping increases manageability and information-seeking coping strategies increase comprehensibility (Strang & Strang 2001). This model was used in Strang and Strang's (2001) study to investigate whether this model was related to the coping experiences of a brain tumour patient and was further used in a control trial of psychotherapy for people with brain tumours evaluating the effectiveness of the 'Making sense of a brain tumour program' (Ownsworth et al., 2015). Goals of the program related to understanding and

managing the cognitive, behavioural and emotional effects of brain tumour, exploring existential issues and the concerns of family members, and improving occupational and relationship functioning. The evaluation found that those who received the intervention reported significantly higher levels of existential wellbeing, functional wellbeing and global quality of life (Ownsworth et al., 2015).

Adjustment to illness is not a static event, it's a dynamic process and rethinking of persons biography and self-concept (Bury, 1982). It seldom occurs only once as people are forced to adapt repeatedly as they experience new losses (Charmaz, 1995). Brennan, (2001) explains that adjustment is not an end-point of coping with the threat of cancer, rather it refers to the processes that occur over time as an individual learns to adapt to the changes brought about by their illness. In the context of chronic illness, Bury (1982) explains that illness disturbs a person's assumptions about the relationship between body and self and disrupts a sense of wholeness of body and self. Demonstrating the relevance of the chronic illness experience to this particular study; explanatory models of adjustment to loss in terminal illness have been described by Knight and Emanuel (2007), who put forward a 'reintegration model' which assumes that the basic human capacities for adjusting to loss are similar for people who are seriously ill and dying as for those who are not. Further, Charmaz (1995) explores adaptation as an approach to living with impairment in the context of chronic illness. The author describes adapting in illness as a means of altering life and self to accommodate the bodily losses and limits and resolving the lost unity between body and self. Cognitive and trauma theories, such as those outlined by Janoff-Bulman (2010), Folkman, (1997, 2001), Thompson and Janigian, (1988) and Taylor (1983) proffer that circumstances or losses which are most difficult for individuals to cope with, are ones that fail to make sense, however, Foley and colleagues (2014) counter that adaptation for people with ALS involves adapting to loss without the ability to control it. Similarly, Charmaz (1995) suggests that adapting involves struggling with rather than against illness.

2.7.1 Coping in illness

Cramer (2000) reports that social psychologists have continued to re-discover the existence of processes by which humans deceive themselves, enhance self-esteem, and as a result foster unrealistic self-illusions. Cramer (2000) argues that the denial or refusal to recognise the implication of reality has been recast as positive illusions. Taylor's (1983) cognitive adaptation model developed in the context of adjusting to life-threatening illnesses, specifically cancer, stresses the necessity and importance of an individual's ability to maintain personal themes of mastery, self-enhancement, and the search for meaning. Taylor (1983) suggests that these adaptive cognitions are optimistic 'illusions' which enable the individual to maintain a positive attitude in the face of disturbing events. This is also reflected in the work of Janoff-Bulman (2010) who terms the concept 'positive bias' which provides us with a means of trusting ourselves and our environment. Using understandings from Taylor's (1983) theory, Taylor (2000) suggests that as a result of the paradoxical psychological reactions to threatening events, a diagnosis of breast cancer may actually help women to increase their hopeful thinking.

Susan Folkman (1997) conducted a study that examined how individuals coped in the context of caregiving partners of men with AIDS. The study highlights the co-occurrence of positive and negative psychological states apparent in coping; that people can also experience positive psychological states during hardship (Folkman, 1997). In later work Folkman (2001) stressed the importance of benefit finding in the negative experience, claiming that successful coping is made possible by 'positive reappraisal'.

The approaches to coping discussed in this section suggest that the sick or bereaved engage in adaptive cognitions that focus on the reconstruction of meaning or positive reappraisal of their circumstances. The following section will provide an outline of the literature which integrates these approaches with that of the cancer and/ or glioma experience.

2.7.2 Adjustment and coping in the glioma experience

Cassell (1982) suggests that illness and suffering cannot be understood without taking personal meaning into account. The search for meaning in response to illness has been reported in the literature as a means of posttraumatic growth in response to a negative life event and seeks to reconstruct the meaning of the event in one's life (Neimeyer, 2001) or to enable benefit finding in order to make the event more manageable (Helgeson, Reynolds, & Tomich, 2006; Kangas, Williams, & Smee, 2011). O'Connor et al. (1990) found that patients with cancer searched for meaning in a number of circumstances in order to cope. The authors found that this was done by restructuring and revaluing life, self and others; viewing the journey as a learning/growing experience; renewed appreciation of friends, family and in 17% of respondents, religious faith. One third of the respondents in the study by O'Connor and colleagues expressed questioning thoughts such as "Why me?".

People with glioma often search for meaning or seek to attach a purpose to their illness as a means to adjust to their diagnosis (Ownsworth et al., 2011). Adjustment within the context of illness refers to the psychological processes that occur over time as the individual, and those in their social world, manage, learn from and adapt to the multitude of changes which have been precipitated by the diagnosis and its treatment (Brennan, 2001). Ownsworth et al. (2011) found that patients with glioma and their caregivers engage in key sense making appraisals in an attempt to adapt to the illness. Similarly, Edvardsson and Ahlstrom (2005) highlighted that one of the most frequent coping mechanisms used by people with low-grade brain tumours was 'searching for a solution'. Salander et al. (1999) found that delays to the diagnostic and treatment process may present difficulties in the adjustment to the illness, and Ownsworth et al. (2011) confirm that adjustment to a brain tumour diagnosis was influenced by interactions with those in the healthcare system, reactions and support of from their personal support network, and by a diversity of coping efforts.

Continuing on from the discussion in the previous Section surrounding 'illusions', 'positive reappraisal' and 'positive bias', Salander et al., (1996) explain that although most patients were aware of the fact that the brain tumour exposed them to grave

danger, they were also able to use various cognitive manoeuvres to cope and therefore create protection and hope. This study highlighted sources of hope such as the body, helpful relations, cognitive schemata, and the handling of information. Similar to Taylor (1983), Salander et al. (1996) suggest that the use of these processes allows the patient to bring together reality and hope, thus creating their own 'illusion'. These findings were mirrored by O' Connor et al. (1990) who stated that subjects needed a way to acknowledge the reality of the diagnosis and thereby minimizing its threat; reframing the cancer as "just an event", consequently putting the diagnosis into perspective while at the same time acknowledging it.

The different aspects of the processes of adjustment to a brain tumour diagnosis have been explored by Adelbratt and Strang (2000), Cavers et al. (2013) and Strang and Strang (2001). While examining the ways in which people with brain tumours and their caregivers cope and find meaning in a brain tumour diagnosis, Strang and Strang (2001) found that meaning was central to quality of life. Strang and Strang (2001) adopted a "sense of coherence" framework to explore how individuals make sense of (comprehensibility), cope with (manageability) and create meaning (meaningfulness) from their illness. They found that individuals generated their own theories and explanations to understand their illness, although many experienced unresolved existential issues. Various personal resources and coping strategies (e.g., seeking information and support and positive reinterpretation) helped to increase manageability of their situation. Individuals derived meaning from their illness by strengthening their relationships and redefining their roles and values in life (Strang & Strang, 2001). In line with this Cavers et al. (2013) suggest that receiving reassurance and support could help patients and their caregivers to come to terms with the disease, particularly during the early phase of the illness when distress and uncertainty were most acute. In Albratt and Strang's (2000) study, patients with a brain tumour could seldom approach acceptance. The authors speculate that this may be due to early mental and cognitive deterioration across the disease trajectory, although, their caregivers reached a level of acceptance early in the illness trajectory.

In their study on the experiences of people with low-grade tumours Edvardsson and Ahlström (2005) identified different coping strategies adopted in order to manage the problems associated with their illness on a daily basis. The coping strategies were directed at supporting the person with practical issues (such as the use of aids and behaviours in order to manage problems in daily life); and emotional challenges (such as sadness and loss of self-esteem as a result of the tumour). Both Edvardsson and Ahlström, (2005) and Salander et al. (1996) identified information-seeking behaviours, making comparisons and maintaining hope as ways that people with glioma coped with their illness. People limited the information they received regarding their illness in order to make coping more manageable, compared their situation to that of other persons through downward and upward comparisons, and maintained hope with a confident perspective, while considering the illness as a parenthesis in life (Edvardsson & Ahlström, 2005, Salander et al., 1996). Coping through comparisons was included as an element of the theory of adjustment (Taylor, 1983) to threatening events (discussed above).

The studies by Salander et al. (1996) and Edvardsson and Ahlström (2005) examined high-grade and low-grade gliomas respectively. The commonality between their findings suggests that there is a degree of universality of experience between the two diagnoses. Although the survival times for the two tumour subsets are different, the above findings suggest that supportive service provision for one maybe applicable to the other.

Approaches to coping with glioma have been documented as including efforts to maintain normality, and to acknowledge and adapt to the illness (Ownsworth et al., 2011). Philip et al. (2013) found that in order to cope, patients involved in their study overwhelmingly directed their focus to the here and now. The authors state that this approach to coping was perceived by the participants to be preferred by health care professionals. As a result, patients were always waiting uncertainly for their future. The authors acknowledge that this method can be useful as a means of coping with the uncertainty, however, limitations include the inability to appropriately plan future, carers missing out on opportunities to be linked into support, and healthcare

professionals missing out on matching medical care with patients' goals (Philip et al., 2013).

2.8 Conclusion

The existing literature reveals that the diagnosis of a brain tumour is a unique experience with devastating consequences. The implications of a brain tumour are multifaceted and negatively impact all elements of a person's life, whether or not death is imminent. As outlined by Edvardsson and Ahlström (2005) even those with a longer expected survival time faced losses to their physical and cognitive abilities, resulting in significant impact on their social, family, and financial circumstances.

Problems surrounding information provision and communication feature frequently in the existing research and hence indicate an immediate need to develop this element of care. Further, more research is needed to understand the experiences and impact of receiving varying amounts of prognostic information and how this influences the illness journey. Although the causes of, and difficulties prompted by, the uncertainty inherent in the glioma diagnosis and treatment journey are outlined within the existing literature, more research is needed in order to understand what, if any, impact uncertainty has on the patient's experience of the illness. If, as McKeown, (2014) suggests, long-term certainty in illness can generate a renewed understanding of one's circumstances, what does this mean for the glioma patient and their illness experience, and can this understanding be used to improve their care?

There is a paucity in the available literature surrounding the experiences of glioma patients throughout the disease trajectory, whereby the patients themselves identify their greatest concerns, and the significant elements in their illness journey. The methods employed in this study prioritise the participants' greatest concerns in order to establish an in-depth understanding of 'what is going on here'.

As this is a narrative – as distinct from a systematic - review of the literature, the chapter has largely steered clear of scrutinising the methods used in the existing

research. However, the methodological limitations of the included studies (such as the inclusion of a variety of tumour types, stages of the illness at inconsistent points in the treatment journey) highlight a need for more specificity in the samples recruited if we are to generate findings with real-world applications and inform best-practice for under-researched patient groups.

Most of the studies discussed in this section included both patient and caregiver perspectives, while at least one study included the perspectives of the patients' general practitioners (Cavers et al., 2012). Although the value of the caregiver perspective as a source of substantial information of the patients experience is appreciated (Pär Salander et al., 1999), there is a dearth of research focused solely on the patient experience. To the best of my knowledge, only two of the studies included in this review focused exclusively on the patient perspective. The following chapter will proceed from a perspective which places the patient at the centre of enquiry, and appreciates that all interpretations of reality are valid. More information is needed about the subjective experiences of the glioma patients so that service provision is patient-centred and can meet the needs of the person within their experience of reality, rather than that mediated through the caregivers.

The review highlight that there is no consensus on when the end-of-life phase of a glioma patients experience begins. A better understanding of the different processes glioma patients experience across time is required as it holds critical importance for the person and their family and their ability to cope with the illness, along with the ability of care providers to offer appropriate and timely support throughout the disease trajectory. This review revealed that there is no research available on the experiences of glioma patients in the Irish context. It is evident that more research evidence is required regarding the Irish patients' experiences of the services made available throughout their illness journey, and the impact this has on the experience.

This review outlined the existing literature relating to the 'loss of self' throughout the experience of living with a brain tumour. Some of the available literature discusses the impact of glioma on the sense of 'self' and identity, however this is mainly in relation

to memory loss and other cognitive issues. There is no existing literature of the glioma patients experiences of their body throughout the illness experience. Given that one's sense of self and identity is also mediated through their body, as well as their mind, a greater understanding of this impact on glioma patients is required in order to understand the experience from their perspective.

The next chapter will outline the selection of qualitative methods for this study. These methods were chosen due to the fact that they are ideal for probing the individual experiences that this review of the literature has shown to be relatively under-researched. The following chapter on the methods used for this study will go on to outline these in detail.

Chapter Three: Research methodology and methods

3.1 Choosing qualitative methodology

The use of qualitative research methods in health and social care research has increased in popularity in recent years. This has been paralleled with an interest in eliciting the views of the service users, as well as understanding of the value of the service user voice regarding their health experiences and service provision. This chapter seeks to outline both why and how qualitative methods were adopted to capture the experiences of people with glioma across the treatment trajectory. In the case of this study, the choice of a qualitative research strategy was informed by the research question (Charmaz 2014, Silverman, 2011).

We conduct qualitative research to study a group or a population, because a problem or issue needs to be explored, to identify variables that cannot be easily measured, or to hear silenced voices (Maxwell, 2008). Qualitative research can identify patients' values and attitudes, which shape their perceptions of illness, health, and health care and thus influence their behavior (Tong, Winkelmayer, & Craig, 2014). As such, key

stakeholders should be considered experts in their care (Foley & Timonen, 2015). Involving patients at all stages of their illness trajectory is necessary to understand patients' illness experiences and their needs associated with it. To ensure an ethically sound research study the researcher must balance any potential risk with potential benefits of participation and knowledge gained (Reid, 2009, Todd et al., 2009).

Qualitative approaches are well placed to provide direct narrative reports of experience and need (Dixon-Woods & Fitzpatrick, 2001) and seek to embrace and explore the complexities of human experience by recognizing how individuals construct multiple realities (Denzin & Lincoln, 2011). The telling of the personal story gives voice to people who often find or consider themselves in a position of powerlessness (Holloway & Freshwater 2007; Sandelowski 1994) and it is considered central to the process of how human experience can be made meaningful.

In a study exploring the wish for hastened death amongst patients receiving palliative care, the authors found that using a flexible, less burdening, qualitative methodology which could be adapted throughout the research process was best suited for a participant population such as this. The authors employed a grounded theory methodology which allowed for a systematic understanding of patients' experiences and attitudes and a careful in-depth exploration of the population (Stiel et al., 2010).

In a health care setting, qualitative research helps with understanding how social practices and patterns in health care are created and what meaning these practices have for people within specific or varied contexts as well as recognizing that participants are the experts in their own lives and experiences (Foley & Timonen, 2015). Due to the fact that this is a poorly understood and novel topic in the literature, qualitative research is useful to describe novel, poorly understood phenomena and to engage in causal inference, hence being of particular help when building new theory or adjusting theory that has been shown to be deficient (Foley et al. 2015, Hurley 1999).

3.2 Grounded Theory

Grounded Theory is an established research methodology consisting of three prevailing traditions; Classic, Straussian and Constructivist Grounded Theory. These approaches are differentiated by somewhat contrasting philosophical frameworks and differing methodological directives. The grounded theory methodology (Charmaz, 2006, 2014) works on the basis of generating theory from data. Although all conventional qualitative research approaches adopt an inductive approach, many approaches to grounded theory advocate use of deductive and abductive methods alongside induction (Timonen, Foley, & Conlon, 2018). The origins of Grounded Theory lie in researching illness in a study conducted by Glaser and Strauss (1965) into the treatment and experiences of dying patients in hospital, which underlines its relevance to this study. Foley & Timonen (2015) documented that this method is commonly used in healthcare research and that grounded theory methods are particularly valuable when the topic of interest has not previously been studied, or remains poorly understood.

Grounded Theory involves a process of data collection, coding/categorising, theoretical sampling and theoretical development. The four main strategies of Grounded Theory are coding, memos, theoretical sampling and theoretical saturation (Charmaz, 2008). Further, Timonen, Foley, and Conlon (2018) summarise the four core principles of Grounded Theory as; adherence to the 'grounded' nature of the study, capturing and explaining context-related processes and phenomena, pursuing theory through engagement with data, and pursuing theory through theoretical sampling.

The defining feature of grounded theory is that the resultant theory is grounded in, and generated from, the data. As such, grounded theory allows for the identification of the main issues of concern for patients and the processes they undergo within the experience (Hurley, 1999, Carey, 2010). Further, the iterative process of constant comparison between data in pursuit of theory-building is a vital characteristic of Grounded Theory (Corbin & Strauss, 2008). This will be further outlined in Section 3.7.8. Grounded Theory seeks to move data beyond descriptive accounts and into

realm of explanatory theoretical frameworks, thereby providing abstract, conceptual understandings of the studied phenomena (Charmaz 2014).

3.3 Combining Critical Realism and Grounded Theory

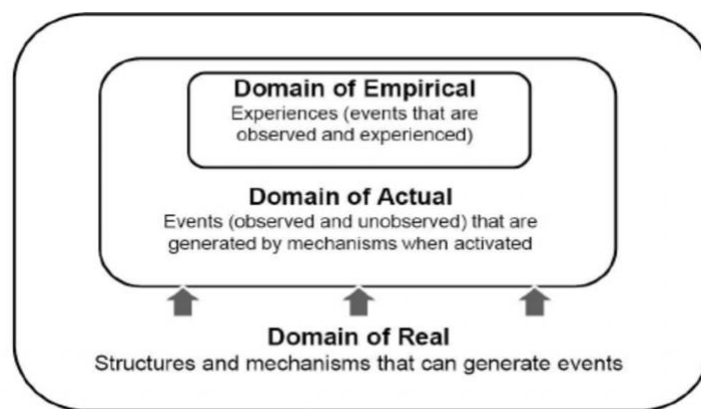
As noted above, there are several approaches to Grounded Theory, each informed by various philosophical approaches to 'knowing' and generating knowledge. For this study, I chose a variant of Grounded Theory which corresponded with my own ontological and epistemological position, that is, the position of a critical realist. Critical realism (CR) acknowledges the existence of one reality that is open, fluid, and shaped by how people interpret it. In the case of this study, it allows for the identification of underlying structures and key causal mechanisms that explain how and why people experience their illness in certain ways.

3.3.1 Critical Realism

Positivist assumptions assert that one external reality exists, research should be generalisable, and the researcher is an objective observer with little influence on the data and the analytic process (Wertz et al., 2011). They maintain that only phenomena – and hence knowledge confirmed by the senses – can genuinely be warranted as knowledge (i.e. it must be tangible or observable). In contrast, constructivist approaches maintain that the researchers own accounts of the social world are specific to their own interpretations and constructions, rather than a definitive one reality (Bryman, 2016). However, Longhofer (2013) explains that often there are events that occur without our experiencing of them, and can only be inferred only from their effects (e.g. an illness). Such is one of the core propositions of CR, that events, structures and causal mechanisms exist independently of their identification (Lee, 2016). Thus, for critical realists it is acceptable that generative mechanisms or structures are nonphysical and unobservable, and are admissible on the grounds that their effects are observable (Bryman, 2016). Critical realists assume that the studied world exists of events, experiences, underlying structures and causal mechanisms, and that all events are produced or generated by these underlying causal mechanisms and structures (Lee, 2016).

CR makes important distinctions between the world and our experience of it, maintaining that the world is layered into different domains of 'reality'. A directly observable pattern of behaviour (the empirical domain) can be explained by investigating causal relationships between different variables (the actual domain) (Bhaskar, 2008). Understanding the empirical events of experience depends on the explanation of the 'actual domain', and that is derived from causal mechanisms and structures, (the real domain) (Bhaskar, 2008, Lee, 2016). When the underlying causal mechanisms and structures are identified and understood, the empirical and the actual events or domains are jointly understood (Lee, 2016). In short, critical realism seeks to identify the structures at work that generate these studied events and discourses (Bhaskar 1989). Figure 1 provides an illustration of the abovementioned domains of 'reality'.

Figure 1. The overlapping domains of reality in the Critical Realist Ontology (Mingers, 2004)



As this study sought to understand peoples' experiences in light of the diagnosis of glioma, the ontological position of CR becomes useful in mapping out a theory of causality compatible with qualitative research methods. Roberts (2014) proffers that CR has been an important advance in social science methodology because it develops a qualitative theory of causality, and as such, avoids some of the pitfalls of empiricist theories of causality.

A key feature of critical realism is the rejection of the epistemic fallacy which conflates reality with our knowledge of it (Oliver, 2013). In contrast to the positivist position that the scientists' conceptualization of reality actually directly reflects that reality, critical realists argue that the scientists' conceptualization is simply one way of knowing reality. Bhaskar (1975) explains that research is a way of expressing in thought the structures and ways of acting of things that exist and act independently of thought. CR acknowledges that things can happen with or without our experiencing of them. Therefore, through the lens of CR, this study could explore the subjective lived experience of a brain tumour while acknowledging a number of fixed, currently unchangeable factors such as the nature of the brain tumour, the available treatment options, and the larger health care sector.

3.3.2 Critical realism applied to the experience of glioma

As previously outlined, the study will use a Critical Realist paradigm, one which accepts that there are certain incontrovertible realities (such as the existence of a brain tumour) but which combines this acceptance of an objective reality with a primary interest in the individual's understanding of this reality and how that guides their actions.

Upon embarking on this study, I initially adopted the ontological position of constructivism (as opposed to objectivism). This ontological position asserts that social phenomena and their meanings are continuously being accomplished by social actors and maintains that social phenomena and categories are in a constant state of revision. (Bryman 2008). I struggled to incorporate the physical reality of the brain tumour into the subjective lived experience using a purely constructivist perspective. The realities of a malignant tumour, a particular health care system and a particular sociocultural setting underpinned the experiences and processes under study to such an extent that a constructivist approach alone did not provide the ideal tools to make sense of the processes under study. In essence, CR presupposes a reality which exists independently of our thoughts and whose discovery is one purpose of knowledge

acquisition. However, it also maintains that all description of reality is mediated through the filters of language, meaning making and social context (Oliver 2012).

CR offers a useful way of bridging the divide between constructivism and realism, and therefore is ideally situated to address the complexities of understanding how people experience a glioma diagnosis. CR assumes that phenomena exist independent of an individual, and maintains that phenomena exist at the level of events and experiences, but also at a deeper level that may not be observable (Longhofer, Floersch, & Hoy, 2012). In the context of this study, the physical tumour itself, or the diagnosis, exists as a distinct reality insofar as it does not require human institutions or understandings to exist, although it cannot be seen. With or without acknowledgement of its existence the glioma will alter the person's life, impact their experiences, and prematurely end their lives. This concept is referred to in critical realism as 'brute facts'. Brute facts do not depend on our attitudes, feelings, ideologies or myriad social constructions to exist (Longhofer et al., 2012).

CR plays close attention to agency, structure and context. It allows for the important acknowledgement of research participants' experiences of powerlessness, loss of agency over their lives and their bodies in the present or in the future. It recognises and examines the impact that the hospital and existing treatments have over people's experiences and in this study provided for the illumination of people's lack of control and self-determination within this context, where they were subsumed into the medical system and a rapidly moving treatment trajectory.

Further, CR allows the researcher to abstract any possible underlying causal powers of an object and to think conceptually about structures and how they operate within a certain domain. Critical realists think of these structures as systems of human relations among social positions. For example, the illness or the existing health service may be thought of as a social structure, within which lie various causal powers such as the type of supports on offer, and the types of treatment to opt for. This study, then, examines how people with glioma experience and operate within these structures and context,

recognizing the influence of these causal mechanisms in the generation and understanding of their experience.

3.3.3 Critical Grounded Theory

Researchers suggest that the overlapping assumptions and the mutual aims (generation of explanatory theory) of Grounded Theory and CR mean that a CR perspective on developing knowledge about the social world reflects the key tenets of Grounded Theory (Kempster & Parry, 2011; Oliver, 2012). The complementary nature of Grounded Theory and CR and their relevance in understanding the experiences of people facing a glioma diagnosis made critical grounded theory an ideal approach for this study, while still acknowledging the core characteristic of Constructivist Grounded Theory; the researcher's key role in co-constructing the knowledge generated throughout the study.

Deviating from conventional Grounded Theory, Critical Grounded Theory (CGT) begins with critical observations and experiences of critical issues prior to the study. In line with this, I engaged in a year-long locum social work position in Ireland's only radiation oncology hospital. This position provided me with the opportunity to observe and experience key issues relevant to the care of people with glioma, and the potential to develop specialist interview skills appropriate to this patient-group. Observing people undergoing treatment for glioma triggered my curiosity as to how people with life-threatening illness could cope and engage in daily activities.

In CGT the researcher adopts a position, not as a disinterested observer, but rather as an active member of a society, seeking explanations to problems in order to attempt to change them (Belfrage & Hauf, 2017). Initial conceptualisations gained from experiencing and examining problems (by consulting various sources of qualitative and quantitative origin and pre-existing theory) are then brought into the field and explored and developed upon in conjunction with participants through interviews, in order to develop greater understandings of problems within the studied world (Belfrage & Hauf, 2017). This initial conceptualisation guides semi-structured or

unstructured interviews while the researcher remains open to new emerging findings. Data collected through interviews can then be analysed through the tools of Grounded Theory. As a professional qualified social worker, this approach works for me personally due to its explicit emancipatory goal both at the moment of data production and dissemination (Oliver, 2012).

While Constructivist Grounded Theory (Charmaz, 2014) maintains that abductive reasoning advances theory construction, retroduction is the central tool of critical realist inquiry. Oliver (2012) explains that retroduction is abduction with the addition of a specific question; 'what must be true for this to be the case?'. Asking this question of the data and considering possible explanations abstracts causal mechanisms and can offer the vertical explanations linking events and experiences to their underlying generative mechanisms. Rather than offering descriptive accounts of phenomena, retroduction seeks to understand why, and what caused it. Examples of retroduction and how it assisted the generation explanatory findings in this study will be detailed in Section 3.7.8.

3.4 Ethical considerations prior to data collection

Involving patients at all stages of their illness trajectory is necessary to understand patients' illness experiences and their needs associated with it. However, in order to ensure an ethically sound research study the researcher must balance any potential risk with potential benefits of participation and knowledge gained. Existing research provides evidence that glioma patients up to and including their arrival at end-of-life can are able and willing to take part in qualitative interviews (Lipsman, Skanda, Kimmelman, & Bernstein, 2007; Philip et al., 2014; Reid, 2009; Todd et al., 2009). Consideration was given to the potential risk and benefits for participants and every effort was made to limit risk and maximize benefit.

While constructing the research design and prior to commencing the fieldwork element of the study, and drawing on the assistance and expertise of my supervisor, we established an advisory committee consisting of a number of relevant professionals

with experiences in the field of palliative care, qualitative research, and oncology. This committee aided with the development of an ethical study by providing insight and guidance.

In the majority of cases the diagnosis of glioma is a terminal diagnosis and therefore the research design took into consideration that the participants could be receiving palliative care and be processing end-of-life issues. Research that focuses on end-of-life issues is often considered by gatekeepers or ethics committees to be too burdensome, potentially distressing, or harmful to terminally ill patients. Yet in order to deliver client-centred care, we must move away from 'patient-proxy' research and conduct 'patient-informed' research in order to ensure the care and supportive needs of those with brain tumours are met (Hopkinson, Wright, & Corner, 2005). We currently know very little about glioma patients' experiences of living with their glioma and their subsequent needs. These considerations generated a powerful justification for interviewing people with glioma, while adhering to the highest standards of research ethics.

3.4.1 Capacity and cognitive impairment issues

Given the potential for changes to cognition, extensive consideration was given to matters of capacity and cognitive impairment. The hospital research ethics committee requested that the Standardised Mini Mental State Examination (Molloy & Clarnette, 1999) or a similar tool be used prior to the commencement of each interview, to monitor the participant's cognitive function. This committee did not specify what should be done with the results of this test or what should be done if the assessment concluded that a person's cognitive function had changed.

The standardized Mini-Mental State Examination (SMMSE) is a 30-point questionnaire used extensively in clinical and research settings in order to measure cognitive impairment. In line with ethics approval granted by TCD and St. Luke's Research Ethics Committee, the SMMSE was used at the beginning of each interview. This was used to alert the researcher to the presence of cognitive difficulties. In situations where the

consultant indicated issues with the use of the MMSE it was discussed and a decision was made by the researcher in conjunction with the consultant (or medical team) regarding whether or not it was suitable for the person to participate in the study. Issues with conducting the MMSE in this instance particularly related to the presence of aphasia or impairments to hearing or sight. I regularly engaged with the relevant Consultant regarding the patient participant's level of cognitive functioning. In the case of each interview, I was satisfied that the person had the mental capacity to participate fully, and was in a position to give informed consent.

3.5 Reflexivity and the researcher

Reflexivity refers to researchers' awareness of their role in the research process, particularly within the context of interacting with participants and interpreting the data. It is a term used to refer to a reflectiveness among social researchers about the implications for the knowledge of the social world they generate of their methods, values, biases, decisions and presence in the situations that they investigate (Bryman, 2016). Throughout the study I paid attention to the possible impact that my role as a social worker previously employed by the hospital as well as and my presentation as a young, professional woman, may have on my interactions with people and the research process.

Reflexivity is a vital component of qualitative research and holds importance in the Grounded Theory approach adopted in this study. Key to Grounded Theory is the acknowledgement of subjectivity and the researcher's involvement in the construction and interpretation of data (Charmaz, 2016). Rather than viewing the research as separate from the researcher, Charmaz suggests that the theories researchers construct through Grounded Theory are undoubtedly affected by the researcher's interactions with people, places, education and opinions (Charmaz 2006). In other words, researchers cannot separate themselves and their experiences from their research or be objective about the data.

The significant influence reflexivity had on the generation and development of theory throughout this study is described in detail in Chapter Seven. It is likely that my own experiences and responses to the participants' experiences was influenced by my repeated interactions with them and the relationships developed as a result. From initial recruitment meetings to scheduling interviews to the interviews themselves, my repeated interactions meant I developed a level of familiarity with the participants, creating my own perceptions of their experiences.

I monitored my own emotional reactions during interviews through memos. Remaining alert and aware of what I was feeling enabled me to better understand what was happening in the data in instances where the meaning was unclear. Using this method enabled me to interrogate my interpretation of the data; 'why did a certain part of the person's story seem more upsetting than others? Is there something else happening here? Might this be significant to the analysis...?' Further, reflexive memos enabled me to monitor my biases; I felt more upset for a participant who was a similar age to me, and for a woman who reminded me of my mother. Being aware of this and incorporating this into my analysis ensured I did not force the data in any way, and that the emergent understanding remained grounded in the data.

3.6 Sampling glioma patients

Although the diagnosis of a malignant glioma is devastating for both the patient and their family/caregiver, this study placed the person with glioma at the centre of enquiry. The majority of the existing research and literature exploring the experiences of people with glioma also included the perspectives of caregivers as well (Flechl et al., 2013; Fox & Lantz, 1998; Janda et al., 2008; Newberry et al., 2013; Petruzzi, Finocchiaro, Lamperti, & Salmaggi, 2013; Pär Salander et al., 1996; Sherwood et al., 2004; Strang & Strang, 2001). However, the central aim of this study was to develop a substantive theory describing the experiences of people with glioma diagnoses throughout the initial stages of treatment. A key aim of Grounded Theory is to capture processes over time and this study aimed to capture processes through repeat interviews. Within the scope of a PhD study with a single researcher, the inclusion of

caregivers would inevitably have reduced the number of people with glioma that could be interviewed, thus impacting on the depth of understanding generated from the study. The inclusion of caregivers would have run counter to the aims of the study to capture the patients' experience of their illness.

3.7 Research design

The primary aim of qualitative research is to expand our understanding of human behaviour and experiences and what influences behaviour and experiences. This study sought to understand and describe how people experience living with glioma, how people come to terms and cope with the diagnosis. It seeks to capture how people's experiences change over time as different treatment phases are encountered and so the study design is based on the concept of repeat in-depth interviewing. A secondary aim of the study is to inform service-provision for those with glioma. This study was motivated by the paucity in psychosocial research and understanding of glioma patients' needs and the resultant deficit in informed service provision. It is hoped that this study can inform the provision of support to patients with glioma by highlighting their subjective experience.

3.7.1 Longitudinal Research

In comparison with a cross-sectional study (study of a cohort at a single point in time), in qualitative longitudinal research (QLR) a sample is surveyed and is surveyed again on at least one further occasion with a view to improving the understanding of causal influences over time (Bryman, 2016). A desire to identify and explore change over time is, for many, a defining feature of QLR (Steinhauser et al., 2006). There is a broadly shared understanding that QLR is concerned with the exploration of individual lives as they develop (Farrall, Hunter, Sharpe, & Calverley, 2016). Longitudinal designs are somewhat better able to deal with the problem of ambiguity about the direction of 'causal influence' that presents in cross-sectional designs. In other words, in this case, repeated interviews allows for a greater understanding of how people's experiences changed over time as treatment and their illness progressed.

Involving repeated measurements and/or data collection from the same group or multiple visits to the same research location, QLR is the best way to identify and analyse the dynamic processes that impact upon individual lives. This focus on change is a chief benefit to *any* longitudinal study and provides the opportunity to study relationships between particular phenomena as they unfold over time (McLeod & Thomson, 2009). As the aim of this study is to capture variation in context and in experience, with a view to developing a substantive explanation of how people experience their diagnosis of glioma, QLR offered the opportunity to achieve variation in how people responded over time. By interviewing at set points across the treatment trajectory the study included the causal factor of temporality. As such this provided for the ability to understand what part of the person's experience could be attributable to a certain time in the illness journey, and further the influence of time over people's experiences. As Bryman (2016) clarifies, longitudinal research studies can allow for insights into the time order of variables and therefore, may be more useful in making causal inferences. As a result, the findings of this study can make inferences based on causal factors; that people experience certain elements of their diagnosis as a result of a certain treatment/temporal experience. The above statements are not intended to suggest a mechanistic relationship between time and experiences, but rather to enable an exploration of such relationships, which vary between individuals and contexts.

3.7.1 Sourcing the sample

The sample was obtained from a specialist radiation oncology hospital in Dublin which provides a service to patients from all over the country and treats people on both an inpatient and outpatient basis. Patients with glioma were typically referred to the hospital in which the study took place to commence radiotherapy treatment 4 weeks after receiving neurosurgery in a different hospital. The time I spent working in the radiation oncology hospital provided me with the opportunity to develop working relationships with key stakeholders in Ireland's oncology setting such as consultants, support groups and researchers. It assisted greatly in the negotiation and approval by the relevant medical ethics board as well as enabling access routes to this vulnerable population for inclusion in this study.

In order to source the sample for this study I was permitted access (after undergoing training) to the hospital treatment planning system. Through this system I could access the details of those who were due to begin treatment for glioma in the following 4-6 weeks, and sort potential participants based on diagnosis, gender, age, occupation, address, marital status, and treatment type. However, the system did not provide any information which could illuminate whether or not the person was eligible to participate in the study i.e. whether or not they could contribute to developing theory or participate in interviews in a meaningful manner. Upon obtaining the details of potential participants I then spoke to the relevant Consultant regarding whether they could participate. As per ethics, given the Consultant's responsibility for the patients during their time in the hospital, the Consultant had to approve the invitation for the inclusion of each potential participant. The Consultant would then advise whether or not they thought the person would be suitable for the study. Upon identification of people suitable for the study the Consultant or a member of the medical team would provide the person with an information leaflet and inform them of the details of the study.

Although I primarily identified potential participants via the online system, on a number of occasions I received recommendations of incoming patients from members of the medical and multi-disciplinary teams (e.g. physiotherapist, social worker). On these occasions I still brought the proposed individual's names to the Consultant (unless they themselves had recommended the patient) to seek approval to approach and recruit. Sampling this way minimized confusion and delay and reduced dependency and placing burden on busy staff.

3.7.2 Ethical approval to conduct the research

Ethical approval to conduct this study was granted by St. Luke's Radiation Oncology Network Research Ethics Committee on the 19th of June 2015, and by the Research Ethical Approval Committee at the School of Social Work and Social Policy, Trinity

College Dublin on the 20th of January 2016. Both institutions insist on detailed and thorough protocols, which were fully complied with.

3.7.3 Obtaining participant consent

Informed and voluntary consent was obtained from each participant in the study by the researcher. Consent was then re-clarified by the researcher at each point in the fieldwork process (i.e. prior to repeated contacts and interviews). The process of obtaining consent involved a number of steps. Continuing on from the process described in Section 3.7.1, those determined to be eligible to participate in the study were;

1: Approached and provided with an information leaflet by a member of their medical team. Said professional provided information about the study and sought permission for me to contact the patient regarding their participation in the study.

2: Upon consenting to be contacted in relation to the study, I either phoned or met face-to-face with the person and provided them with details about the study and participation.

3: Participants were encouraged to consider their decision for 7-10 days after my initial contact but many were eager to consent to participation immediately. In other cases I contacted the potential participants after the 7-10 day interval in order to ascertain whether they wished to partake in the study or not.

4: Before the commencement of the first interview, the information sheet was reissued and reread. At this point the consent sheet was signed. Participants were made aware of their rights under Freedom of Information legislation and were advised that they may withdraw from the study at any time without any negative implications.

5: In cases where participants wished to partake in a repeat interview, separate consent was negotiated and then reaffirmed. I rerecorded consent to partake in the study as well as consent to be contacted for another interview.

Throughout the study there was no assumption of continued consent. Rather, requests to participate in subsequent interviews required fresh consent. The option to withdraw from the study at any time and without any penalties was clearly conveyed.

Consent forms sought permission to speak with their doctor about any relevant details of their medical condition that may hold bearing over their participation in the interview, conveyed an understanding that the person understood their rights under the Freedom of Information Legislation; that all information collected would be anonymized; except for their consent forms; and that if I had concerns for their safety, I was obliged to pass that information on.

3.7.4 Ethics and sampling

Access to the hospital's treatment planning program removed many of the logistical problems usually associated with recruiting people with life-threatening or terminal illness. Most of the people approached regarding participation in the study were appreciative of the opportunity to share their experiences; only two people approached declined. One person declined because they did not believe their tumour to be malignant and became upset with the nurse who had made the approach on behalf of the study. Another individual declined on the grounds that they did not want to spend any additional time in hospital.

Ethical problems are potentially heightened in longitudinal research, including concerns around serial consent, especially if the patient is deteriorating or vulnerable (Kendall et al., 2007; Lawton, 2001). Prospective participants were made aware that the research design envisioned ideally meeting with people on three separate occasions but that agreeing to participate in the initial interview did not oblige them to participation in all interviews. Almost all participants agreed to take part all three

interviews. Three of the participants, however, displayed 'silent refusals', that is, instances where the person does not decline researcher's invitation to participate in an additional interview, nor did they agree (Calanzani, Higginson, Koffman, & Gomes, 2016). Vinod (participant 6) returned to his country of origin after treatment and did not respond, Rachel (participant 13) responded to explain she was unavailable and then did not respond to invitations for alternative dates and Phil (participant 16) did not respond to any contact made after completion of treatment. In comparison to this, in a past study seeking to use repeated or serial interviews to capture experiences of glioma patients Wideheim, Edvardsson, Pahlson, and Ahlstrom (2002) were unable to conduct any of their follow-up/second interviews because of fatigue and cognitive impairment in the participants after radiotherapy. This was not an extensive issue in this study.

In accordance with the principles of ethical research set out by the University (Trinity College Dublin, 2009), each individual was fully informed about the purpose and the potential risks of the study. As the person was undergoing intensive treatment for a life-threatening cancer, and as previously mentioned in Section 3.7.3, it was required that participants in the study consent to the researcher liaising with the medical team to ensure that they remained happy for the person to continue their involvement in the study. The person was assured that I would not discuss anything other than details of their medical condition which were relevant to their participation in interviews, and that (with deference to the limitations of Confidentiality) none of the information they had shared during the interviews would be discussed with their medical team.

3.7.5 Recruitment: Sampling for variation and theoretical sampling

The purpose of theoretical sampling is to gain a better understanding of the characteristics and possible variation in categories and concepts that are emerging in the data (Timonen et al., 2018). Its distinctive feature is that the emphasis is upon using theoretical reflection on data as the guide to whether or not more data is needed, rather than the statistical adequacy of the sample (Bryman, 2008). Charmaz explains that many researchers claim to theoretically sample but fail to execute the approach

appropriately; theoretical sampling is often misinterpreted and confused with 'initial sampling' or conventional qualitative research approaches (Charmaz, 2006). The concept of theoretical sampling is the source of much confusion and debate amongst early-stage researchers, partially due to the fact that the criteria for recognizing or establishing when theoretical saturation has been achieved is rarely articulated in detail (Guest, Bunce, & Johnson, 2006). In this case, theoretical saturation was reached after sixteen participants (43 interviews). It is possible that saturation was reached at this 'relatively' early point due to the homogeneity of the participant sample and their experience in terms of trajectory. A similar occurrence was documented by Guest et al. (2006) who reported reaching theoretical saturation after twelve interviews, and an early indication of core categories was evidenced after just six. It is not unusual to reach saturation with a sample of twelve interviews in palliative care research projects with Grounded Theory (Stiel et al., 2010).

Using simultaneous data collection and analysis to inform each other (Charmaz, 2008) I was able to engage in theoretical sampling within interviews. Theoretical sampling refers to the seeking and collecting of pertinent data to elaborate and refine data in your emergent theory (Charmaz, 2006) and involves sampling to develop the properties or characteristics of your category, until no new properties arise. This is what is meant by the term saturation of the data. As the interviews progressed it became apparent that the key experiences of people with a recent glioma diagnosis as they moved through the various stages of treatment were largely universal. While theoretical sampling was the main sampling technique, I also purposefully sampled for variation in age ranges (19-70 years), life-stages (education to retirement), geographical locations and family contexts, in order to introduce a manageable degree of variation in the sample. Variation was also provided through the differing ways people received their diagnosis communication and the extent to which the doctors disclosed prognostic information. As such I sought participants who had been treated by a variety of the Neurosurgeons and Consultant Radiation Oncologists, all of whom have differing approaches to prognostic communication and emotional support. Recruitment was (insofar as possible) driven by my goal to saturate emergent categories, identified by ongoing analysis.

Initially this study sought to explore people's experiences of the services they encountered and availed of during their treatment (both medical and supportive), but it became apparent at an early stage in the fieldwork process that this was not an issue of significant concern to the participants at this time. The participants were much more concerned with processing the shock of the illness, making sense of it, and trying to cope with it. The aim of this study was to capture and describe the experiences of people with glioma. People's experiences of glioma during the period of time under examination centred around coping with their illness. As the findings will portray, at this point in time, participants were not concerned with support services, rather they were much more concerned with mental and emotional survival. This experience reinforces the mantra frequently featured in much of the Grounded Theory literature; the importance of remaining open to emergent findings and of maintaining an open-mind. By remaining open and sensitive to the data, early analysis and emergent categories encouraged me to shift the direction of my data collection in order to address this issue of concern in the participants' lives.

3.7.6 Data gathering

3.7.6.1 Qualitative interviews

Steiner (2008) stipulates that qualitative research interviews attempt to understand the world from the subject's point of view, to unfold the meaning of people's experiences, to uncover their lived world prior to scientific explanation. In this study it was decided that in-depth qualitative interviews were the most suitable tool to capture the participants' experiences. Although other methods of data collection such as focus groups or participant observation are common in qualitative research and Grounded Theory, based on the context of the study and the overall aims of the project it was decided that interviews would be the most suitable (e.g. focus groups would have been too cumbersome to organise for this patient group, and observation could not have tapped into their subjective experiences). However, other manners of data collection were used in addition to interviews. Consistent with Grounded Theory methodology, both reflexive and theoretical memos were generated in tandem with

the analysis of interviews and informed theoretical sampling and the development of core categories and theory (Charmaz, 2014). A description of the use of these memos during analysis will be included in Section 3.7.8.

3.7.6.1.1 Ethics and the qualitative interview

Ethical objections to the study of people approaching the end of life regularly arise from the potential for harm outweighing any benefit (Hopkinson et al., 2005). Lasagna (1970) stipulated that the terminally ill should only be included if it can be shown to be of direct benefit to them. However, Ferrell & Grant (2014) argue that the achievement of an ethically sound research process is the outcome of weighing potential harms and benefits for both researcher and researched, in order to minimize undesirable consequences.

The last 20 years has started to reveal a growing understanding and appreciation of the benefits of qualitative research for participants. Through this study I have found that in the context of healthcare research with the terminally ill/those with life-threatening illness, it is possible that qualitative interviews may be a very therapeutic experience for participants.

Hutchinson, Wilson and Wilson (1994) listed seven potential benefits of taking part in qualitative research interviews: catharsis, self-acknowledgement, sense of purpose, self-awareness, empowerment, healing and providing a voice for the disenfranchised. In studies on the topic of palliative care, Stiles (1994) discussed the therapeutic potential of a research interview, where relatives were helped to come to terms with their impending loss. Morse & Field (1996) highlighted that even though participants may become upset during an interview they generally expressed appreciation that someone has at last listened to their stories. Appreciation was also a factor in the feedback received by Ferrell and Grant, (2014) as participants expressed appreciation that research was being conducted on a topic important to them. The same authors proffer that research with the dying provides the participant with an opportunity to feel like they are contributing to others, deriving meaning from illness and have an

opportunity to feel heard. The following extracts from my data speak to similar experiences:

...really appreciate the way that you are conducting the research, I'm so glad that there is a way that you can actually gather people and information about their lives, their experiences, their thoughts, and then that can actually help.
Vinod (participant #6).

It's been good for me, it gives you an hour or whatever to get away from-, otherwise what would you be doing? Waiting to get a call to go to treatment.
Anthony (participant #9)

Participants in psychosocial end-of-life research are unlikely to experience significant burden from participation (Pessin et al., 2008). Qualitative interviews can be minimally burdensome if conducted in a sensitive manner and may even be beneficial. To quote one of my participants:

If anything that I have to say helps anyone else, I am happy. Ian (participant #2)

Participation was seen as a way of processing one's own thoughts and experiences. For researchers who might align with a social constructionist position in which language is understood to be both performative and constructive (Burr 2003), this is self-evident. Through dialogue with the researcher, a reality is constructed, reconstructed, or co-constructed:

"I've actually found it very helpful, very interesting as well. It's opened up discussions that I might not necessarily have had otherwise. You might have asked questions that I wouldn't have been asked otherwise and said, "Okay how do you feel about that?" "Well, I have no idea, I haven't thought about it." and now I'm thinking about it... So anything that's additional has to be helpful, but I certainly haven't found it upsetting" Owen (participant #14)

I've enjoyed it. It's interesting the things that are in your head and you don't know they're in there, I wholeheartedly recommend it, I'd almost even see it as some sort of element of counselling. Ursula (participant #7).

Participants were made aware that they did not have to answer some of the questions in the interview if they so wished, and that they could stop the interview at any time, and that they did not have to continue in the study if they did not want to. Prior to the commencement of each interview anonymity and confidentiality were explained, along with the limitations to Confidentiality. I clarified to participants that if a participant disclosed something that I was concerned about, such as potential harm to themselves and others, I would have to bring this information to the attention of their Consultant, but that I would speak to them about this beforehand if it became relevant.

It was anticipated that some participants may become upset during interviews given the research topic. As such, a care plan was put in place; should a participant become significantly distressed at any time during the interview process, the interview would be paused, and the researcher, as a qualified social worker with experience working with this patient group would suspend the research interview while attending to the participant's emotional needs. Depending on the situation the interview may be postponed, and various support options discussed. As the researcher I would take responsibility for ensuring that if necessary support options are made available for them including the option of referral to several different sources of support including the hospital's Brain Tumour Support Group, the Medical Social Work Department, and the Psycho-Oncology service. The radiation oncology Medical Social Work and Psycho-Oncology teams in the hospital acted as a support and facilitator throughout the study and in relevant circumstances agreed to accept referrals if participants needed more ongoing support than is possible for me to provide in the capacity of researcher. Throughout the course of the study however, no participant required referral to these services as a result of emotional upset.

As a result of the hospital research ethical committee's direction that all interviews must take place in the hospital, I was restricted in terms of opportunities for follow-up meetings. I was keen to complete follow-up interviews approximately 2-4 months post-treatment. People with glioma are restricted from driving and thus dependent on friends/family to bring them to hospital appointments. In order to minimize participant burden (and to maximize retention by reducing any inconvenience) I aimed to schedule follow-up interviews in line with the days that the patients returned to the hospital for their follow-up appointments. However, often it was not suitable for people to remain in the hospital after their follow-up appointment, either because they had a family member or friend waiting to drive them home, or they had another appointment to attend.

3.7.6.1.2 Conducting the qualitative interviews

The approach to interviewing tends to be much less structured in qualitative research in comparison to quantitative. Grounded theory primarily seeks to understand what is most important for the participants. Semi-structured interviews are an effective way of achieving this due to their flexibility and their ability to pursue new (or unexpected) lines of enquiry brought up by the interviewee. As I sought to understand the participants' experiences of their glioma and how they made sense and coped with it, I used an open/semi-structured interview guide to ensure I covered key topics in each interview. This type of guide allows for the focus to remain on how the participant frames and understands issues and events, what the participants views as important when explaining and understanding events, patterns, and forms of behaviour. (Bryman, 2008). However, as outlined by Conlon, Carney, Timonen and Scharf (2015), as the interviews continued, they became increasingly focused as I sought to elaborate on emerging concepts in the data and directed my questions at developing my understanding of the complexity of key processes in the data.

Of particular note, Bryman (2008) points out that qualitative interviewing allows the interviewer to alter the wording or language of the interview and their questions. Such an ability was an important factor in this study given the proximity to their recent

diagnosis and the sensitive and uncertain nature of the participants' prognostic awareness and their preferences for how they expressed their awareness.

The previous section highlighted that story-telling in research can hold therapeutic benefits. In this study people were asked to share their experiences since receiving their diagnosis. Typically, participants detailed their experience in chronological order, beginning at the first indication that something was wrong. This gave them an opportunity to tell 'their story' from the start, and the follow-up interviews allowed them to provide updates on how things had developed or had changed since their last interview.

It is accepted that qualitative interviews are most effectively conducted in a naturalistic setting (Denzin & Lincoln, 2011; Gilgun, 2013) where the research participant is most comfortable. However, as per the direction of the Research Ethics Committee, all of the interviews took place in a sitting room in the hospital building. Typically, those attending the hospital as outpatients organised their interviews to take place either before or after their treatment/meetings with their doctor. Those who were inpatients in the hospital were content with meeting at any time. Interviews with those staying in the hospital typically lasted longer than those with outpatients who tended to have family members waiting for them. Participants who were inpatients found they had little to occupy themselves with in the hospital and so were happy to partake in the interviews to pass the time.

Participant retention and attrition is an issue for all longitudinal studies, particularly in the field of oncology and palliative care (Murray et al., 2009, Steinhauser et al., 2006). In line with existing research providing recommendations for retaining participants (Steinhauser et al., 2006), people in this study were offered an interview by phone for the final follow-up interview if they were unable to attend the hospital. If they chose to interview by phone, when possible, they were asked to sign a 'consent to contact' form stating that they consented to me contacting them to discuss conducting a telephone interview. I spoke with them beforehand to explain the nature of the interviews and ensured that they understood what was entailed. Again, this was all

carried out with the agreement of the Consultant. All phone interviews were conducted from the hospital. Another care plan was put in place should someone become distressed over the phone; they would be advised of support services including their medical team in the hospital, the Medical Social Work team, their GP and would be provided with the number of helplines including the Samaritans. The patient's Consultant and the Principal Medical Social Worker would be advised of any significant distress or concerns. Again, interventions of this type were not required during the course of the study.

Each participant was interviewed between one and three times. Duration of the interviews ranged from between 25 minutes to 2 hours 20 minutes³; the average duration of interviews was 1 hour 10 minutes. All interviews were transcribed by either me or a professional transcription service shortly after the interview took place. Reflective memos were written immediately after each interview in order to document feelings, perceptions and observations experienced during the interview. These were later used in tandem with the data and theoretical memos in order to capture both that which was and was not tangible.

Most participants were very comfortable speaking about their experiences, only rarely did they express notable upset. Many of the participants explained that the interview was first opportunity to speak openly and freely about their diagnosis in an impartial setting, without the fear of shocking or upsetting the listener. The semi-structured nature of the interview allowed me to follow-up on important elements of the illness experience that the participants had identified, and to explore developments and changes within their experiences as time passed. Interestingly, only very rarely did participants drift off topic. I believe that given the location of the interview, the ongoing interactions and engagements serving as a reminder of the reality of their illness, and the recent/close proximity of the shock of receiving their diagnosis meant

³ Four of the interviews were over two hours in duration. Two of these interviews were with the same participant. All of the participants involved in these longer interviews were inpatients in the hospital and as previously mentioned, did not have any further arrangements or appointments occurring that day. As such these individuals talked at length throughout the interviews, often providing long descriptive accounts of their experiences without prompting.

that participants' focus centred around their illness, and hence they were not easily distracted by other streams of thought. I was also surprised that the participants were quite content with speaking for lengthy periods of time, despite the difficult nature of the topic and the fatigue associated with treatment.

The experiences of this patient group were a particularly delicate topic to study. As the findings will reflect the participants displayed a variety of insights into the difficult facts of their diagnosis and as a result, at times, it was difficult to ascertain what participants knew about their diagnosis and prognosis, and what they were unaware of. Qualitative, in-depth, semi-structured interviews were ideal for addressing the complexities of this issue. They afforded me the flexibility and responsiveness required to sensitively probe and establish participants' level of awareness and what they were and were not comfortable describing and exploring. I found no problem in prompting or probing for more detail in most circumstances. However, despite my need to pursue lines of inquiry pertinent to developing categories and theory, I also had to remain cautious about the questions I asked and how I phrased them. I often worried that a question might contribute to a participant's realisation regarding their prognosis which they might not otherwise have been aware of. Raudonis (1992) previously highlighted the danger of qualitative researchers erring on the side of caution and being over-protective of potentially vulnerable participants, nonetheless this was something that I did not believe a researcher should have a role in as Yates & Stetz, (1999) explain; intrusion, dependency, and distortion of life experience must be avoided. From my own experience during this study, as intruders in the lives of those we study, those who are generous in their time and emotion, I believe we must refrain from leaving irreversible imprints of a negative nature. The role or the needs of the researcher cannot supersede that of the participants' manner of coping with their illness.

A minority of interviews were conducted in the presence of the interviewee's significant other. In these instances, I remained cognisant of the fact that the person's experiences would be co-constructed by the significant other. As the focus of this study was to elicit the experiences of people with glioma, rather than the experiences of

their caregivers, I directed (as much as possible) all questions to the participant themselves.

To illustrate my interviewing practices when a family member was present, I outline the case of Jennifer (participant 8) who was accompanied by either her son or her husband in all 3 of the interviews in which she participated. Jennifer explained that she wanted a family member present due to her difficulties with speech and memory, and that she believed she would be better able to contribute to the study with their assistance. During the initial interview in which she was accompanied by her son it became apparent that he was worried that I was going to disclose prognostic information that the participant was not aware of, and had assumed a protective role, attempting to answer on his mothers' behalf and interrupting my questions with reassurances that 'everything would be ok'. When he realised that I was not intending to inform his mother of her prognosis, he relaxed and only intervened when his mother asked for help recalling an event or struggled with word-finding. This instance highlighted the tension surrounding participants' awareness of the difficult facts of their diagnosis and the interactions they may experience relating to this tension.

In the case of Ben (participant 15), his mother's presence in his final interview had a positive effect on the development of my categories. Where Jennifer's family (above) sought to protect her, Ben's mother encouraged him to be more explicit and honest about his experiences throughout his illness journey. Where Ben's solo interviews had centred around his positive resolve and fighting spirit, his mother encouraged him to speak about the anger and frustration he felt. The distinction between the two sides of Ben's experience provided rich insight for my analysis and prompted me to search the data for other instances such as this as I sought to generate an understanding of what the motivations and behaviours prompting this contrast were.

3.7.7 Member checking

Grounded Theory seeks to give a voice to participants and in the case of this study it sought to share the experiences of how people with glioma coped with and made

sense of their diagnosis. Member checking is an element of Grounded Theory which prescribes returning to participants at an early point in the analysis to check whether the researcher's interpretations of the data reflect the participant's understanding of it. Member checking ensures the data remains grounded in the participants' experiences and further strengthens the co-construction of the study.

This study used repeat interviews to understand how people's experiences of their illness changed over time, and to capture how their understandings developed as treatment progressed. Repeat interviews also provided me the opportunity to check the development of my analysis in a way that did not inconvenience or burden the participants. During interviews I explained my understandings generated from the data and checked that my understanding and representations of the emerging concepts were correct. Member checking particularly aided with my development of the concept of *constructing a tolerable reality in order to cope*, which will be detailed in Chapter Six. During the emergence of this category I returned to confirm and develop my understandings of it in many of the final follow-up interviews.

3.7.8 Data Analysis

Consistent with Grounded Theory, the analysis of the data occurred in tandem with data collection, in order to inform future sampling procedures and ensure the findings were inductive in nature. The analysis of the data collected through the repeated, unstructured interviews was in line with Constructivist Grounded Theory (CGT) methods (Charmaz, 2014). The analysis was conducted initially by coding line-by-line. During this 'initial coding' I studied fragments of the data closely for their analytic importance labelling them with gerunds in order to ascertain 'what exactly is going on here', 'what is their biggest concern', 'what are the participants trying to tell me'. By breaking down the data I found I was better able to see and understand what was happening within the data which furthered my understanding of the participants' experience and helped direct further data gathering. Charmaz (2014) stipulates that Grounded Theory analysis through initial coding continues the interaction that the researcher shared with the participants while collecting data, and thereby brings the

researcher into an interactive analytic space while Timonen et al., (2018) refer to this process as 'breaking open' a topic in order to develop a better understanding of it.

Charmaz (2006) promotes the use of line by line coding, i.e. coding each and every line within the data. However, I found as I began to do this that I was overly fragmenting the data. In response to this I chose to conduct my initial analysis through sentence by sentence and section by section analysis (Campbell, Quincy, Osserman, & Pedersen, 2013). I found this allowed me to be fully present with the individual and the data. I also used *in vivo* coding as some sentences and expressions fully captured what was going on for the participant at the time and summarized their experience more accurately and succinctly than any code formulated by me could have done.

After a period of initial coding I moved into more 'focused coding'. Focused coding allows the researcher's understanding and rendering of the data to become more conceptual (Glaser, 1978). It condenses and sharpens the understanding garnered from the initial analysis and involves critically viewing initial codes and assessing which makes the most analytical sense to synthesise. In short, focused coding conceptualizes the findings into larger segments in order to advance the theoretical direction of the analysis (Charmaz 2014).

Reflexive and reflective memos were written immediately after each interview. In part they served the purpose of helping me to process and debrief after the interview, however they were also used to identify observations, methodological insights and comparisons between data. These reflexive memos informed the analysis of the data and during the 'focused' and 'theoretical' stages of the analysis they became part of the theoretical memos in which I recorded the ongoing development and insights into connections between concepts and categories. Memoing is an important component of grounded theory analysis (Corbin & Strauss, 2008). These memos promoted relationship building between concepts and comparisons between data. This in turn informed theoretical sampling as I began to pursue emerging concepts (for example, 'awareness' and 'communication and the illness'), having identified these as key elements of the experience within the early stages of data collection.

Through the iterative process of conceptualizing, memoing and constant comparison between data (Belfrage & Hauf, 2017) theory building began when I found I could make conceptual descriptions detailing how concepts and categories might relate to each other. Theory building was ongoing throughout the course of the write-up until Chapter Seven was completed as I continuously moved between the data and the literature. By asking analytic questions during each step in the iterative process, the researcher raises the abstract level of the analysis and intensifies its power (Denzin & Lincoln, 2011).

Consistent with Critical Realist Grounded Theory, emergent categories were furthered through the process of retrodution (Oliver, 2012). Key behaviours identified were interrogated via the examination and exploration of 'what must happen, for *this* to happen' (Archer, 2013). For example, rigorously asking the data why the participants were so focused on 'accepting that they had no control over their illness' allowed me to see that 'they needed to accept so that they could adjust'; adjustment was required in order for the participants to be able to cope on a daily basis with their illness, which in turn allowed them to enjoy everyday life.

In isolation these concepts made no sense. However, asking these aforementioned questions of behaviours typically illuminated the causal mechanisms at play, and then provided explanations of those behaviours. As the analysis advanced and core categories emerged, it transpired that 'the core category' was the answer to each thorough interrogation and theorizing of the data. Conversely, testing the core category against seemingly unconnected concepts illuminated their relevance and their role in the studied world.

The 'core category', which represents a major part of the emergent explanatory theory, can be identified by the fact that it incorporates or supersedes other categories in explanatory importance (Timonen et al., 2018). In this case, early indications of the core category emerged during the initial interviews and subsequent analysis of those interviews. Upon identifying the importance of this category, amongst others, my

focus shifted to exploring and strengthening my understanding of the relationships between 'it' and the categories and concepts informing it. I found that towards the end of the analysis, the majority of the concepts and categories motivated behaviours pertaining to the core category, and in turn the core category related to and sustained the smaller categories and concepts. As a result, at this point I was satisfied that I had developed a substantive description detailing how people with glioma experience their illness which was grounded in the data.

Nvivo12 (QSR, 2018) was used to facilitate this process. As Nvivo uses 'nodes' which can be assigned to memos, it provided a valuable workspace for the exploration of emergent ideas and their integration into theory development (Hutchison, Johnston, & Breckon, 2010).

3.7.9 Ethics in data management

Each of the participants consented to interviews being digitally recorded. Participants were informed that the recordings of their interview would be kept in my possession in a locked press in Trinity College Dublin. Participants were made aware that the interview recordings would be transcribed and anonymized, no identifying names or information would be included in the transcripts, and audiotapes will be kept until the degree is completed and deleted upon completion in line with best data protection standards. Consent was given by the participants on the basis of these arrangements.

Under Freedom of Information Legislation participants were advised that they were entitled to ask for any personalized information relating to them. All personalized data pertaining to the study was securely stored on encrypted computers and hard copies (of consent forms) kept in locked storage. Digital recordings were transcribed and anonymized during this process. Securely stored data and anonymized transcripts are held for a minimum of ten years in accordance with Trinity College Dublin guidelines. Following this period the data will be destroyed in accordance with Trinity College Dublin data management policy.

3.8 Characteristics of the sample

Sixteen people with a recent diagnosis of glioma participated in this study. Ten of the participants were male and six were female. The ages of participants ranged from 19 to 70 years. Seven of the participants were outpatients; they travelled to and from the hospital on a daily basis in order to receive treatment. As a result, they typically lived no more than 1.5 hours' drive from the hospital. Nine of the participants were resident in the hospital during their treatment. Of this nine, four were staying in onsite accommodation, while the remaining five were staying on hospital wards. Typically, those who had a caregiver/family member available to monitor them stayed in the onsite accommodation, while those who possessed a greater symptom burden or displayed risks of seizures stayed on the hospital ward to be monitored. Ten of the participants had a diagnosis of glioblastoma multiforme (GBM) (Grade IV), which, as outlined above correlates with a poor prognosis (approx. 15 months survival). Five of the participants were being treated for an astrocytoma (Grade III) which typically progresses into a GBM, while one participant had an oligodendroglioma (Grade II), a typically slower growing tumour. At the time of finalising this thesis two of the participants are alive. Most participated in 2-3 interviews in the hospital. Three follow-up interviews were conducted over the phone due to participants' difficulty attending the hospital.

	Pseudonym	Age	Diagnosis	Residence status during treatment	Personal details	Interview details
P1	Dave	58	Glioblastoma Multiforme (GBM)	Outpatient	Married with Adult Children Electrician	3 Interviews
P2	Ian	61	GBM	Outpatient	Married with Adult Children Public Servant	3 Interviews

P3	Gerard	70	Grade III Astrocytoma	Outpatient	Married with Adult Children Retired Carpenter	3 Interviews (1 phone interview)
P4	Liam	61	GBM	Inpatient	Married with Adult Children Retired Public Servant	2 Interview (RIP before 3 rd Interview)
P5	Heather	62	GBM	Outpatient	Married with Adult Children ChildCare Worker	3 Interviews
P6	Vinod	29	Grade 3 Astrocytoma	Onsite hospital accommodation	Single Software Engineer	2 Interviews
P7	Ursula	51	GBM	Inpatient	Married with Young children Civil Servant	3 Interviews (1phone Interview)
P8	Jennifer	62	GBM	Outpatient	Married with Adult Children Informal Caregiver	3 Interviews Accompanied by son or husband in each.
P9	Anthony	48	Grade 3 Astrocytoma	Onsite hospital accommodation	Single Factory worker	3 Interviews
P10	Sarah	41	Grade 2 Oligodendroglioma	Onsite hospital accommodation	Married with Young Children Home-maker	3 Interviews
11	Tom	62	GBM	Inpatient	Married with Adult Children Farmer	3 Interviews (1 phone interview)

12	Aoife	51	GBM	Inpatient	Married with Adult Children Healthcare worker	3 Interviews
13	Rachel	21	Grade 3 Astrocytoma	Outpatient	Single living with parents Student	1 Interview
14	Owen	48	GBM	Onsite hospital accommodation	Married with Adult and Young Children Artist	3 Interviews
15	Ben	19	Grade 2/3 Astrocytoma	Outpatient	Single living with parents Student	2 Interviews Accompanied by mother in 2 nd interview
16	Phil	42	GBM	Inpatient	Single living with parents Construction worker	2 Interviews

3.9 The researcher and the research design: A critical review

I remained consistently aware that the participants were seriously ill, going through a very stressful time, and that the research might be an inconvenience for them. This caused me to feel nervous and apprehensive about re-contacting them for follow-up interviews. I worried that I might be adding to their stress by calling to arrange appointments. Approaches to remedying this included frequently reminding participants of their voluntary participation, their ability to cease participation at any time, and my flexibility regarding their time schedules. My concerns were eased by the positive feedback I often received from participants upon 'checking-in' on how they were feeling at the end of interviews. Participants appreciated the non-biased and

comfortable atmosphere from which they could openly explore and express their feelings and experiences. In line with reflexivity, participants described realizing feelings, thoughts or behaviours they had been experiencing, and had not been able to make sense of until prompted in the interviews.

With this in mind, if I was to conduct the study again I would strive to be less concerned about inconveniencing people with requests for interviews and study participation. This study has highlighted the need to move away from paternalistic and protective approaches to care of the terminally ill, and to give greater credence to patient agency, autonomy, and the ability to protect themselves should the need arise. As seen with 'silent refusals', participants are capable of leaving a study in many ways, some in a less conventional manner, should they wish to.

Prior to conducting this study, I had limited experience in conducting qualitative research. As a result, undertaking a PhD was in and of itself a learning experience. I initially found it difficult to shift from my professional social work role to that of a researcher. I occasionally caught myself trying to support the person as they expressed hopelessness or anxiety (or taking an investigative approach as I would in a psychosocial assessment) rather than an exploratory one. Researcher reflexivity, memoing and self-awareness aided in these instances and assisted me in correcting my approach. I kept a researcher/fieldwork diary for a period of time.

Most notably, throughout the interview process, I did not feel comfortable using the cognitive screening tool as discussed in Section 3.4.1.; the MMSE. As outlined by Robinson, Biggs and Walker (2015) cognitive screens lack sensitivity in detecting cognitive deficits after brain tumour. As a Medical Social Worker, I have never been trained in the use of cognitive screening tools. I made numerous requests and applications to the hospital ethics committee to seek an alternative approach. The committee provided me with discretion regarding its use, when deemed unsuitable by the consultant, however they still sought its inclusion in uncomplicated cases and circumstances.

After the data collection element of the study had ceased, I received a number of text messages and phone calls from participants who wanted to update me on the developments of their treatment journey or share new insights into their 'lived experience' of the diagnosis. Additionally, a number of participants contacted me to request copies of their interview transcripts for personal use. One participant wanted to give the transcripts to his wife to aid his communication with her surrounding his experience. Another wanted to keep the transcripts in a scrap book as a memory of the adversity he had overcome and one participant was having bracelets made for his children in anticipation of his death and wanted to have quotes from his interviews inscribed on them.

Despite my experiences both training and working within an oncology and palliative care setting, there were many occasions in which this study was upsetting. This is in part due to the connection I developed with the participants and their families during our frequent interactions throughout the course of the study. Medical updates and developments rarely resulted in good news and I regularly felt torn between my pragmatic professional knowledge and my desire to cast off that knowledge and hope along with the participants and their families. Although my upset pales in comparison to the struggles of those included in this study, self-care was an important aspect of managing stress. Exercise, memoing and debriefing with my colleagues and supervisors were methods which supported me throughout the study.

3.10 Conclusion

This study set out to capture how people with glioma experience their illness across the initial phases of treatment. As a critical realist I sought to understand the complexity of living with a life-threatening illness, and how people could cope and continue to engage in daily life by placing people with glioma at the centre of the enquiry as the most reliable informants about their lived experiences.

Conducting qualitative research in a clinical setting requires negotiation and adaptation by both the researchers and the ethics committees. Flexibility within the

research design is required while maintaining a firm understanding and commitment to the chosen methodological approach. The researcher must strive to inform and advocate for the use of qualitative research methods in the clinical setting by continuing to highlight the tenets and objectives of the methodology while respecting the structures and everyday operations of a hospital.

The successful completion of the fieldwork component of this study suggests that people with malignant brain tumours (of varying prognoses) are happy to partake in conversations about their experiences provided it is approached in a sensitive and respectful manner. Participants appreciate taking part in patient-centred research seeking their own explanation of their experience. Some found meaning and purpose through participation while others found it actually benefited them.

The findings described in the following chapters detail the experiences of people with glioma as they move through the treatment journey, although it is acknowledged that these findings do not represent all people with glioma. However, the findings are substantive because they reflect experiences of a broad range of people of varying ages, backgrounds and circumstances.

Chapter Four: Illuminating the journey from glioma diagnosis to treatment

4.1 Introduction

This chapter will detail the participants' experiences throughout the initial stages of the diagnosis journey. The findings of this chapter will primarily centre around insights generated from the initial interview conducted during the initial 7-10 days of radiotherapy. This chapter seeks to outline the initial symptom experience indicating the onset of the disease and the common pathways to receiving a diagnosis of glioma. Participants' initial reactions and responses to the life-threatening diagnosis are outlined, providing insight into the participants initial attempts to understand what had happened to them. The findings included in this chapter provide an insight into the shock resulting from the unexpected nature of the diagnosis and the speed at

which participants found their lives were 'turned upside down'. This chapter will therefore illuminate participants' experiences of the *diagnosis communication* and events which influenced their initial understandings of the disease, treatment and the implications for their future.

The examination of the initial stages of the illness trajectory reveals attempts to adjust to a drastic change in ones circumstances, and highlights the importance of finding a way to cope. Despite the grave implications of the disease, participants navigated their way through the early stages of the illness journey in a manner which enhanced their possibility of maintaining hope for their future and their outcome. I will start by giving detailed accounts of the participants' journeys through this initial stage of discovery, diagnosis and treatment, and following the exposition of the data that pertains to these experiences, I will proceed to discussing these findings. Throughout, I will illustrate the emergence of the central concepts of coping and hope in the data.

4.2 Experiencing the onset of the diagnosis

All participants could vividly recall the events and experiences leading up to their diagnosis and dedicated a large portion of the initial interview describing the time leading up to the disease onset. They clearly recalled dates and times and locations. The experiences leading up to diagnosis varied significantly but they can be classified into those who experienced acute symptoms and received medical attention and diagnosis immediately, and those who experienced more moderate symptoms over a period of time (often weeks) and which could be attributed to an alternative, less serious diagnosis.

Half of the sample experienced a sudden onset of noticeable symptoms resulting in immediate action. The sudden symptoms involved intense and painful headaches, numbness or loss of power experienced in limbs, facial weakness or various types of seizure activity ranging from strange sensations passing through the body to more extreme seizure activity resulting in loss of consciousness. Overall, those who received

rapid medical care and quick diagnosis experienced symptoms that could not be ignored or dismissed.

To illustrate this, Owen (participant 14) went out to mow the lawn one morning and woke up in his local hospital having been placed in a medically induced coma after experiencing a seizure. In hindsight Owen recalled experiencing unusual headaches and feeling 'strange' although he did not register their significance until after the fact. Similarly, Dave's (participant 1) symptom onset occurred unexpectedly while working on a building site. He felt a strange sensation passing through his body, phoned his wife to say he didn't feel well and then sought assistance from his colleagues. They called for an ambulance which brought him to hospital. These seizures occurred unexpectedly for Owen and Dave.

I'm only two weeks into my treatment and it's all happened so fast and there was no real-, other than [his wife] pointing out and saying, "Actually, there was a couple of times you said you felt a bit tired and thought you'd go for a lie down" but that had only been about two weeks maybe prior to having the first seizure and being rushed into A&E. So there was no real warning or signs that this was happening. It's been that quick. I haven't really had time to take it all in, in some ways and I suppose it's the same for everyone else. Owen (participant 14) Interview 1.

In comparison to this, John (participant 3) experienced a seizure related to another illness six months before he had a seizure resulting in his diagnosis of glioma. His last recollection before waking up in an ambulance was going to bed. Similarly, Liam (participant 4) had no indication that he was unwell apart from a momentary weakness in his leg while carrying his granddaughter on his shoulders. It wasn't until he experienced headaches so severe that he compared them to the force of a jet flying through his head that he knew that he had to see his doctor immediately.

Tom and Heather (participants 11 and 5) experienced sudden loss of power in their limbs. Tom (participant 11) experienced a strange sensation passing through his leg

until he lost sensation completely. This lasted about 10 minutes. He attended his GP after the weekend and was referred to his local hospital, commencing his journey to diagnosis. Heather (participant #5) woke up one morning and found she was unable to get out of bed having lost power in her legs. Other than her husband complaining that she was acting strange in the days preceding this event, she could not recall anything that would have indicated the impending diagnosis:

I was alright one day...and the next day the whole thing was just turned upside down completely, like I was working one day and then the next day I went to get out of the bed and I wasn't even able to walk around the bed. Heather (participant 5) Interview 1

Ursula (participant 7) had attended her GP for an unrelated matter when her GP noticed a droop on one side of her mouth. Her GP convinced a reluctant Ursula to attend her local hospital for a CT scan. An abnormality in the CT scan prompted the need for an MRI, followed by a brain biopsy. Aoife (participant 12), a nurse, had no prior indications that something was wrong. She was at a conference when she felt a strange sensation pass up and down her left side and settle in her stomach. Afraid she would faint if she stood up, she remained seated and waited for it to pass. She described the experience to a colleague at work, a doctor, who suspected a TIA ('mini-stroke') and told her to seek medical help if it happened again. A week later she felt the sensation start again while in work, she sat down and prepared herself, only this time it was more intense, her throat felt constricted and her vision blurred. Colleagues called an ambulance and she was rushed to hospital.

Compared to the others in the study, these participants had a relatively straightforward process leading to diagnosis. The remaining participants experienced more moderate and less alarming symptoms. These symptoms presented as unthreatening enough to be dismissed for a period of time, or attributed to alternative ailments by the GP, ultimately postponing the confirmation that something was wrong. These moderate symptoms manifested similarly to the undeniable symptoms outlined

above in the form of low level seizure activity, headaches and facial pain (often attributed to sinus infections), and impairments to speech.

Vinod and Rachel (participants 6 and 13) experienced what was mistaken as sinus issues for months prior to receiving their diagnosis. Vinod believed his anxiety regarding his health prevented him from attending the GP sooner. His symptoms progressed as he experienced strange smells, dizzy periods, nausea and finally severe headaches with blurred vision. He felt reassured by blood tests that came back negative for any issues, furthering his ability to dismiss any concern, but his symptoms persisted. It wasn't until he was found unconscious in his bedroom by friends and brought to hospital by ambulance that he received his diagnosis. Rachel knew her headaches were different to her normal sinus headaches but she was momentarily reassured after her doctor prescribed regular over-the-counter painkillers for her pain. She attributed her neck pain to a car collision she was involved in years earlier, and she was prescribed glasses for her blurry vision. Knowing something wasn't right, she acquired an MRI through the private health system⁴ where her brain tumour was finally detected.

Similarly, Ben's (participant 15) GP attributed his vomiting and headaches to the stress of upcoming school exams. Weeks later Ben suddenly lost all power on one side of his body and attended the hospital for a scan leading to his diagnosis. Phil (participant 16) was feeling generally unwell and was recommended painkillers by his doctor for his headaches. His symptoms progressed until he attended out-of-hours medical services and from there he was rushed to hospital for a CT and MRI and emergency surgery.

Like Vinod, Anthony (participant 9) believed he was fine when blood tests investigating his headaches came back clear. Tom did not believe his family when they told him he was 'blacking out' for periods of time. When colleagues at work began to notice, his

⁴ The healthcare system in Ireland currently consists of a two-tier system; publicly funded healthcare and private healthcare. Availing of the private healthcare system typically accrues significant financial costs however it is associated with shorter waiting periods for diagnostic tests.

manager told him he could not operate machinery until he was examined by a doctor, finally prompting him to receive medical care.

Ian and Jennifer (participants 2 and 8) experienced impairments to their speech. Ian initially felt numbness on his lower lip but dismissed it as he often worked outdoors and presumed he had been hit by a branch. On another occasion while speaking with his wife he realised he couldn't recall or formulate the words he wanted to communicate. The experience was short lived and he dismissed it until it began to occur more frequently and he knew he needed to attend his GP. Ian delayed going to his GP until after Christmas, he reasoned that whatever lay ahead for him in the future, he wanted to enjoy this Christmas. Like the other participants who fall into this category of longer journey to diagnosis, Ian knew something was wrong, however he did not suspect the true extent of the severity of his situation. Similar to Ian, Jennifer became distressed by dizziness and a difficulty in communicating. She described that she had always been a great conversationalist until suddenly she found it became too difficult to communicate confidently. Initially she was treated for vertigo but when she continued to struggle to speak she attended hospital and received her diagnosis.

Sarah (participant 10), like Jennifer, started suffering with intense dizzy spells but also experienced headaches, mild facial pain and ringing in her ears. She searched the internet for possible explanations but stopped after becoming frightened of what she read. Sarah was a sales representative and did a large amount of driving. When she would take a coffee break at a service station, she often had to pretend to look at newspapers and magazines while she waited for the dizziness to pass. Having done this a number of times she reasoned that something was wrong and attended her GP who referred her to the neurosurgery department immediately.

I will now turn to illustrating the next step in the journey of the participants, namely admission to hospital and what ensued there.

4.3 Beginning to realise the diagnosis

Upon admission into their local hospital⁵, participants underwent initial exams and MRI scans, and doctors began to provide the first indications of what the diagnosis might be. It was at this point that the participants began to receive the first pieces of information regarding their diagnosis, and when the severity of their situation began to dawn on them. At this stage, participants were informed of likely lesions, abscesses and abnormalities in their brain, and a few were informed of the possibility that the abnormality could be a brain tumour. Participants were relieved that they had at least some knowledge of what was happening instead of having to grapple with frightening uncertainty:

Now even at that early stage I was glad she had said that to me because I would have people coming to see me and I would prefer to tell them from that stage what could be down the line. I was, I was, as I say glad she had said, even mentioned the words tumours because, you know, there was nothing false then. Dave (participant 1) Interview 1

Although the accounts detailed above reveal that the physical symptoms participants experienced prompted most of them to consider that something was wrong, none suspected that they had a brain tumour. Ian and Aoife (participants 2 and 12) thought that they had experienced strokes. Having been told that the scans revealed a shadow on his brain, Ian (participant 2) outlined his shock at learning about the tumour, which he saw as the worst case scenario:

I remember she [the medical Consultant] said to me what are you feeling now... I said I'd prefer if I got a stroke (...) I hadn't a clue but I thought in terms of, Jesus, it's serious and I thought, no, tumour oh no, stroke manageable... do you know what I mean... (Interview 1).

⁵ The participants in this study originated from various towns/cities all over the Republic of Ireland. Having either been referred by primary care/GP or admitted through the Emergency Department, the first hospital in which the majority of participants received medical attention was typically their local, regional hospital. From here they were transferred to a large acute hospital specialising in neurosurgery.

Rachel (participant 13) suddenly realised she had a brain tumour when her MRI scan was paused to inject her with a contrast dye, something she recalled from her relative's experience as signalling very bad news:

...they pulled me out halfway through...and put a dye in my arm and I remember my aunty telling me that happened her...so when they put me back in I was just crying my eyes out like 'cause I just knew that something was wrong...(Interview 1)

4.4 Hospital admission

From their local or regional hospital, participants were informed they would be transferred to the national centre for neurosurgery [hospital name anonymised]. This reassured participants as they understood they would be reviewed and cared for by specialists and experts. Most participants were impressed by the speed at which the transfer and admission to the neurosurgery ward occurred and appreciated that their situations were being taken seriously by the medical staff that they encountered. They believed they were receiving responsive care. Events moved quickly once admitted to the specialist hospital, participants underwent more scans and all were informed they would require neurosurgery. Some participants worried about the potential risks of surgery but all consented without hesitation, seeing surgery as their only option and as a means to resolving their symptoms. This stage of the journey was typically very quick, the participants had to take in a lot of new and shocking information; in short, it was generally experienced as 'a blur'.

In contrast to this 'blur', participants recalled events after surgery more clearly than the short time prior to surgery. Some participants were overwhelmed by the number of different professionals they met on a daily basis and struggled to retain the information that they received from them. In response to this, participants often asked the nurses to relay the information to them so that they could update their family members accurately. Many participants struggled with the nature of the ward itself.

For most participants it was their first opportunity to begin to process what had been happening and this resulted in upset and difficulty sleeping. Being surrounded by critically unwell people prompted one of the several incremental moments of realisation of the severity of their situation:

I remember I was sitting in the beds and like I was in this ward with really sick people and I was like looking at them and I was like, I feel so sorry for them and then I'm like 'Rachel' [laughing] you're here too, you're really sick as well. Rachel (participant 13) Interview 1.

Participants were surprised by their quick recovery in comparison to the crucial nature of their surgery. This 'mismatch' was the first of the discrepancies in the experience of a glioma diagnosis encountered by the participants. Namely, the contradiction between their clinical diagnosis (of a life-threatening brain tumour) and how they physically experienced their illness (feeling relatively well) caused confusion for the participants in their attempts to process their sudden illness. These discrepancies will be discussed further in Chapter Five.

4.5 Receiving the diagnosis

The participants were typically called back to the Hospital approximately a week after surgery. Participants were not informed that they had a tumour prior to returning the Hospital. They were met in a small room on the neurosurgery ward by the neurosurgeon and nursing staff. Participants appreciated meeting the same staff they had dealt with during their time as inpatients. Participants were usually accompanied by family. At this point they received their diagnosis. All participants came to the understanding that their tumour was cancerous or malignant:

So they came in and they sat down and they were saying, "Yes, we got the results and it's probably not good. It's glioma astrocytoma and it's stage four." So at that I was like, "Okay that's not good. Stage four of anything is not good." So he says, "You'll be needing radiation and chemo and a lot of it and it's an

aggressive tumour and it possibly will grow back again.” So tears started and it was a bit stressful that day to say the least. I suppose they’re so black and white about it, which they have to be, they have to tell you as it is, but for us it was, “God, now what?” About half an hour of tissues and tears. So then trying to get our heads round it then I suppose. They were very good, they sat on and they didn’t rush me or anything like that, but it’s still hard to get your head round because it had been so quick and out of the blue. Aoife (participant #12) interview 1.

Despite the similarity of the diagnosis each participant had received, the method and content of the communication of the diagnosis and the disclosure of the prognosis varied from case to case. Most attended the meeting themselves and received varying levels of information based on their own preferences and that of the neurosurgeon. Many participants accepted the basic information they were given and did not request additional information regarding their future, although a minority requested information on their likely timeline for survival. Some participants received information pertaining to the difficult facts of their diagnosis without requesting them.

Some participants found themselves hoping that there had been a mistake with their test results. Unfortunately, where there had been a mistake, it required a revision from less to more severe diagnosis. Rachel was initially informed that her tumour was benign only to be devastated when she learned the doctor made a mistake and her tumour was malignant. Similarly, Owen was initially told his tumour was a grade 3 and felt hopeful for a longer survival rate. He was later informed that the tests had been incorrect and his tumour was grade 4. He continued to hope that his renewed diagnosis was incorrect and that he had been mistaken for a patient with a similar name. I will return to this cultivation of hope by the participants in subsequent chapters.

4.5.1 Choosing not to know

In contrast to the majority, Phil and Ian (participants 2 and 16) opted out of receiving information detailing their diagnosis. Phil (participant 16) asked not to know anything further than his formal diagnosis, because he did not believe additional information would benefit him. This suggests that Phil was aware that the troubling information involved in the diagnosis communication may impact his ability to cope and so chose not to know. Similarly, Ian (participant 2) chose not to attend his own diagnosis communication and instead asked that the team meet with his family without him. He qualified this by explaining that he did not need to know the details, he only needed to know about what was happening now i.e. the treatment plan. He recognised there were things his family may need to know and scenarios and questions they may want to explore without him being present. By doing this Ian acknowledged that he knew the situation to be serious, and like Phil, he realised that there may be information relayed in that meeting that would have negatively impacted his emotional state. By 'not knowing', both men could maintain uncertainty regarding their future, focusing on what is happening in the here-and-now and in turn protecting their ability to cope. These processes highlight the participants' need to cope on a day-to-day basis, enjoying the present because they recognise the potential future uncertainty:

[Family] needed to, they needed to know what exactly what I was facing into, wherever, wherever that leads, for me it wasn't so much... I would just prefer the basic as possible- so I could ask, what's the plan, what are you gonna do, and that's all, I don't need anything after that. Ian (participant #2) Interview 1

In contrast to this, Aoife (participant 12) was more explicit about her wish not to know the details of her prognosis:

I don't particularly want to know, unless something drastic happens and I think, "Right, I'm going to need to know. Now, is there things I need to put in place?"
Interview 1

The processes surrounding awareness and knowledge of the disease and its implications, as well as the key concept of *maintaining uncertainty in order to cope*, will be discussed in greater detail in the following chapters.

4.5.2 “Life turned upside down”

Some participants were told that their tumour was inoperable, and that they had received a biopsy only⁶. Those who underwent a biopsy because their tumour was inoperable understood that this approach was taken because they would suffer great impairment should the surgeons attempt to remove the tumour. The participants were in complete agreement with this decision, citing care preferences relating to quality of life over risk of serious and life-altering impairment. This self-protection and weighting of living well in the present over potentially damaging one's ability to do so is similar to the approach taken by Phil and Ian and their request ‘not to know’ and, as previously noted, is a behaviour which features throughout the illness journey and the findings of this study. Participants did not discuss their views on the fact that receiving a biopsy rather than surgical removal would impact their overall survival time, although some expressed wishes that their situation was different and it could be removed.

They were saying like if they had operated- it was an inoperable tumour but if they had operated like they'd have to take away 85% of the tumour... but I said if I was left brain damaged I wouldn't be able to cope...I wouldn't be able to hack that...you know so...what do you do you just get on with it and hope for the best. Heather (participant 5) interview 1.

During the ‘diagnosis disclosure meeting’, those who underwent surgery to remove the tumour were informed that their surgery was a success, and that a large percentage of the tumour was removed. Although it is not possible for all of the tumour could be removed and some small particles remained, participants understood

⁶ In comparison to a surgical ‘resection’ or ‘debulking’ where an attempt to remove as much of the tumour is made (and is associated with a better prognostic outcome), a biopsy simply seeks to retrieve a sample of the tumour in order to determine the histology of the tumour and inform diagnosis. A ‘biopsy only’ approach is typically associated with a poorer prognosis than those who can have part of the tumour removed.

that the surgeons did their best to eradicate as much of the tumour as possible, or as much as could be 'visualised'. Participants felt reassured when told that 95% of their tumour had been removed. However, they also understood that their tumour was highly malignant with a significant chance of recurrence as a result of the remaining 5% of tumour:

So if they'd have got too close to that [part of the brain] they could have done damage, which could have led to paralysis and all the rest of it. So, they said, "No, we'll have to leave some behind." I think they got about 95% out or thereabouts. Owen (participant 14) Interview 1.

Participants were then informed that they would require secondary treatment which caused shock and disappointment for some. Some participants had initially presumed that the cause of their symptoms would be resolved once surgery was over. After feeling great relief having successfully made it through neurosurgery, their disappointment and upset was furthered upon realising that they needed to undergo an intensive radio- and chemotherapy regime, lasting approximately 8 months in total. Learning about their treatment plan, again, prompted some participants to incrementally develop their understanding of the severity of their situation. As a result, people had to process and come to terms with the treatment itself, in addition to the diagnosis. This unexpected revelation compounded the shock and suddenness underlining the diagnosis as highlighted in Heather's (participant 5) first utterance in her initial interview:

Well my life has turned upside down... like I was alright one day...and the next day the whole thing was just turned upside down completely... (Interview 1)

Most appreciated what they comprehended as their doctor's honesty at this time and considered honest communication during diagnosis disclosure essential. In addition to this, most of the participants appreciated their doctor's manner and style of communication, in particular they noted the sense of organisation that went into the doctor's preparation for the diagnosis disclosure meeting. Participants praised the

characteristics of their doctors and nurses and entirely attributed their ability to cope during this time to the staff and the hospital. They appreciated knowing what the doctors were thinking, knowing that the team weren't trying to protect them by hiding anything from them:

If I thought they were trying to hide something from me, I'd be really worried. So at least they come up and say, "This is what it is and this is what we're going to try and do." Sarah (participant #10) Interview 1.

Although most people said that honesty is the best policy when it comes to diagnosis provision, it is not a straightforward matter. Within the doctors' 'honesty', the actual amount of the information being provided varied and often did not contain the 'full picture'. However, the participants unanimously reported that they did not want to be protected, lied to, or placated into a false reality. Primarily where peoples communication preferences differed was the extent of information that they actually wanted.

The methods of attempting to process and make sense of the sudden diagnosis as participants progressed along the treatment and disease trajectory will be fully explored in the next chapter. The participants' most immediate responses to their diagnosis communication centred around whether or not it was their own fault, whether they had done anything to cause the diagnosis, and if not, what caused the tumour. Participants explained that the diagnosis could not be attributed to their own behaviours or characteristics, and in a sense, its occurrence was 'random' in nature. The tumour may have been there for years, lying dormant. In order to make the shock and pain of their diagnosis easier to manage, participants maintained thought processes which focused on the fact that it was not their fault:

I've had a few self-pitying moments, but the majority of the time you just come back to I didn't do anything, it's just happened. And that's one of the things as well with the brain tumour is that they don't know what causes them. If it's lung cancer and you're a smoker, you've got something, "There you go, it's because

you smoked." But they have no idea what causes [brain tumours]. So a lot of people, when they get a diagnosis of cancer of any kind, they're like, "What did I do that did this?" In this instance there's no trigger that they can say, "It's because you did this," or "It's because you did that". They just happen. So at least that takes any guilt off. It's not my fault, I didn't do anything, it just happened. Owen (participant 14)

4.6 "Why me – Why not me?"

Throughout the initial stages of the illness journey participants tried to understand and accept the indiscriminate nature of the diagnosis. They struggled to process the sudden, inexplicable diagnosis and its occurrence 'out of the blue', while characterising its unforeseen onset with such considerable implications as unfair and unjust. Most participants oscillated back and forth between asking 'why me' and accepting and asking 'why not me?'. Typically, thoughts of 'why me' were experienced when the participants were feeling low in mood. In contrast, some participants specifically made a point of 'not asking why me', and accepted the inexplicable nature of the disease. These participants viewed 'asking why me' as a negative and pointless exercise and associated it with 'wallowing' and 'self-pity'. They avoided dwelling on the diagnosis and recognised that acknowledging or accepting the disease as 'random' and out of their control prevented them from ruminating or suffering from thoughts of the injustice and unfairness of their situation which would not help them to cope. Additionally, some participants focused on trying to normalise their hardship by viewing illness as a part of life:

Yeah I think definitely at the start I was kind of like never angry like and people are like why aren't you angry but I don't know I just never had anger in me? I just kind of like... just felt an unfairness as in like, why does this have to happen to me! Rachel (participant 13) Interview 1.

Interviewer: *You never ask "Why me?"*

Anthony (participant 9): *No. Why not me? There is people married with four, five, six, seven kids (...) and they'd be far more upset than someone like me. There's people who are in a lot worse situation than me. That's the way you have to look at things* (Interview 1).

I know from experience, I know people that feel sorry for themselves. I've seen them depressed because they're sitting there feeling sorry for themselves. I think you need to get up and do something to keep going. Ben (participant 15) Interview 2.

I still find it a bit, "Okay." I'm not going down the whole route of, "Why me?" Why not me? It is me so I have to deal with it as best I can. I'm a very positive person, I'm going to fight this. Whatever it takes. Aoife (participant 12)

The sudden onset of the disease and the consequential need to adapt quickly to a new reality influenced the participants' experiences throughout the illness journey, and as such will be further discussed throughout the following chapters. The participants acceptance of the illness in response to its inexplicable nature will be further explored in relation to the core concepts of hope and coping in Chapter Six of this thesis.

4.7 Doing "whatever has to be done"

Participants prioritised the possibility of a cure (or the possibility of a better outcome) over everything else. In order to promote this possibility, they vowed to do 'whatever needed to be done'. As a result they prioritised the possibility of a better outcome over any of the discomforts, burdens or inconveniences inherent in the challenges of treatment. Within this context, 'prioritising' was a decision made by the participants based on their determination to create the best chance possible of achieving a better outcome, within the context of having limited options, while wanting an opportunity to fight their disease and give themselves the best chance of possible.

[It's] not something you want to hear but... the treatment has to be done (...) you would always put the treatment first, to being the cure for what is wrong with you, (...) that's the way I would look at it. The treatment is first and foremost. The side effects could be permanent, they might not be. Dave (participant 1) Interview 1.

...but whatever has to be done has to be done and that's the end of it. Phil (participant 16) Interview 1.

Look, what's been done [treatment] is either in the morning or the middle of the day or the evening time and it's just bzzzzzzzz [demonstrating sound of his treatment]... 8 minutes in the day, no problem, it has to be done. It's just what has to be done, has to be done and that's where you just get on with it and that's it... Liam (participant 4) Interview 1.

I didn't mind that I was going to have the surgery because if that's what was going to clear it up then, whatever it takes, that would be my take on everything, whatever needs to be done, let them do it and...so I was pencilled in for surgery... Dave (participant 1) Interview 1

In order to cope with the various challenges presented in the initial stages of the treatment journey, participants adopted the approach of 'doing what needs to be done' and the mindset of 'getting on with it'. Similar to the above discussion on 'not asking why me', 'doing what needs to be done' relates to the participants' reluctance to dwell on the unfairness or the upsetting nature of their situation, deeming that it would not serve them in their task of getting through treatment. 'Doing what needs to be done' stems from the strong desire to survive (or survive longer), combined with the realisation of powerlessness and having no control over their situation. Therefore, participants tolerated, prioritised, adjusted and coped with various difficulties in order to get through treatment and increase their chances of having a better outcome. These challenges included side effects of treatment; hair loss, fatigue, memory loss and changes to appearance, but also being away from home for days at a time during

treatment⁷ and learning to tolerate the mask used for treatment⁸. Some participants were also open to enrolling in clinical trials if it meant they had a chance of an improved outcome.

The [treatment] mask you can handle, you have to handle it. You have to. The mask has to come on for me to get the treatment so I know it has to go on. I just let them put it on and let them carry on. If they have to do, they have to do it. It's not for their good, it's for my good that they're doing it. Nothing else you can do. Just get the treatment, I can go through it as good as I can. Tom (participant 11) interview 1.

...everything he [doctor] tells me to do I will do it. I will stand on my head, if he tells me to do I will do and more because (...) I have too much at stake here. Ursula (participant 7) Interview 1.

I'm happy enough to go with whatever. As I say, if it's more surgery that's needed go for it. If it's, I don't care. I'm up for anything to fight this. Aoife (participant 12) interview 1.

Being in the hospital prompted some participants to reflect on their own care preferences; the majority of participants who spoke about their preferences prioritised quality of life over longevity. Despite an overwhelming desire to recover or survive, participants did not want this if it was at the expense of their ability to 'live well' or to maintain a good quality of life; they prioritised quality of life over quantity of life. In other words, participants saw no point in living longer if they could not live independently.

⁷ Due to the nature of radiotherapy being administered on a daily basis for a number of weeks, many patients who do not live locally to the hospital must stay in the hospital or in onsite accommodation from Monday-Friday. In the case of this group of participants, they were required to attend six weeks of treatment.

⁸ Patients receiving radiotherapy to the brain must be fitted with a custom-fitted mask in order to ensure their head does not move during treatment. The mask covers their entire head, face and neck and is securely fastened to the bed beneath them. The mask can often cause problems with claustrophobia and anxiety.

4.8 Managing uncertainty

The uncertainty relating to the participants' future was evident in their understandings of treatment although it is apparent that uncertainty in general permeates the entire experience of living with glioma. More often than not, at the early stages of the illness, uncertainty was identified as a troubling aspect of the experience as it induced feelings of loss of control and agency, and increased perceptions of powerlessness. The sense of uncertainty was intensified by the lack of concrete information available to participants regarding their diagnosis, prognosis and treatment. Such frustration was amplified with friends' and family members' requests for updates on the effectiveness of treatment and the participants' inability to provide answers. In response to this uncertainty, participants continued on as directed and did 'what needed to be done' until they were told otherwise:

There is a future, we don't know what it is. We don't know how long it's going to be. It will come back eventually. It's just a question of how soon and how big. I'm well aware it will get me in the end, it's just a question of how long. Owen, (participant #14) Interview 1.

We don't know what's going to happen, what the future's going to bring, but I'm going to keep going as long as I can. Tom (participant #11) Interview 1

I could ask [the consultants], "When will that happen?" They'll say, "We don't know, everyone is different." I go to them, top experts in the country, they can't tell me because of the nature of this disease. The uncertainty of it, it is difficult. It's a difficult thing. When you hear your highly qualified consultant in front of you, [saying] "We're not sure, everyone is different. That's the way it is." Ursula (participant #7) Interview 2.

Participants struggled with the loss of agency associated with the perception of waiting while not knowing what direction their treatment would take next. Participants felt wholly dependent on their doctors for direction and news:

I just have to listen to the medical people, I don't know when it's going to end until they, until they're satisfied. Dave (participant #1)

Well sure I suppose it's hard to, you just have to wait to see what happens you know, you can do nothing only wait. You know. Tom (participant #11)

Yeah, yeah and then like obviously when you're in treatment you're like... it's just I think it's the waiting, it's the waiting game that's really hard...and not knowing like. Rachel (participant #13)

4.8.1 Maintaining hope through a positive attitude

Uncertainty, however, also offered participants the opportunity to locate hope during the initial experiences of their illness because uncertainty left an opportunity for participants to adopt a positive attitude. During the initial stages of the treatment journey, all participants strongly endorsed the approach of maintaining a positive attitude as an essential means of coping with the day-to-day challenges presented by the experience. Ian and Phil's decision to maintain uncertainty by restricting their knowledge of their diagnosis (as outlined above) can be viewed as an overt expression of participants' maintaining their ability to be positive. As long as the 'difficult facts of the diagnosis' were not fully confirmed or heard, participants could 'hope for the best'. In other words, as long as they had uncertainty, they also had hope. Participants also adopted a positive attitude out of not having any alternative methods of approaching their situation. Almost as an act of desperation, in the face of uncertainty and an uncontrollable, incurable disease, they opted to have a positive attitude that things might work out for them and therefore enabling them to cope better throughout treatment:

Yes and a positive thing-, I think if you can as I say train yourself-, teach yourself to be positive throughout, I think it's a huge help and when I say positive, even if it's just you lying in bed or sitting on the sofa, to teach yourself to relax, but to think positive thoughts. I think it's very, very helpful and I still do it and I do definitely think it's a big boost for yourself to be able to do that. Think positive, even though some days are better than others and some days are worse than others, but in general, to think positive I think is a big help. Dave (participant 1) Interview 2

4.8.2 Losing and finding hope

Hope was also generated through perceived positive communications with the doctors, primarily through interpretations of uncertainty. Liam (participant 4) perceived that his doctor's good humour and the act of laughing indicated good news in terms of his outlook. Others felt bolstered by positive messages they understood to be contained in their meetings with doctors. Jennifer (participant 8) understood that her doctor could not put a timeline on her survival because she was currently doing so well, and she derived hope from this communication:

In [hospital] I asked him straight, what way am I going to be. I said, "Can I die from it?" I asked him and he said, "Well, you could die from it. You could live for three months, six months," he said, "You don't think about things like that you have to think about how you could get on." He said my attitude was very good. He said he'd never seen an attitude like mine. The way I went on, like how I was getting on. So at least that kind of helped me. If you take away hope from anybody you destroy them and basically the fact that he has said (...) the ways things are going. We don't know, we can't tell you. The way you're taking all this in and the way you're going through your treatment is brilliant. Jennifer (participant 8) Interview 2

... we were having the chat about it and, no problem, if it was serious I know he [the consultant] wouldn't be laughing, whereas on Thursday it was a lovely conversation and I had a bit of a laugh with him, he is absolutely brilliant... Liam (participant 4) Interview 1.

After their diagnosis disclosure meeting, some participants felt lost and alone as they returned home to await a phone call regarding commencement of treatment. The intensity of this feeling varied depending on how much prognostic information they were given. A number of participants who received information relating to the serious facts of their diagnosis left the meeting feeling that they had no hope for a time when their lives would return to normal. Participants grieved the loss of their life as they knew it, realising their reality was now irrevocably changed and that the tumour would never be gone:

They actually didn't give you any hope. No cure for this. Category four and there is no cure. Tom (participant 11) Interview 2

...it's very easy to be completely deflated leaving that room. You think you're not going to see tomorrow and I know doctors can't give you hope because they can't, they can't because they don't know and it's different (...) if there's a way that [patients] can feel that they're not completely isolated, they have this devastating disease and they walk out the room and they feel like they're being hit with an avalanche (...) "Look, we'll get through this together, I will see you in two weeks." You're not giving them promises, you're not giving them hope, you're not changing your story, but you're saying in some way there's somebody else there, "I'll see you in two weeks. We'll step through this together"... Ursula (participant 7) interview 2.

At the early stage of the illness journey, despite their loss of hope for the return to a normal life, participants still portrayed strong and clear hopes for alternative outcomes. This hope was usually instigated by the participants' awareness of rare long-time glioma survivor stories (brought to their attention by their hospital consultant)

which allowed them to hope that they too may 'beat the odds'. The participants goal to do whatever necessary to improve their chances (as outlined above) was strengthened by their awareness of these accounts of long-term survivors. Actions undertaken by the participants in order to increase their chances of beating the odds were visible across the interviews (and will be explored in detail in the Chapter Five):

[Doctor] did say he had someone ten years on his books. So, looking forward to the ten years on the books. It's something to aim for (...) So even hearing that piece of information was something. Ursula (participant 7) Interview 1

...there was one story I found about a guy who's had it for 15 years and was given the same prognosis as me, you'll get 15 months if you're lucky. He's got 15 years, but even at the end of that story it said, "This is a very unusual case, you can't take this as, I'm going to get 15 years". Owen (participant 14) Interview 1

Additionally, the existence of treatment itself generated hope for participants despite the deleterious nature of the diagnosis being communicated. However, as seen throughout this chapter, participants often did not seek information that would potentially undermine their positive attitude or constructed hope, and damage their ability to cope:

So I was thinking in the back of my head he's not going to give me stuff [treatment] unless he thinks it's going to do something, but I didn't say that to him. In case he said, "No." So that's in the back of my mind. He must think it's going to do something and I was happy enough to believe that. I still believe in that. Tom (participant 11) Interview 1.

4.9 Understandings of treatment

The uncertainty inherent in all aspects of the diagnosis and treatment resulted in participants feeling adrift in a new and unknown reality and compounded the

realisation that they had seemingly lost control over their lives overnight. In response to this, participants figuratively handed over control by putting all of their faith and trust in the hands of the doctors, thus enhancing their ability to cope. Participants trusted doctors implicitly due to their perceived 'expert' status. Participants reconciled their loss of control by focusing on the abilities of the experts caring for them as having the possibility to save them, thus making the situation more manageable for them. It is possible that participants idolised doctors apparent 'control or mastery over disease'; the thing that they themselves desired most:

...you're going from being up at 7 o'clock in the morning and going 'til 12 o'clock at night and then everything is just gone like that (...) it's horrendous, your whole life is just turned upside down... You know but that's the way it was...but sure then you just put your health in their hands and you hope for the best.
Heather (participant#5) Interview 1.

At that point in your life you've got God and they're right beside him, they're on God level. Not quite God, but he [doctor] is there with God and you look at this one person who is going to have full control of your life. Ursula (participant #7) interview 2.

Participants broke treatment down into separate phases and stages in order to make the overwhelming nature of their sudden diagnosis more manageable. As they completed surgery and moved through radiotherapy, they saw themselves having completed a phase/stage, prompting a sense of accomplishment. This allowed treatment to seem less vast, more achievable, and allowed participants to work on a shorter timescale and with smaller amounts of information. Although part of the same 'treatment regime', participants saw their concomitant chemotherapy as a separate phase of the process:

Well as I say, you move from one to the next one. (...) after you come from the surgery, they say to you, "The next one is, come here and have the radiotherapy." So when that's finished then, you're waiting for whatever the

next step, and the next step then was [anonymised] Hospital and obviously, a different type of treatment, just tablets, just chemo tablets and that's five consecutive days in the month. Dave (Participant 1) Interview 2.

The existence of treatment offered a beacon of hope for participants despite the uncertainty related to its long-term effectiveness. All participants believed that treatment was their only opportunity to address their situation and did not consider any alternative options such as alternative treatment methods or opting against treatment. They understood that the purpose of radio- and chemotherapy was to remove any remaining fragments of tumour which could not be removed during surgery. Those who underwent biopsy only understood that the chemotherapy treatment sought to reduce symptoms and to hopefully prevent the tumour from growing any bigger. They hoped that this would have a positive effect on the symptoms they were experiencing, namely headaches, speech and physical impairments, seizures, and memory loss.

There's no other way to do it, you have to. You can't sit back and not do it. They said about the treatment, he says, "You have to, you have to this. There's one chance. You can't sit there and do nothing, you have to do something." I said, "Right, I'll do it." Tom (participant 11) Interview 1

However, there was a widespread understanding that treatment might not work, and that future surgery or treatment may be required, depending on the results of their scans post-treatment. Participants regularly acknowledged that their futures would involve a decline in their health although the uncertainty and lack of available information related to treatment and prognosis prevented any possibility of forming clear expectations surrounding this:

Now whether down the road it will get worse, I don't know what it's going to be when I'm off this treatment. I could be onto something different then, but when I come off it-. Jennifer (participant #8) Interview 1.

Others hoped that an excellent tolerance and performance throughout treatment would indicate that the doctor's initial predictions regarding their likely outcome may be incorrect or that their follow up scans might reveal a different prognosis. Therefore, from the beginning participants focused on tolerating treatment better than others, and hoped this would bode well for their overall outlook. This hope stemmed from the initial discussions with the consultant radiation oncologists and medical oncologists. Participants took three key points from this meeting which underpinned and influenced their experience across the disease trajectory. Participants understood that (a) treatment would be intensive with difficult side effects, particularly extensive fatigue; (b) people tolerated treatment differently, thus determining future treatment plans and options; and (c) their consultants were aware of long-term survivors of glioma. The influence these understandings had on the illness experience and how people made sense of their treatment will be discussed in-depth in Chapter Five.

Although some participants recognised that their treatment and diagnosis was not curative (its intent was to manage symptoms and prolong survival), Owen (participant #14) was the only participant who expressed a clear understanding that the treatment was palliative, its goal being to prolong survival by a couple of months:

I am aware from what I've read and from what I've been told that the treatment is not curative treatment it's palliative treatment. It's warding off the inevitable and it's all a question of how long that is. Interview 1.

4.10 Awareness of the implications of the diagnosis

Some participants seemed realistic about their timeframe (based on my own knowledge/ standard survival rates) while others appeared to be somewhat optimistic or express a lower level of awareness about their future. Within the context of the initial interview (Interview 1), different levels of awareness were observed and could be broken down into 4 categories:

1. Those who expressed no awareness of the likely outcome of their disease (death) and did not express concern of a limited future or a threat to life (n=3).
2. Those who displayed some awareness of the threat to life (n=6) which was either expressed explicitly (references to threat to life) or displayed covertly i.e. closed awareness (e.g. Ian's and Phil's request not to know the details of the diagnosis).
3. Those who knew and openly expressed awareness of the threat to their lives and the likely outcome of their diagnosis (n=4).
4. And finally, those who knew and requested or accessed additional information regarding their disease (n=3), such as an exact timeline for survival or the manner in which they would die.

For some, their awareness changed over time and as they developed perceptions of how their body was reacting to treatment. For instance, Dave (participant 1) originally fell into category 1 but displayed greater awareness within follow-up interviews. These transitions will be further explored in Chapter Five.

Those who chose to know the facts relating to their diagnosis identified as proactive individuals who typically preferred to plan for the future and wanted to acquire information so that they would know what to expect. Unlike Ian and Phil, these participants believed they would be able to cope better if they were aware of what their futures looked like.

The few who did attempt to develop a more accurate picture of their prognosis and its timeline were informed that everyone is different, and the doctor usually double checked that the person was sure they really wanted to know the implications of their diagnosis. Participants appreciated this response, sometimes opting not to receive information regarding their specific prognosis. Along with learning about survivor stories, hearing that everyone was different in the context of responses to treatment prompted participants to hope that they may be different and 'beat the statistics'.

Possibly related to this, participants often individualised their experience, their symptoms or their own diagnosis. Participants often tried to distance or differentiate

themselves from the general facts relating to glioma or from the stereotypical perceptions attached to cancer patients by stressing the uniqueness of their symptoms or their situation. It is possible people did this to remove themselves from the 'norm', thus allowing themselves the possibility to hope that they may 'beat the odds/statistics'. Individualising oneself was also done through comparison, distinguishing oneself from others, and by gaining and displaying expert knowledge of their illness:

It's a very unusual beginning actually because I'd been looking at things and books that they provide about living with a brain tumour and that kind of thing. They say, "You will have been to your GP and you will have experienced symptoms" and all the rest of it. I didn't. Nothing. Owen (participant 14) Interview 1.

It was this rejection of generalising the experience and the diagnosis that resulted in participants' avoidance of brain tumour support groups. Finding ways of identifying as individual or different to others allowed participants to continue to hope that their outcome might be different to others. The desire to maintain some uncertainty was also a key factor in participants' decisions not to attend support groups. Participants did not want to meet people who were further along the disease trajectory, for fear it would extinguish the potential to hope.

4.10.1 Realising the severity of the illness

The diagnosis came as completely unexpected for all of the participants. Only Rachel (participant 13) casually speculated about the possibility of a brain tumour being the cause of her pain, without fully believing it. Similarly, with the exception of Heather (participant 5, whose family member had died 8 months earlier from the same diagnosis), participants were unaware of the outlook and implications of glioma prior to their diagnosis. The sudden shock of the diagnosis and their developing knowledge of what it entails impacted the participants' experiences across the disease trajectory:

It seems the brain thing is a whole different conversation to breast because even reaction to people when I talk and I say about the breast cancer and I say about the brain, "Oh, but that's a different conversation." (...) I just didn't understand that brain cancer is so different. I just didn't understand. Why? I don't know, I would have looked at stuff, I don't know why I didn't, I just didn't. Maybe it was just as well, I don't know. Ursula (participant #7) Interview 1.

Because of the sudden and unexpected onset of the disease, combined with the quick progression to diagnosis and treatment, participants felt caught unawares, unprepared and as if they had to play catch-up to this fast-paced, ever-evolving process. Participants experienced sudden realisations of the severity of their illness at various different points across the disease trajectory. For most, these realisations happened incrementally as the diagnosis and treatment unfolded, leading to further realisations of the implications of their disease. This compounded the feeling of uncertainty and loss of agency over their own lives and futures:

...they [medical staff] were very happy with the surgery (...) but I would have to have secondary treatment (...) you've had the surgery and you think that's going to be what gets you right, but then, there is something else that they have to do and I think from there on you realise that after each step, there may be going to be another step... and that's... you know, that's what you kind of have to deal with then, that it's not just going to suddenly end... that that there is another step and there is another step, and how far down the line that goes is only determined each time you have a treatment, you have to wait a while and get results, and then tell you what's next, is there another... you're waiting with the knowledge that this might not be the end of it, this treatment mightn't be the...you're waiting for, there's always somebody telling you the next thing. There's something else... yeah and you can only wait until one treatment is finished, see what they say to you and then deal with that...as the next step, whatever they decide. Dave (participant 1) Interview 1.

4.11 Conclusion

This chapter introduced many of the core concepts and causal factors influencing the participants experience of their illness. As such, these concepts will be developed and abstracted throughout the subsequent chapters as their impact on the journey is illuminated in relation to the central story-line. This chapter sought to provide an introduction to the early stages of glioma patients' journey and primarily focused on patient reports at the point of the initial interview. It provided an insight into the unexpected and sudden shock of the diagnosis, and the rapid, devastating change that people with glioma experience. Many of the existing studies have focused on the experiences of glioma patients from the time they were diagnosed onwards (Adelbratt & Strang, 2000; O'Donnell, 2005). Ownsworth et al. (2011) emphasise that many participants reflect back on this period leading up to their diagnosis with strong feelings (e.g., regret and anger), it is important to include this period in research as it can have an integral influence on emotional adjustment in the longer-term. In recognition of this, as outlined in Chapter Three, participants were prompted to discuss their experiences leading up to diagnosis, and their understandings of and responses to the initial indications of their illness.

The findings related to the onset of the disease resonate with the general experiences of glioma patients documented in the literature. Ownsworth and colleagues (2011) confirm that symptom onset for many people with brain tumour is sudden and has a clear neurological origin (e.g., seizures or speech disturbance), which usually leads to early contact with medical professionals and rapid diagnosis. However, when symptoms develop more gradually or are non-specific in nature, medical investigations and diagnosis can be delayed or drawn out. As discussed in Chapter Two, Salander and colleagues (1999) identified a combination of personal and social factors which were found to contribute to delayed diagnosis. This included individuals' misinterpretation of their symptoms and passive reactions in pursuing medical investigations, as well as professionals' alternative diagnoses and delays in undertaking investigative procedures. Salander and colleagues (1999) suggested that the prolonged or difficult

pathways to diagnosis impacted people's ability to adjust to the illness. These findings are in line with the findings of this chapter which revealed a variety of responses to the onset of the disease. In addition to this, examining the participants' experiences in the lead up to their diagnosis revealed the sudden and unexpected shock of the diagnosis and the speed with which people's lives were altered, factors which were integral in shaping the participants experiences across the illness journey.

The existing literature recognises the information needs of people with glioma as an area requiring evidence-based development (Ownsworth, 2016). The development of an understanding of what to tell patients with life-threatening illness is essential when we consider that only the minority of terminally ill patients do not want to be informed about their prognosis (Gonçalves et al., 2005). This must be considered in light of the fact that although all of the participants in this study verbally stated that honest communication was essential, their behaviour in terms of 'information avoidance' and 'maintaining uncertainty' would seem to contradict this. This issue will be further developed and explored towards the end of this thesis, however this chapter outlines that the participants felt that disclosure should be patient-led, with added safety checks as seen in the above findings when Jennifer (participant 8) was provided the opportunity to change her mind regarding knowing her prognosis.

This chapter detailed the participant search for meaning in their illness and their initial desire to attribute the tumours occurrence to something. This caused distress and confusion as participants grappled with coming to terms with the 'random', indiscriminate nature of the occurrence of glioma. In response to this difficulty, participants often stopped themselves from searching for answers to questions such as "why me". As seen in this chapter, participants steered clear of thoughts and behaviours associated with self-pity, however, I argue that this behaviour could also be indicative of their awareness of the lack of sense or meaning behind their illness.

These findings highlight the fragile relationship between knowledge of and insight into the diagnosis, and begin to introduce us to the participants' need to cope on a daily basis as a result of the need to maintain hope. It is apparent that participants'

perceptions and understandings of their illness, and their management of the knowledge or awareness of the disease, are strongly influenced by their need to cope. Participants were seen to be both unconsciously and consciously mitigating their actions and perceptions in line with their personal requirements to maintain the ability to cope when faced with circumstances involving the provision of information regarding the disease. Similarly, research indicates that a high grade glioma (approx. 15 month survival prognosis) does not necessarily correlate with increased levels of anxiety and depression, in fact Arnold and colleagues, (2008) found the prevalence of anxiety was higher in patients with low-grade gliomas (associated with a slightly longer survival rate). This suggests that perhaps in the face of an immediately life-threatening diagnosis with a limited timeframe, people find ways to ensure that they can continue to 'live well'. These findings suggest that even at the early stages of the disease trajectory participants have identified a way to create/manage or maintain a tolerable reality in which they can minimise psychological distress and focus on treatment. This reality keeps the participants in a safe space where they can 'do what needs to be done' and cope throughout treatment. Subsequent chapters will outline what makes this possible, what methods and mechanisms participants use to create this 'tolerable reality' where they can focus on 'doing what needs to be done' and use uncertainty to maintain a positive attitude.

The findings in this chapter reveal that patients prefer not to delve into thoughts that are likely to prompt existential crises, and instead wish to focus on 'doing what needs to be done' in order to give themselves the best chance at recovery. This contradicts existing research suggesting people with glioma value the opportunity to discuss existential issues early in the illness rather than only in the palliative stage of care (Ownsworth et al., 2011). Further, as will be discussed in later chapters, participants expressed a preference for dealing with such issues after treatment, having had an opportunity to come to terms with the implications of their sudden and new reality.

The findings detailed in this chapter outline the participants idolisation of the doctors as a result of their possession of expert knowledge thus representing the patients greatest hope of a better outcome. Further to this, Sterckx et al., (2015) suggests that

the idolisation of the doctor may be related to participants perceptions of the doctors as competent and expert and thus making them a solid source of information. Salander et al., (1996) connects the 'idealisation of the physician' and 'avoiding prognostic information' to the potential for developing hope, and discusses the impact of the diagnosis communication on one's ability to cope, noting that choosing to avoid information is an act of self-protection and a way of keeping threatening information away from oneself. However, Salander did not discuss uncertainty and the potential benefits derived from it as an influencing factor in the decision to 'avoid prognostic information'.

The findings presented in this chapter also reveal the importance of a perceived honest doctor-patient relationship and its influence on understandings of the diagnosis and in constructing an ability to cope. This study reflects existing research regarding participants' acute sensitivity to develop perceptions based on interactions with their doctors (Gonçalves et al., 2005). A poor experience of the diagnosis disclosure can have a negative emotional impact, while those satisfied with the communication, regardless of its upsetting nature, report less distress than those who would have preferred a different approach to disclosure. Overall, this chapter portrays how the majority of participants were content with the manner and experience of their diagnosis disclosure meeting.

Important concepts relating to the participants' experiences, namely uncertainty and the loss of agency, were outlined in this chapter which resulted in feelings of powerlessness and being overwhelmed. The uncertainty created by a cancer diagnosis is an established concept in the literature (Karlsson et al., 2014; Newton & Mateo, 1994). This chapter also revealed the negative impact of uncertainty on the lack of available prognostic information on their disease. In contrast to previous studies which found that people with glioma believed that uncertainty was caused and amplified by the medical team and their lack of information provision and communication skills (Fox & Lantz, 1998; Lobb et al., 2011) the participants in this study blamed the nature of the illness for the uncertainty which they experienced. However, the participants' desire to be more closely guided through the early stages of the illness resonates with the

findings of Fox and Lantz (1998). Conversely, unlike the existing studies, the findings of this chapter also suggest that maintaining uncertainty through deciding not to ask the 'important questions' or by choosing not to attend the diagnosis disclosure meeting, allowed participants to protect their own tolerable or manageable reality.

At this point of the interview process (completion of the first interviews), I was quite frustrated with the apparent lack of awareness and the lack of openness participants displayed regarding their prognosis. However, after completing all of the interviews and the analysis I argue that all participants were aware, on some level, of the life-threatening nature of their diagnosis. Rather, participants developed thought processes and communication styles which enabled them to maintain or construct a reality whereby they could cope with this difficult knowledge, in a manner that suited them. Now, I grapple with the question of whether treatment for glioma should be the standard option, or should communications about treatment be more realistic. Alternatively, as we see in the findings above, hope might be so vital to people with glioma that more realistic communications regarding the potential for treatment would destroy any possibility to 'live well' during their remaining months.

However, when considering whether or not people should be automatically treated for an incurable disease, it is important to refer to the above findings where it was shown that people want to do all they can do in order to have a chance of a better outcome. Because doctors have told them that some long-term survivors exist, treatment was always an option for this group, they chose treatment because of the possibility of additional time and that they may be the ones to survive longer. Therefore, treatment is in a way akin to buying a lottery ticket - if you're not in you can't win - and they all wanted to be in with a chance of winning the survival lottery.

The participants' hopes that they may be 'the ones' (to survive longer) are not entirely unfounded. A review of the clinical literature on survival of glioma, specifically glioblastoma (GBM/grade 4) (experienced by 12 of the participants in this study) Bi & Beroukhim, (2014) outline the heterogeneity of high grade glioma, and the degree of this heterogeneity itself varies between tumours. According to the authors, gliomas

can exhibit varying responses to treatment, with 12% of patients who receive standard chemo radiation surviving four years after diagnosis. It is this variance which provides participants with the possibility to hope that they may be one of the 12%.

Examining the sudden nature of the diagnosis and the speed with which people's lives changed allows for a greater appreciation of how and why the participants felt such a loss in control over their lives. This in turn allowed for a greater insight and understanding into the motivations behind the participants actions and behaviours throughout the illness experience. The next chapter will explore the participants attempts to come to terms and make sense of their diagnosis, in light of their sudden diagnosis and the speed with which treatment ensued.

Chapter Five: Making sense of the diagnosis

5.1 Introduction

The findings discussed in this chapter are derived from information garnered from the second interview conducted with the participants (although information from the first and third interviews have been included where relevant to developing the line of argument). The second follow-up interviews took place during the final week of the participants' six-week course of radiotherapy, approximately 10 weeks after their surgery and diagnosis communication. The important conditional factors such as the onset of the sudden and shocking diagnosis, the uncertainty of the future, and the

speed with which treatments ensued continued to heavily impact and shape the participants' experiences at this time.

This chapter centres around the participants attempts to make sense of their diagnosis within the context of having limited information about their condition and their future. This chapter reveals that participants were faced with an invisible illness which provided no opportunity to monitor its progress and whether or not they were responding to treatment. This chapter furthers the discussion on the all-encompassing role uncertainty and how it influenced the participants' behaviours surrounding their attempts to make sense of their illness, and integrate it into their exiting knowledge of their lives and their 'selves'.

This chapter outlines the importance of appearance and bodily experiences on peoples mood and their understandings of their illness, along with the subsequent impact of these understandings on the participants ability to have hope and cope with their condition. This chapter identifies embodiment as a key element of the experiences of people with glioma; an area not yet explored in the glioma literature. Finally this chapter will explore the participants experiences of loss as treatment progressed, specifically the loss of independence and the loss of physical ability. Some of the insights developed from the third interviews will be incorporated here in order to enhance the clarity of the concepts discussed and adequately portray the participants' changing experiences over time.

5.2 Struggling to process the illness

For many of the participants, their lives had changed in a matter of hours. The speed of this change presented difficulties for participants and their ability to come to terms with their new reality. Participants struggled to fathom how their lives had changed so drastically in such a short period of time, and in turn, they struggled to amalgamate this new 'surreal' life into their pre-existing understanding of the way their lives were expected to be. All of the participants were stunned by the speed at which they had completed treatment, and the dramatic way their lives had been changed:

So much to take in for something that happened two months ago. You're supposed to process something like this for years. Aoife (participant #12) Interview 2.

Participants who were receiving treatment as inpatients in the hospital found that they were subsumed into the structured routine of the ward, being told when to eat, when to attend treatment, when to wake up. Participants found that this structure and routine impacted positively on their emotional wellbeing. Being in the hospital normalised the phenomenon of being unwell so that participants were able to 'press pause' on fully coming to terms with their situation. They were being taken care of.

As the chaos associated with the initial weeks of the diagnosis and treatment began to subside and they acclimatised to their new routine, participants found themselves being less distracted and more frequently alone with their thoughts as a result. Participants realised that in the midst of the chaos, they did not get an opportunity to fully process what had happened, what they had been through, and the profound impact it would have on their lives. This quiet prompted participants to reflect on the time since their diagnosis and the significant ways in which their lives had been altered. This resulted in the emergence of troubling thoughts about their circumstances. These thoughts were intrusive and often centred around their own premature demise, and the circumstances which might surround it. In short, the reality of the diagnosis and its implications started to sink in:

You're so busy, you've got appointments to go to, you've got clinics to go to, your mealtimes are regimented, you have breakfast here and everything's taken care of. You barely get time to sit down and think about things and ponder on it all etcetera. Owen (participant #14) Interview 2.

In hospital it was more like-, I was in an environment where there were patients around, the nurses were coming so I knew that I'm undergoing treatment, going to treatment so it didn't allow me to think anything else. I was more like, "I

need to get myself better.” But radiotherapy is a ten minutes treatment a day. You have weekends to go, you go out, you see the normal world around. Even this is the normal world as well, but you find a relative difference in the life that you just had, you just dealt with and now this is the one that you were dealing with previously and then you start feeling, yes there has been a change and then you realise that happened on the spur of the moment and to cope with that. Vinod (participant #6) Interview 2

5.3 Hoping for a return to normality

Throughout the treatment journey participants progressively realised the severity of their diagnosis, particularly during the final weeks of radiotherapy. It seems that, while distracted by the chaos of the initial stage of treatment and the hospitals busy routine, participants could initially ignore the reality of their condition. Towards the end of radiotherapy participants were forced to recognise that completing this stage of treatment was only one part of the lengthy treatment regime and would not eradicate their tumour. This realisation forced the participants to acknowledge the severity of their disease and its impact on their futures. Where some participants had hoped to return to normalcy when they completed treatment and returned home, they now realised that they, and everything else, had changed; that they were within a new and permanent reality:

You know, I'm looking forward to when, when I go back to do whatever I'm doing by then, whatever that be. You know what I mean? Ian (participant 2) Interview 1

As it began to dawn on participants that they would not be able to return to their normal life after radiotherapy they realised their lives were changed. This prompted participants to mourn the loss of their old reality. Participants suffered from the loss of the person that they were prior to the diagnosis and mourned the loss of their previous lives and their expectations for the future. These losses encapsulate the grief participants felt from the loss of their healthy selves, of a certain future, of their past

abilities and the loss of a sense of security. Participants mourned the loss of the life that they believed that should have been prior to the diagnosis interrupting or limiting life plans. Just as the participants lost important elements of their identity through changes in their appearance, the loss of a return to normality caused them to recognise the further loss of their past selves:

It's still surreal and I suppose going home [for weekend leave from hospital] at the weekends and trying to be normal when I know it's not normal, nothings normal at the minute. Aoife (participant 12) Interview 1

All the plans to go to Prague, all the plans to go to New York have changed, but that's okay health comes first. I need to take care of that. Vinod (participant 6) Interview 2

When you're at home life is normal, but you're not normal. No, but I very much try to make the day normal, don't want to make it a sick house, it's not all about being sick, it's about being normal, spending time together. Ursula (participant 7) Interview 3

Participants experienced an all-encompassing loss of autonomy throughout all aspects of their lives. The loss of autonomy commenced from the point of initial symptom onset, and would likely continue until their deaths. This loss was further augmented through the gradual loss over one's body and cognition. Participants rapidly underwent the experience of being someone who is entirely self-reliant and independent, to someone dependant on the assistance of others in order to complete most tasks despite feeling relatively normal:

It's that stepping back and thinking, "I can't actually do everything." That's I think, the thing that's going to take me the longest to get used to. I've accepted not being able to drive, no less annoyed about it, but it's strange because I've spoken to lots of people and they all seem surprised that that's the thing I'm most annoyed about.

Not that I've got cancer and the type I've got is 90% terminal in most cases and all the rest of it. "So that doesn't worry?" "Well, of course it worries me, but when I used to feel worried I'd pop in the car and go for a drive. I can't do that now." It's that element of a little bit of freedom being taken away and it's also something that I could do that could make me feel-, you know, I could drive down to the daughters and do stuff there. I could be out and give [wife] a bit of peace and quiet, "I'll take [their son] swimming give you the afternoon to relax." I can't do that now and that's a little bit-, It makes you feel less useful because I'd have got very used to being relied on and the weird thing is, probably it will be the case that when I was being relied on I'd resent it and every now and then, and it's strange, now that that's been taken away from me I miss it. So it's weird, very mixed feelings, but no one is going to be asking me to do things anymore, which does make you feel a bit-, not cut off, but it definitely makes you-, not less valued, your sense of self-worth diminishes I think. Owen (participant 14) Interview 2.

5.4 Keeping busy in order to cope

It is possible that the processes outlined in the previous sections provide an explanation for why a prominent approach to coping involved 'keeping busy'. Particularly in the morning time, participants kept busy in order to deter 'negative thoughts' from their immediate awareness. Participants switched on the radio and the television and kept busy with housework in order to cope. Their insistence on being busy when at home often prompted arguments with concerned family members who would rather the participants rested; but for the participants, the benefits of being busy were twofold. Participants could create hope that they were responding well to treatment from their successful ability to be busy and they could reason that they were responding well to treatment as long as they could complete these physical tasks. Further, keeping busy aided the participants in dealing with troubling thoughts about their illness and helped them to remain focused on the present (a coping strategy that will be discussed in-depth in the next chapter):

And when I wake up early at 6 I want to get out of bed immediately. I want to go straight downstairs. I feel very claustrophobic in the bed... feel less claustrophobic when I leave the bed, even though I don't know how I'll get down the stairs. Heather (participant 5) Interview 3

Keeping busy distracted participants and prevented their minds from wandering and from worrying about their future. Similar to their experiences during the initial stages of treatment, keeping busy distracted them from thoughts about their illness. However, just as when they became familiar with and subsequently less distracted by treatment, the quiet moments in participants' daily lives created opportunities for them to be confronted by the troubling thoughts of their reality. Phil and Vinod (participants #16 and #6) both watched videos online in order to distract their minds, and they found it helped them to cope during treatment. The findings of this study suggest that participants sought to avoid negative thoughts, or their thoughts about their futures (this concept will be further explored in the next chapter):

The first thing I do in the morning when I come down the stairs I turn on the radio and it's on until I'm going out of the kitchen at night time. Once there's noise in the background-, and I've the television on as well, husband does say this is like a mad house (chuckles). Well once it blocks your mind I don't care you know. Heather (participant #5) Interview 2.

It's just that sort of routine yino [you know]... if I wake up at 7 o'clock or 6 o'clock or 5 o'clock I'm not there going oh Jesus Christ almighty brain tumour. I put on the radio and think of stuff I'm going to do today or, going to watch Cheltenham, going to meet friends to watch, Cheltenham. Ian (participant #2) Interview 2.

5.5 Using the body as a point of reference

As outlined in the previous chapter, the initial meetings and communications with doctors and other medical professionals, such as radiotherapists and nurses, strongly

influenced participants' understandings of their diagnosis and their perceptions and expectations of treatment. Participants placed great importance on the information provided by these professionals due to the fact that they trusted their expertise and skill implicitly. The participants of this study believed that doctors were their best chance of a better outcome (see Chapter Four). Of particular note, participants illness journey was strongly influenced by the specific detail provided by the physicians regarding treatment; that everyone tolerates treatment differently.

It might be the very same treatment and the very same strength of treatment, but it has a different effect on different people, depending on their makeup I suppose. Dave (participant 1) Interview 2

Participants' understandings that everyone responds to and tolerates treatment differently motivated them to optimise their chances of responding well to treatment. Participants developed the understanding that they may benefit from a better outcome and prolong survival if they responded well to treatment. As a result of the information they received from their medical team regarding treatment and its intensive side effects, participants developed the understanding that fewer side effects experienced was a predictor of a positive response to treatment. Further, the people in this study believed that experiencing fewer side effects indicated a better chance of a favourable outcome. The possibility of responding well to treatment provided participants with hope that they may be one of the fortunate individuals to benefit from a better outcome than others patients, that they may 'beat the odds':

That's another thing that shows for a better prognosis is how well you cope with treatment. Liam (participant 4) Interview 1

As a result of their understanding that the presence of side effects could be indicative of their response to treatment, participants generated the understanding that how they felt physically, could indicate how they were clinically. In response to the impact of their perceptions of how they physically felt, and what they believed it could mean for their outcomes, participants engaged in a process of 'monitoring the body' through

'sensing themselves'. Participants intensely monitored their own bodies throughout their treatment journey and developed a heightened awareness of bodily experiences or changes throughout treatment and, following treatment, they monitored their physical selves for the return of tell-tale signs of tumour recurrence such as headaches or seizure activity. Participants paid close attention to physical sensations, changes to their appearance, levels of fatigue and any responses to treatment or side effects.

The need to monitor the body was brought about in response to the lack of control, information and certainty available to the people in this study throughout treatment, but also due to the 'invisible' nature of the illness (which will be discussed in-depth later in this chapter). Participants developed perceptions of their response to treatment and their expectations for their futures based on these interpretations garnered from their body, thus influencing how they emotionally experienced their illness:

It's hard when [friends] ask questions [about prognosis] 'cause you're like, "I've no idea". I don't want to know like even if there was statistics I don't think I'd want to know them, like I just think I know how I'm feeling myself, and if I continue to feel this way then I'll be fine. And that's what Dr. Murphy said, she was like it's kind of gauged on how I feel so like if I'm feeling good after I'm finished treatment, and everything keeps going good when I come off the steroids, then like it kind of indicates that we could get a good scan. So, like I know if I'm feeling fine then I will be fine. And saying that if I don't feel fine like obviously there's other things we can do so, I'm not going to freak out about it but I'm just kind of going off that and just, just taking it like a day at a time.

Rachel (participant #13) Interview 1.

As a result of these processes undertaken in order to monitor their response to treatment, participants' became extremely familiar with how their bodies physically reacted to treatment. Participants used this monitoring of their bodies as a tool for looking after themselves in the hope that they could improve their outcome. As they were acutely aware of the likelihood of experiencing severe fatigue, a common but

debilitating side effect of radiotherapy, participants closely monitored their energy levels and intervened quickly when they found they were becoming tired. Also, it is possible that - given the unexpected onset of the disease, whereby the onset of symptoms presented (in half of the participants' cases at least) as non-descript physical sensations - people felt the need to be more aware of their body and hence to closely monitor for additional warnings of impending ill health.

Initially this 'monitoring of the self' led to positive feelings regarding their performance during treatment and fuelled hope for a positive outcome, but as they completed radiotherapy and returned home, such monitoring resulted in disappointment and a decrease in hope. This disappointment will be discussed at a later point in this chapter.

5.5.1 Feeling physically well

Despite the life-threatening nature of their diagnosis and the intensity of their treatment regime, the majority of the participants were surprised that they were feeling physically better than they had expected upon reaching the final week of radiotherapy. Many participants were surprised at the relatively few side effects they experienced in light of the warnings they had received from the physicians prior to commencing treatment, identifying the occurrence of severe side-effects very likely. Participants expected treatment to be significantly more difficult than it actually was. In addition to unpleasant side effects, the participants expected that treatment would feel like a long, drawn out experience, however upon reflection, they were shocked at how quickly the time passed. The people in this study experienced immense relief that their fears for treatment did not materialise. Feeling well was such a prominent aspect of the experience because it was quite unexpected for the participants:

Since treatment started like it's been fine like I don't have those scary thoughts anymore and I think it's because it's the fear of not knowing your symptoms like I'm being told all these side effects from the treatment like loss of appetite like nausea, hair loss, extreme fatigue like your kind of like oh my god I'm going to be a walking misery but then once you start and like you feel fine I don't have

any of those symptoms you're like oh like my normal life can go on and I'm going to be ok and I think it's just the thought of all those horrible things happening to you, and if they did happen like you'd deal with them but, I just I've been lucky that I haven't had any of them. Rachel (participant #13) Interview 1.

I was expecting horrendous side effects from that. I was thinking I was going to be really sick and tired and ill and not able to eat and hair all falling out and it's really only been the last couple of weeks that I've lost my appetite. (...)The cancer itself is described as being one of the most aggressive and hardest to treat, which is quite scary when you hear that. That's the bit that you have to adjust to, but the actual treatment itself is very unobtrusive. Owen (participant #14) Interview 2.

The shock that treatment was both easier and quicker than they had expected it to be brought about an overall lift in mood for many of the participants. Based on my own observations and perceptions while conducting the interviews, the majority of participants presented as significantly more upbeat and hopeful in the second interview compared with the first interview. Based on the findings of this study I argue that participants interpreted their lack of hardship during treatment as a positive sign that they were responding well to treatment and that they had surpassed the medical teams expectations by not becoming unwell during radiotherapy and as a result they were able generate hope for a more favourable outcome. In summary, feeling good provided an evidence-base for hope that they may have a better outcome than expected, and they used this hope to fuel their determination to fight:

Yes I think the treatment is going well. No ill effects, I'm not sick, I'm not over tired. I'm not in pain. So I'm just hoping it's going well. I think it's going well and it feels too good for it not to be going well. My mind is making good... and imagine something wrong with your brain, your mind would be affected. The [family] are thinking the outcome could be better than what the doctor said it was going to be. They're hoping it's going to be better. They seem to think that once I get through this without more or less any setbacks-. It's given us a bit of

hope anyway. We were expecting it to be worse. Tom (participant 11) Interview 2.

Many participants believed that their ability to avoid the difficult side effects of treatment was due to actions and behaviours they undertook throughout treatment. Participants sought to maximise their chances of a better outcome and believed this could be achieved through regular exercise, self-care practice and a healthy diet. Such a belief in causality indicates a perceived level of controllability on the part of the participants in relation to tolerating treatment well. Participants felt proud of their success at tolerating treatment and boasted about feedback they received from healthcare professionals in a manner similar to that of a personal achievement:

So I do think I'm lucky. I do count my blessings as well. I don't think it's just down to pure luck either. Good treatment and I do think being a [healthcare worker] has helped because I think we have the constitution of a donkey. Our immune systems are shot to pieces. We either have no immune system or they're way up there that we can take anything. Aoife (participant 12) Interview 2

I've been very well on treatment and I feel well, I'm up walking. Definitely, the last week which was week five and week six [of treatment], definitely a bit more tired this week. Definitely a little bit more tired, but more conscious of it. So I'm actually sitting down and resting, not letting myself to the point of tiredness because I know it's taking me longer to recover. So I am trying to put the rest in. I suppose being aware of myself. Ursula (participant #7) Interview 2.

If you're using up your energy, it set my appetite up. Once you've an appetite and you're eating you end up with better resources to stand up to [intensive treatment]. That's the way I looked at it anyway. I used the time [while an inpatient receiving treatment]. I walked plenty and was out, I didn't lay in bed. I kept moving about and went into town and walked round the grounds [of the hospital]. Tom (participant #11) Interview 2.

5.5.2 “Do I look ill to you?”

Surprised by feeling relatively well in light of their circumstances, the treatment experience passed quickly for the participants and felt straight-forward in comparison to what they had been anticipating. However, as a result of the relative ease of treatment and a lack of side effects, participants began to grapple and struggle with the concept of the clinical severity and life-threatening nature of their illness, in contrast with how they felt physically. Participants struggled to reconcile this; surely they should feel like they have a life-threatening illness?

It is weird because I feel so healthy now and I haven't hit the-, the tiredness [side effect of treatment] hasn't hit me yet but it is kind of weird to think that like, you know, you are physically really sick, I am really sick but I physically don't feel sick. Rachel (participant #13) Interview 1.

I don't actually feel ill and that's one of the things, it's double-edged. Sometimes I think if I felt ill I wouldn't mind so much, it's the fact that I'm just getting on with my day. Owen (Participant #14) Interview 2.

In addition to the struggle surrounding how they felt physically not corresponding with how clinically unwell they were, in the initial stages of the treatment journey participants experienced confusion regarding their appearance. Looking and feeling relatively similar to how they felt prior to their diagnosis challenged their ability to understand and come to terms with the diagnosis. However, since they looked and felt better than expected, this inconsistency allowed some of the participants to create hope that their outcome could be better than initially expected if they continued to respond to treatment as well as they had been. Participants developed the understanding their physical appearance, as well as how they physically felt, could provide an indication of their health and how they were responding to treatment:

As far as I'm concerned I feel too good to be dying. Tom (participant #11)

Interview 2

In addition to the confusion stemming from the discrepancy between how they looked and their clinical status, participants also found themselves feeling frustrated with peoples' misconceptions and underappreciation of the severity of their illness due to their 'healthy' appearance. These misconceptions were usually on the part of people outside of the participants' immediate family circle, who they would see in social settings. It is probable that these interactions served to further the participants' frustration and distress with their perceived discrepancy surrounding their experience:

That's the trouble, people think once this is all over I'm going to be fine and [wife] has had to explain to people, "No, he's not going to be around for much longer. Make the most of him while you've got him." It's hard for a lot of people to get their heads round because if you were to bump into me in a pub you wouldn't think, "There's a guy with brain cancer." That's what's hardest for a lot of people because a lot of the time I think if I was sitting not able to move and drooling they can say, "There's something wrong with him", and there's a lot of conditions where there's visibly something wrong, it's almost easier for people to handle because they can see you're ill. I don't look ill, I don't sound ill.

Owen (participant #14) Interview 1.

As previously discussed, the participants found that the experience of glioma was filled with uncertainty. Although they understood that the nature of their illness prevented their medical team from providing them with certainty, they struggled with the lack of concrete information surrounding their diagnosis, updates regarding their response to treatment and with not knowing what to expect in the future. Participant's wished for more certainty regarding their circumstances and in turn to regain control of their lives. However, as outlined in Chapter Four, some of the participants engaged in behaviours which protected them obtaining additional information pertaining to their diagnosis and prognosis. The findings reveal that the people in this study did not attend support groups or engage in patient education opportunities in order to remedy their lack of

information. It can be argued that the certainty participants sought was related to immediate matters of their day-to-day lives rather than information pertaining to their long-term outlook.

In response to the high levels of uncertainty and the lack of concrete information associated with this illness, participants sought information and certainty from the only source available to them; their physical body. As a result, participants monitored and listened to their bodies and garnered facts relating to their health in this manner. In doing this they could feel they were receiving feedback on their response to treatment rather than dealing with an extremely high level of uncertainty. Therefore, I argue that the behaviours of monitoring and interpreting meant participants saw their bodies as an expert information source during this uncertain time.

While people felt well, and their illness remained unseen, even invisible, to themselves and those around them, the reality of their situation did not need to inhabit the forefront of the participants' awareness at all times. Feeling well allowed for the creation or maintenance of uncertainty regarding their health status. While maintaining they were constantly aware of their diagnosis and its implications, due the diagnosis being unseen, some participants found the immediacy of the diagnosis could slip from their consciousness, or even allowing them to momentarily forget the extent of their illness. Having an 'invisible' illness created room for the temporary suppression of the difficult facts of their diagnosis (this concept will be discussed in-depth in Chapter Six). The ability to suppress or alter their awareness of troubling aspects of diagnosis builds on the concept that varying levels of awareness of the implications of their illness exists within this group of participants (discussed in Chapter Four). The invisible nature of the disease means the facts can be temporarily suppressed for those who are struggling to process or come to terms with it. Further, this dismissal may even be reinforced by the external feedback participants received from those around them regarding their 'healthy' appearance. The invisible nature of this disease provides the opportunity to maintain uncertainty for those who need it:

It's not like other illnesses where you can see a swelling going down or you see a bruising getting better, you've nothing to see, you've nothing tangible to hold onto. Ursula (participant 7) Interview 3

...it's sort of-, not praying on me as such, but it's kind of in the back of my mind, not constantly, but every now and then I'll sort of, "Oh yes, I've got cancer." Because you just get on with it and I don't look sick, I don't sound sick. There's a lot of people who their speech would be slurred or they'd be walking with a stick or their hairs fallen out, the weight's fallen off, but everyone who sees me, "Oh, you look really well." "Yes, I'm not, but I look it." Even people at the brain tumour group are saying the same... every now and then they have to step back and remind themselves that they're sick, "Oh yes, there's a reason I'm feeling tired and I want to go and sit down." Do I look ill to you? Owen (participant 14) Interview 2.

When discussing his choice not to access information about his diagnosis online, Anthony (participant 9) highlighted how his normal appearance (or the hidden nature of his illness) allowed him to some extent, suppress his awareness of the immediacy of his illness and avoid addressing it for the time being. This enhanced his ability to cope with the illness and continue to live each day as well as possible; a priority identified by many of the participants (this will be discussed in-depth in the next chapter):

My sister has MS and when she was first diagnosed [accessed information online] and I think that only gets you down. There is a chance of course it will take your life, but why would you sit around worrying? I don't want that, where your whole life is just going to be consumed that you have cancer. Apart from the fact that I know I have it, I wouldn't-, you just get very tired, you're more fatigued and you wouldn't have the same appetite you had before, but apart from that if I hadn't lost my hair people wouldn't even know I was sick. Interview 2.

5.5.3 Appearance and mood

As participants experienced a positive impact on mood brought about by perceptions of looking and feeling relatively well, they developed the understanding if they could remain looking and physically feeling as well as possible, they could increase their chances of benefiting from a better outcome. Participants' appearance had both positive and negative effects on their mood. Perceiving oneself as identifiable as a cancer patient, requiring a wig, and experiencing changes in one's appearance caused significant distress and upset.

The positive or negative influence on their mood was linked to perceptions of how participants were responding to treatment. Participants were able to cope better when they felt physically well, due to derived perceptions that they were responding well to treatment. Believing they were responding well to treatment provided people with the opportunity to have hope for their outlook and for their future. Similar to 'monitoring the self', discussed above, participants also closely monitored their appearance. Women monitored hair loss, men were conscious of their scars and bald spots resulting from surgery, and both genders were aware of their changes in body weight. Six of the participants discussed their weight gain over the course of treatment. Equally, participants, particularly men, were scared and upset at the prospect of losing weight and associated it with poor health. Some were conscious of the facial swelling they experienced from steroids:

[your hair is] as much part of your face as your face is. Even you know yourself, if [your hair] doesn't look right, you're looking at yourself and going, "Oh god." It just makes you even feel bad, doesn't it. Do you know when you might get up late and you might not have time to wash it and you feel all day, it's driving you mad. When it's not right it's part of you. So hopefully, I'm holding on to enough to cover it up. Just to keep a light cover until it starts to grow back. Ursula (participant #7) Interview 2

In the earlier parts of the illness journey, participants spoke about knowing that hair loss was a likely side effect of treatment, however they still hoped that it would not

happen to them. At the time of the first interview, many participants believed that they would not be upset by any hair loss they experienced, some cited it being the least serious of the problems they faced. Further, participants qualified any side-effects as being worth it for the opportunity of a better outcome. Relating to the concept of 'doing what needs to be done' discussed in Chapter Four, participants verbalised internal agreements that they had made with themselves, that they would put up with difficult side effects and upsetting changes to their appearance if it meant they had a better chance of survival.

Despite their expectations, participants became distressed when hair loss commenced around the time of the second interview. Participants were frustrated by the perception that their appearance made their diagnosis obvious to others. Hair loss challenged their identity and sense-of-self (discussed below) and provoked feelings of loss, frustration and shock as some were forced to confront the reality and extent of their illness, along with its associations with declining health:

...when they say your hair is going to fall out you're kind of like, OK I can deal with that, but when it actually starts to fall out you're like oh god this is horrendous like this is horrible, I didn't realize how horrible this was going to be, because it's not how you think it would fall out like it's not little bits it literally happened a day, two days and for me it just... I'd touch it and it would just come out. Rachel (participant #13) Interview 1.

The upset caused by their changing appearances was worsened by participants' 'need to feel individual'. Looking like everyone else (other cancer patients) meant that they were like everyone else and therefore by extension may be subject to the same fate as the general population of people with glioma. As I will now discuss, participants sought to maintain their individuality, to be seen as unique and not as an 'average cancer patient':

When you look in the mirror you don't see yourself. You look in the mirror and it's not you. For me, that was very difficult. You see different people at different

stages and you know when you look at some people, you know that they have cancer. Part of a wig or whatever else like that, you know they don't look well or they're often very, very thin, different things you know they've got a cancer diagnosis, but when you see people lying in a bed and drips and all the different things that's happening. Ursula (participant 7) Interview 2.

5.6 Striving to preserve individuality: the challenges to identity

Participants were upset by changes to their appearance which could identify them as sick or as a 'cancer patient'. They believed changes in their appearance such as hair loss, wearing headscarves, wigs and weight fluctuations meant they could be identified as sick. Typically these elements of appearance were associated with poor health, and although the participants felt well physically, these changes to their appearance served to further highlight the contradiction between how they felt and their actual clinical status. From the above discussion it can be construed that the participants associated looking sick as a negative predictor in terms of their prognosis and further, it challenged participants' ability to suppress or dismiss the undeniable facts of their diagnosis :

I think the hardest part as well, I know it sounds so stupid is when my hair started to fall out yeah no it's just kind of the physical appearance of looking sick, cause I don't feel sick like it's weird. Rachel (participant #13) Interview 1.

Participants struggled with the identity of 'being a patient' or 'being a sick person'. They strove to reject the identity of the cancer patient and the ensuing pity accompanying it. Being identifiable as someone with cancer communicated an identity to the outside world which conflicted with how relatively well the participants actually felt. Participants resisted special treatment or being treated differently due to their illness:

People I worked with, a lot of them still treat me the same, but there's one-, even when they text you, "I don't know what to say to you." It's like I'm still the

same person I was that you were working with, nothing has changed. Anthony (participant 9) Interview 1

Participants were frustrated by various acquaintances and strangers deriving they were unwell from their appearance. The people in this study did not want their illness to define them, they did not want it to encompass them or their identity. It is possible that appearing sick denied participants the ability to communicate their own experiences or their own stories as their appearance informed other people's perceptions. The findings of this study suggest that the frustration participants felt was compounded by the loss of individuality and dignity which accompanied the identity of 'cancer patient':

When I was first told about it that was my first reaction like I don't want to be thought of as 'that person' [with cancer] like not that having cancer is something you should be ashamed of but like, it doesn't define me, doesn't make me like a different person to what I am (voice trembling) and that was like my biggest fear. Rachel (participant 13) Interview 1

Sometimes I don't want them to, I want them to leave me in peace, but just things like people calling over just to see how you are. They give you this look, "Are you alright?" and I'd be saying, "Yes, I'm fine. I prefer you wouldn't speak to me like that." Especially like the way I am now, I don't feel sick and they're going, "Well pet, are you alright?" They're being kind, but sometimes I feel oh no. It's like a sympathy thing. The soft voice and they turn their head, "Are you alright?" Sarah (participant 10) Interview 2.

I did get scarves and I wore it one day coming [to the hospital] on the [hospital] bus. It's like a wee cotton hat with a scarf, a lovely thing. I never felt more conscious and down in the whole seven weeks [of treatment] than I did that day and it was simply because I was wearing the scarf. I got off the bus at [service station] where we would stop and all I could think of was, "We're getting off a bus that says [hospital name]. There's four of us wearing scarves. Everybody in

there is going to be thinking cancer patient, cancer patient.” It really, really got to me and I thought, “I cannot do this, I can’t wear this scarf.” So it was put to one side. It just made me feel so conscious and so cancer. A beacon I think. That was the first day that I really felt, “You have cancer.” Up until that not so much. From when I took it off, not so much.

Aoife (participant #12) Interview 2.

To remedy this, people tried to individualise themselves in order differentiate their circumstances from the ‘typical cancer patient’. Attempts of achieving this involved resisting submitting to the typical activities associated with being a patient such as staying in bed throughout the day, wearing pyjamas for long periods and spending less time on aesthetic appearance. Participants emphasised self-discipline in terms of getting out of bed at their usual time, putting on normal everyday clothes, going for regular lengthy walks for exercise and attending to their appearance:

...[when in hospital] If you want to stay in bed all day you can. Whereas, I don’t. I get up and I get dressed where everybody else on the ward doesn’t. I am the only one that will get dressed on the ward. Everybody else stays in their pyjamas or in their beds, but I get up every day. Have my shower, get dressed and even if I don’t do much to me that’s how I cope because I wouldn’t sit around at home without getting up and getting dressed. Aoife (participant #12) Interview 1.

Similarly, a large number of the participants stressed their identity as a person who was fit and healthy prior to receiving this diagnosis. Participants spoke at length about their excellent health, having never been sick before, and emphasised their active lifestyles. It is clear that participants did not want to be generalised as the ‘average sick person’, they needed to be seen as individual by others. Participants also emphasised their qualifications and the importance of their roles in their workplaces. Participants identified as valuable, necessary experts in their areas of employment and in their hobbies. This was combined with discussions on their central roles within family and friend groups. This emphasised participants’ need to be associated with their identity prior to becoming sick, rather than being associated with the identity of ‘a cancer

patient'. It is also worth considering that participants emphasised these points as a result of the interview location. Interviews were conducted in the hospital; had the interviews been conducted in the participants' homes this may not have been as important a point for the participants to make.

I never get ill, I never get sick. I'm always the healthy one. I'm the one that looks after everybody else. Owen (participant 14) Interview 1

I have been working since I was 15 and I could nearly count on the fingers on my two hands, the number of sick days I've actually taken off. Dave (participant 1) Interview 1.

In summary, participants' experiences of changes to their appearance forced them to confront an externalisation or an actual manifestation of the disease that was otherwise invisible, thus making it undeniable. Participants found their appearance impacted and altered their identity which caused upset and frustration, prompting participants to feel self-conscious and inextricably linked to the stereotype of a 'cancer patient'. Being associated with the stereotypical cancer patient caused concern for participants and challenged their hopes to 'beat the odds' based on their individuality.

5.6.1 Responding to hair loss

Participants hoped that their hair loss would not be extensive enough for them to require a wig. Overall participants did not like the idea of requiring or wearing a wig. The experience of going to buy the wig itself served as an upsetting event to all participants who required them. Again, the requirement of a wig and the physical act of having one fitted served to confirm the reality of the diagnosis and removed the ability for any denial of the severity of the illness. Despite the internal protective measures deployed by participants in order to manage their knowledge and their awareness of their situation (which will be discussed in the next chapter), acquiring a wig forced participants to confront the severity of their situation:

I was supposed to go last week to have, you know, if I wanted to have looked at for a wig but sure my hair is falling out in big clumps like in the last three or 4 days... but I didn't go, I don't know whether I'm going to go down that route or not, you'd have to think about that wouldn't you... you know it's a big step to take. Heather (participant 5) Interview 2

I went to the hair place, and they tried on a wig and obviously that was like so scary and just even putting on a wig you're like oh god that's horrible but then...that was, that was hard (tearful laugh) it wasn't the easiest. It was an emotional day. You never think at 21 [years of age] you're going to need a wig. Rachel (participant 13) Interview 1

At the point of needing or obtaining a wig, participants were only approximately 6-8 weeks post-diagnosis. I argue that the upset caused by the need for a wig is linked with the quick and sudden requirement to adapt to their new reality. Perhaps the reality presented or confirmed by the wig generates overwhelming emotions which take the participants by surprise. In other words, participants have not yet had time to fully come to terms with their diagnosis, and the change to their appearance, the need to buy a wig, is a challenge for them to manage in addition to everything else.

5.7 Developing awareness

In the first chapter I outlined that awareness of the undeniable facts of glioma was a dynamic process constantly evolving throughout the treatment journey. By the second interview, this awareness had developed in some ways. At this stage of the treatment journey, many of the participants appeared to have undergone moments of realisation of the severity of their diagnosis, such as the ones outlined above, which furthered their awareness of the implications and the likely outcome of their illness. However, some participants were more open to verbalising their awareness than others. It is possible that participants felt able to discuss this awareness because they were somewhat protected by constructions and perceptions which consolidated and

confirmed their ability to hope for the best. This construction of hope will be discussed in the sections below.

As I outlined in the first half of this chapter, participants' understandings of their illness were informed by interpretations of their bodies' responses to treatment, while their emotional state was influenced by whether or not the feedback received from their body was in line with their expectations. People's developing awareness was portrayed in different ways throughout the interviews. As seen in the first chapter, while some were able to discuss their likely outcome explicitly, for others it was more unspoken and covert. Some participants chose not to, or avoided verbalising their awareness of the seriousness of their disease, but instead revealed their actual awareness through reactions, behaviours or expressed emotions such as fear, relief and distress. The findings of this study suggest that some participants needed to hide or avoid communicating their awareness of the severity of their illness in order to protect themselves, or to prevent the reality of their situation manifesting itself outside of their own private thoughts, and therefore making it easier to cope.

Additionally, instead of explicitly speaking about their knowledge of what the outcome of their illness could be, or what their future looked like, people referred to moments in which they acknowledged the severity of their diagnosis. At times, my own understanding of a participants' actual awareness could only be developed through examining the data for moments where they realised the true severity of their diagnosis. Through deduction and retroduction, analysis revealed that on some level, each of the participants had some awareness of the threat to their lives presented by the diagnosis rather than the low level of insight, or the covert awareness that they presented to the outside world. For example, participants who spoke about intending to be cured through treatment or those who did not worry about the diagnosis revealed the development of their awareness of the severity of the diagnosis through accounts of sleepless nights, fear, or avoidance of prognostic information. In the case of Dave (participant 1), who at first did not seem to be aware of the unfavourable nature of his disease, described his interpretation of the uncertainty of his illness as follows;

...it's like you've taken a coin from your pocket and you've looked at it and it's heads or tails and you flick that coin into the air and it's up there still, you've flicked it as far as you can and it's spinning and someday it's going to come down and you hope it comes down on the side you picked. That's the type of illness I think it is. It can be as black and white as that. Interview 2.

Such an interpretation is not indicative of a person who was as unaware as I initially perceived him to be. Similarly participants who declined doctors' offers for more information regarding their prognosis, as previously highlighted in the case of Ian and Phil (participant #2 and #16 respectively) but was also seen in a number of other participants' accounts (such as Aoife's, included below), suggests that although they may not discuss their awareness, their actions and decisions indicate their awareness or indicate their knowledge of the severity of their situation. These responses indicate that the person is aware that a decline in health is likely, however, for reasons related to their need to emotionally survive, participants did not refer to the likely outcome of their disease:

My son wanted me to ask about prognosis. I didn't really want to. So I did ask and he [the doctor] goes, "Do you want to know?" "Not really." He said, "Then I won't tell you. I don't work on that kind of statistics anyway. I like to see how we go. We'll talk today and half way through the treatment we'll talk again", and he says again "But I can certainly tell you if you want to know." "Not particularly." My son was annoyed-, I says, "No, it's me. If I want to know I'll ask. You can just wait." but then of course, Google. I think they'd been on Google the day after I got the diagnosis. Aoife (participant 12) Interview 1

Awareness was further developed through the unavoidable associations made through knowing someone with a similar diagnosis. A number of the participants either personally knew someone or were aware of people, some public figures, with brain tumours who had died as a result of the diagnosis. Some in this same group of participants did not express explicit awareness or knowledge of their own likely

prognosis yet spoke about the fate suffered by those they had known with a brain tumour. Although the participants may not explicitly display open awareness of the implications of their diagnosis, we can assume that awareness exists on some level as knowing someone who had a brain tumour makes the reality unavoidable. Sarah (participant #10) had a friend who died from glioma close to the time of the second interview. Despite displaying a limited awareness of the difficult facts of the diagnosis, she explains why she could not bring herself to attend the funeral:

When I found out he'd passed I couldn't go. I don't think I would have been able to face [friend's wife]. It was guilt that I was still here and he wasn't. Do you know what, I'd have been selfish and I'd have been thinking, "Oh god, imagine that was me." I just couldn't do it. Sarah (participant #10) Interview 2.

Similar to this, spending significant amounts of time in the hospital, surrounded by others with cancer, forced some participants into a confrontation with the reality of their situation:

...and other times I get tired and I start to think, "Oh god" and the mind takes off and goes into orbit. So you have to stop thinking and when you walk through the ward, some people are very ill there and I'm so conscious they're very ill. You see them and I know the first two weeks I was going, "Is that me, is that me? How far away is that?" You know, you walk by a door and it's open and there's someone on a bed and there's an air mattress there. That whole care at the end and you just knew when you saw this air mattress. Ursula (participant #7) Interview 2.

People often described these realisations or developments in awareness as negative or dark thoughts. This description characterised the sometimes distressing nature of these realisations or increased awareness of the severity of their diagnosis. The upsetting impact of these thoughts meant that participants were not prepared to voice their awareness. It is possible they were more aware than they were prepared to admit or talk about. In the next chapter I will outline how participants managed these 'bad

thoughts' and how they found ways to cope in spite of these intrusive thoughts about their future.

5.8 Experiencing physical limitations and loss

In addition to the psychological and emotional losses participants had experienced, as treatment progressed, participants began to experience the impact of their physical limitations on everyday life. As participants neared the end of their six week treatment, and in the immediate months following radiotherapy, participants began to notice their diminished abilities while realising they could no longer do what they used to. This loss of ability served to further highlight the drastic change their lives had undergone within a matter of weeks. Through these limitations, the profound impact of the diagnosis on everyday life became apparent. Physical limitations on the participants' lives, preventing them from returning to a normal way of living, were caused by symptoms of the disease itself⁹, side effects of treatment¹⁰, the loss of the ability to drive, the loss of autonomy and the loss of self-determination.

Participants were forced to recognise and become familiar with their newfound limitations or restrictions to their abilities. They tried and struggled to maintain their prior roles within their families and their households but were often forced to realise it was no longer possible. The limitations highlighted the impact of the diagnosis on one's ability to parent when dealing with a life-threatening and life-limiting illness. The burden of parenting while sick caused emotional strain for participants as they tried to balance their need to rest with their parenting obligations:

I'm missing out on the chitchats in the car with my children. The fact that I'm not picking [children] up from work and getting that 20 minutes in the car on the road together, just me and them one-to-one. The car is a very intimate space for a chat with children. You're moving and things like that. It can be a good spot, it's often what I use if I wanted to raise an issue. So apart from the

⁹ Speech impairments, loss of mobility or strength in certain body parts.

¹⁰ Short-term memory loss and fatigue.

independence and all that goes with that in your life, I'm missing out on that point and they're missing out on that as well because I'm not hearing these bits of news so there's gaps in what I know about what's happening in their daily lives. Ursula (participant #7) Interview 3.

Additionally, many participants wanted to be able to continue with their household chores or tasks but found they struggled to do so due to fatigue and mobility issues. In response to this, some participants attempted to adapt their roles within the household and tried to re-establish their purpose in other ways, while other people experienced significant distress and disruption to their sense of identity by not being able to partake in their usual roles within the home:

We live in the country, I used be a farmer going back the years so I- just looking after (stutters) place was about 20 acres... I can't do things. Now I will be out cutting sticks, but there's a lot of stuff that I can't do. I'm not...(struggles to find word) there's nothing I can do about it. So for me there are other projects that I had going on-, all of a sudden, like there's another project was going to be on ...(trails off) but I can't do that now, so I got to get around it and get organised and try get people in which is, that's fine too. So it was just practical stuff, you just can't do it. And I'm getting slowly to the stage where I got to say listen I can't do these things ok so there's a guy coming in, put in ... lighting, and normally I would do that myself but I can't do that. So that's just the practical... I can get up and clean the house. I have to be very careful because we have an [open top stove] and I said to [wife], do you want a cup of tea, and she says I'd love one, and I went out and was 'where I put the cup?', and so I put the electric kettle...on the [hot plate on the stove]! So that's gone! But that's the sort of nonsense I'm doing. But now you get to the stage [where you] think ok you need to stop doing that. So just for the practical point of view, it's just not feasible to do, a lot of stuff. That's the annoying thing from my point of view because I'm fine here (indicates to his legs) I am (indicates difficulty with his right hand). Ian (participant #2) Interview 1.

According to the participants, the loss of the ability to drive¹¹ was unanimously one of the worst consequences of the diagnosis. The shock of the diagnosis communication was quickly compounded by the news that the person was no longer able to drive. Over the six weeks of radiotherapy the participants' experienced the severe impact that not being able to drive had on their and their families' lives, particularly for those living in rural parts of the country. Being unable to drive impacted the ability to complete daily tasks and prevented them from participating in their usual pastimes or hobbies, which would often have simultaneously been their method of addressing or dealing with hardship or stress:

So I'd love to be able to jump in my jeep and go off out to the mountains some Saturday which I've been doing all my life, meet the boys and go for a walk you know so I don't know what's going to happen, now they may say I'm ok I'm seizure free, after I've had this treatment, maybe that might shorten the sentence [driving ban]. Gerard (participant 3) Interview 1

Really, it was one of the worst things he could have said to me. You can't drive. Yes. Whatever about medically what's wrong with you, I just found that, very, very hard. Yes there is a certain amount of sadness in it and there's a certain amount...maybe there's a certain amount of resentment in it as well...but that's...the nature of it you have to abide by the rules, you won't be insured if you drive and the doctors told you not to drive, and, you have to live by, you have to accept it. Dave (participant #1) Interview 1.

The loss of driving stripped participants of their independence, of their sense of autonomy, and of their freedom. Within this study driving was characterised as being habitual, a part of everyday, and to be of vital importance to most people's lives. Participants felt upset, frustrated and angered by their loss of driving. For those who wished to drive to work, they had lost the ability to do so independently. Many began

¹¹ Those with a glioma/brain tumour diagnosis are banned from driving due to the risk of seizure. Additionally insurance companies will not insure someone with the diagnosis.

to feel burdensome to friends and family, requiring assistance to attend daily treatment (if outpatients) or even completing simple tasks such as going to the shop for groceries. Participants tried to compensate by reducing their burden on others by adapting their schedules so that multiple tasks could be completed in one car trip. Driving impacted family life where the participants believed more pressure was being experienced by their spouse as the only adult in the household able to drive:

This driving is the killing part. My wife doesn't drive. We can't do anything, we can't go anywhere. We have to get someone to take us. Even if you just wanted to go to the town. You have to phone someone to come and get you to get milk. That part of it is a disaster. Tom (participant 11) Interview 2

Yes, driving is colossal, I live out in the country. I can't even get a litre of milk. I'm a mile from a shop, but it's actually quite a windy road, it's a dangerous road for walking. The independence, a lot of independence like that. Even if I want to go shopping. This time of the year you're picking up stuff for back to school, you're dragging people with you all the time and you know they're waiting, "How long are you going to be?" It's quite busy so you very much lose your independence for doing what you want. You're like a child really, you have to wait for everyone else to go into town and trying to work round their timetable. Ursula (participant 7) Interview 3

Ian (participant #2) was outlier within this group in relation to the sense of upset and loss caused by not being able to drive. He explained that there were more important things to worry about:

Its again, it's not it wouldn't be annoyed [sic], anywhere near the top of my list of oh jeez I wish it was. People are very good, I can get anywhere with a phone call. The shops are a 25 minute walk, but if I'm going somewhere I prefer to have people with me so, there's no point giving out about driving. Interview 3.

5.8.1 Feeling disappointed

The onset of symptoms and side effects occurred suddenly and brought about an overall feeling of decline in abilities as a result of extensive fatigue, headaches and changes to physical abilities. The people in this study felt disappointed and disillusioned as a result of the physical limitations they experienced in their daily lives, stemming from the onset of the side effects of treatment. In comparison to the sense of elation I perceived from many of the second interviews, the third interviews seemed to find participants more subdued, many were more frank about their struggles. This perhaps was due to the realisation that their diagnosis was incurable and would remain a permanent fixture in their lives. It was apparent throughout the third interviews that as time had passed, participants had reached a point of realisation. This 'realisation' could be interpreted through the overall tone of the third interview, participants seemed slightly less upbeat as they had in the second interview. As discussed throughout this chapter, participants were largely upbeat and hopeful due to their perceptions of their positive responses to treatment which were based on the lack of side effects and feeling physically well. By the time of the third interview however, the side effects that participants had been expecting during treatment had finally manifested, albeit later than anticipated. Although the participants still looked for hope and tried to be positive, their mood was interpreted as resigned and more serious:

Interviewer: *So what's a typical day like for you at the moment?*

Participant: *Suppose typical day I wouldn't wake 'til about half 10 so I get up and take tablets and take a bit of breakfast, stroll about then try and get out for a walk and yino, back in and rest myself, maybe try get out again, you have to try and keep going you know? It's definitely not easy. I'd love to be able to do a bit more work and that. It's just my nephew looking after the cows and that's it and nothing else is being done. So we'll see what happens you know. Can't go out and do it myself. There's not much you can do at home now, just at the minute, energy levels are fierce low you know, its suppose taking more out of me than I thought, than I expected. I didn't I thought I would have more energy, go ahead more you know Like when I was in hospital I was flying. Then*

I suppose this other stuff is a bit tougher. It takes it out of me more. Tom (participant 11) Interview 3

Although participants understood these physical reactions were side effects, considering the findings discussed throughout this chapter, it is likely that they also associated them with a decline in their condition. It is possible that this association caused them to believe that they were not responding well to treatment and was indicative of a negative outcome for them. Building on the concepts discussed earlier in this chapter, I suggest that feeling physically unwell brought about further realisations of the severity of their situation and confronted participants with their undeniable facts of their illness. Where their lack of symptoms and side effects had allowed the participants to hope that they may be one of the lucky ones to 'beat the odds', the appearance of side effects caused participants to feel deflated and low, and above all, disappointed that their hopes did not transpire.

Throughout the course of the study, a number of the participants received bad news regarding their response to treatment and that either the treatment had not had its intended effect, or that the tumour had not changed in size. At this point of the illness journey participants developed a greater understanding of the severity of their diagnosis and the extent of its impact on their lives. It had become more of a tangible reality rather than a distant concept. Having experienced a seizure post-radiotherapy Owen (participant 14) recounted his realisation of how serious his circumstances had become;

Being told that I might need to ring my parents and bring the children in to say goodbye and all the rest of it.... more upsetting because it's like the realisation that the doctors thought that things had got that serious and that we were at the stage where I could be going [to die] any minute. Interview 3.

Despite acknowledging that a difficult future lay ahead (as discussed in Chapter Four) participants were still disappointed and deflated when the decline in health did occur. It is possible that they hoped that time would never come. The perceived level of

controllability over their bodies response to treatment indicated a belief that the onus was on the person to tolerate treatment and to respond well. When the body responded positively it allowed people to feel as if they had an element of control over their body and their illness. However, when side effects, a decline in health or prolonged physical limitations occurred, this caused feelings of disappointment their bodies submission to the illness:

Interviewer: *So, were you surprised [at the decline in health]?*

Participant: *Not really no, I kind of knew myself, my body, it was kind of telling me itself that it was going downhill... 'cause I came out to the hospital a few days and the doctor said to me do you think you'd be able for the rest of the treatment, and I said no definitely not, I knew myself I wasn't, no I didn't feel I would be able to go through it, and I didn't want that.* Heather (participant 5)

Interview 3

The hope that participants had developed throughout treatment suffered upon the arrival of side effects and the decline in health post-treatment. News that the tumour had been unaffected or had recurred confronted them with the reality of the situation and damaged their ability maintain a hopeful attitude for the future. Having experienced a seizure post-radiotherapy Aoife (participant 12) outlined the upset she felt at realising her tumour had recurred:

So the Tuesday that we got the scan, when we came out from the doctor, when he had said that there was an abnormality and went through the options, like it would be a perfusion MRI that he would recommend and then see what the radiographer said when they read it and see what [consultant radiation oncologist] said when she read it. He had said a perfusion MRI, and it should be done sooner rather than later. So then two days later I got the call to say, "No, we're not doing it [the MRI]. We're waiting for a while and see what [the consultant radiation oncologist] says". But then when we came out of his office after that, I was kind of like, "Okay we know what it is, we're leaving it [no

action is going to be taken].” Michelle¹² stopped me in the hall. That’s the liaison nurse and she’s like, “How are you?” Well, just the tears started then. If she’d left me we’d probably have gotten to the car (...). So we were taken into a room and we were grand then, but it was I suppose, here we go again. An abnormality. That was the first thing that was said to us last year. So shock, definitely. As I say, more for the fact that we thought it wouldn’t be this quick and then having the seizure then on Sunday, I was like yes, definitely it’s back, and it was the very same kind of seizure. I thought. “Don’t tell me this is it starting again now?” Aoife (participant 12) Interview 3

Participants felt disillusioned by treatment and dismayed at the knowledge of recurrence or and that their extensive and exhaustive treatment had had little or no impact on their tumour. This upset and disappointment was compounded by the loss associated with the eventual physical impact of the disease as they experienced diminished abilities in everyday life. Having developed a positive attitude based on the information provided by their bodies, the unpleasant experiences of the side effects of treatment, coupled in some cases with tumour recurrence, prompted disappointment and damaged the participants hope for a better outcome. However, it is important to recognise that until this point, hope for a better outcome, which was strengthened by processes relating to embodiment provided participants with the motivation to cope with and complete treatment:

Participant: *I feel like I'm going backwards. I feel like I have no energy or nothing my whole body is after shutting down, you know?*

Interviewer: *Do you feel worse than before treatment?*

Participant: *Yeah. I am kind of disappointed because we were getting on so well then all of a sudden bang you know? Yeah. I am kind of disappointed because we were getting on so well then all of a sudden bang you know? I was delighted with myself, you know which you would be... I think everything happened at once so I just wasn't expecting it, the mobility, headaches, tiredness. We knew*

¹² Name anonymised

there were side effects we knew it was going to happen but I don't think we thought it was actually going to happen until- until it did happen. Heather (participant #5) Interview 3.

Interviewer: *How do you feel?*

Disappointed, I wasn't surprised and I wasn't not surprised, what I'd like is to get my general health back, I'm tired and find it hard to walk, my muscles aren't that great my leg muscles, so I'd like to build it back up again, I'd be happy. They looked at my MRI scan and said that the treatment wasn't shrinking the tumour but the tumour wasn't growing so, maybe that is kind of good news you know?

Gerard (participant 3) Interview 3

In comparison, to this, Anthony (participant 9) felt physically well at the time of the third interview and still felt upbeat and physically well. Although he was no longer working, he had managed to regain some degree of normality in terms of being able to conduct everyday activities and tasks. Even the night before his post-treatment scan, typically an anxiety inducing experience, Anthony felt positive and slept soundly as he explained;

I got the results of the MRI scan which was very good. Very, very good. There's a wee bit of swelling or could be scar tissue from the operation or it could be the treatment would have caused it. They're not very worried about it because [doctor] said, "If you're not getting any headaches or anything that's very positive." And she said, "You look really, really well as well". So I have to have another scan in January when I've all my treatment done. So they'll have a better idea then (...) You know yourself that you've made headway, made progress. You feel a lot better. (interview 3).

The experiences detailed in this section further highlight the significant impact of ones bodily experiences on their mood and emotional wellbeing. Where many participants felt disappointed, disillusioned and upset at the increase in symptoms and side effects experienced by their bodies, Anthony still felt hopeful and upbeat for his future based

on his perceptions of feeling and looking well, and not suffering from a significant loss of abilities.

5.9 Looking forward

Having completed 6 weeks of combined radiotherapy and chemotherapy, the participants then returned home full-time to recover, treatment free, for one month. Then they would commence six months of actively taking chemotherapy tablets for five concurrent days per month.

As mentioned above, participants, particularly those who received treatment as inpatients, found that the routine of treatment and the hospital wards had helped them to cope. Those who did have to stay in the hospital¹³ as inpatients to receive their treatment were glad, in hindsight, that they had the opportunity to do so. Some believed they were able to care for themselves better and achieved more rest while being away from home. The hospital routine was used almost as a crutch in terms of guiding and supporting people through their day. The schedule set by the healthcare professionals in the hospital guided how participants spent their time, it cared for them even through determining their meal times meaning daily routine become almost automatic. Participants could adopt a passive stance and let the routine and scheduling of the hospital and treatment guide them through their days. Being in the hospital normalised illness and suspended the reality of the outside world:

I think because when you're here, it does become such an established routine and it does become your life, which is I think why a lot of the people that I've spoken to said, "When you get home and life goes back to being life", so that whole thing takes a little bit of adjustment. Owen (participant #14) Interview 2.

Participants worried about returning home (full-time) and about losing the structures which supported them throughout their treatment. They recognised the protective

¹³ As discussed in Chapter One and Three, those who experienced a high symptom burden or lived too far away to attend the hospital daily were received their treatment as inpatients in the hospital. Those who were well and lived nearby could receive their treatment as outpatients.

factors offered by the hospital and worried if and when reality would hit them, how they would cope, and some worried about their children seeing them unwell. Returning home meant that finally the diagnosis and the participants' normal lives were no longer separable. They realised they now had to learn to be sick at home without the hospital staff attending to and caring for them. While in hospital they could suspend elements of reality, they now recognised reality would be different while trying to return to normal lives, having gone through such an immense change. Below Aoife (participant 12) experience of navigating the different roles both home and hospital played in her treatment journey:

You get your tablets at a certain time you get your dinner at a certain time, you get your treatment at a certain time and everything is structured and for me during the week that's fine. I'm happy doing that. I think it maybe takes some of-, what's the word? Not your independence, it helps me deal with it I think a bit during the week because it's structured or maybe it's a way of not dealing with it because it's structured and this is the time you get your tablets and this is the time you get your dinner. Whereas, at home then I am dealing with everybody's emotions and everybody's dramas. Times are different and visitors. Home is different, where here is clinical. This is my treatment and I can deal with that. I think if I was at home and having to travel to get my treatment every day and deal with emotions and deal with dramas, I think that would be hard. Whereas, I find this good. I can read if I want, I can sleep if I want. I can go for walks, but I know that at a certain time I'm going to have my treatment and I'm going to have my tablets. It's fine and then at home over the weekend, I can deal with what I have to deal with in that two and a half days. So when I go home after all this treatment I don't know how I am going to be. Interview 2.

Many pre-empted, expected and accepted an increase in fatigue over the following weeks while they recovered from radiotherapy treatment. Participants also anticipated that they may struggle to cope once treatment was over, this may be due to the sudden loss of meeting medical professionals on an almost daily basis, or concerns that the tumour may begin to grow back once active treatment had been

completed. Participants found comfort knowing something was working to eradicate their tumour during active treatment. Some wished they could continue undergoing a form of treatment which would allow them to feel that they were actively doing something to help. They anticipated being fearful of sensations or pains that could be interpreted as recurrence but may also be inconsequential.

As discussed in Chapter Four, in light of recognising they were powerless to generate any great change in the outcome ultimately while still wanting to feel they could do something to care for themselves, participants vowed to monitor themselves and stay vigilant for any indications of new symptoms. They found that the only action they could take was to look after themselves and do what they could to improve their chances of a better outcome.

5.10 Conclusion

This chapter outlined the many challenges and losses participants experienced as they progressed through their treatment journey. The findings indicate that participants need to make sense of how they are responding to treatment, in order to cope with the overall uncertainty surrounding their diagnosis. The uncontrollable nature of the cancer was made worse by the tumours largely invisible, internal nature, knowing (for the most part) that treatment could do little to control the eventual progression of their disease.

A vital part of understanding the experiences of those with glioma is understanding the role that knowledge and awareness of the facts of their illness plays in their daily lives, and people's ability to continue coping despite their external reality. Based on my engagement with the participants and the data, I believe all of the participants were aware of the life-threatening nature of their disease. Grounded theory and qualitative investigation affords us the opportunity to study not only what people say, but why and in what way they are communicating their stories. Therefore, as outlined in this chapter, although some participants did not explicitly reveal their awareness of the terminal nature of their illness, interpretations of peoples behaviours, what they

were saying, and equally, what they were not saying, indicates each participant possessed an awareness of the threat to life. Accepting that participants were aware of the difficult facts of their diagnosis, this group of people managed to be aware of their likely outcome without suffering from the troubling nature of this reality. This findings of this thesis will explain how participants managed this, and what their motivations for achieving this dichotomy.

In response to the uncertainty of their circumstances, the participants in this study viewed their body as a source of information and hence sought to elicit information from it in order to monitor their response to treatment. This initially resulted in a positive impact on mood and provided reassurance to the participants that they were responding well to treatment, improving their ability to hope and cope on a daily basis. The participants in this study experienced their bodies as a both a source of threat but also a source of stigma. This chapter highlighted how participants sought to avoid being identifiable as a 'cancer patient', for fear of connotations associated with the identity, and the assumptions that the outside world might make.

Charmaz (1995) explains that serious chronic illness undermines the unity between body and self and forces identity changes. The findings outlined in this chapter suggest that this understanding is applicable to those with glioma and arguably other cancers and terminal illness. The experience of undergoing treatment for glioma threatened the connection between the body and the self as a result of the perceived loss of congruity between the two. As such, this chapter illuminated the importance of the physical experience of glioma and its influence in how people make sense of, understand and react to their illness. At the time of writing, to the best of my knowledge there is no existing literature exploring this concept in relation to glioma patients, however the role of the body in the creation of hope for the future is discussed by Salander and colleagues (1996). These authors found that perceptions of a sound body and feeling physically well enabled people with glioma to suppress their knowledge of the disease and made threatening information less credible. This chapter revealed how the body's experience of treatment influenced the participants perceptions of how they were responding to treatment, and as a result influenced or

damaged their ability to have hope for the future. The findings of this study build upon the findings of Salander and co-authors (1996) by illuminating the processes and contextual factors influencing the participants close observation of their bodies along with the subsequent impact this enhanced connection with their bodies had on the participants mood, ability to hope and cope.

As discussed in Chapter Two, within the context of chronic illness Charmaz (1995) outlined the three stages of adaptation to impairment in response to threats to the unity of body and self. Understanding these stages, and applying them to the findings of this chapter, provides greater insight into the participants decision to turn to their body in search of answers. The first and second stages of this model bear some relevance to this chapter while the third stage holds relevance to the findings of Chapter Six and therefore will be discussed in detail there. Charmaz explains that adapting to impairment firstly depends upon experiencing an altered body, defining the impairment or loss and making reassessments. Relating this understanding to the findings of this chapter, participants experienced an altered body due to their knowledge of their diagnosis, awareness of the facts of their illness and their anticipated expectations of the impact of the treatment on their body. When these experiences did not materialise through how one physically felt or appeared, the participants experienced a threat to the sense of wholeness of body and self, momentarily the two appeared separate, disconnected. As adapting to an impaired body means resolving the tension between body and self-elicited through the illness (Charmaz, 1995) the participants in this study reassessed their understandings and beliefs of treatment and their illness.

Charmaz explains that people then make bodily assessments and subsequently identity trade-offs as they revise their identity goals. In the case of this study participants were continuously assessing their appearance and in particular assessing how one physically felt in response to diagnosis and treatment. Charmaz (1995) found that in the context of chronic illness people make identity trade-offs, having assessed their situations, losses and gains they opt for one identity over another. In contrast to this, the participants of this study stood fast in their resistance to re-assess their

identity and strove to maintain their identity as an individual, and resist that of a 'sick' person or a 'cancer patient'.

Much of the existing literature relating to the experience of the body and health centres around chronic illness (Bury, 1982; Kathy Charmaz, 1995; Corbin, 2003). However, as Kirmayer, (1992) explains, "any theory of meaning that hopes to address the experience of illness must give due weight to the primacy of the body not only as an object of thought but as itself a vehicle for thinking, feeling, and acting" (p. 325). Studying embodiment within the context of illness provides insight into how, and to what extent selfhood is related to the body and the types of identity and emotion work that patients engage in to either support or undermine those relationships (Waskul & van der Riet, 2002). As detailed in Chapter Four, the participants started the interviews recounting a healthy self, until their 'illness story' emerged when they experienced an acute event or something more subtle such a change in sensation or pain in their body (Corbin, 2003). Nonetheless, before they 'knew' about the existence of a tumour, the participants experienced the onset of their diagnosis through their body.

Existing studies use the term 'abject' when discussing the experiences of embodiment within the context of those with cancer and terminal cancer (Parton, Ussher, & Perz, 2016; Waskul & van der Riet, 2002). The presence of a body usually implies a self, therefore abject embodiment threatens the accomplishment and the maintenance of dignified selfhood; in the context of cancer the body is out of control and can present a threat to the self (Waskul & van der Riet, 2002). Parton and colleagues (2016) found that women concealed and resisted elements of their identity and further repositioned their understandings of their bodies in response to the abject embodiment of their cancer diagnosis. To the best of my knowledge there is no research exploring the concept of embodiment in relation to the experiences of glioma patients. Within the context of this study the experience of living with glioma caused a disconnect between the body and the self. This disconnect can be seen through the confusion experienced when the body did not reflect what the self was experiencing or feeling. This confusion created such a level of uncertainty that the participants felt it necessary to interpret the discrepancy under a positive bias rather than negative, allowing for an increase in

hope for the future, resulting in the upbeat attitude observed in the first of the follow-up interviews.

The findings discussed in this chapter display the ways in which the participants attempted to assert control in response to this perceived loss of control over their body. Within the context of Parkinson's disease Roger and Medved (2010) found that needing to be in control and independent is linked with vital elements of the afflicted persons' identity. The loss of self-determination, characterised by their loss of independence and control threatened the participants sense of self and their identity. Within the existing glioma literature the threat to or loss of self primarily surrounds patients experiences with cognitive changes such as memory loss (Fox & Lantz, 1998; Ownsworth, 2016). In contrast to this, the participants of this study found their sense of self and their identity were most threatened by changes to their appearance and their physical abilities. The participants strove to maintain their identity and independence by emphasising their individuality and by trying to remain appearing and feeling well. It is important to consider that this difference in the findings may be a due to the early stage in the illness journey in which this study focused, where some of the participants had not yet experienced problems with their memory. However, some of the participants of this study were experiencing issues with their memory at the time of the interviews and did discuss these problems in relation to a threat to self in the same way that the embodied experience did. The findings of this study suggest that participants experienced their identity, sense of self and their physical body as intrinsically linked and as such, changes in their body in response to treatment held implications for their 'selves'. This understanding is supported by Waskul & van der Riet (2002) who clarify that the body represents the self and hence the self can be presented in the body.

Similarly, the loss of the ability to drive, to the best of my knowledge, is not widely documented in the glioma literature. This is surprising given that the participants of this study identified it as one of the most challenging losses that they faced. Perhaps this is a specific issue within the context of Ireland, however, the resulting impact of

the loss of independence is something that extends beyond good alternative modes of transport and better infrastructure.

The confusion caused by feeling physically well despite the severity of the diagnosis is touched on by Sterckx et al. (2015) however the authors do not discuss the impact of this confusion on the participants experience in terms of its ability to be used to create both uncertainty and hope, and in turn serve to benefit the person, as was outlined throughout this chapter. Further, similar to the findings of this study, the Salander and colleagues (1996) suggested that the contrast between participants' expectations of treatment and the relief that treatment was easier than expected caused a post-operative euphoria which seemed to immunize patients against intimidating information. This elation was also experienced by the participants in this study. Having experienced treatment as easier than expected, rather than dismissing intimidating information, the participants in this study generated hope that despite what they knew about their illness, their completion of treatment without the side effects predicted by medical staff provided evidence of the individual nature of their condition thus improving their chances of 'beating the statistics'.

Much of the existing literature relating to adaptation or adjustment to illness or traumatic events is considered within the context of the possibility of returning to a level of normality, or good health. Within this study, despite hoping for the best participants recognised that a return to their past lives and selves was unlikely thus instead they sought adjustment or adaptation to their circumstances to a degree which allowed them to cope, and to make the most of daily life. Therefore it seems that adjustment within the context of a terminal disease has alternative purpose to those within a reversible or an objectively alleviable situation.

Undergoing treatment allowed participants to feel like they were proactively doing something about their circumstance, that they were fighting. Maintaining a fighting spirit in the face of their diagnosis was essential as it allowed the participants to continue to hope for a better outcome. The instinctual human need to preserve life, and doing what needs to be done in order to promote this possibility can be seen

throughout the different stages of these interviews and is reflected in these findings chapters. In the next chapter I will outline the frame of mind that participants adopted in order to ensure that they could psychologically and emotionally withstand the constant attempts at intrusion into their mind made by 'troubling thoughts' and hence continue to live each day to the best of their ability.

Chapter Six: Coping with glioma

6.1 Introduction

The previous chapters portrayed the participants' initial experiences of their diagnosis and their quest to make sense of their altered lives. The elements of the journey outlined in this chapter focus primarily on the second and third follow-up interviews, approximately 10 weeks and 20 weeks post diagnosis (although some data from first interviews is also used, where relevant to the developing line of argument). This chapter will discuss how the participants adapted to and coped with their diagnosis in a way that ensured optimal emotional well-being throughout their illness journey within the context of enormous uncertainty. This chapter will highlight the coping mechanisms that the participants utilised in order to make their awareness of the implications of their diagnosis and their difficult future easier to manage.

This chapter will outline a mind-frame adopted by the participants which enabled them to continue living their lives in spite of their awareness of a difficult future. Participants sought relief through several methods, discussed below, which could allow them to continue to live their lives on a day-to-day basis, and make the most of the time that they had while well. I will explain how participants achieved a balance between accepting their diagnosis and their lack of control through the management of their awareness, and by regaining control through the acquisition of knowledge and the transference of control. I will discuss how what could be seen as a form of denial in fact encapsulates the participants' ability to create conditions whereby they could maintain a positive attitude and as a result continue to cope. The final section of these

findings will provide insight into the smaller cognitive manoeuvres participants used in order to minimise the events or information which could threaten their ability to cope.

6.2 Reassuring in response to threat

This next section of this chapter will outline the ways in which participants reassured themselves, creating an easier place to occupy while living with their illness. Finding benefits by locating a 'silver lining' to their situation allowed participants to construct the understanding that their situation could have been worse. By convincing themselves of their good fortune, they strengthened their ability to maintain a positive attitude. This process was done in order to avoid seeing oneself as the 'worst-case scenario'.

6.2.1 "It could have been a lot worse"

Locating the silver lining in their situation often served to soften the pain of their own loss and hardship, making it more manageable for the participants to deal with. Finding benefits or upsides to their circumstance further allowed participants to believe that their situation could be worse, that there were others in worse situations than them, thus allowing them to feel better about their own circumstances; participants could feel grateful for the existence of a silver lining and that the hypothetically worse situation had not occurred or was not their reality. Such reminders provided reassurance and comfort to the participants. It was apparent that participants would rather feel grateful for small victories within their circumstance, than to experience upsetting emotions while dwelling on their hardship.

By in large it's not that bad and they make life very easy for you [in the hospital]. They're very, very good. Everyone's in a good humour all the time. Anthony (participant 9) Interview 2

[talking about hair loss from treatment] *In the grand scheme of things it's not really important. I've my hat and I've scarves at home. Sarah (participant 10) Interview 2*

The overall motivation fuelling participants' search for benefits or silver linings in their struggle was the attempt to make it easier for them to cope. Again, considering the participants' aversion to engaging in self-pity (discussed in Chapter Four), finding benefits in their struggle allowed them to locate something to feel grateful for rather than to pity. Similar mechanisms which sought to achieve the same result included trying to find meaning and trying to find a purpose in their suffering. Both instances represent cognitive manoeuvres which break down their difficulties and highlight benefits to their suffering, making their hardship seem less severe by generating perspective, and subsequently making it easier to deal with:

I think in one way, they probably nearly saved me with this diagnosis because if they hadn't caught me when they did I'd say I'd have been dead. I was very close. At the end of it I was very, very sick. Jennifer (participant 8) Interview 1

My wife is extremely good at seeing silver linings in things and it's rubbed off on me over the years and one of the things she said, "Well that's 15 months say and if they go undiagnosed and untreated, three months. "that's the median survival rate. being able to see silver linings in things and that it did happen, it could have happened a lot worse than it did. The fact that I wasn't driving the car and that I wasn't there on my own. It could have literally been that quick. That I think is one part of seeing the positives in things. It's not so much seeing the good in it than seeing that things could have been a lot worse. Owen (participant 14) Interview 1

6.2.2 The worst case scenario

It was important for participants to not be associated with 'the worst case scenario'. Frequently, particularly throughout the final follow-up interviews, participants would stop themselves short when beginning to complain about challenging or frustrating elements of their situation. They would rationalise and minimise their concerns, citing

the belief that 'things could be worse'. In particular participants used examples of the paediatric patients they saw in the hospital:

The minute you think you're bad and then you see a wee child coming in there and there in the wee time of their life. That's my look on the thing anyway. Tom (participant 11) Interview 1.

From the perspective of a person without terminal cancer we may believe it entirely understandable for these participants to express unhappiness with their situation, however, within the context of the participants' 'new normal', living under threat became a typical element of everyday life. Their 'new normal' consisted of a large amount of time spent in hospitals, treatment for an incurable disease, with other people with cancer as their only point of reference or comparison. Therefore they both did not, and could not see themselves as the worst case scenario within this new world. Challenging events which may have been considered unbearable prior to diagnosis, had now become 'normal' to the participants within the context of their changed world and not something that they would have considered worthy of complaining about.

You know when I finish this treatment now, well I have another treatment to do for 6 months (...) like so that's going on until Christmas nearly you know? You know, that's a long time away you know... but sure that's life what can you do. That's all you can do and keep a positive outlook on it you know, nothing else you can do. Heather (participant 5) Interview 2

As outlined in Chapter Five, participants believed that their appearance was an indicator of their response to treatment and their physical health, and hence sought to avoid appearing like a 'typical cancer patient'. Being the 'worst-case scenario' could be construed as being closer to death than those who were better off. Further, constructing the belief that it could be worse makes it easier to maintain a positive attitude and remain hopeful for the future. Similarly, it can be inferred that participants did not want to be seen to be complaining or taking their own situation for granted when they believed that they could be much worse off. Equally,

participants did not want to wallow in 'self-pity'. Not being the worst-case scenario created a much easier space for participants to occupy, in turn making it easier to cope:

You have to keep positive, keep smiling and think there's someone worse off somewhere. That's always been in my head. There's always someone worse off. So ever since then I've just thought, "I've a long journey ahead of me and I'm going to get through it. There's always someone worse off and just stay positive."

Ben (participant 15) Interview 1.

6.2.3 Minimising and distancing threat

In the previous section I discussed participants' struggles with being confronted by thoughts relating to their unchangeable reality. In response to these unwanted and threatening thoughts participants engaged in several cognitive processes in order to reassure themselves. Participants sought to reduce the level of threat to their selves and the related impact on their ability to cope. Often these threats arrived through external events or observations and reminded participants of the severity of their situation, prompting difficult thoughts regarding their futures. In situations where participants found themselves too close to a threat, or bearing too many similarities to an undesirable comparison i.e. the 'worst case' scenario, they engaged in practices which served to reassure and comfort them, aiding them in re-establishing their position within their tolerable reality. Participants reassured themselves by minimising or distancing themselves from troubling information or painful emotions that they encountered. Distancing themselves from, and minimising threats to their ability to cope allowed participants to reframe the threat, or their own positioning in relation to the threat, making living everyday life easier to manage:

"Don't be stupid, you've seen kids, you have seen people aged 70, 80 getting surgeries done." In WHO [World Health Organisation] terms you can call it a tumour, but why do people become so surprised? Six year old kids have

tumours. We youngsters have tumours. It's just a growth of cells. Vinod
(participant 6) Interview 1

*Now she [doctor] did say that the, what looked like the abscesses, or tumours,
were very small, she said they're very, very small on the scans...* Dave
(participant 1) Interview 1.

These approaches provided participants with a greater ability to face and manage challenging or distressing thoughts that occurred to them throughout the illness journey which might disrupt their ability to adjust and adapt to their new reality. Within the context of this study the act of minimising sought to normalise the interpreted threat, to neutralise the danger it posed by minimising its relevance to their own circumstances. By normalising whatever concerned them, the level of threat attached to it subsided thus making the threat easier to manage or to tolerate. The use of humour was employed in a similar sense to relieve tension caused by distress or fear and to dismiss threat.

We all have problems sometimes and we have to deal with them. Phil
(participant 16) Interview 1

*It's hard, but I kind of make jokes about it like, that's my way of coping with
things and I'm like.. I think sometimes I make people feel a little bit
uncomfortable and I'm like oh brain tumour humour, it's fine, it's funny! We can
laugh about it it's fine, if we don't laugh I'll cry so we might as well laugh.* Rachel
(Participant 13) Interview 1.

The act of distancing served to create space between the person and the perceived threat and was usually achieved by emphasising differences, creating comparisons or minimising the relevance of the challenging event. This provided comfort to the participants by reassuring them that the threat was not applicable to their circumstance. Participants often readjusted their own understanding of events or experiences by minimising or distancing threatening stimuli. Throughout the illness

journey participants provided explanations for indicators of threat which neutralised any potential harm the threat may hold over their ability to maintain a positive attitude and hope for the future:

This person came to me saying, "I'm the advanced cancer specialist"... "I'm not ready for you yet." The only reason that she came in was because it was her field, she was the one who was best qualified to explain what I was going through [brain swelling and seizure activity] and why it was happening and what these things all meant and also ask the right questions. She was very nice. I didn't really have a problem with it, but when you hear certain words. Once it's explained why this person's there to see you it's okay. Owen (participant 14) Interview 3.

Hearing the term 'advanced specialist' caused Owen to feel threatened. In response he both distanced himself from the need for this advanced cancer specialist, and rationalised away the threat of her presence as the one most qualified to speak with him. Both of these processes served the purpose of minimising the threat of his proximity to dying prompted by the arrival of a palliative care nurse.

Reassurance through distancing was achieved by locating or creating comparisons between the participants themselves and other individuals or circumstances deemed to be a threat to their ability to cope. As discussed in Chapter Five, participants sought to avoid similarities between themselves and the 'typical cancer patient'. Further, as outlined in the previous section, participants did not want to be situated in proximity to the 'worst case' for fear it would bring about, or reflect their own deterioration. Distancing through comparison was conducted in relation to subjects who the participants believed they were similar to. Participants differentiated between themselves and others that they deemed to be poorly in order to distance themselves from possible relatability and the consequential threat to their lives. Focusing on the aspects which differentiated them from someone they believed was worse off provided reassurance and served to both distance the participants from the perceived threat and prevented them from fixating on the difficulties of their own hardships.

Focusing on the fact that others were in worse situations allowed them to move away from feelings of despair for their own situation and enabled them to feel grateful for what they did have. Such a frame of mind afforded participants with a more tolerable way of thinking and living on a daily basis:

I do take medication... but I don't take as many as other people take. Phil (participant 16) Interview 2

[the doctor] gave me the letter [confirming diagnosis for his medical card application] and I read it, it was saying usually with the kind of tumour I have, the prognosis is very, very poor. Usually people only last about two months with it. It's a standard letter that they send out, it wasn't just referring to me. It's just when you start reading it, you think "Jesus Christ." but the letter was not referring to me per se, it's a standard letter he had on his computer and he just printed it off. It's just so bizarre. Anthony (participant 9) Interview 1

In Chapter Five I briefly touched on the pride participants experienced upon receiving positive feedback from the medical team regarding their tolerance of treatment. As time passed, it became clear that this pride stemmed from the reassurance participants needed in order to allay their fears. Positive feedback, be it explicit or interpreted, served to reassure participants and in turn propagate hope for a better outcome. Participants gathered evidence which strengthened the reality of this reassurance which in turn reinforced the hope they had developed:

Dr Murphy said that she's going to taper the steroids now because they're very happy with the way things have progressed. Literally, I've been a model patient through everything, other than this one little bizarre hiccup with the seizure. Owen (participant 14) Interview 3.

In a way it could be argued that participants avoided some elements of reality in order to maintain the ability to cope. Avoiding certain information by reframing it and reassuring themselves served to shield the participants from the troubling elements of

their illness, thus allowing them to continue making the most of each day. Through normalisation, distancing, minimising and by creating comparisons between themselves and others, participants reduced the perceived threat to their lives, strengthening their ability to cope.

6.3 “So again...Limbo land”: struggling with waiting

As seen throughout all of these findings chapters, uncertainty was omnipresent throughout all aspects of the participants' illness journey. The primary source of uncertainty was the lack of control and resulting loss of agency generated by the waiting involved in accessing any updates or information regarding their illness and treatment plan. Specifically, participants struggled with the need to wait in order to find out whether or not treatment had worked. The largely invisible nature of the illness (discussed in Chapter Five) meant that the impact of treatment was concealed from participants. Having to wait 3-6 months (depending on the physician's preferences) for the follow-up scan following the completion of radiotherapy resulted in unpleasant anticipation and anxiety as participants felt they were in a state of 'limbo' while not knowing:

The difficult bit is it's now a waiting thing because now that the treatment's over, I've got to start my second cycle of chemotherapy. It's four weeks off, but then it's every four weeks you take five tablets. But I had anticipated getting a scan when I'd finished the radiotherapy and I only found out last week that that's not how it's done. I won't know for about six months whether any of it's worked. So that will be the difficult bit, it's quite a long time to have to wait until you've got any idea whether or not any of it's worked or whether it's shrunk or whether it's come back, whether it's spread and basically, until I get a scan I won't know. I know how aggressive the grade fours are and I know that they can spread. Six months doesn't sound like a long time, but when you think at the start they're saying, "The average survival is 15 months" and you've got to wait half a year to find out if your treatment has worked. That's quite a big chunk of your 15 months gone right there. Owen (participant 14) Interview 2.

Participants were waiting for side effects (particularly fatigue) to appear; for post-treatment scans; to find out whether treatment had been effective; to receive information so that they could make decisions regarding their futures (work, college, driving, future treatment); for more bad news. Participants were waiting for the reappearance in symptoms such as seizures, headaches, loss of mobility, and they were waiting for an ultimate decline in health. The sense of uncertainty inherent in this diagnosis and the approach to care left participants in a state of powerlessness due to the loss of self-determination, and with no ability to plan for, or make decisions, regarding their own future:

Yeah it's kind of very frightening, you know you don't know where your life is going...or what's going to be at the end of it, you know, you're hoping that the whole thing will come back on track. Heather (participant 5) Interview 2

We won't know if I'm going back to college until I have to go back to college, it's not like I can tell now whether I'm going to be able to go back. That's really, really shit 'cause like I just like knowing but obviously you can't [know]. I think the 6 months to wait to get the [follow-up] scan is going to be horrendous, like not knowing! (...) it's just I think it's the waiting, it's the waiting game that's really hard...and not knowing like. Rachel (participant 13) Interview 1

Participants were content with the standard of care they received in this particular hospital but they struggled to access any form of concrete information regarding their future outlook and found that their only option was to 'wait and see'. By the time of the final interview, a significant element of the participants' illness experience centred around waiting for news or information which could offer them some autonomy or self-determination over their lives. The uncertainty surrounding their response to treatment, and in turn their survival, removed a sense of security and predictability from participants and their lives. As discussed in Chapter Five, each participant maintained hope that they would be the one fortunate enough to contradict the statistics and survive longer than average. They awaited news of their treatment in the

hope that it might confirm these desires, heightening the sense of anticipation and frustration:

I ask them [the medical team, for information], they just kind of look at you. You have to kind of drag it [information] out of them, I think you have to wait and they'll tell you eventually. Gerard (participant 3) Interview 3

Yes so, I'm just waiting for this MRI scan now for them to tell me everything is clear, "go out and live your life now". My life's been put on hold. Ben (participant 15) Interview 2.

Uncertainty allowed participants to create space to 'hope for the best' and maintain a positive attitude while still acknowledging the severity of their illness. This builds on my discussion in Chapter Five, whereby feeling and looking well allowed participants to interpret that they were responding well to treatment and therefore to create hope for a better outcome. The overall boosted attitude experienced by participants enabled them to prioritise living life while they looked and felt well, while intending to deal with their decline when the time came. It is clear that it is only by creating a *tolerable reality* through this altered form of 'denial' or rather a protective compartmentalisation or illusion of a positive outcome, that participants could find the ability to live life, while simultaneously hosting an awareness of their difficult future:

[My son] got engaged at Christmas. So I think they are maybe thinking about getting married before I get sicker. Then who knows when I'm going to get sicker or not and I mean, I know all the research says up to five years and possibly more or less or whatever, but who knows. I could walk out in front of a bus tomorrow. So no, I just take each day and if I've stuff planned I do it. Aoife (participant 12) Interview 3

6.3.1 Making the most of every day

A constant awareness, of varying intensity, of the 'difficult facts' of the diagnosis occupied the minds of the participants as they attempted to navigate daily life. This

awareness contained the knowledge that their circumstances would worsen and their health would deteriorate at an uncertain point in the future. Being confronted by these thoughts challenged participants' abilities to continue enjoying daily life. However the uncertainty embedded in the experiences of this illness brought about a change in perspective in terms of approaching everyday life with a terminal (or at least degenerative) illness. This study identified that the participants' greatest priority was to be able to 'live well', that is, to make the most of daily life and enjoy the time that they had whilst physically well enough. :

You don't know [how long one has left]. My attitude is keep positive and however long we've got, we make the most of it because that's all you can really do with it. I think that positive attitude and this, let's make each day matter attitude, I think it's something that we've arrived at together. Myself, my wife, the kids, friends... Owen (participant 14) Interview 3.

Okay I have this diagnosis and we don't know what goes with this treatment, but you still have to try and live every day. That you don't want to make every day-, every day we have or I have, living and living life and I am very fortunate, I am very well. I very much try to make the day normal, don't want to make home a sick house, it's not all about being sick, it's about being normal, spending time together... Ursula (participant 7) Interview 3

In light of the understanding that their circumstances would worsen in the future, participants' main goal was to be able to function psychologically and emotionally on a day-to-day basis, and to continue with daily life as 'normally' as possible. In spite of the uncertainty encompassing their lives and the knowledge that a difficult future lay ahead, participants sought to make the most of the time they had left as they felt it was their only choice in terms of living with their illness. The methods which allowed them to do this involved staying in the present tense and maintaining a positive attitude:

[speaking to himself] *"Vinod come on. Relax and enjoy life" I said... "No, I'm suffering from something." So that was a bit anxious of me and I think I need to stop that. I have gotten myself to places now in terms of the level that I can beat that stupid Vinod. I can, but I want to keep improving, I want to be even more positive because without that, I'm not going to enjoy the life and that's very much important.* Vinod (participant 6) Interview 2.

Positive mental attitude. As I say, if you were worried about it and uptight, you're going to make yourself sick anyway. I've done so well and what's to say I'm not going to do better in the next whatever amount of years. Sarah (Participant 10) Interview 1.

I'm very much of the mind that I want to be as well as I can for as long as I can and when I get to that point we'll have to recalibrate or relook or whatever, but for now I'm well. Ursula (participant 7) Interview 2

Participants saw a vital connection between being positive and their ability to enjoy each day that they had. In order to enhance their ability to cope, participants began to concentrate on the positive possibilities which could stem from an uncertain future, rather than the negative possibilities. Focusing on the good side of uncertainty allowed participants to 'maintain a positive attitude' regarding their outcome. Creating and maintaining a positive attitude was identified as a key element of dealing with their illness. Participants used the space created by uncertainty to maintain uncertainty regarding the possibilities of their outcome, thus making it easier to cope. If they rejected the possibility of their outcome being set in stone, allowing the possibility for a positive or more favourable outcome, participants could develop a more *tolerable reality* within which to reside. In summary, *participants maintained uncertainty in order to cope*. Consequently, focusing on the uncertainty of their situation served to reassure the participants regarding their futures at times of stress or anxiety:

I think it's important to keep the house as positive as we can for as long as we can, please God. Obviously, there may come a time where that might not be possible, but then when we get that far we can deal with it then at that point. I'm not ignoring it, it's like what I do when I walk through the [hospital] ward. There was a couple of people quite ill there in a couple of rooms and I saw the air mattresses [associated with end-of-life care] and all this. My mum had one a couple of years ago. It really upset me for a couple of days and again, I had to sit down and process this through my head, "Okay that's not me today. It may be me some day, but it's not me today. So let's deal with today." I try and do the same at home. Try and keep life at home as normal and enjoying what I have here now. I may not have next November or next January, enjoying this now as best we can. Ursula (participant 7) Interview 3

I think if you can train yourself-, teach yourself to be positive throughout, I think it's a huge help and when I say positive, even if it's just you lying in bed or sitting on the sofa, to teach yourself to relax, but to think positive thoughts. I think it's very, very helpful and I still do it and I do definitely think it's a big boost for yourself to be able to do that. Think positive, even though some days are better than others and some days are worse than others, but in general, to think positive I think is a big help. Dave (participant 1) Interview 2.

That can only be a good thing. Why be negative about things? Why think "I'm not going to get through this"? What good is that going to do you? Be positive and be brave and be upbeat. That's the way to be. At the same time we're all going to die at some point. Anthony (participant 9) Interview 1.

Having embraced the uncertainty of their situation in order to maintain an upbeat and positive attitude regarding the possibilities of treatment, participants experienced a broader change in their world view. Through consideration of the uncertainty surrounding their own lives participants began to appreciate that there was never, and had never been any certainty or guarantees in their lives (or the lives of others) to begin with. By applying this understanding to their own situation, participants

developed a change in perspective by further using uncertainty to prompt them to live each day well. Participants developed the belief that anyone's life was surrounded by uncertainty, regardless of whether there was an illness present. Participants *normalised their suffering* through generalising illness, hardship and adversity as an unavoidable part of life. This framework allowed them to minimise the severity or the starkness of their own suffering, thus making it easier to manage:

So you don't know and that's the whole thing about this. You don't get the hope, but it's trying to live with the information you have today and living. None of us have guarantees. I know people always do the, "Well, you could be knocked down by a bus" and that's everyone's example and they don't know... Ursula (participant 7) Interview 2.

Participants welcomed this change in perspective and used it to strengthen their ability to cope with their uncertain timeline.

6.3.2 Dealing with it when the time comes

As previously discussed, participants were aware of the likelihood that their futures would be difficult. Given that the participants' overall aim was to be able to live each day well, spending time worrying about the future would hamper their ability to enjoy life while they were well enough to live life in a manner they wanted to. While accepting that they had no control over the future decline in their health (discussed below), participants chose to deal with or address this difficulty when the time came and thus decided there was no point in pre-emptively worrying about these difficulties until they actually occurred:

To be honest, I don't really have any worries now at the moment. The only worry is it [the tumour] might come back again, but it is what it is. Worrying about it isn't going to make it any better so, I just don't. Sarah (participant 10) Interview

So I don't even think in terms of is [treatment] working, or is it getting better, is it helping- has it reduced [the size of the tumour] ...I can't do anything about it, in time they'll tell me. I can't do anything about it... so there's no point in me- I can't control it...do you know what I mean? I can't, eh, there's nothing I can do about it, there's no point in me- eh it's a question of dealing with something when it's time to deal with it, then we'll deal with it, and that'll be that, do you know what I mean? Ian (participant 2) Interview 2.

In order to successfully compartmentalise future difficulties, participants focused intently on remaining and living in the present tense. Similar to the previous section regarding coping through uncertainty and using uncertainty to maintain a positive attitude, participants' focus shifted from worrying about the possibilities of their uncertain future, to a greater appreciation of enjoying the 'here and now'. They began to recognise that, in the context of complete uncertainty, the present was the only certainty they had:

That moment will always be there, when it [symptom presentation] happened, but I tend not to go back to it now as often as I did. What is, is now. I deal with what I have. Dave (participant 1) Interview 2.

So I'd be looking at every day I have as a blessing. I hope there's going to be many of them. The brain tumour obviously, it's a devastating diagnosis, but at this stage I feel well today, thank god. Looking forward to my summer with the boys, I know there'll be scans and that will come another day and I will have decisions to make on those days, but for the meantime, I'm going to try and enjoy every day to the best of my ability as I normally would in a normal way. I know some people will go, "Oh, we have to go here and we have to go there and we've got to do the bucket list and, and, and." No. Just do ordinary things, live a life. So every day I have, live my life, but that took me a bit of processing to get that far. Okay, it's still there. The diagnosis is still there, the scans are still there, but I can't do anything about the scans until the days the scans come. Ursula (participant 7) interview 2.

While *maintaining uncertainty in order to cope* and while *maintaining a positive mindset* and *focusing on the present*, participants believed that their perspectives on life developed, bringing about feelings of appreciation for the small positives they enjoyed, allowing them to believe that their situation could be worse (this will be further discussed below). Experiencing an overall changed perspective helped participants to see what was truly important to them in the context of a terminal diagnosis. Stemming from their renewed awareness that anyone could die at any given moment, the only way to live life was to strive to make the most of the time that they had while well. This changed perspective aided participants in coming to terms with the powerlessness and loss of control that they experienced and in turn finding ways of enjoying the present:

[my death] could be three months, could be three weeks, could be three years, you don't know. It's that whole not knowing thing. That's what I think makes you want to make the most of each day because the strange thing is, in some ways that's an attitude that everyone should have anyway. It's odd, it shouldn't take being faced with your own mortality to make you value life. So I'll just have to make sure that everything's as good as it can be while I am still there and that's the only real attitude I think that's going to work. Look at the positives, look at the upsides, make the most of things and that whole thing that I was saying before about trying to make memories, "Remember when we went here with dad". Owen (participant 14) Interview 3.

Dealing with it when the time comes provided participants with the ability to cope with their awareness of an impending difficult future in a way which still allowed them to enjoy the present moment and the time that they had while able to live a relatively normal life.

6.4 Seeking adjustment and adaptation

Making the most of everyday while it was possible to do so required emotional adjustment and adaptation to the illness and its resulting emotional and psychological consequences. Above all, participants sought to achieve a level of emotional adjustment and adaptation to their illness so that they could continue to live daily life as close to normal as possible, while they could. Coping with the daily stresses of their illness promoted the participants' adjustment and adaptation to the disease and their new normal. Participants needed to cope so that they could enjoy everyday life. Failing to adapt and adjust could result in distress and upset, impairing their ability to live everyday life or make the most of each day. Therefore, adjustment and adaptation were achieved through acceptance of their circumstances, rather than resisting and becoming further distressed by it.

6.4.1 Accepting

The participants sought to accept their circumstances in order to optimise their ability to adapt and adjust to their new reality, thus enabling them to enjoy daily life while they were well enough to do so. Accepting their circumstances promoted emotional wellbeing and the potential for adjustment and successful adaptation to the illness. Within the context of this study, acceptance was not a fixed or static state or destination where, once reached, participants remained throughout their illness. As Owen (participant 14) outlines below, participants could possess a knowledge or awareness of their circumstances, and could accept the existence of its resulting reality, without welcoming its implications on their lives or futures. For some participants, this represented acceptance. Participants accepted that they must change the way they lived their lives in light of their illness:

I've accepted it, I haven't necessarily embraced it. You can accept something, but you don't necessarily have to be happy about it. So it would be that. This is what's going to happen, how do I handle it? That sort of acceptance. So I think that's where I am still. I've accepted it, but I haven't yielded to it. Interview 2.

It could be argued that the approach participants took to managing their awareness while maintaining an ability to cope amounted to denial; a claim reportedly made by several of the participants' family members. However, throughout the study it was clear that participants were not denying the existence or severity of their illness. As mentioned in the section above, participants hosted an awareness of their unfavourable future at all times. Due to their desperate need to *achieve emotional adjustment* and therefore live everyday well, participants had to find a way to deal with their 'constant awareness', believing they would not be able to enjoy the time they had while entertaining thoughts of their illness or death. In-depth investigation into the processes behind the cognitive constructions which sought to engender adaptation and adjustment (and allowed participants to cope while living with an uncertain yet destructive diagnosis) revealed that they provided protection to the participants and allowed them to know their reality while maintaining an ability to continue living their lives and hoping for a better outcome:

I think [my daughter] thinks I'm too blasé about it. It's like, you are sick mum and I'm like, "But I'm fine". I know I'm sick, but I'm taking what I'm supposed to take and I'm dealing with it. Even the seizure on Sunday, when I knew it was a seizure I was like well, I'm going to come out of it. I'm going to deal with it. We're going to get doing whatever we have to get doing. What am I going to do? I can't lie down under it, I'm not going to lie in bed every day and think this is me. Let's not see the light of day again. I think she thinks I do too much maybe or I don't accept that I'm-, she knows that I've accepted that I'm sick, but I don't like saying I'm sick because I don't feel sick or that I have this... Aoife (participant 12) Interview 3.

Further to this, although most participants described themselves as accepting of their situation most of the time, they also maintained a powerful hope that they would benefit from a better or alternative outcome. This poses the question of whether participants were 'accepting' their diagnosis in the standard/traditional sense of the word, or whether the experience of accepting has a unique definition in this context. The participants associated accepting with coping. It is apparent that participants

wanted to be able to accept their diagnosis within their day-to-day lives. Accepting their diagnosis, rather than resisting it or struggling with it, contributed to a an easier circumstance to cope with. Therefore, we see that the *ability to cope, and their ability to accept, are two sides of the same coin*, and both are essential to be able to achieve adaptation to their illness and hence continue living daily life making the most of the time they have left. While they were coping they were accepting their diagnosis, and vice-versa. Therefore, the most important part to understand, for service providers and practitioners, is how did these participants cope, in order to feel they could accept their diagnosis on a daily basis?

The doctor has said he has people there [treating glioma patients] for ten years. I hope I'm one of them, but I can't make plans on that. I don't believe-, in my heart I'm hoping and hoping for the five years. I don't know, no one knows, it could happen tomorrow morning, it may not. Ursula (participant 7) Interview 1

Participants' emphasis on 'accepting' (as they understood it), which subconsciously enabled them to cope on a day-to day basis, must be understood from their point of view. The level of insight into their likely outcome (prognosis) was on par with the amount of information participants could tolerate while still accepting and subsequently coping with their reality. As I will outline below, participants engaged in various cognitive manoeuvres which allowed them to *inhabit a tolerable version of reality*, which in turn allowed them to accept and adapt to that version of reality and therefore continue to cope and function on a daily basis, and continue to live the time that they had 'well'. The participants existed at a halfway point between denial and acceptance on a hypothetical spectrum of responses to illness. Rather than denial of reality allowing them to create hope from ignorance, participants created conditions whereby they could be hopeful while still acknowledging and accepting the presence of the diagnosis within their reality. Participants found ways to create a balanced space between being hopeful and optimistic about their outlook while addressing and acknowledging matters relating to their reality.

Participants' ability to accept was largely based on how they could manage their thoughts about their reality. Participants could accept their diagnosis when they could emotionally cope with their lack of control over their circumstances at that point in time. When participants were lower in mood they were confronted with negative thoughts relating to their situation, making it more difficult to accept their illness. As will be discussed in detail in Section 6.6, participants could manoeuvre their attention between their tolerable reality and the fixed undeniable reality of their diagnosis. They sought to remain in their tolerable reality for as long as possible, keeping the real world reality at a distance, in order to continue to accept their circumstances.

Resulting from this, participants moved between points of relative acceptance and non-acceptance when confronted with the challenges of their diagnosis. When faced with difficult elements of their reality participants struggled to cope and were therefore struggled to maintain an accepting attitude at that time. The vital need to cope prompted the participants to modify their way of thinking to a way which would allow them to maintain a positive way of thinking and remain in their tolerable reality for as long as possible, therefore promoting their ability to accept and subsequently cope with their illness.

Participants 'accepted' their circumstances because they believed that they had no alternative choices in terms of facing the difficulties posed by their illness. Further, they believed they had no choice but to 'accept' due to their lack of control over their entire situation; therefore, participants tentatively accepted that they had no control. Because they recognised that they had no control, participants knew that their own responses (such as resisting or denying) would have little bearing over the general outcome of their circumstances (surviving or not surviving). In order successfully adapt and adjust to the illness and make the most of everyday in the context of a terminal illness, participants needed to be able to cope and this would in turn enhance their ability to keep the thoughts of their distressing reality out of their immediate awareness. Managing their awareness, or limiting their focus on the reality of their diagnosis would allow participants to find ways to continue living rather than having their daily lives interrupted by intrusive, unwanted and anxiety inducing thoughts.

Participants had to be able to distract themselves or compartmentalise their knowledge of their reality, in order to live life well.

6.5 Transferring and regaining control

Participants experienced frustration at the ferocious loss of control forced into their lives in the form of their incurable diagnosis. Participants were forced to recognise that the developing phases or processes relating to their illness and treatment would occur with, or without them. This forced participants to recognise that they held no control over their situation, and that ultimately they could do little to influence the overall impact of the disease. The feeling of having no control over their lives or bodies was produced by the limited autonomy afforded to them over the course of treatment, and the absence of agency in terms of decision-making:

You feel a bit detached almost. That things are happening around you that they're out of your control, that's one of the things that I have found probably the most difficult. All you can do is literally follow the path. If the next stage is chemo, you do the chemo. If there's an MRI to go to -... Owen (participant #14) Interview 3.

To build on the above discussion on 'acceptance', it seems that participants 'accepted they had no control' on a somewhat superficial level. They wanted to accept that they had no control so that they didn't suffer from the distress of having lost of control over their own lives. Participants accepted a lack of control so that they did not fight or resist their loss, as to do so would damage their goal of adjusting and adapting to their illness. Struggling with, or resisting the loss of control was not conducive to coping or adapting to the illness. In light of wanting to be able to cope and to live life well, participants believed their only choice was to make peace with their lack of control over their diagnosis. *Accepting a lack of control could be seen to be an approach to coping.* Accepting they were powerless to change their circumstance allowed participants 'to get on with it', to relinquish control and to cope:

Just worry about what you need to worry about today, or not worry, deal with it, deal with whatever it is, that's what you have to do. Not to worry about tomorrow because you can't, you're not in control and once you've accepted you don't have control, well certainly for me, where I said oh I can't do this, I sort of resigned myself and I was calmer for it, I can't do anything about this.
Ian (participant 2) Interview 3.

An effort to regain control was apparent through some of the participants' attempts to develop an expert knowledge of their diagnosis. This effort was commonly portrayed through the use of medical terminology and clinical language in conversation. Participants sought to counteract the loss of autonomy and agency brought on by the extreme uncertainty of their situation and subsequently their survival. As seen in Chapter Four and Five, participants rejected the notion of self-pity and equally recoiled from the pity of others. Regaining control or displaying expert knowledge of their condition could serve to deter pity based on perceptions of one's helplessness. Developing and displaying expert knowledge could allow participants to feel they were regaining control over both themselves and the self-image they displayed to the outside world.

In Chapter Four I outlined the idolisation of the doctors by the participants, as a result of their role as expert, and as those who are perceived to possess the participants' only chance of a better outcome. Similar to the concept of 'trying to preserve identity' highlighted in Chapter Five, as the diagnosis threatened the participants' identity and their dignity, it also threatened their selves. By portraying knowledge akin to that of the professionals, participants regained a sense of power and control, believing their knowledge and the portrayal of it could engender a sense of knowing, of being more in control, and of not being afraid. This could distance the participant from the position of 'passive victim' and return a sense of individuality.

I argue that the participants' motivations for gathering, seeking and displaying expert levels of information, and communicating in a way similar to the professionals, was a response to the intense uncertainty and threat surrounding their lives. Attempting to

cope with this uncertainty prompted a desire to know more about this uncertainty and this threat, to put a shape or a boundary on it. By placing defined structures or borders on the threat to their lives through knowing the threat, participants sought to make the uncertainty and loss of control less vast, foreboding and unclear.

6.5.1 Hoping for the best while preparing for the worst

Similar attempts to assert control over their situation can be seen through the participants' approach of '*hoping for the best while preparing for the worst*' (paraphrasing a term used by several participants). Preparing for a negative situation offers the feeling of having control over that situation if or when it arises and may engender a sense of mastery within the context of losing control. Rather than dismissing the possibility of a negative outcome entirely, some participants gained reassurance from the knowledge that they had prepared themselves should something happen, owing to a sense of control over uncontrollable deterioration. While preparing (or accustoming themselves) for the worst, participants could feel they were asserting control over their situations while simultaneously reducing their fear of this difficult future:

You have to -, of course you hope for the best, but you have to be prepared for the worst as well. There's no point in just blindly thinking you're going to be okay. Of course, you hope to be okay, but you can't just assume everything's going to fall into place. Anthony (participant 9) Interview 2.

Equally, a minority of participants chose not to pay attention to the medical jargon used in their presence and preferred to take a passive stance regarding their treatment journey, deferring all control to the medical professionals. However, this too could be viewed as an element of reasserting some level of control, with control existing in the active decision to hand over control to the professionals. Although some participants claimed to have entirely given up their expectations or attempts to control their medical circumstances, it is likely that this was a possibility only because participants devised other ways of maintaining hope that things might work out for the best. An

alternative response to dealing with a lack of control, particularly at the time of the third round of interviews, was achieved by transferring all their expectations of control to their doctors (as discussed in Chapter Four). By transferring control to the physicians, participants could keep their distance and reassure themselves and leave all medical matters 'to the professionals'. This allowed them to accept their own lack of control over the illness and their circumstances.

6.5.2 Accepting the loss of control

In order to adjust to their loss of control, participants found it more tolerable to accept their lack of control over their situation rather than to resist it. This approach reflects the previously discussed reluctance to 'ask why me' (see Chapter Four). In order to deal with the injustice of the diagnosis participants opted not to challenge it, understanding that doing so was futile and would not change reality, instead participants tried to accept it, to adapt to their new reality or 'to get on with it':

It's definitely not easy. Definitely, it's not easy, but you have to-, you can't change it. I can't change it, nobody else can change it. That's the way I look at the thing. The only thing I can do is just go through what I have to go through, keep going as long as you can. Hopefully, you never know. Tom (participant 11)
Interview 1

Sure what else can I do. Not really, you just get up and try to do what you can do, that's the only thing you can do. Heather (participant 5) Interview 3

Participants understood that their situation was unchangeable, and thus incorporated the diagnosis into their reality quite quickly. It seems that participants had no choice but to accept what was happening to them in order to adjust to the diagnosis and get through treatment. Similar to 'doing what needs to be done' in order to get through treatment, an approach adopted early on in the illness journey, participants accepted their unfortunate diagnosis in favour of being better able to adapt and hence manage on a day-to-day basis.

So after that four weeks [break from treatment] then I go back to chemotherapy again. I don't mind it. I have to do it. Jennifer (participant 8)

Interview 1

6.5.3 The 'Fighting Spirit'

Despite opting not to resist the diagnosis, participants continued to fight. In most cases they relinquished control without submitting to the diagnosis by accepting while hoping and fighting. This promoted participants ability to emotionally adjust and adapt and therefore live daily life well better than they would if they entirely submitted themselves to their illness or if they refused to adapt and find a way to live with their illness.

Despite 'accepting' the diagnosis and tentatively accepting a 'lack of control over their circumstances' in order to optimise their ability to cope, participants were still resolved to fighting the diagnosis. 'Fighting' is a commonly used word when discussing cancer in general. It is often said that a person is fighting cancer, or that they lost their fight with cancer. At first glance the approach of 'accepting powerlessness' while simultaneously 'fighting' seems to be a contradiction. Within this context, accepting the diagnosis while undertaking an intensive and exhaustive treatment journey in order to improve their chance for a better outcome represented 'fighting'. Fighting the illness was imperative to coping with the diagnosis, choosing not to fight would mean submitting to the illness thus relinquishing their ability to *hope for a better outcome*:

I will not just lie down, I will fight this and see where it takes me. I'll do what I have to do. I suppose I said to myself, "I'll see how far this goes." Just do my best and stay alive as long as you can. That's, what more can you do? Lay down you don't, it's the only chance of surviving for another while. We'll have to wait and see. Tom (participant 11) Interview 2.

Ultimately participants were aware of the life-threatening nature of their diagnosis (at some level) *yet they still chose to hope for a better outcome*. It is possible that within the context of the participants' realities, fully accepting the diagnosis, to the point of submitting to it, would lead to cessation in fighting. However, fighting was an essential requirement of coping on a long-term basis for these participants, as it gave participants the momentum and purpose they needed to get through treatment. Therefore, perhaps participants could not fully accept their diagnosis in the traditional sense because fully accepting meant they were no longer fighting.

6.6 Creating a tolerable reality; A coping mind frame

As discussed throughout this chapter, in order to make most of each day and 'live well', participants needed to be able to function on an emotional level. Participants prioritised finding a way to function throughout the day without suffering from thoughts of their diagnosis and its implications. Participants needed to be able to move their focus away from encroaching or invasive thoughts about their illness so that they could feel emotionally well and adapt to their new reality.

So you're always mind managing, not all the time, but I find when I get tired and then the head starts the scans, "Where am I going?" Your head goes into orbit then and you can't do anything until the scans. I know you have to wait for the scans. There's nothing anyone can do for that, it's just being able to manage yourself to stop yourself from being dragged into the 'what if's' and all that about things you can't do anything about today. Ursula (participant 7)

Interview 3

As mentioned throughout the earlier sections of this chapter, participants found ways to create a *tolerable reality* within which they could function and partake in daily life. In order to create and maintain this tolerable reality, participants needed to possess some level of hope for their future. This hope was not for a cure (participants largely accepted that this was not possible), but most hoped that their circumstances would not transpire to be as bad as predicted. This hope was cultivated through their positive

attitude and preserved through their commitment to staying in the present. In summary, in order to make the most of each day, participants required a positive mind frame in order to cope with their troubling reality.

Yes because if you let it take over everything, then you have no quality of life, you've got to-, it's again, living with something as opposed to having something. It's living with it, the important word being 'living' because life has to continue. Owen (14) Interview 2

The primary function of coping within this context was the endeavour to manage the constant awareness of the implications and impact of the diagnosis so that it did not impinge on the participants ability to function day-to-day. As outlined above, participants needed to be able to cope so that they could continue living their lives until such a time came where they were no longer able to do so. Participants experienced ongoing confrontations with troubling thoughts of their reality which, if entertained, would make continuing to live their lives in any enjoyable way impossible. In order to be able to enjoy the time that they had, participants had to process their illness in small pieces, one piece at a time. Many participants coped with their illness by striving to 'live one day at a time'. These approaches bear similarities to participants' approaches of living in the present, and dealing with difficulty when the time comes as they serve the same purpose of allowing the participant to create a personally tolerable reality. Participants had to manage their thoughts to prevent themselves from focusing on the enormity of their situation, as many found the gravity of their situation too vast to process at once. Participants feared they would not be able to cope if they allowed themselves to consider the enormity of their situation.

So to some extent the brain cancer is chopping that chapter and the future and children, grandchildren, all that life. As I said, my mother died four years ago and she was 74. I'm only 51, that's 23 years of a life that's under threat. Well, 23 years under threat, there's no way you're going to get 23, but obviously, I'm here for the battle for as long as I can (...) 51 is too young. There's a big chapter of a life still left there. A new phase of my life, a whole new phase of my life.

Now, I know life doesn't have guarantees, there's road accidents, you hear all the different things, but it's just hard to know you're not going to get that chapter in your life. As I said though, if I dwell on that-, if I let that take over my head, I don't live what days I do get. Ursula (participant 7) Interview 1

This behaviour was seen from the offset of the illness journey when participants immediately fragmented their extensive treatment plan into phases and stages (refer to Chapter Four for more on this). Participants found focusing on a smaller, set amount of time made the enormity of their treatment plan easier to manage. Within the broader illness journey, dealing with the experience on a step-by-step basis aided participants in managing intrusive, troubling thoughts about their reality. To manage these intrusive and confronting thoughts, participants found ways to banish them from their immediate attention and to suppress them so that they could focus on the more tolerable version of reality that they had constructed. Upon member checking this concept during an interview with Owen (participant 14) he explained:

I can relate to that perfectly. When you're able to function you function, you do as much as you can, but every now and then you do step back and look. When I'd be in a large group of people, I it's almost like viewing it through a window, it's like you're standing outside looking in and everyone else is chatting amongst themselves and talking and you think, yes I'm going to miss this. It's not that it becomes routine, it's always there, but if you dwell on it constantly then it's ruling you, you're not living your life. Interview 2.

This more tolerable version of reality involved remaining in the present tense as much as possible, not dwelling on the future and not speculating or wondering hypothetically. During the interviews this was reflected in participants' reluctance to elaborate on certain topics involving future projections through speculation or contemplation. Participants at times provided clipped and short responses when prompted to discuss such topics. Such responses could indicate the level of self-

discipline enacted in order to ensure self-preservation in light of needing to cope with an uncontrollable fate:

These thoughts as well, these contrasting thoughts keep striking into my head and as I've already said there are things which help, there are things which try to subside those and there are things which let them come again for a while, but as long as that keeps happening you know how to get rid of those because you know that's a thought which is going to come at this point in time and then there's going to be another thought which you know is going to keep it away and then you learn. So it's a gradual process. Vinod (participant 6) Interview 2.

Many of the behaviours displayed throughout the illness journey served the purpose of protecting the participants. Creating a tolerable reality by managing their awareness and controlling and suppressing intrusive thoughts was a form of self-preservation. Participants created a tolerable reality to protect their mental survival and their ability to cope. Similarly, as seen in Chapter Four when some of the participants chose not to receive information regarding their diagnosis, they protected their ability to cope by avoiding information and avoiding confirmation of the difficult facts relating to their diagnosis. Ultimately protecting themselves was a way of managing their difficulty of hosting a constant awareness of their fate within their minds:

Blindness, memory loss, paralysed, but like I said, but like I said I'm not letting it affect me at the moment. We'll see if anything does happen we'll just take that hurdle the same as we've taken all these ones. No. I'll think about that when the time comes, if it does come. Like I said, I'm not letting it affect me. Ben (participant 15) Interview 2.

It's that sort of realisation I think, of mortality. Somehow I never really thought about before, prior to any of this happening. You wake up, you put in your 24 hours, rinse and repeat. So now it's sort of-, not praying on me as such, but it's kind of in the back of my mind, not constantly, but every now and then I'll sort

of, "Oh yes, I've got cancer", because you just get on with it. Owen (participant 14) Interview 2.

6.6.1 Oscillating

Throughout the study it was apparent that participants occupied two realms of awareness simultaneously; the fixed and undeniable reality of their diagnosis (acknowledging the severity of their illness), and their constructed tolerable reality (thinking positively about their circumstances). Participants oscillated back and forth between these realms depending on the level of awareness they could tolerate without causing harm to their ability to cope overall. When participants' momentarily facilitated thoughts of their undeniable reality they subsequently suppressed them when they became too difficult to continue thinking about and returned to a more tolerable version of reality.

It was within their tolerable reality that participants were able to continue living everyday life and enjoying the present moment. Accordingly, participants sought to avoid troubling or negative thoughts in order to propagate their ability to continue coping. Participants allowed themselves to enter into the fixed and undeniable reality of their diagnosis and its associated troubling connotations at times where they wanted to emotionally or practically prepare for their impending difficult future:

I have the odd moment where I have-, not down, but maybe-, not even reality because it's all reality anyway, but I don't know what the word is I'm looking for. Negative thoughts probably would be it and I think, "You might have a funeral to organise Aoife. What would you do for that?" and I'd be thinking of the songs and the whole thing and the readings and I think no, you don't need to be thinking about that. Get that out of your head that's your five minutes [of worrying] done. That's enough and that's generally around two, 3 o'clock in the morning if I wake up in the middle of the night and it's quiet. That's generally about it and then it goes. Aoife (participant #12) Interview 2.

This notion of oscillating between realities is linked to participants' movement between the states of acceptance and non-acceptance (discussed above) based on whether they could situate themselves within their tolerable reality or were being confronted by the undeniable reality of their situation. While oscillating between the two realities, participants were simultaneously moving between acceptance and non-acceptance. The need to accept and therefore 'not struggle' against the diagnosis, allowing them to perceive they were coping better, motivated participants' prompt return to a tolerable reality, and away from the troubling elements of their fixed reality.

In summary, participants viewed coping as their only option for emotional survival. Therefore the cognitive mechanisms deployed sought to protect participants' ability to cope and to continue living. When participants found themselves confronted by reality, they worked hard to make these confrontations only momentary in order to enhance their ability to continue coping and adapting to the diagnosis and subsequently living each day as well as possible. Dwelling on the enormity of the situation and thinking deeply into their circumstances caused difficulties in managing their ability to cope and live well by making the situation too difficult to accept. In order to cope, participants had to break down the enormity of their situation and deal with it bit by bit or piece by piece and limit their thoughts to these pieces. Similarly participants focused on remaining in the present and prevented their thoughts or their imagination from escalating into thoughts and fears of their uncertain future:

I was there saying that if I don't take this and manage it in some bite size pieces, I want to live every day. There's no point letting the enormity of this hit me. Okay, it's still there, I have to deal with it in its chunks and in its bites, but I need to live every day that I have between now and then. Ursula (participant 7) Interview 2.

6.7 Conclusions

Lazarus outlined that due to the diverse nature of threats that people with cancer may be dealing with at any moment, research on the coping process must specify 'the particular threats of immediate concern to the patient and to treat them separately rather than broadening the focus of attention to the overall illness' (1993, p.236). This study succeeded in identifying and portraying these threats through the form of challenges to participants ability to cope or to maintain hope, and the impact these threats had on the participants' throughout their illness experience.

The importance of the goal to live everyday life as well as possible can arguably be construed as a means of finding and attaching meaning to daily life when faced with a life-threatening or terminal illness. This finding resonates with that of Karlsson and co-authors (2014) who found that the present could be experienced as more certain, as opposed to the future, which appeared more uncertain as a result of living with advanced cancer. This understanding is enhanced by Salander's suggestion that "everyday life can act as an anchor that we can rely on when subjected to stressful situations" by providing us with a meaningful context within which to occupy when faced with a threat to life (2016 p.357). Salander (2016) suggests that the routines of everyday life secure a foothold thereby avoiding the burden of existential questions. The support offered by everyday routine reflects the findings discussed in Chapter Five which revealed the protective routine of treatment and the daily hospital schedule, and the subsequent difficulty participants experienced when this routine lost its novelty, no longer providing a distraction. This understanding, when applied to the findings of this chapter, suggests participants' goal of making the most of everyday may provide them with a distraction from the threat to life posed by the diagnosis by allowing them to find and attach meaning to the everyday experiences of their illness.

Resonating with the findings of this chapter, Salander (2016) explains that the approach of distracting oneself through finding meaning in daily life when dealing with life threatening situations is sometimes perceived as denial. It is apparent that many of the behaviours discussed in this chapter amount to various forms of defence mechanisms. Cramer (2000) defines defence mechanisms as unconscious and "non-

intentional" in use and argues that the use of 'illusions' also amounts to a defence mechanism. The main findings of this chapter contradict this as participants actively and purposefully engaged in methods of protection in order to defend themselves from painful stimuli. Cramer (2000) suggests that refusal to recognise the implications of reality is a form of denial that has been recast as positive illusions. Further to this, Taylor (1983) advised that the use of the term 'illusion' in terms of coping was not meant to be derogatory, where historically to use illusions was associated with experiencing poor mental health.

Again reinforcing the findings of this chapter, the author argues that patients are rarely in denial of their illness, rather, they are elaborating on facts or 'playing with reality' in order to find a way to continue living (Salander, 2012, 2016). The concept of 'playing with reality' advances insight into the processes involved in constructing a 'tolerable reality', outlined in this chapter. Salander refers to the 'intermediate area'; where, without losing contact with the here-and-now, patients can create another mental space between their internal world and external reality, allowing them to manage problematic experiences and thus 'playing with reality' (2012; Winnicott, 1989). This consolidates the understanding outlined in this chapter that the participants were not 'in denial' of the severity and the implications of their diagnosis when constructing and maintaining a tolerable version of 'reality', rather, by 'playing with reality' they were enabling themselves to continue living while acknowledging external reality.

The findings of this chapter outline that participants sought adjustment and adaptation to their disease in order to make reality tolerable and maximise their ability to cope. Several researchers have used qualitative approaches to explore different aspects of the adjustment process, such as receiving the diagnosis, acute and post-acute treatment phases, and managing the illness in the longer term, including end of life issues (Adelbratt & Strang, 2000; O'Donnell, 2005; Strang & Strang, 2001). As discussed in Chapter Two, Salander and colleagues (1999) focused on the process of receiving a brain tumour diagnosis and accessing medical care. Their findings indicated that a combination of personal and social factors relating to the patient (e.g., avoiding

medical contact), their family (e.g., reacting passively to symptoms) and doctors (e.g., adhering to alternative diagnoses) hindered the diagnostic and treatment process, thus complicating adjustment to the illness. Also mentioned in Chapter Two Albratt & Strang's (2000) found that patients with a brain tumour could seldom approach acceptance and speculate perhaps due to early mental and cognitive deterioration. These findings contrast with that of this study, where this chapter outlined that reaching relative acceptance was a key element in the cognitive processes of adjusting to and coping with the diagnosis.

The first two of stages of the Charmaz's model of adaptation were discussed in Chapter Five, however the stage of adjustment most relevant to the content of this chapter is the third step in the process which involves surrendering the sick self by relinquishing control over illness and by 'flowing with the experience of it' (Charmaz, 1995 p.657). The author defines surrendering as to stop fighting the illness and that resisting surrender means holding on and, in the case of advanced illness, refusing to die. This contrasts with the findings of this chapter which revealed that not fighting was not an option for people with glioma because fighting encompassed an approach to coping, despite accepting, and enabled them to maintain hope for the future.

This chapter has described how the people in this study coped with a glioma diagnosis in a manner which allowed them to adjust to their new reality thus enabling them to continue living their day-to-day lives. The findings highlight that when faced with a terminal illness, participants prioritised being able to live their everyday lives well above all else. Each of the strategies and mechanisms outlined in this chapter was employed in order to allow for this possibility. Many of the processes undertaken by participants throughout this journey served to minimise and underemphasise the severity of their own suffering by generalising or normalising the difficult elements of their journey. This reassured participants, thus making their own situation easier to manage cognitively and curtailed potential panic caused by thoughts of their fate.

As referred to in Chapter Two, Ownsworth et al. (2011) identified key sense making appraisals which were central to the adjustment of people with brain tumours.

Supporting the findings of this study Ownsworth and colleagues suggested that these appraisals and subsequent adaptation were related to and influenced by (amongst other factors) a diversity of coping efforts. In contrast to Ownsworth et al. (2011) this study revealed the important and transformative influence of uncertainty in relation to coping. Participants in this study maintained uncertainty in order to maintain a positive attitude regarding their outlook, thus optimising their ability to adapt and adjust and continue enjoying life. Similarly, the findings outline that the participants restricted their attention to the present, deferring consideration of concerns for their future until they actually occurred. This was done by assuming that there was nothing to be gained from worrying through speculation when their future was so uncertain.

These findings suggest that participants must create a tolerable reality where positive outcomes are possible due to the uncertainty embedded in their diagnosis. When prompted by varying emotional responses and cognitive states, participants moved between this preferable tolerable reality and the fixed external reality of their diagnosis. Participants primarily sought to remain within their tolerable reality but entered into the fixed reality either unexpectedly when faced with tiredness or low mood, or when they wanted to prepare themselves for their difficult future. When confronted with reality participants responded with cognitive manoeuvres which enabled them to suppress the painful thoughts and reassure themselves, allowing them to enter back into their tolerable reality where they could function in everyday life.

In the case of this study, the 'illusions' in which participants created in order to construct a tolerable reality centred around the positive reconstructions of uncertainty, cognitive manoeuvres of reassuring themselves; minimising, distancing, rationalising, creating comparisons. These 'illusions' provided the foundation for a tolerable reality within which people could cope with their illness through adaptation, acceptance and hope. Participants created a tolerable reality in order to help them manage the difficult and painful knowledge relating to their diagnosis, prevent them from fixating or dwelling on the future, and other thoughts they believed would hinder their ability to cope in the here-and-now.

This tolerable reality enabled participants to accept their circumstances, however this acceptance was conditional. Participants' ability to accept their circumstances was based on their ability to cope, while their ability to cope was dependent on their ability to construct a tolerable reality. Acceptance of their diagnosis and their changed lives was not voluntary: they sought to accept because they believed they had no alternative option in terms of addressing their diagnosis. Participants accepted because they believed they had no control over their circumstances regardless of their efforts. This suggests that participants hoped that accepting their circumstances and having no control over them would make their illness experience easier to manage. Participants therefore associated acceptance with their ability to cope with and adjust to their situation, and ultimately this enabled them to fulfil their need to live every day as well as possible. The connection between adaptation, adjustment and acceptance is reinforced by studying Charmaz's (1995) examination of adaptation to impairment in chronic illness. Charmaz explains that (in the context of chronic illness) bodily limits and social circumstances often force adapting to loss, and hence, "adapting shades into acceptance" (1995 p. 657). Such findings relate the experiences of the participants of this study as their understanding of having no control over their circumstances left them with no option but to accept if they wanted to adjust to their illness successfully.

Despite recognising and accepting that they had little control over their situation, participants used accessing and avoiding prognostic information to garner a sense of control within their lives. Participants regained elements of control over their diagnosis either through choosing to develop expert knowledge about their diagnosis, or by relinquishing all control and deferring to the medical professionals. Both choices constituted assertions of control. Similarly participants exerted control over their mind set in order to maintain a coping frame of mind. Asserting control over one's mind set promoted coping and mental survival by restricting thinking in a way which promotes coping. Through this, the participants avoided being passive subjects of their illness by actively asserting control. Participants took control of what they could, while still acknowledging that elements of their future remained beyond their control.

The findings of this study resonate with Foley, Timonen, & Hardiman (2014) who found that people with terminal illness, specifically those with motor neuron disease (ALS), coped with the losses resulting from their illness by attempting to assert control over their health care services, similarly the findings of this study revealed some participants sought to regain control by accessing, developing and portraying expert knowledge of their illness akin to that of their health care providers. Whereas Foley, Timonen and Hardiman (2014) found that participants attained a sense of control by rendering control to professionals when it was on their own terms, knowing they could revoke it at any time, the participants of this study found they regained a sense of control and safety by entirely deferring their control to the doctors and other healthcare professionals, not having wanted the control over their care in the first place. As a result, the participants of this study found their circumstances easier to manage by accepting that they had no control. Perhaps this is to do with the immediate, heavily medicalised and expert-directed interventions in cases of glioma (whereas in ALS it is widely acknowledged that a cure is not available and people immediately receive palliative treatment), the 'invisible nature of the glioma' (see Chapter Five) in comparison to the often more noticeable impact of ALS on the body, a shorter life expectancy from diagnosis and the fact that ALS is always fatal, whereas in cancer, and as this study has highlighted, there is always a degree of uncertainty and hope.

Salander and Spetz, (2002) spoke about patients abilities to regulate their awareness and as a result of that awareness can fluctuate over time. This study builds on this notion and suggests that participants regulated their awareness through the processes used in order to construct a tolerable reality such as maintaining uncertainty and positivity and focusing on the present. Piil et al., (2015) reported that the glioma patients in their study gradually gained prognostic awareness as the disease journey progressed. The authors suggested patients were more interested in greater amounts of prognostic information in part due to a decrease in anxiety. This findings of this study sheds more light on this process. I argue that rather than gain awareness as time went on, patients more readily expressed their awareness as time went on, having developed successful coping strategies which allowed them to manage the knowledge

of their situation, without having it adversely impact them, i.e. the coping mind frame and a tolerable reality.

The participants' oscillation between their constructed tolerable reality and the fixed undeniable facts of their diagnosis echoes the processes detailed in Stroebe & Schut, (1999) 'dual processing model of coping with grief'. Stroebe and Schut's (1999, 2001) 'Dual Process Model' suggests that the bereaved (or sick) person faces tasks in two distinct domains; 'loss-orientated coping', referring to those activities that deal with separation from a lost attachment figure; and 'restoration-orientated coping' refers to the activities by which one begins to build a new life and identity. The authors explain that adaptation involves a process of oscillating between these two opposing orientations in a dynamic give and take, until the individual reaches a point where they can occupy both domains evenly (Stroebe & Schut, 2011). Stroebe and Schut (2001) report that the central drive that motivates these tasks is the search for meaning in the loss and the construction of their new reality in light of that loss. Similar to how Stroebe and Schut found people grieving moved between the points when faced with different tasks, the participants in this study moved between realities in order to adapt to their diagnosis and maintain their ability to function and cope on a daily basis. However, the motivations behind this oscillation differ; this group of participants did not seek to occupy both 'realms', or amalgamate the knowledge of the implications of their diagnosis into their tolerable reality. The people in this study suppressed painful thoughts in order to return to their tolerable reality where they could adjust and function as close to normal as possible, returning to the painful thoughts when they were low in mood or wanting to prepare for the future. Participants in this study were not working towards a final point as one would be with 'grief work', rather they sought to become more practised in their ability to move from one reality to the other when a need or situation called for it in order to continue functioning on a day-to-day basis.

The findings of this chapter contrast with research conducted with patients at the end-stage of glioma (Philip et al., 2014). The authors reported that participants coped on a day-to-day basis, as reflected in these findings, however they found that this approach to coping caused feelings of uncertainty and waiting rather than, as reflected in this

study, remaining in the present and coping one day at a time as response to uncertainty. Further, the authors explain that the patients' approach to focusing on the 'here and now' was influenced by the healthcare professionals' preference for such an approach, however, the participants of this study opted to address their journey in such a manner by choice based on what worked for them.

Chapter Four described the sudden onset and the shock experienced by the participants as they navigated the initial stages of their illness journey. The participants struggled with the uncertainty of their future and their loss of control over their lives. Chapter Five explored the participants attempts to make sense of their diagnosis and its implications for their emotional and physical selves. Chapter Six explored the ways in which participants coped with their diagnosis and promoted their ability to continue living everyday life. The next chapter will discuss, in-depth, the findings of the last three chapters, and how they inform and relate to the central storyline of this thesis.

Chapter Seven: Conclusions

7.1 Introduction

The findings discussed in this thesis have described the processes experienced by people with a recent malignant cerebral glioma diagnosis from shortly after diagnosis, to the initial months post-radiotherapy. This concluding chapter will synthesise the findings discussed in the previous chapters, with reference to the core concept underpinning the experiences of those with glioma: hope.

The existing research into the experiences of those with glioma centres around their negative experiences of loss and grief, identifies supportive and care needs or explores issues surrounding accessing prognostic information and communication preferences. There is little research that explores the resounding inner strength and resilience expressed through the ability to cope and hope during such a challenging situation. Rather than peoples' emotional wellbeing being detrimentally damaged through the suffering and anxiety imposed by their life-threatening diagnosis; this study

discovered that resilience and strength exists alongside and despite the suffering. Participants in this study were resilient in the face of extreme uncertainty and loss, and found a way to hope in highly challenging circumstances.

In this concluding chapter I will describe how, from the initial stages of their treatment trajectory the participants' behaviour, actions and beliefs were motivated by their need to create and preserve hope. Equally, participants' ability to maintain hope influenced and impacted their actions, behaviours and beliefs, specifically, their ability to cope and adjust to life with a life-threatening illness. Examining the role of hope in the participants' experience provides an understanding of the actions and behaviours undertaken throughout the illness journey as they ultimately sought adjustment to their diagnosis to ensure emotional wellbeing, allowing them to live daily life to the best of their ability.

7.2 The reflexivity of hope

I undertook this study in order to fill a gap in the existing literature, to better inform both my own and other health and social care professionals' everyday interventions and interactions with people with life-threatening and terminal glioma diagnoses. My fascination with the topic stemmed from my curiosity about how people could receive a diagnosis with such a dismal prognosis, yet on the surface, appear to be able to continue living normal, everyday life. In short, I was curious about how people could cope with the knowledge of the implications of their diagnosis, that is, knowledge that their lives were coming to a sudden and premature end. Salander, Bergenheim, & Henriksson, (1996) observed that glioma patients can be aware of their illness without being depressed. My study illuminates both why and how people continue to function in daily life in the face of terminal diagnoses, and finds that people cope with the knowledge of their impending death by asserting control over their thoughts, so that they can cope with their illness, and maintain hope.

In the initial stages of this study my preconceptions, bias and assumptions were shaped by my role as a professional in a healthcare setting. Having operated as a

Medical Social Worker in a hospital/oncology setting, my understandings were shaped by my perspective as a service provider. In the early stages of the project I assumed that the research participants' attention would be intensely focused on their fate. I assumed that the survival statistics and the standard outcome of the disease would be understood as being both fixed and certain. I also assumed that best practice for working with people with glioma or any other terminal diagnosis should involve full disclosure of the diagnosis and its implications and early referral to palliative care services. I believed that participants had the right to make informed decisions regarding their care and to do so they needed to be explicitly informed about their prognosis. The findings outlined in this study quite clearly contradict my previously held understandings and beliefs.

In the initial interviews I approached the participants' expressions of hope for a better outcome from a professional stance. I privately pitied their hope for a better future and remained grounded in the clinical facts maintained by my professional self. I maintained my belief that their hopes of being the exception to the rule in terms of survival were in vain, and that they would suffer the certain and undeniable fate guaranteed by the diagnosis of glioma. At times I felt impatient and frustrated by the participants' unshakable hope, of my perceptions of their denial and the resulting paucity of discussions surrounding death and dying; a topic I assumed would be discussed in great depth given the unavoidable facts of the short survival of this participant group. I believed I was participating in collusion through the mutual avoidance of the topic of their demise. Similarly Sterckx et al. (2015) and Salander & Spetz (2002) were also surprised that conversations around impending death did not feature as a more prominent aspect of the experience of living with glioma. These observations are in line with my argument, presented in detail in Chapter Six, that participants' priority was to focus on living life to its fullest potential, rather than focusing on dying. The participants needed to sustain a 'tolerable reality', where they maintained beliefs which allowed for the possibility of a more positive outcome.

The important function hope served, as well as its powerful influence in people's lives, became apparent to me in the second round of interviews. In contrast to my detached

and occasionally impatient attitude to the content of the initial interviews (and the lack of discussions around end-of-life care), I found myself both convinced of each participant's arguments, and hoping on their behalf that they could be the ones to survive longer, to 'beat the odds'. I too became convinced that they may be OK, in fact, I privately and strongly hoped that they would survive and get better. Hope within this context was contagious, it drew me in and carried me along. I felt invested in their survival, I felt how important survival was to them and I was no longer convinced of the certainty of their fate.

At this point of the study, as I began to see the importance assigned to the ability to function on a day-to-day basis, I began to understand that despite the unimaginable diagnosis, people still had a need to live their lives. I began to understand this desperate need to have hope because how could one continue to function, how could one get out of bed each morning, if one could not have hope for the future? My hope for each participant was further strengthened and impassioned by the participants' upbeat, relieved and increasingly hopeful attitude resulting from their positive experiences, and their perceptions of their body's positive responses to treatment (as discussed in Chapter Five). As their hope developed that they may be the exception to the statistics, so did mine.

As the study continued I began to notice that in the instances where the participants' hope was challenged; when the losses had amounted, when poor scan results were returned, when participants felt disappointed and disillusioned with treatment, I felt my own hope was challenged. I too began to experience the need to hope, I wanted to be hopeful and have hope on behalf of the participants. I noticed I struggled with the feelings of hopelessness expressed by some of the participants in the final follow-up interviews, having become accustomed to their upbeat strength. I struggled while witnessing the disappointment participants experienced when their hope was challenged. I wanted them to continue to be hopeful, having seen resilience in the face of resounding despair I wanted their hope to return.

By noticing my own responses to the participants' developing hope, I began to understand its power and its ability to create a 'tolerable reality' (see Chapter Six). Witnessing the power of this resilient and adaptive hope aided the development of my understanding of the role that hope played in the lives of the participants. I now understand, and will discuss in detail in this chapter, that hope is essential to being able to cope and in turn, to function on a day-to-day basis within the context of having a limited time to live.

By witnessing and being influenced by the participants' hope, I became more sensitive to the nuanced approach required when working with those with glioma. This study outlined the importance of understanding the patient/ service-user perspective from a subjective and personal level. This study allowed me to shed my preconceptions developed while working as a healthcare professional, and understand the needs of patients, as identified by themselves. Of stark importance is just how incorrect my preconceptions were, highlighting the need for greater emphasis on understanding service provision from the service users' point of view.

7.3 Creating and maintaining hope throughout the illness journey

Throughout this study I sought to understand how people make sense of their glioma diagnosis. I assumed that the experience of living with glioma would centre around a search for existential meaning in order to assign a purpose to one's suffering in order to make the illness journey more manageable. Rather, the findings of this study illuminate the participants' coping behaviours maintained by their persistent hope for a better outcome. Contrary to what I anticipated, above all else these participants sought to be able to function on a day-to-day basis, to be able to continue living daily life, as best as they possibly could, for as long as they possibly could. In light of the massive uncertainty surrounding their experience, participants simply sought ways to make daily life manageable.

Chapter Five described how participants both sought and generated evidence to sustain hope from any available source. Their ability to find hope was possible due to

the space of possibility left open by the uncertainty surrounding their diagnosis and treatment. Throughout the illness journey participants protected themselves by leaving room for hope in order to ensure their ability to cope on a daily basis.

Participants reconstructed their ways of understanding and knowing the world and their illness, so that they could cope, and as a result function, on a day-to-day basis. The influencing factor making it possible to cope with terminal illness, in this case, was hope. In order to successfully adjust to the diagnosis of malignant cerebral glioma, people must be able to maintain hope for their future. The ability to maintain hope lends itself to adjustment and emotional wellbeing which in turn enables people to cope on a day-to-day basis. Equally, while striving to cope so that they could psychologically and emotionally adjust to the diagnosis (which insured that they could live everyday life well) participants created, maintained, and protected their ability to hope, and in doing so strengthened their ability to hope and subsequently cope with their circumstances.

7.3.1 Managing information and knowledge

The need to maintain and preserve hope was particularly evident through the participants' behaviours and actions within the diagnosis communication/disclosure process. Participants' cautious approach to interactions regarding information provision, and their sensitive management of information which could impact their awareness of the implications of their diagnosis highlighted their prioritization of maintaining their ability to have room for hope. Cavers et al. (2013) highlighted the tension between wanting to feel informed yet not wanting potentially distressing information. As seen throughout this thesis participants made both conscious and unconscious decisions in order to protect and optimize their ability to have hope for their future, specifically "choosing not to know" certain elements of their diagnosis, "not asking 'why me'" to deter self-pity, "doing whatever needs to be done" to improve their chances of a better outcome, and "prioritizing treatment and the possibility of a cure". The relationship between the management of information in a

manner which could allow for the maintenance of hope will be discussed in depth below.

In terms of the participants' decisions surrounding their knowledge or awareness of their diagnosis, the level of knowledge participants could manage while still preserving their ability to cope and subsequently hope varied. The spectrum of participants' information requirements varied between choosing not to know anything and wanting to know everything available regarding their diagnosis and their prognosis. This suggests that participants' preferences for information provision were influenced by their individual coping abilities, the success or protective strength or durability of their coping mechanisms, and the level of insight or information they believed they could manage while still maintaining their ability to cope and have hope for their future. Further, this illuminates the requirement for an individualized approach to information provision and diagnosis communication, while still providing the 'honesty', respect and autonomy that the participants sought and valued (see Chapter Four).

7.4 Retrieving information and hope from the body

Chapter Five focused on the participants' experiences towards the end of treatment, captured by the second follow-up interview. At the time of the second interview, participants were upbeat and relieved because they did not experience the difficult side-effects that they had anticipated and found treatment easier than expected. This relief prompted confusion for participants due to the contradiction between the participants' clinical status and how they physically experienced their illness.

Under pressure to create hope in order to cope, participants restructured their interpretation of the discrepancy between the body and how they felt in a positive light. Similar to the abovementioned appreciation of uncertainty regarding information provision, the space between the clinical facts of their diagnosis and how they physically experienced their illness created room for uncertainty and doubt surrounding the actual severity of their illness, especially when combined with the lack of information available from the healthcare professionals. Realising this doubt,

participants began to rely on their interpretations of their own bodily experiences and sensations in order to monitor and receive feedback on their response to treatment. By basing their understandings of their health on perceptions retrieved from monitoring their body, participants strengthened their evidence base for hope, making them more confident of the possibility for a better outcome.

Chapter Five outlined the participants' belief in the relationship between their tolerance of treatment and their chances of a better outcome. The positive messages received from their bodies' experiences reinforced the participants' beliefs about tolerating treatment well and consequently bolstered their feelings of hope for their futures. Further, the chapter described the methods that participants used to come to terms with, and make sense of, their diagnosis. These cognitive appraisals or sense-making processes were conducted in order to gauge their bodies' responses to treatment. As the participants created hope by interpreting their bodies' responses to treatment, how they felt physically impacted their emotional state. Therefore this study revealed that participants' levels of hope varied as treatment progressed, side-effects manifested and symptoms lessened or increased.

7.5 Challenges to hope

From the patients' viewpoint, the length of treatment prescribed for glioma was representative of the severity of the diagnosis. The realisation of the extent of the treatment plan for glioma posed an initial challenge to the participants' hopeful perspective of their illness. Upon realizing that the diagnosis was more serious than they imagined and having their initial hopes dashed, participants were fearful and deflated.

The bolstered hope garnered from the body's tolerance of treatment was challenged by the disappointment experienced by participants in the initial months after treatment (see Chapter 5 for a more in-depth discussion). As participants progressed through treatment, they found their hope challenged by developments of their illness and experiencing side-effects of treatment.

The importance of the relationship between positive bodily experiences and the participants' ability to cope is evidenced through the examination of Heather's (participant 5) experience of her illness journey in comparison to that of the rest of the participants. Heather was an outlier throughout the analysis as a result of the worsening impact of the disease on her body, resulting in a decline in her abilities and mobility from the point of diagnosis and throughout treatment. Heather did not experience the 'invisible' nature of the illness and therefore could not elicit positive and hopeful messages from her body regarding her response to treatment and as a result she did not present as upbeat as the other participants. Although she maintained hope that treatment would have some positive impact on her and her ability to return to a past level of functioning, she was unable to create hope to the same extent as those who saw an improvement in their symptoms throughout treatment. While the rest of the participants received positive feedback from monitoring themselves and as a result were motivated to continue fighting their disease, Heather opted to delay her chemotherapy due to the feedback received from her body. She did not believe her body would be able to tolerate any additional treatment at the time of the final interview.

Similarly, Heather's experience reinforces my understanding of the resignation and disappointment felt by the remaining participants upon perceiving indications of a deterioration in their overall health. Often throughout the interviews Heather presented as frustrated, disappointed and deflated due to changes in her appearance and the impact of her physical limitations on her ability to function in daily life. When applied to the rest of the people in the study, this understanding illuminates how participant's moods decreased at times due to their conclusions that not feeling physically well (something that might be expected when undergoing months of intensive radio- and chemotherapy) was a negative indicator of their overall health status.

These processes underline the prominent relationship between embodiment and the creation of hope, and by extension its relationship with one's ability to cope. As

previously mentioned this relationship has not been explored in relation to the experiences of people with glioma. Negative perceptions of the body reduced the ability to have hope, making it difficult to maintain the coping mind frame and a 'tolerable reality'. Equally, positive feedback from the body promotes one's ability to have hope for the future, strengthening one's ability to suppress threatening stimuli and cope on a daily basis. Therefore I posit that decreased uncertainty would reduce one's need to refer to the body for answers to their questions. Of note however, such certainty may, as discussed in Chapter Six, impede a person's ability to create and maintain hope, and cope, and consequently remove their ability to enjoy the time that they have left. The use of uncertainty to maintain hope will be discussed in Section 7.10.2 of this chapter.

As discussed in Chapter Five, participants were further challenged by physical and undeniable manifestations of their illness such as hair loss, changes to their appearance and physical limitations and impairments. These difficulties challenged the participants' sense of self and identity. Due to changes in their appearance, participants felt they could be generalised as part of the broader cancer population and were distressed by the connotations attached to the generalisation in relation to them. The more similarities participants perceived between themselves and the stereotypical 'cancer patient', the greater the loss they experienced of their previous selves and their sense of dignity.

In response to this, participants strove to preserve their individuality, dignity and personhood by avoiding any behaviour or activity which could be construed as submitting to their illness, while also differentiating themselves from other people with cancer. Participants strove to set themselves apart from the norm in an attempt to prove their individuality, that the survival statistics did not apply to them, and that because of their individuality they stood a good chance at beating the statistics. This concept of individualising prognostic information was touched on by Lobb, Halkett, & Nowak, (2011) although their study did not develop on the fact that individualization may be a method of preserving or creating hope, rather than simply as a means to stay positive. The participants in this study attempted to preserve their ability to hope for

a better outcome by individualizing themselves and holding onto the possibility that they would benefit from being unique and survive longer than expected.

7.6 Hoping for a better outcome

The need to create and maintain hope (in order to cope) was the key element of the experiences of this group of people with glioma. Of note, contrary to what one may expect, their hope did not revolve around a cure or to be rid of their tumour entirely. Participants acknowledged the likelihood that their futures would contain significant difficulty, and frequently indicated awareness of the incurable, life-threatening and time-limited nature of their illness. In order to achieve their aim of living everyday life to their best ability (as discussed in Chapter Six), and to motivate themselves to do whatever needed to be done in order to complete treatment and improve their chances of a better outcome (discussed in Chapter Four), they had to be able to possess hope for something, thus enabling them to continue functioning on a daily basis. Hope gave participants the ability to cope with their illness.

The participants in this study needed to be able to create hope between the fixed reality of their present, and the uncertain possibilities of their future. Their most predominant hope was for a better future than that which was expected. Similarly, Sterckx et al. (2015), reported that participants rarely expressed hope that they might receive a cure, rather they hoped to survive for as long as possible. Participants hoped to benefit from the best case scenario within the confines of their situation i.e. an incurable, likely terminal illness. The findings of this study, however, contrast with those of Clayton, Butow, Arnold, & Tattersall (2005) who reported that very few participants with varying forms of terminal cancer expressed hope to beat the odds and live longer than expected. Given that Salander et al. (1996) also identified a similar hope to remain as well as possible for as long as possible, it is possible that this hope for a better outcome is unique to the experiences of people with glioma or other cases where the cancer diagnosis is terminal and death is impending.

As I discussed in Chapter Six, such hope does not stem from denial or dismissal of the diagnosis or its implications. Hoping for the best-case scenario is based on, and rooted

in, the patients' awareness of the difficult facts of their diagnosis. Building on my discussion in Chapter Six, people can accept their circumstances while still hoping for a better outcome or for the best-case scenario, particularly in the face of such uncertainty. The existence of extremely exceptional cases of individuals who have survived past the standard survival time (Caruso, Pesce, & Wierzbicki, 2017) enables the possibility for people to create hope for their circumstances while still accepting their clinical diagnosis and likely fate. In the case of acceptance and hope, one does not preclude the other, both can co-exist in a functional way, allowing people to continue to make the most of living day-to-day life while facing extreme adversity. This understanding will be discussed in-depth in Section 7.9.2.

7.6.1 Subcategories of hope

Participants' hopes were time-orientated in nature and can be categorized as either future-orientated hoping, hopes for the maintenance of current conditions, or hopes for a return to their past lives. These hopes enabled the participants to create meaning from the time that they had left by providing them with a means to fight and to cope. I will now explain the nature of these forms of hope in greater detail.

As discussed in the previous chapters, participants' most compelling needs motivating their actions and decisions were; being able to *continue living daily life to the best of their ability* and, also, to afford themselves the *optimum chance to obtain the best outcome possible*. Hope for a better outcome provided participants with the strength, motivation and resilience to do just that. In Chapter Four I discussed the concept of 'doing whatever needed to be done in order to get through treatment', while Chapter Six introduced the concept of 'illusions' as a manner of constructing a tolerable reality. I argue that participants locate or create hope out of necessity, out of their need to cope and to be able to live daily life well. Whether or not the source or subject of that hope was an illusion or wishful thinking, it enabled the participants to navigate adversity and source the strength required to complete treatment and make the most of the time they had while well, allowing them to manage living with glioma.

As discussed in a Chapter Five, participants hoped for a return to 'normality'. Normality in this context was the participants' manner of living prior to the onset of their illness and included physical abilities, appearance, cognition and memory, and the ability to undertake everyday activities and tasks. The loss of these abilities represented a loss of control but also a loss of purpose and the sense of meaning in life. As previously discussed, a number of the participants sought to re-establish their purpose within their household by finding or creating activities which they could undertake successfully. A small-scale study focusing on patients' early experiences of the diagnosis and prognosis communication found at these initial moments participants shifted between a hope of returning to life as it was before, and the new reality of having a brain tumour (Vedelø, Sørensen, & Delmar, 2018). Similarly participants in the study of Sterckx et al., (2015) also hoped to regain some meaningful activities although in comparison their findings do not extend to a broader wish or hope to return to their previous lives.

Similar to the concept of accepting while fighting (outlined in Chapter Six and discussed in-depth in Section 7.9.2 of this chapter), participants expressed hope for a return to normality while maintaining the knowledge that such an outcome was unlikely. This poignant hope to return to normality could also be viewed as longing for one's previous life and the safety and security it offered. This sense of safety and security of their previous lives was influenced by, among others, one's appearance. Chapter Five portrayed the influence of participants' appearance on their sense of emotional wellbeing. Perceived changes to appearance as a result of treatment caused participants to feel affronted or challenged by the reality of their illness coupled by the sudden inability to deny or dismiss the severity of their illness when it physically manifested itself. Appearing sick challenged their identity and diminished their ability to maintain hope due to the perceived correlations between appearance and health status. Participants hoped they would return to looking like their previous selves in order to derive the comfort and security of a healthy appearance.

Hope concerning the present tense involved participants' hopes that treatment would work. Again, in this context the hopes participants had for treatment were not hopes

that treatment would provide a cure; participants hoped that treatment would fulfil its purpose and do what it was meant to do and that it wouldn't do further damage to their brain or cause their condition to worsen. This is also indicative of the level of uncertainty participants had regarding whether or not treatment would actually be effective, and their knowledge of the possibility that it may not.

Similarly participants who felt physically well hoped that their circumstances and condition would remain as it was at that point in time, for as long as possible. Hoping to remain well or stay well does not signify hope that their condition will remain the same long-term, rather this speaks to the participants' awareness that their futures would consist of a decline in their condition and they sought to delay this for as long as possible. As discussed in the previous section, feeling well was a necessary element of participants' construction of a tolerable reality (within which things would turn out for the best), enabling them to continue living daily life to its utmost potential.

Despite striving to stay in the present tense and embracing the positive potential of their uncertain future (discussed in Chapter Six), participants maintained strong future-orientated desires or hopes. Hopes for the future provided participants with a point to focus on. Similar to *dealing with it when the time comes* (discussed in Chapter Six) people delayed addressing anticipated challenges or problems so that they could enjoy the present moment. Delaying dealing with problems until an unspecified point in the future provided participants with a point from which to anchor their worries or concerns. As outlined in Chapter Two, the existing literature states that people with glioma possessed hope for future good, particularly relating to post-treatment scans. Similarly, the participants in this study attached their hope to their follow-up scans and as a result attempted to postpone any worrying until then. Attaching their hope to a point in the future allowed them to maintain their illusions of the present, supporting their construction of tolerable reality, and allowing them to enjoy the present and make the most of everyday life.

7.7 Treatment and hope

The findings of this study prompt us to consider the impact or role of 'treatment' in the experiences of those with glioma, other than its intended physical effects. While discussing this topic which emerged through interrogation of, and engagement with the data, I wish to make it explicit that I am, obviously, not a specialist in the effectiveness of medical treatments. The intent of this section is not to discuss whether or not the treatments are effective, as outlined in the previous paragraph, but rather to outline how the participants viewed the treatments and their effectiveness.

Arguably, treatment may not provide extensive improvements to one's survival, however it may psychologically help them to cope on a day-to-day basis with their illness. I proffer that treatment allowed people to maintain hope for a better outcome, which enabled them to cope on a day-to-day basis, which in turn allowed them to adapt to life with glioma and make the most of daily life. Thus, the presence of treatment (be it effective to their survival or not) allowed people to find meaning in life, despite their illness, by living everyday life to the best of their ability.

The majority of the participants referred to their knowledge that their diagnosis was 'incurable', however, they hoped that treatment would have a positive effect on their illness and they would benefit from a better outcome. Treatment for glioma typically offers the patient an additional couple of months of survival, and may aid in the management of deficits and symptoms of the disease. Conversely, treatment for glioma involves side effects including extensive fatigue and a general feeling of malaise due to initial swelling of the treatment area. Additionally, treatment is lengthy and intensive. For the type of tumours included in this study, following recovery from surgery, treatment requires people to attend (or reside in) their hospital daily for 6 weeks, followed by (at least) monthly attendance at clinics to monitor recovery from radiotherapy and their chemotherapy regimen for an additional 8-12 months, or until their disease progresses, and follow-up scans on a 3-monthly basis (at minimum) to track responses to treatment in the months after that (Weller et al., 2017).

Despite the aggressive treatment of glioma, most tumours recur (Davis, 2016), in many cases prompting further treatment (either radio- or chemotherapy) or surgery (Weller et al., 2017), inevitably leading to the deterioration of the person's health and the end-of-life phase of the disease. A change in attitude involving a less pessimistic view of glioma has resulted in an increase in treatments given after the recurrence or progression of the disease (Stupp et al., 2009); a possibility participants were emotionally soothed by and subsequently derived hope from. From this, should radical and/or aggressive treatment always be considered 'standard' when the pay-off amounts to at most an additional few months of life, with the standard of that life not necessarily adequate? Given the time- and energy-consuming nature of treatment, at times resulting in a worsening of one's condition prior to any (marginal) improvement, should the automatic recommendation of treatment be reconsidered, or should the diagnosis communication disclose the reality of the prognosis, even with treatment? As Owen (participant 14) echoed in Chapter Six, *"the average survival is 15 months and you've got to wait half a year to find out if your treatment has worked. That's quite a big chunk of your 15 months gone right there"*.

This study found that participants' priority, in the face of life-threatening or terminal illness, was to be able to live everyday life to its greatest potential while they were well enough to enjoy it. The findings of this study portray the processes undertaken by participants to enable them to achieve their priority to the best of their ability. When it comes to treatment, it is conceivable that treatment somewhat hampers their ability to make the most of everyday life as a result of its side effects and extensive time commitment; prompting the question of whether the impact of treatment is worth it.

The participants of this study did not doubt their (and their doctors') decision that treatment was the best, if not the only, viable option available to them. Participants sought an opportunity to fight their illness; the ability to fight their illness created the ability to have hope. As outlined in Chapter Four, at the point of diagnosis and prognosis communications, participants recounted feeling as though they had been left with no hope for their futures, however, having learned of the existence of

treatment they then went on to express hope that they may live longer as a result. The prospect of treatment and the connotations of treatment itself offered them hope.

At the point of the initial interviews with participants, they had already developed a strong sense of hope for a better outcome. Perhaps hope is both created by treatment, but also, is sustained by treatment. How could one motivate and energise oneself throughout the process of a lengthy, aggressive treatment regime, and all of the side effects it entails, without hope for some benefit?

Within the context of hope theory (Rodriguez-Hanley & Snyder, 2000), hope differentiates between high-hope and low-hope individuals and centres primarily around people's belief and abilities to adapt to potential difficulties and losses. High-hope individuals typically maintain positive internal monologues and view obstacles or challenges in a positive light, comparatively low-hope people experience more negative emotions when their goals are blocked or challenged (Rodriguez-Hanley & Snyder, 2000). By this definition, each participant in this study appears to qualify as a 'high-hope individual' at the time of the interviews. Despite possessing the knowledge that their illness was incurable (Chapter Four), and openly acknowledging that their futures would contain great difficulties (or would at least not be as good as their present – see Chapter Six), participants could still maintain hope. It is unlikely that it was a coincidence that each individual recruited for this study possessed the characteristics of high-hope individuals prior to their illness. The findings of this study suggest that systemic forces and institutional factors in this treatment-focused context instilled and fuelled hope in the participants and thus made the existence of low-hope people unlikely. Further, I proffer that as a result of the treatment regime and professional stances that the participants were surrounded by, they assigned complete priority to treatment and the possibility of a better outcome. From this they endeavoured to do whatever needed to be done in order to get through treatment (as discussed in Chapter Four), which in this case was to have hope in order to cope.

Snyder et al., (1991) explains that high-hope people are skilled at finding alternative paths to their original goals. The authors explain that high-hope individuals maintain

'realistic' or somewhat 'attainable' goals, and can generate numerous life goals upon recognising when particular life goals have been immutably blocked. Assuming this group of participants became high-hope individuals based upon their recognition that hope was essential for coping, I believe they recognised that some of their initial goals were unattainable and so they altered and adjusted their hopes, allowing them to maintain their ability to hope and to cope.

Support for this conceptualisation is evidenced throughout the findings described in the previous chapters. For example, having been informed that their tumour was incurable, the participants felt that they had been left with no hope for their future (i.e. that their lives would ever return to pre-diagnosis normal). Given that all participants were aware that they were irrevocably sick they realised that in order to maintain hope and to cope they must alter their expectations and their goals as their preferable goal of surviving was no longer attainable. In order to be able to possess hope (so that they could cope), participants adapted their goal to something more 'realistic' i.e. hope for a better outcome/the best case scenario, rather than a cure. This enabled the participants to continue coping throughout treatment and making the most of the time they had left.

In short, the treatment is typically intensive, invasive and ongoing. It is experienced by many patients as exhausting. Questions should be asked around the desirability of giving patients a more realistic picture of the typical course of treatments, and its side-effects, which need to be balanced against the advantages, for some patients at least, of not experiencing the confinement and side effects that the treatment involves. In other words, it perhaps needs to be acknowledged more openly that some patients might prefer not to undergo treatment.

7.8 Hope

To date, this study is unique in its portrayal of the form and function of hope and in its tracking of the influence and impact of hope in the lives of people with a recent diagnosis of glioma. This study builds on and adds to the foundation provided by Salander, Bergenheim, & Henriksson, (1996) and their contribution to our

understandings of how people develop hope once diagnosed with glioma. The findings of my study echo the main findings of theirs; “the majority of patients made use of an extensive repertoire of cognitive manoeuvres to raise hope when confronted with a brain tumour diagnosis” (Salander et al., 1996 pp. 992-3). The authors found that their participants raised hope through the body, helpful relations, cognitive schemata and the handling of information. In contrast, my study offers an explanation as to why hope is such a prominent feature in the experiences of glioma patients, how it is created and maintained, and importantly, why it is created and maintained. This study outlines the purpose of hope during the illness journey of glioma patients and therefore, why it is necessary to cultivate and support patients’ abilities to create and maintain hope when facing this devastating diagnosis.

Salander and co-authors (1996) make a connection between the participants’ creation of hope, and the defensive function of denial. They suggest that the patient ‘denies’ incoming information, and fills the spaces left vacant by denial with hope, having protected themselves through cognitive manoeuvres. Their arguments resonate with understandings derived from this study such as the notion of ‘tolerable reality’ (seen in Chapter Six; a way of managing awareness while trying to maintain hope) which the participants of this study constructed and fought to remain in. In this instance however, I argue that rather than avoiding or denying intimidating information, the participants in this study used the uncertainty of their circumstances to create space in which to harbour hope. These processes are also featured in the existing literature under the terms ‘illusions’ (Taylor, 1983) and ‘positive bias’ (Janoff-Bulman, 2010).

Much of the literature on hope in the context of cancer or glioma specifically focuses on the creation and maintenance of hope during prognostic communication with doctors (Clayton et al., 2005, 2008, Diamond, Corner, DeRosa, Breitbart, & Applebaum, 2014, Rosenblum et al., 2009). Piil, Jakobsen, Christensen, Juhler, & Jarden (2015) explored expressions of hope by glioma patients and their caregivers. They found a change in expressions of hope as the tumour and the illness progressed, with patients’ focus more orientated towards quality of life rather than expectations of survival. In contrast, this study found that participants maintained ‘realistic’ goals for their hopes

from the start of the illness journey, hoping for a better outcome relative to the confines of their circumstances, i.e. a hope to stay well for as long as possible or hope to benefit in some way from treatment. Most participants did not express expectations of survival, rather they acknowledged that their tumour would always be present. Participants' hopes indicated preferences for maintaining quality of life and of making the most of the time they had left.

7.9 Acceptance as a response to losing control

It is apparent that the processes of adjusting the subject of one's hope to something more attainable (making it possible to cope and in turn attempt to adapt to the illness), influences the participants' ability to accept their illness. Notably, participants *accepted that they had no control over their illness, and, they accepted their illness because they had no control*. As Waskul & van der Riet (2002) explain, having cancer 'means experiencing powerlessness and alienation while also attempting to preserve power and control, maintaining dignified selfhood within the extremes of both stigma embracement and distancing, and feeling a condition of pain and suffering that potentially transforms subjective meanings' (p. 491). Accepting their circumstances, deliberately not asking "why me", while reminding themselves of the fact that their situation could be worse, allowed the participants to more easily accept their situation. Accepting their illness, rather than resisting it, enabled them to maintain their constructed 'tolerable reality' where they could remain positive and focus on the present, and as a result could continue to hope. Within their 'tolerable reality' people needed to avoid dwelling on the unfairness of their illness in order to prevent self-pity, thus allowing them to continue accepting their disease and consequently hoping.

In this section I will detail the relationships between hope, acceptance and control within the context of living with a glioma diagnosis, and how these concepts serve to provide people with the ability to cope and adjust to their diagnosis.

The findings of this study reveal that the diagnosis immediately undermined participants' sense of control over their selves and their lives. Participants lost control over their lives in a rapid and sudden way very early on in the illness experience. The

loss of control was compounded by the significant uncertainty surrounding treatment, their survival and their futures. They experienced a loss of control of their bodily autonomy as their days were dictated by their illness and their treatment regime. Further, they lost control through their loss of independence and their physical abilities through driving restrictions and physical impairments. Participants suffered from a loss of control over how they defined their selves, their identity, as they found themselves rapidly pulled into the identity of 'cancer patient' and 'victim'. The grief and impact on one's self-esteem as a result of the loss of abilities reported here is reflected in previous research on the experiences of people with glioma diagnoses (Adelbratt & Strang, 2000, Halkett, Lobb, Oldham, & Nowak, 2010, Sterckx et al., 2015, Strang & Strang, 2001).

Typically, in line with the existing literature, people seek to re-establish control in illness by attaching meaning to the cause of their illness (Roger & Medved, 2010, Fife, 1994, O'Connor, Wicker, & Germino, 1990). Although the participants of this study initially sought information on the cause of their tumour, these questions were asked in order to place blame, either on oneself or on external factors. As seen in Chapter Four, the participants gained solace from knowing they had done nothing wrong. More notable was the lack of searching for existential meaning. When dealing with their diagnosis, participants accepted the status of their diagnosis early on in the journey in order to protect themselves from the distress associated with a lack of sense or existential meaning attached to their suffering. Avoiding searching for answers and assuming a state of acceptance represented early utilisation of protective measures undertaken in order to ensure one's ability to continue to cope on a daily basis.

Accepting their diagnosis early on allowed the patients to move forward and participate effectively in the numerous tasks required of them throughout treatment and prevented them from exploring potentially distressing thoughts such as the notion of 'why me', which could impact their ability to cope with the illness journey. As seen in Chapters Four and Five, participants felt uncomfortable complaining about their circumstances. Based upon my understanding to date, I believe this aversion to expressing self-pity and complaining about their circumstances was based on the

awareness that it would conflict with their state of acceptance and the protections that it offered. To fight against this acceptance would likely dredge up the feelings of distress related to their knowledge of their lack of control, therefore reinforcing the points made in Chapter Six, that people's ability to cope with their illness is dependent on their ability to accept their reality.

Predicated upon my previous points, accepting that they had no control over what was happening to them prevented them from hopelessly attempting to alter or control their circumstances. This early acceptance consequently permitted them to exert their effort in activities which would improve their chances of benefiting from a better outcome, enabling them to maintain hope for their future.

While all participants hoped there would be further treatment options available to them after their scan results, only four of the participants in this study hoped for medical advancements which could extend their life. I argue that most participants didn't hope for medical advances because to do so would negate their acceptance of their circumstances, and the control they are afforded through that acceptance. Similarly, to question why this happened to them, or to express self-pity would contradict the protective cognitions reinforcing their constructed tolerable reality, hence threatening their ability to have hope and to cope with the illness.

[7.9.1 Readjusting hope in order to continue accepting](#)

Snyder (1996) explains that hope is particularly likely to decline when the individual perceives that a goal is truly unattainable. In order to avoid a decline in their ability to hope when confronted with the reality of the undeniable facts of their diagnosis, knowing it could negatively impact their ability to cope and to continue functioning on a day-to-day basis, participants readjusted their hopes for something more attainable, thus protecting their ability to hope.

As discussed in Chapter Six, accepting the illness was related to adjustment to the diagnosis and the resulting experiences. Acceptance was a means of adapting and

adjusting to the diagnosis, making reality more tolerable and subsequently enhancing one's ability to have hope and to cope. Similarly, in order to readjust their hopes participants accepted (at a cursory level) that their initial goal, i.e. a return to normality, was not feasible. Accepting their disease by adjusting the parameters of their hopes, protected participants from the disappointment associated with realising their hope was unattainable. This behaviour manifested throughout the interview as an apparent lowering of one's standards of what they could tolerate in order to still maintain hope. It could also be considered as a type of bargaining with themselves, that they will continue to cope as long as their situation does not worsen. This bargaining amounted to a restructuring of one's hopes in light of the limitations of one's circumstances, which in turn maintained the ability to hope.

This process of readjusting one's goals and hope in light of striving to maintain their ability to cope may provide insight into participants' seemingly rapid 'acceptance' of their illness (as discussed in Chapter Six). Participants readjusted or adapted their hopes for their future upon realising that hoping to be entirely cured was unrealistic. They adapted their goals so that they could maintain hope, thus allowing themselves to continue coping and deriving meaning from daily life. Hope is vital to one's ability to cope, one cannot cope without hope of some sort.

It is possible that provided one can continue to adjust one's goals or hopes whilst accepting what is unattainable, one can continue to possess hope, and to cope. Despite the disappointments experienced by the more frequent encounters and realizations of their physical limitations, the participants still maintained the ability to create a tolerable reality and hence maintained the ability to hope and to cope.

7.9.2 Fighting while accepting: the power of hope

The determined approach to coping was fuelled by a vital need to maintain a *fighting spirit*. The participants of this study appeared to engage in the paradoxical approach of both accepting the reality of their illness and their loss of control, while simultaneously adopting a fighting attitude. This fighting approach was apparent from

the point of the initial interviews as participants sought to do whatever was necessary to maximise their chances of a better outcome, indicating it was a mind frame adopted quite soon into the illness journey. Participants often characterised these behaviours and their approach as simply 'fighting'; the existing literature refers to it as 'the fighting spirit'. The 'fighting spirit' has been shown to correlate with reduced mood disturbances in patients with both early-stage and advanced breast cancer (Classen, Koopman, Angell, & Spiegel, 1996, Watson et al., 1991), and cancer in general (Cordova et al., 2003). Strang and Strang (2001) found that people with a 'fighting spirit' managed 'relatively well' with their brain tumour diagnosis; they had an optimistic view of the future and believed they could exert some level of control over their illness.

In Chapter Six, I discussed the emergence of the relationship between acceptance and fighting as a method of coping. The participants of this study accepted their illness yet they sought to avoid submitting to it. They adopted the approach of fighting, believing it was necessary in order to cope with the challenges of their treatment and their diagnosis. I argue that the determination with which people strove to maintain a 'fighting spirit' is due to its ardent relationship with hope. The fighting spirit can, in this instance, be considered to be the result of the participants' need to have hope. Possessing hope for a better outcome provides people with the motivation to fight while facing adversity.

The fighting spirit, or fighting despite the reality of their illness, conflicted in some ways with the participants' emphasis on acceptance. How could one fight while accepting? The fighting spirit is an element of hope, and as an active coping response it allows people to cope, just as people need to be able to possess and maintain hope in order to cope on a day-to-day basis. Maintaining a 'fighting' attitude - which can be characterised as a refusal to submit to the illness - allowed participants to bridge the gap between accepting their diagnosis while still maintaining hope for the future.

The successful adjustment to the illness displayed by the majority of participants, combined with the importance assigned to maintaining a 'fighting spirit', suggests there are emotional benefits of coping with a 'fighting spirit'. In the context of a glioma

diagnosis, people suffer a loss of agency as early as the initial onset of symptoms, compounding the experience of losing control, making it more difficult for them to maintain focus on their goals (hope). By fighting, people to remain active in the pursuit of their goals (to benefit from a better outcome) and maintain high levels of agentic thinking (re-establishing a sense of control), and as a result they can remain engaged with the world as they move through the treatment trajectory (Taylor, 2000). By regaining control and agency, participants could negate the identity of a 'passive and helpless cancer patient' as discussed in Chapter Five. Furthermore, fighting reinforced the participants' ability to continue accepting their reality while not submitting to disease, and promoting their ability to cope with their illness.

7.10 Uncertainty, controllability and predictability

Perceptions of controllability, but also of predictability, play vital roles within hope theory (Michael, 2000) and hence provide an explanation for the prevalence of difficulties experienced in response to the lack of certainty within the experiences of those with glioma. This study saw participants relinquish their attempts to predict the upcoming events of their illness as they *accepted their illness without submitting to it*. The existing literature fails to capture the extent of the impact of uncertainty on the experiences of those with glioma.

Although the illness experience was underpinned by a lack of certainty of what the future may hold, primarily the participants suffered from the uncertainty of more concrete issues (namely plans for treatment, questions of how to practically conduct themselves in daily living, and future appointments), rather than broader existential questions regarding survival. Such findings resemble those of Salander & Spetz, (2002). The lack of concrete information regarding their treatment trajectory was nonetheless distress and anxiety inducing, however it is likely that this distress was rooted in the overall unpredictability of their illness. They could not pre-empt or know with any certainty what their futures would hold, or in what manner their disease would progress.

The participants' search for certainty and their necessary adaptation to uncertainty (inherent in the experience of the illness) highlights the need for predictability in order to cope. The lack of predictability challenged the participants' ability to cope due to the heightened sense of a lack of control. Just as this group of participants initially sought meaning in the cause of their illness, they also initially sought certainty through attempts to re-establish control and predictability in order to increase their ability to cope. Snyder et al. (1991) found a positive correlation between hope and perceptions of control and their ability to solve problems i.e. a sense of mastery over their circumstances. In this case, mastery was sought accessing and seeking information surrounding their diagnosis and prognosis. These perceptions of mastery increase the sense of controllability and predictability in most circumstances (Michael, 2000). The concept of mastery was importantly used by Taylor (1983) within the context of adjusting to life-threatening events. Taylor cited mastery as a vital element of the adjustment process, in the manner of "gaining a feeling of control over the threatening event so as to manage it or keep it from occurring again" (1983 p.1163).

The impact of an uncertain and unpredictable life-threatening diagnosis on one's sense of mastery and control can challenge the ability to cope with illness and to maintain hope. Maintaining hope, in response to this lack of control, can allow people to adjust to their diagnosis. Hope can offer protection against perceptions of vulnerability, uncontrollability, and unpredictability (Snyder et al., 1991), underlining its importance in the experiences of those with glioma. Michael (2000) found that in the context of a threatening event where lack of control and predictability is commonplace, a hopeful individual is likely to make interpretations that facilitate the re-establishment of perceived controllability and predictability. Stemming from their need to hope and to cope, the participants positively interpreted incoming information and protected themselves within a tolerable version of reality which in turn enabled them to re-establish a degree of perceived control and predictability.

7.10.1 Information seeking and certainty

As previously established, hope is influenced by perceptions of controllability and predictability, albeit such perceptions are challenging to obtain within the context of a glioma diagnosis. Based on this understanding, the omnipresent uncertainty contained within the participants' treatment and illness journey presents a challenge to their ability to hope. In this study, people's need for predictability was occasionally allayed through the acquisition of information and knowledge of their illness, lending participants some ability to inform themselves as to what their futures may consist of. Some participants identified acquiring as much information as possible regarding their circumstances as their method of coping. This need for information regarding their illness actually strengthened some participants' ability to cope by making treatment and the illness more predictable, regardless of the troubling content of the information.

Receiving additional information regarding their illness helped those individuals who found they needed additional information in order to cope. Knowledge gave them the ability to predict elements of their future and how they may prepare for it. Furthermore, knowledge provided participants with an element of control over their lives. The ability to prepare for what was to come enabled some to reassert control over their lives. In contrast, Chapter Four outlined examples of individuals who asserted control by choosing not to receive information regarding their diagnosis and prognosis. For these participants, the unpredictable nature of their situation enabled them to cope. These participants found it easier to cope with not knowing (or not confirming) the difficult facts of their diagnosis. Ultimately, by the time of the final follow-up interview, each of the participants had adopted this way of managing their knowledge of their illness. In the next section I will discuss how participants maintained uncertainty in order to preserve their ability to have hope for the future.

7.10.2 Maintaining uncertainty in order to cope

The existing literature on this topic categorises uncertainty as a cause of low mood, distress or anxiety (Acquaye et al., 2016, Lin et al., 2013, Philip et al., 2014, Sterckx et

al., 2015). This study revealed that contrary to the existing research, participants created a positive outlook from the uncertainty of their lives.

The uncertainty (inherent in the diagnosis of glioma) regarding their survival challenged perceptions of controllability and predictability. Mishel (1990) offers that people strive for control and predictability when faced with a threat to health; given that health is connected to survival, uncertainty is highly undesirable in the presence of illness. Within the context of this study, as discussed in the previous section, in addition to generally craving control and predictability in illness, perceptions of control and predictability were essential to participants' ability to maintain hope throughout this illness.

As discussed in Chapter Six, participants struggled with the lack of certainty regarding the impact/effectiveness of their treatment, and the ability to predict in what manner, and within what timeframe their illness would progress. Newton & Mateo (1994) explained that distress caused by uncertainty could be alleviated for people with glioma through patient education, support groups and counselling. Although the authors acknowledge that support groups are not appealing to many of those with glioma (a finding reflected in this study), many of the participants of this study also opted against patient education and counselling opportunities. I argue that these actions reflect a preference to maintain uncertainty despite the emotional discomfort it caused. Participants did not wish for any additional services while undergoing treatment, frequently stating that all of their current needs were being met.

Rather than avail of services (counselling, patient education and support groups, as discussed above) which could offer potential answers to their uncertainty, participants in this study preferred to use their 'selves' as their preferred source of information regarding their responses to treatment and gauging their own limitations. In response to uncertainty they trusted the knowledge of their 'selves'/bodies, at times above that of external information sources. This trust contrasts against the findings of Nijhof (1996) who found trust in the body suffered as a result of the uncertainty of Parkinson's Disease, further emphasising the unique nature of glioma. This 'trust of

the self' furthered a person's ability to protect themselves from external threats to their ability to cope and enabled them to maintain the space created by uncertainty, enabling them to continue to have hope.

The participants of this study fought against their continuous loss of control by trying to assert control over both their lives and their illness. In this instance they sought to reassert control through accepting a lack of control and uncertainty. Salander & Spetz (2002) summarised that extensive prognostic information does not make life easier for patients and found that participants controlled external information in order to maintain hope for their future. Such findings are reflected in this study, however, this study offers the understanding that such control also offers the opportunity to maintain uncertainty in order to maintain hope, allowing people to continue to cope. As discussed in Chapter Six, maintaining uncertainty promotes the person's ability to remain in their 'tolerable reality', a manner of regulating awareness of a difficult reality, enabling the participants to cope on a daily basis.

Therefore, I argue that the existing literature does not illustrate the abilities of people with glioma to utilise this uncertainty to remain hopeful for their future, enabling them to cope with their illness on a daily basis. This study found that participants eventually sought to maintain uncertainty regarding their illness rather than actively achieving certainty. Rather than avoiding the distress of uncertainty, participants focused on it and derived solace and hope as a result. Along with protective cognitive manoeuvres, this group displayed a strong propensity for benefit-finding (discussed in Chapter Six), which when applied to uncertainty, allowed them to see the positive possibility (also in Chapter Six) inherent in their ambiguous futures. These participants maintained uncertainty in order to cope, out of their necessity to have hope.

7.11 Concluding remarks; requirements for hope

Much of the existing literature on the presence of hope in the lives of people with cancer is discussed in relation to professionals' roles in helping people to create hope (Acquaye et al., 2016, Clayton et al., 2008, Rosenblum et al., 2009) or the importance of hope as identified by family members/caregivers. In contrast to much of the

literature, participants did not identify the unmet need of hope in terms of the care they received from professionals. This study's conceptualisation presents the characterisation of hope within the context of the patients' experience of a glioma diagnoses as both necessary (created out of their requirement to cope), resilient, and adaptive. There is a paucity of literature discussing the needs relating to hope as identified by, and from the perspective of the patients themselves. I argue that in this context, people, when faced with a life-threatening situation and needing to cope, become high-hope individuals, thus allowing them to adapt their goals in order to achieve their goals (in this instance, coping enough to function on a day-to-day basis).

As previously stated, perceptions of controllability and predictability are essential to maintaining hope when faced with challenging situations and threats to one's health. This thesis has portrayed the uncertainty and the widespread loss of control that occurred in all facets of the participants' lives. This study has identified the need to possess and maintain hope as the central component of the experience of these participants. By this reasoning (supported by both the existing research and the findings of this study), uncertainty and the loss of control served to challenge one's ability to have hope for the future. Uncertainty and loss of control cause distress as a result of one's inability to perceive that one can control or predict the future. Therefore, in order to maintain their ability to hope the participants of this study sought to regain control of certainty.

These participants encountered a difficulty obtaining certainty via accessing information regarding their futures. Where some sought out additional information regarding their diagnosis (not always available given the uncertainty of the illness), and less frequently, their prognosis (as information or knowledge can remedy the loss of control and uncertainty), others avoided or limited their exposure to such information. It was apparent that all of the individuals included in the study were aware that certain information regarding their illness would impact their ability to have hope.

This study described the participants' use of 'illusions' (Taylor, 1983) or 'positive bias' (Janoff-Bulman, 2010) in order to create and maintain a tolerable reality whereby they

could benefit from protective cognitions and maintain an ability to hope for a better outcome, while continuing to cope on a day-to-day basis. One of the processes generating these protective illusions involved using the body as a point of reference. As discussed in Chapter Five, this connection with one's body was developed as a result of the lack of certainty and information available regarding the diagnosis. Garnering information through bodily experiences allowed participants to re-assert control over their experience by enabling them to obtain perceptions of certainty independently. Participants monitored their 'selves' (whom, as stated above, they trusted more than external source at times), and determined that they were responding well to treatment because they were feeling physically better than they or the medical team expected. The information received from their bodies allowed them to maintain hope for a better outcome than was initially communicated to them.

This study did not include the views of medical professionals, however, given the findings of this study it is worth considering the role that the medical professionals play in the production of hope. A brief overview of the findings reveal that participants created hope from sources, many of them offered or provided by the doctors. For example, the stories of survivorship, the emphasis on everyone's response to treatment being individual, the reassuring feedback and the 'overemphasis' of treatment side effects all offered the participants' important opportunities to produce hope for their future. Based on the accounts of the participants, along with my observations throughout the study, it could be argued that that the doctors 'collude', to some degree, with patients in the production of hope. This understanding needs to be investigated separately and merits further research.

As discussed in Chapter Six, participants developed a cognitive manoeuvre or 'coping mind frame' in order to manage their thoughts when confronted by threats to their 'tolerable reality', in turn preventing themselves from dwelling on the difficult facts relating to their illness and their future. Within their 'coping mind frame' the participants of this study refocused their attention away from the difficult facts of their diagnosis, and back on the present tense, by actually reassuring themselves of the uncertainty, or the lack of certainty regarding their situation. They sought to avoid

considering the facts of their diagnosis for extended periods of time, knowing such knowledge would cause distress and impact their ability to cope. Such a manoeuvre signified an exercise in control exerted over their thoughts in a manner which protected them from threats to their ability to cope. This indicates that ultimately all participants, regardless of their information preferences, were aware that the knowledge obtained from gaining absolute certainty regarding their future could jeopardise their ability to maintain hope and subsequently to cope.

As well as asserting control over their cognitions to continue to have hope and to cope, participants also asserted control by accepting that they had no control. The immediate and task-centred nature of their treatment journey made the presence of the illness in their lives undeniable. Accepting they had no control empowered participants with the ability to control and regulate their expectations and emotions regarding their illness and their treatment journey. This group of people accepted their circumstances because to not do so would inflate their distress as they attempted to reject the everyday tasks required by their treatment. Participants felt dignified in their acceptance rather than struggling and rejecting their illness.

In order to counteract the vulnerability associated with accepting one's lack of control over their illness, participants maintained uncertainty in order to cope. By doing so they focused on the prospective positive possibilities available to them within their uncertain future, left open to interpretation or reconstruction through positive bias. Focusing on the lack of certainty created a space for positive possibility thus enabling and preserving participants' ability to have hope for a better outcome. I argue that for as long as the information regarding their illness was uncertain, this group of people would continue to be able to find space to create and maintain hope for their future. Hope is a necessary element of being able to cope with glioma. This group of participants sought to continue 'living life well' with their glioma for as long as possible.

7.11.1 Strengths and weaknesses of this study

The findings in this thesis arise from 43 serial interviews conducted with 16 people with glioma. The findings are not representative of the glioma population as a whole, nor are they intended to be. The rationale of this study was to explore in-depth, how people with glioma brain tumours experience and cope with their diagnosis and to develop a theory explaining the same. This required using qualitative methods.

The use of Grounded Theory through the constructivist paradigm outlined by Charmaz, and the use of core characteristics of CGT - iteration, constant comparison and theoretical sampling - provided for a robust insight into the lives of people with a recent diagnosis of glioma. I believe that the outcomes of this study can serve to inform interactions and interventions with this patient group due to the greater understanding of processes behind what is required in order to cope with a terminal illness. The use of serial interviews in this study allowed for in-depth understanding of the experiences of this group of people, an approach previously adopted by Cavers et al., (2012) and Salander et al., (1996) but few others.

This study took place in a single specialist radiation oncology hospital in Dublin, Ireland where care for people with cancer is reasonably well developed. The hospital is not an acute setting and as a result benefits from a less busy, and more attentive environment by comparison. Further it is possible that the findings of this study were influenced by interviews being conducted in the building of the hospital. The location of the interviews conducted in this study was restricted to the hospital building by request of the Hospitals Research Ethics Committee. Although the interviews occurred in a visitors sitting room in the hospital, made homely and comfortable with suitable furnishings owing to the room being quite 'non-medical', the consideration given to a constructivist epistemology throughout this study means we must acknowledge the potential influence of the hospital surroundings on the interviews.

The findings presented in this thesis capture the experiences of the participants during the initial 6-7 months of their illness journey. As a result I cannot claim that this group managed to maintain hope for a better outcome as their disease progressed, their

health deteriorated, and they approached the end of life. However, I proffer, given the resilience of the hope portrayed in the initial months of the illness, that as long as participants engaged in the behaviours of accepting what is unattainable for them and adjusting their goal or their hope, they may be able to continue to possess hope and therefore manage to cope on some level. These behaviours are dependent on whether or not people have the strong need to cope, as they did during the initial stages of their illness journey. The strong need to cope in order to live their lives, ignited their fighting spirit and subsequently their hope. To lose their fighting spirit would be to lose their desire to cope and their ability to hope.

This study is unique in its presentation of a theory and a conceptual framework detailing how people with glioma cope and maintain hope during the initial months of their diagnosis, from diagnosis to 3-4 months post-radiotherapy. The study reports 'real time' (albeit very short-term) longitudinal data rather than relying on retrospectively collected data. Repeated interviews allowed for the development of close relationships and helped me to gain a more private account of the participants' experiences. Meeting with people on multiple occasions allowed for follow-up questions on events, experiences or developing concepts within the analysis.

Unlike previous studies, this study outlines in detail the methods and manner whereby people cope with the diagnosis of glioma. The findings allow for speculation that had treatment not been a viable option for someone, or had one opted to forego treatment, they may not have had the same opportunity to develop hope. This study did not capture the experiences of those who opt to forego treatment or for whom treatment was not an option. Understanding the relevance and sources of hope (or lack thereof) for those who did not or could not receive treatment requires further investigation.

In this study, I strove to include a variety of glioma patients and to avoid exclusion on the basis of cognitive problems, aphasia and/or functional decline that are all typical in glioma patients. As discussed in Chapter 3, up to 20% of people with glioma suffer from some form of aphasia, and to discount them on the basis of a poor score on the

MMSE (Mini Mental State Examination, please see Chapter 3 for more information) would dismiss a large portion of the experience of this patient-group. While these deficits were not formal exclusion criteria in this study, the severity of these deficits did impact my selection of participants. Several patients were not approached for the study because their severe cognitive problems or aphasia made an informed consent or interview impossible.

Unlike the majority of previous studies conducted with glioma patients, this study focused primarily on the experiences of people afflicted with glioma, rather than also including the caregiver perspective. Some previous studies have collected caregivers' experiences and interpretations of the patient as a means of triangulating the data for validity and perspective. The rationale for this decision was partially due to the small sample size and matters of ethics and confidentiality, and the potential for recognition within the context of a small specialist hospital and a specific and narrow disease subset. Also, within the limited scope and timeframe of a PhD study and the aim of collecting data from repeated interviews across the disease trajectory, priority was given to achieving 'saturation' in the data relating to the experiences of patients. This study adopted a critical realist paradigm, an understanding that there is a fixed reality to be known (in particular, the existence of glioma and its terminal nature), while acknowledging there are multiple ways of knowing and experiencing this reality. This study accepted the experiences of participants as their reality, and did not seek to triangulate the validity of their reality through caregiver perceptions of personality or cognitive changes. With or without personality/cognitive changes, the reality of the participant is valid, and psychosocial/emotional support and care must be designed to meet the needs of their experienced reality. Regardless of whether or not the content of this study was derived from narratives skewed by cognitive changes, the findings of this study reveal and reflect a common reality within the experiences of people with glioma. This common reality was apparent upon reaching 'saturation' of the data after interviewing sixteen participants.

7.11.2 Recommendations for care

The decline in functional ability impacts people's ability to partake in everyday life and can cause suffering (Morgan, Currow, Denehy, & Aranda, 2017; Svidén, Tham, & Borell, 2010). The participants' overwhelming prioritisation of continuing to live everyday life to the best of their ability informs the need for healthcare professionals to endeavour to support people's ability to do so whenever possible. Considering the results of this study, people sought to maintain hope, so that they could cope with their illness, enabling them to enjoy the time they had left. Someone burdened by grief over their illness will not be able to participate in everyday life activities in a meaningful way, therefore supporting people's coping promotes adjustment to the illness, allowing them to engage in everyday activities. People in this study sought adjustment in the hope it could assist them in coming to terms with their illness, so they strove to cope, allowing them to live everyday life well. This section will outline the ways in which health and social care professionals can support glioma patients during the illness journey.

7.11.3 The provision of prognostic information

Similar to Salander et al., (1996) who advise that prognostic communication should involve implementing a situation where the patient has space to create illusions, the findings of this study suggest that healthcare professionals should leave room for the construction of hope through uncertainty, while prioritising honest communication. Reflections of glioma patients at the end of life included in a study by Philip et al., (2014) outlined that the uncertainty and waiting inherent in the disease was made worse by negative prognostic information being withheld from them to save them from distress, because upon reflection, it simply meant the patients 'waited' longer. The recommendations for providing prognostic information developed from the findings of this study reflect that provided in existing research; the most helpful way to discuss prognosis may be to ascertain how much information each person wants, respect that preference and revisit this decision at multiple time-points, rather than considering this as a one-off communication episode (Clayton et al., 2008).

The existing literature on the provision of prognostic information to people with glioma and other advanced/terminal cancer varies with regards the specifics of what people want to know and don't want to know, however most advise that communication should be done in an individualised way while providing patients with hope (Cavers et al., 2013). The recommendations for care based on the findings of this study echo that of existing studies that suggest that clinicians seek patient preferences for the amount and type of information they require and that prognostic information be individualized (Cavers et al., 2013; Lobb et al., 2011). The authors also emphasised the obvious need to balance honesty with hope when communicating the typical prognosis of a glioma diagnosis. The participants of this study, however, sought respect from the medical professionals working with them, and valued honest communication above all else. When operating in such an emotive context, professionals must heed caution and observe the thin line between leaving room for the person to create hope and offering false hope. As identified in this study, participants sought hope from any source available. Constructing their own hope based on false hope may prove devastating when reality is revealed or discovered.

Receiving honest communication in a sensitive manner empowered participants and engendered a sense of respect and appreciation for their capacity as an individual. Despite the upsetting nature of the prognosis communication, I argue that a number of the participants would choose to forgo the option of being given hope in favour of the option of honesty, if being provided with hope threatened their dignity. The participants did not want to be patronised, rather they wanted to be afforded the respect and dignity associated with honest communication. This study illuminates the need for communication to be conducted carefully and in an individualised, case-by-case manner, while appreciating patients' agency and their ability to protect themselves from threats to their ability to cope. The findings of this study portrayed people's immense capacity to build hope for themselves from one of the most devastating illnesses. Such an ability should be understood and afforded to the patient group.

From my experience of multiple meetings with the participants at various points across the treatment trajectory it was apparent that each participant, regardless of their expressed level of awareness or insight, was undoubtedly aware of the serious threat to life and the likely deterioration of their health in the near future. Despite this awareness participants could still create and maintain hope for their future, and cope on a day-to-day basis. The onus is not necessarily on the medical professionals to provide hope, given that people have the ability to create hope themselves, rather the onus is on the professionals not to remove the option of hope, by providing prognostic information in a sensitive and patient-directed way, tailored to each person's individual information preferences. At times within these communicative interactions, to attempt to provide hope can inadvertently provide false hope as a result of patients' perceptions. The findings of this study advise that rather than attempt to provide hope and inadvertently providing false hope, professionals should instead attune themselves to the extent to which information is desired by their patients, while maintaining room for the creation of uncertainty regarding their survival timing and therefore the creation of hope. The need for an individualised approach to information provision is supported by previous work including that of Lobb, Halkett, & Nowak (2011) and Salander, Bergenheim, Bergstrom, & Henriksson (1999).

The findings of this study contradict that of Lobb et al., (2011) who found that receiving a specific timeframe for survival was hope reducing. Similarly the findings of this study are not in line with the findings of previous studies of people with advanced cancer who viewed statistics on survival as potentially hope destroying (Lobb et al., 2011; Salander, Bergenheim, Bergstrom, & Henriksson, 1999). Participants in my study who had awareness of the exact timeframe of their prognosis were still able to maintain hope throughout the timeframe under examination. In this study, hope was resilient, buoyant and adaptable in the sense that it could survive despite the participants awareness of the likely outcome.

After interviewing Aoife (participant 12) for the final time, she went and met with her doctor who informed her that her tumour had recurred and that her survival time was approximately six months. I passed Aoife and her family on the corridor, outside the

doctor's office, after her meeting and Aoife told me that '*She [the doctor] said six months...but still, maybe I'll get a year*'. Aoife's daughter immediately and tearfully corrected her, '*No. She [the doctor] said six months*'. Despite the fact that Aoife had, only moments before this conversation, been advised that her prognosis now had a six month timeline, she still maintained hope for something better. The buoyancy of hope was apparent in Aoife's retelling of the event; no matter how far it was pulled down by the bad news and distressing information, hope was able to find its way back to the surface and into the participants' lives.

7.11.4 Meeting the needs identified in this study

On a practical level, many of the participants felt they would benefit from services that could support them in light of their loss of ability to drive, particularly in terms of attending hospital appointments and grocery shopping. Such support would negate some of the distress caused by the loss of independence and would allow people to preserve their sense of dignity (as outlined in Chapter Five). Some of the participants in this study also struggled to access advice surrounding the consumption of alcohol and suitable methods of hair care while in receipt of treatment. Readily available advice regarding these matters would be beneficial as the participants in this study felt too embarrassed to ask the healthcare professionals involved in their care.

As mentioned throughout the findings chapters, participants were happy with the care they received in this particular hospital throughout their treatment journey. The sense of disregard experienced from medical professionals reported in previous studies (Halkett et al., 2010a; Sterckx et al., 2015; Strang & Strang, 2001) was not an issue for this group of participants. Participants did not wish for anything additional with regards service provision, however it is possible that this acceptance, their perceived lack of control, their focus on the present, their gratitude that their situation was not worse and the immediacy of their need to cope stifled them from thinking critically regarding the care they received.

The participants themselves could not identify any additional support or service provision which could make their circumstances better. The two great losses in their

lives; the loss of independence and of their futures could not be remedied by enhanced service provision, reinforcing their loss of control over their lives. At the early point of the illness journey upon which the study focused, support groups were not a popular choice amongst those who took part. The majority of participants were reluctant to attend support groups for those with glioma because they feared confirmation of their futures from those who may be further along the disease trajectory. Of note, these findings show that a limitation of this study is that I did not sample for people who are inclined to join support groups.

Support for patients and families is required particularly around preparation for end-of-life and the care required in the lead up to death. Participants' greatest fears surrounded how their family would cope financially and emotionally after their death. Many participants believed the entire illness experience was more difficult for their family than it was for them due to perceptions of helplessness. Participants rationalised that it was easier for them because they could actively partake in treatment in response to their illness, whereas their families could only watch and wait. Therefore, this study identified a role in assisting and promoting communication between patients and family members regarding their fears for the future, along with supporting individual patients and their families to make provisions for the future in order to ease concerns about life after their death.

Further to this, however, this study found that unless people experienced significant impairments or symptom burden throughout treatment, it was in fact the time after initial treatment when the greatest amount of support was required. The third and final interview (which took place 3-4 months after treatment had finished) found that participants had reached a point of realisation regarding what their reality now consisted of. Along with experiencing sadness and grief for their circumstances, it was at this point of the journey that participants finally felt able to begin making provisions for the end-of-life stage of the illness and after their death. In line with how participants deferred addressing difficulties until the difficulty arose, participants felt more able to deal with matters of the future once they had navigated the chaos of treatment. In terms of the provision of support during treatment; participants' needs

during treatment were immediate and short-term in nature, usually centring around easing the uncertainty of their treatment plan. So, with reference to my argument in the previous paragraph, care for patients with glioma should be provided with consideration to where they are in their illness journey, particularly in attempts to support them in making plans for the future.

Of note, the people in this study wanted the opportunity to explore their fears in a safe and private space, without the concern of upsetting someone. When receiving support from family members and friends the participants stifled their distress and their concerns so as to protect their loved ones from upset. They strove to be strong throughout the illness journey, believing it was what their families wanted. They wanted to be permitted to be able to express their deepest fears to explore their feelings of helplessness with professionals. In exploring their fears for the future and their anxieties surrounding their death, the participants sought occasions where their fears were not quelled, reassured or minimised, having developed the ability to do so themselves when required. Participants found the research interviews provided a forum for expressing and exploring their private feelings without fear of repercussions or causing upset.

At this point I wish to express my sincerest and most grateful thanks to all of the participants who so generously gave their time and energy to this study. The participants shared their stories with an openness and bravery that I will always admire. Without these individuals this study could not have been conducted. I learned more than I could have imagined from these patients through their approach to life, death and illness. They transformed my understanding of what it means to hope in adversity and I will endeavour to use and promote these understandings in all aspects of my work. Throughout this study I was constantly mindful of findings ways to give back to the participants. Many participants explained that a handbook of past patients' experiences and coping strategies would have been beneficial to them, so this is what I intend to do next. Those who took part in this study wanted raise awareness of the importance of 'living' in spite of their diagnosis and dedicated their time to this study in the hope that other patients may benefit from a more widespread

acknowledgement of this. In recognition of that I hope that I have in some way captured and shared what is important to people with a malignant brain tumour as they experience the initial phases of their diagnosis and treatment.

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Appendices

Appendix A: Patient Information Leaflet



The lived experience of a primary glioma

Invitation to participate in a research study

Investigators: Sorcha Farrell, PhD Candidate, Dr. Claire Faul, Consultant Radiation Oncologist

You are being asked to take part in a research study looking at the lived experience of a primary brain tumour (glioma) diagnosis. In order for you to decide whether or not you should agree to be part of this study, it is important for you to understand why the research is being done, what it will involve, as well as the possible benefits and discomforts. This process is known as Informed Consent.

This patient information sheet gives detailed information about the research study that your doctor or nurse will discuss with you. Please take time to read the information carefully and make sure you fully understand it. If you would like to know more about something mentioned in this information sheet, or have any questions about this research study, please be sure to ask your doctor or nurse.

Thank you for reading this information sheet. Please take time to decide whether or not you wish to take part.

Background Information

Little is currently known about the patient's experience of living with a brain tumour diagnosis, from the point of diagnosis through different stages of treatment. In

providing information on patients' experiences, services can be better informed to be more responsive to patient need. Participating in this study may not benefit you personally but it is hoped that the findings of this study will improve the quality of services for future patients.

What is the purpose of the study?

The aim of this important study is to describe and explain how patients experience their diagnosis throughout the different stages of treatment. This study also aims to develop best practice protocols in oncology services, which are informed by service-user perspectives. For this reason, research which focuses on the experiences of service users as they come to terms with their diagnosis and engage with the necessary medical services will allow service providers to develop best practice protocols that are informed with the contribution of the service user's perspectives on how services should be. Therefore, it is hoped that this study will be of benefit future patients with a brain tumour diagnosis and their families.

What will happen if I take part?

If you choose to participate in this study, participation will involve in-depth face-to-face interviews in the hospital. In order to make use of the interview material fully, I will also ask you to give consent to the digital recording of the interview.

The interview will start with a few short questions asking you to recall your experiences of your diagnosis and treatment so far. There is no set time length for the interviews however it is anticipated that they will last no longer than 45 - 60 minutes. You can decide to continue with the interview for as long as you feel comfortable. You can choose to end the interview at any point, and you can choose to leave the study at any time.

How many patients will take part and for how long?

This study aims to speak to approximately 20 patients. As one of the main purposes of the study is to learn more about how service-users experiences change over time during the course of treatment, participants will be encouraged to consider participating in an additional 1 or 2 repeat interviews, one towards the end of

treatment and another a few weeks after treatment has ended. The purpose of these interviews will be to check-in and see how you are doing, as well as to give you the opportunity to update me on how things have been throughout treatment and since your treatment has ended. For now, you only need to consent to one initial interview if you wish to take part.

It is envisaged that the interviews will take place between January 2016 and December 2016.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign the attached consent form and will be given a copy of this information sheet to keep. If you decide to take part but later change your mind, you are free to withdraw at any time without giving a reason. This will not affect the standard of care you receive. As your treatment schedule and wellbeing must take priority at all times, if it is in your best interests, your doctor might advise you to withdraw from the study.

Are there any possible benefits?

Studies have shown that taking part in research interviews can have a therapeutic effect for patients, as they contribute their knowledge of their experience of the diagnosis and services. The findings of this study will hopefully serve to benefit and inform the service provided to future patients with brain tumours and their families.

What are the possible side effects associated with the study?

Given that this may be a very stressful and frightening time for you, it is possible that you may become upset while telling me about some difficult moments in your journey.

What if something goes wrong?

Although most people find taking part in this kind of interview a positive experience, in the event that you should become upset or distressed during the interview we can pause the interview, or take a break, and discuss what support you may need. This may involve speaking to your Consultant, or accessing one of the support services in the

hospital. If I am concerned about your welfare or that of others I must pass this information to your doctor. These are the only circumstances where confidentiality could be breached. A number of support services will be available for you to access if you wish. These services include the Medical Social Work Department and the Psycho-Oncology services in the hospital, and the Brain Tumour Support Group.

Will my taking part in this research be kept confidential?

Yes. Only the medical team will be aware that you have agreed to take part in this research. The content of the interviews will not be available to the hospital in any form that would identify you. The content of the interviews, when transcribed, will be made completely anonymous before the findings are analysed and written up in the form of a doctoral thesis. If you agree to the interview being audio recorded, audiotapes will be kept until my doctoral degree is complete. The written versions of these recordings and/or notes from our conversation, which are completely anonymous will be kept for ten years and then destroyed. No names or identifying information will be included in the materials published using findings from this study. Findings from this study will also be published in peer-reviewed journals and conference presentations to relevant audiences.

If I am concerned about your welfare or that of others I must pass this information to your doctor. These are the only circumstances where confidentiality could be breached.

Who is organising this research?

This research is being carried out and supervised as part of a doctoral study with the School of Social Work and Social Policy in Trinity College Dublin. The researcher carrying out this study is a qualified and registered social worker with experience working in oncology services and with individuals and their families living with a brain tumour diagnosis. This study is being supervised by Dr. Virpi Timonen from the School of Social Work and Social Policy, Trinity College Dublin who can be contacted at virpi.timonen@tcd.ie.

This study is funded by the Irish Research Council under the Government of Ireland Research Scholarship scheme.

Who has reviewed and approved this study?

This study has been reviewed and approved by the Trinity College Dublin School of Social Work and Social Policy Research Ethics Committee, and the St. Luke's Radiation Oncology Network Research Ethics Committee.

If you have any questions about this study, or if you wish to chat further about it without making a commitment, please feel free to contact me at farrelso@tcd.ie.

If you definitely want to take part in this study by agreeing to an initial interview with me, please contact me at farrelso@tcd.ie.

I am working full-time on this study and will be based in either Trinity College Dublin or St Luke's Hospital so I would hope to be able to respond to any calls or messages very quickly.

Sorcha Farrell

Appendix B: Consent Form



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

The lived experience of a primary malignant brain tumour diagnosis

Consent Form for Second Interview (Follow-up interview)

**Investigators: Sorcha Farrell, PhD Candidate, Dr. Claire Faul, Consultant Radiation
Oncologist**

This research is being carried out as part of a doctoral study with the School of Social Work and Social Policy in Trinity College Dublin. The researcher carrying out this study is a qualified and registered social worker with experience working in oncology services and with individuals and their families living with a brain tumour diagnosis.

- It is not compulsory to consent to participate in this study.
- Participation in this study is completely voluntary.
- No repercussions, positive or negative, will ensue from your decision of whether or not you choose to take part.

- I am completely independent from the care that you receive from your medical team.

All information collected in the interview will be anonymised. However, your signed consent forms and contact details will not be anonymised. I will keep them in a secure, locked cabinet in an office in St. Luke's Hospital. The only person who will have access to this consent form is my academic supervisor, Dr. Trish Walsh, a lecturer in Trinity College Dublin.

Given that you are undergoing a stressful treatment process, and your wellbeing must take priority at all times, I will be liaising with your medical team to ensure that they remain happy for you to continue with the interviews. I will not discuss anything else with your medical team other than details of your medical condition that are relevant to your taking part in the interview. I will not discuss any information you have shared during our interview unless I have reason to believe that you or someone you know is at risk of harm, however I will speak to you about this beforehand if this becomes relevant. Your medical team will be consulted and will keep me informed regarding the details of your condition and treatment that are relevant to you taking part in the interview.

You can choose not to answer some of the questions in the interview if you so wish. You can stop the interview at any time, and you do not have to continue in the study if you do not want to. There are no right or wrong answers to my questions, the main thing I would like is to understand your experience of living with your diagnosis.

I would like to audio-record your interview, so that I can accurately document your experiences. If you do not want to consent to recording the interview, but still wish to be involved in the study, I can take hand written notes of your responses. These tapes will be kept in my possession in a locked press in Trinity College Dublin. I will transcribe the interview data and anonymise it, no identifying names or information will be included in the transcripts. If you agree to the interview being audio recorded, audiotapes will be kept until my doctoral degree is complete. The written versions of these recordings and/or notes from our conversation, which are completely anonymous will be kept for ten years and then destroyed.

Under Freedom of Information Legislation, you are entitled to ask for any personalised information relating to you that I have. As per Trinity College Dublin guidelines the anonymised

data will be retained, encrypted, for a period of ten years so that the data gathered can be fully utilized for the benefit of future patients and their families.

The findings from this study will be published in the form of a thesis, peer-reviewed journals and conference presentations to relevant audiences. Any reported findings from this study will be entirely anonymised.

This study is being supervised by Prof. Virpi Timonen from the School of Social Work and Social Policy, Trinity College Dublin who can be contacted at timonenv@tcd.ie

This study is funded by the Irish Research Council under the Government of Ireland Research Scholarship scheme.

If you have any questions please do not hesitate to contact me at farrelso@tcd.ie.

Sorcha Farrell

- I agree to be interviewed for one interview as a part of this research study.
- I give consent for the researcher to speak to my doctor about relevant details of my medical condition that may hold bearing over my participation in this interview.
- I give my consent for the interview to be audio-recorded.
- I understand my rights under Freedom of Information Legislation.
- I understand that all information collected about me will be anonymised except for my signed consent form and contact details.
- I understand that if the researcher has concerns for my safety, or the safety of others, that they are obliged to inform a member of staff in the hospital.

Signed: _____

Date: _____

Appendix C: Information sheet for follow-up interview

Information sheet for follow-up interview

Research study: the lived experience of a primary malignant brain tumour

There is currently no information on what time is like outside of the hospital for those who have received treatment for a brain tumour. Having some information on what this is like for you would be extremely helpful to the healthcare professionals involved in your care. You have been given this information sheet because at our last meeting you agreed to let me call you by telephone 8-10 weeks later so that I could talk to you about the possibility of taking part in a telephone interview. Participation in a telephone interview is completely voluntary and any decision not to partake will have no impact on the care you receive from St. Luke's Radiation Oncology Network.

What would this involve?

- If you agree to take part in this telephone interview I would arrange to call you at a time that suits you, when you would be free to talk to me for a period of time uninterrupted.
- There is no set time for this telephone interview, it can be as short or as long as you like.
- In this interview I would be really interested to hear, in some detail if possible, about how things have been for you, how have you been spending your time since finishing treatment, how have your family been since we last spoke. We may also follow-up on topics we discussed in previous interviews.

If you have any questions about this interview in the meantime, please do not hesitate to email me at farrelso@tcd.ie.

Sorcha

Appendix D: Consent to contact for follow-up

Consent to contact

Investigators: Sorcha Farrell, PhD Candidate, Dr. Claire Faul, Consultant Radiation Oncologist

- I give my consent for Sorcha Farrell to contact me in approximately 8-12 weeks time to speak to me by telephone about the possibility of taking part in a telephone follow-up interview.
- I give consent for the researcher to speak to my doctor about relevant details of my medical condition that may hold bearing over my participation in this interview.

- I understand my rights under Freedom of Information Legislation.
 - I understand that all information collected about me will be anonymised except for my signed consent form and contact details.
 - I understand that if the researcher has concerns for my safety, or the safety of others, that they are obliged to inform a member of staff in the hospital.
-
- Signed: _____
 - Date: _____

Appendix E: Illustrative example of a memo

What is acceptance in the experience of glioma?

Can accepting include denying or fighting? The people in this study are fighting while accepting, that is the confusion or the difference here. What are they accepting? How are they indicating that they are not fully accepting, or that there is a variance to the traditional notion of accepting?

Accepting lack of control

I have no control over this. It's something that's there, it's something that I have to deal with, to live with and make the most of. Participant 14 (Interview 2)

You think in terms of, just worry about what you need to worry about today, or not worry, deal with it, deal with whatever it is, that's what you have to do. Not to worry about tomorrow because you can't, you're not in control and once you've accepted you don't have control well certainly for me where I said oh I can't do this, I sort of resigned myself and I was calmer for it. (Participant 2)

They are not dwelling on the diagnosis, dealing with it involves changing perspective. Changing perspective is a way of coping, making it manageable, easier to handle. This is the result of acknowledging a fixed, unchangeable reality, which participants accept. They are realising how serious things are, realising they have no control, accepting they have no control, wanting to cope, wanting to handle this, accepting because no choice, wanting to live well, finding ways to cope, coping because no option.

As previously explored they struggled to integrate the everyday reality of their diagnosis with their previous selves or lives, struggling with the impact on the self, however when it came to adapting a mind frame which could allow them to live their best lives in the here and now participants quickly accept the presence, reality and implications of diagnosis (death).

Why do people accept?

They accept because they have no choice,(have to do it, have to get on with it, knowing its unchangeable, you have to face it, facing reality, accepting because they are aware, not questioning reality)

They can't deny the diagnosis, why can't they deny it?

Because context, their every day, they must go to treatment every day, they have to get up and do what needs to be done to try to do better, there is little room for denial with this diagnosis. They accept their reality, they accept the present tense, but only superficially accept their future. They protect themselves from thinking about the future.

Accepting involves not being angry, not rejecting their reality, not blaming their situation on something else. Accepting is not questioning it, going with it. Acceptance is getting on board with it. Why? Because they cannot deny it.

Accepting because no choice because they want to cope.

They realise they have no choice but to accept because they have no control, the illness experience is highlighting their lack of autonomy, they are losing independence, realising they have no control through the constant waiting, their lack of information, changes to their body, not being able to direct future, having no certainty. They realise they have no options (so regularly seen in the coding, no options, alternatives, no choices), they have to 'get on with it', so they choose to thrive, to survive.

Accepting they have no control and accepting because they have no control

What if accepting lack of control is more about control than it is about acceptance? This underpins the importance of understanding what is acceptance in relation to the disease. Therefore, what is prompting the lack of control, what are they feeling a lack of control over, how can they accept the lack of control. I think they accept a lot of the issues, including the illness, because they have no choice, they accept that they are powerless to change anything. They accept that it is reality.

Accepting reality: they aren't resisting but they still want to fight. They are not submitting.

Thinking about their external reality, having 'bad' thoughts is seen as a bad thing.

Is acceptance related to maintaining a tolerable level of knowledge which promotes coping? Thinking about external reality negatively impacts acceptance. Acceptance is achieved when they are not worrying about their external reality. When they slip up and dip into the troubling thoughts of their external reality they feel that they are not accepting. When they are worrying reality they are not accepting.

So therefore accepting it's based on their ability to construct and maintain a coping mind frame. Coping well allows for acceptance and living well. So, look through the data, is accepting linked to coping mind set.

You can accept something, but you don't necessarily have to be happy about it. So it would be that. This is what's going to happen, how do I handle it? That sort of acceptance. I'd say I'm pretty much in that same place. You know we were saying earlier when you step back, I think there'd be dips where you step back and you have a little bit of a think about the reality of the situation and all the rest of it, but I think those are not exactly fleeting, but you make those be moments, rather than the majority. So, I think that's where I am still. I've accepted it, but I haven't yielded to it.

So if accepting isn't like we usually understand it, if its more 'I accept reality'/'I'm ok with this' rather than 'I'm at peace with this, people's ability to accept is linked with how they are coping at a moment in time. So maybe their level of acceptance is linked to where they are in the oscillation in and out of a tolerable reality. So, they associate bad times with a lower level of acceptance, in other words 'I'm not ok with this'.

So levels of acceptance, from the participants perspective, in changeable. They see their ability and thus their acceptance level, to be on par with how they are dealing with the difficult facts of the diagnosis. When they don't feel good they aren't accepting it. If so maybe that's why people accept they've no control? People have difficulty accepting when they are having a difficult time with their diagnosis. So that could be anger, sadness, fear, resentment. However, people for the most part report they are coping well, and they are reporting that they are accepting the diagnosis. This is why people say they are accepting, it's not some social norm thing as I initially assumed, they have to accept because they have to cope, in order to cope they have to accept, if 'accept' is defined as 'I'm ok with this'. Maybe is it the complete powerlessness driving this need to accept, so they can cope. As we can see from Participant 14s extract, he actively undertakes the task of making the bad reality only moments, for him it's easier or more tolerable to accept, rather than deny, but they

still fight. Thus promoting his feeling of accepting. He is working to accept, it's an ongoing and active process. So maybe people undertake all of the processes in order to accept, they make it easier to accept.

If feeling powerlessness, acknowledging powerless- prompts accepting then the link to accepting no control becomes clearer. They are accepting because they recognise they have no control therefore no choice, its accept or struggle, but they want to live each day well so they learn to accept and cope. Being powerless, having no control or autonomy, doing what you're told; accepting this allows you to cope better, go with the flow.

I've been drinking coffee, I'm eating again and gradually, even getting back to some semblance of normality.

Getting back to normal so feeling better=things going well= represents accepting to the participants. Things going well allows for coping

It's an ongoing process, but it's one of those things that all you can do is literally follow the path. If the next stage is chemo, you do the chemo. If there's an MRI to go-

Participant 16 wanted to cope well, he didn't want to know anything about his diagnosis, he didn't feel that would benefit him. It can be surmised that he wanted to be able to cope.so when talking about accepting, he said he wasn't angry, if we take angry/struggling to be difficult and not allowing for coping or living every day well. He managed information provision to allow him to cope, his entire approach has been to protect himself, therefore his view on his diagnosis he is accepting and not angry.

I've no reason to be angry or anything like that Yes. I don't have any resentment or anything like that.

Even in terms of accepting massive waiting times in the, other than get angry, which we have already seen is reflective of struggling or not doing well, people can only accept because there is nothing else you can do.

Acceptance is about getting on board with the process and going with because it is better than not.

Appendix F: Illustrative example of an interview

Aoife, participant 12, Interview 1

I: Yes, 23rd June. Thank you so much for that and that's the only piece that will be kept, but that's kept securely. Your name and participation in this project is completely confidential and everything you say is completely anonymous. So if you were the only person doing your job in your town, in your county, that would be completely changed so that you wouldn't be identified at all. So you can say what you want, but basically what we're looking at doing here is trying to get feedback and get some information on your experience of this entire journey. So from start to finish, your perspective of what things are like. Not the doctors or the professionals working with you. From my point of view I would like you to try and help me understand what it's like. Some people find it helpful to go back to the start and talk about how this all came about, what was the lead up to it.

R: There was absolutely nothing, it came completely out of the blue. I'm a "healthcare professional", I was at a 'healthcare professional' conference. Someone was there giving a talk on mental health and his experience of it and I felt like a numbness in my right foot and it travelled up my leg, up my right side, right arm, top of my head and left and it was like a wave, like a pulsing wave, but not sore or not uncomfortable, just strange. It sort of gathered here in my tummy area for a while and it was uncomfortable there. So I said to the girl beside me, "I've got a strange feeling, I don't feel the best." So she says, "Do you want to go outside? Do you want to stand up?" and I said, "No because if I stand up I'm going to fall over because my leg feels numb."

So I sat on and as I say, it left, about five minutes. Nothing from that. I did notice over the next few days that my leg felt a little bit heavy, but nothing really and I drove home on the Saturday. That was Thursday and I drove home on the Saturday, nothing. Sunday, Monday, went back to work Tuesday, spoke to one of the doctors who was on the ward and said just randomly, "What do you think of these symptoms?" because one of my friends had said it sounds like a migraine. Oh yes okay, migraine in my leg, okay. The doctor, he said it sounds like it could have been a TIA. So he said if you have any more feelings like that come and see me. I was like yes, okay and thought no more of it. That was Tuesday. Wednesday then, I was back at work walking down the corridor,

I felt my foot again and I thought, "Right, I better sit down for this." So it was ten times more intense, it was sore, painful. It went all the way through me, but it stayed pulsing and my throat felt constricted and my right eye was blurry and it was just horrible.

I thought I was having a stroke. Called the doctor, same doctor that came over. The matron, she came out, called an ambulance, blue light. So straight into Letterkenny because they thought I was having a stroke. Straight to hospital because as I say, they thought it was a stroke. So apparently, this window of three and a half hours for a stroke. So by the time they got me from the hospital to Letterkenny, it was 90 minutes from when they rang until they got me there and then straight in for CT and then the doctor came in and said to me that evening, he said there's an abnormality. We've noticed an abnormality. I'm like, "Okay, like what and where?" and he says, "Well it's on your brain." he says, "It's the size of a peanut." So I says, "Right, an abnormality, peanut. So what do you think it is?" "Well it could be a lesion on the brain. It definitely shouldn't be there." So he says, "You'll be going to Beaumont, but we'll have to wait for a bed." So I was nine days in Letterkenny then, waiting for a bed in Beaumont. They kept coming in, just saying, "Yes, abnormality." I had an MRI the next day and he was like, definitely there's something there. So I had three more seizures.

I: Okay so, they were seizures what was happening there.

R: The second one was a seizure. The first one not so much. Definitely, the second one was because I was all over the place with it. Third one, yes it was a seizure. The next two were again. One was post-op, one was after the operation, but it was minor, but before I left Letterkenny I'd had four altogether. Three at Letterkenny, two in Beaumont. So that was it. At that stage it was like limbo land, waiting. Wasn't sure what it was, didn't know how serious. Didn't think at all that it was a tumour, not at that stage. Not until we came to Beaumont. The first doctor came in and said, "So, you have a tumour."

I: That was the first you'd heard of it.

R: Yes. It was the first time someone had said the word 'tumour' and he goes, "Yes, did your doctor at Letterkenny not tell you this?" "No, he didn't actually

- use the word 'tumour'. Everything else was used bar tumour." Lesions and abnormalities.
- I: They just came out with it there.
- R: So he just says, "Yes, it's a tumour."
- I: Okay and they could tell that from looking at your scans or had they done anything at that point.
- R: Yes. They hadn't done anything at that point. Just from the scans, but they didn't name it or they didn't give it a name. They didn't specify what kind it was at that stage until they'd gone in and took it away.
- I: So you had surgery then.
- R: I had surgery-, I went down to Beaumont on the Thursday of the bank holiday weekend, being told, "They work all over the bank holiday." No they don't. It was very quiet. So I was there and Tuesday they took me down for surgery. He says, "I won't be removing any of your hair." So it was just like at Alice Band across here. He says, "All I will do it cut a little circle out and remove it." because it was on the surface of the brain so, he says, "We don't have to go looking for it." which was good. So then I was like, "How long do I then have to wait for the results?" he says, "Usually a week, maybe a little bit more." So again, limbo land.
- I: Are you sitting in the hospital at this point?
- R: Sitting in Beaumont at that stage then. So that was Tuesday so that brought us up to the weekend. One had said, "You'll get home Friday probably and you'll have to come back next week for the results." Physio came and saw me on the Friday and said my mobility wasn't good enough to go home so they wanted to keep me over the weekend. So the doctor comes in on Saturday, tells me, "You're fine, you can go home. So get your husband down tomorrow." Sunday and off we went home with the view to coming back when they rang us during the week for the results. So I had to come back down to Beaumont for that. He says, "We won't give results over the phone so down you come." That was fine, we waited, Monday, Tuesday, Wednesday. I thought right, by Wednesday if they haven't rung us by Wednesday, we'll ring them. So rang them on Wednesday, got through to the liaison nurse and she was like, "Oh yes, can you

come down Friday at 12 o'clock?" "Yes, we'll be here for Friday. So me and my husband came down on the Friday and we met with the team, Mr Crimmins over in Beaumont, his team and the liaison nurse and another doctor, She's from Letterkenny, she was on the team as well. So the ones that I dealt with all the time in Beaumont were there. So they came in and they sat down and they were saying, "Yes, we got the results and it's probably not good. It's glioma astrocytoma and it's stage four." So at that I was like, "Okay that's not good. Stage four of anything is not good." So he says, "You'll be needing radiation and chemo and a lot of it and it's an aggressive tumour and it possibly will grow back again." So tears started and it was a bit stressful that day to say the least. I suppose they're so black and white about it, which they have to be, they have to tell you as it is, but for us it was, "God, now what?" About half an hour of tissues and tears. So then trying to get our heads round it then I suppose. They were like, "You'll have to come to Luke's." and they gave us all the details about here and that I'd be an in-patient and how long it would take. They were very good, they sat on and they didn't rush me or anything like that, but it's still hard to get your head round because it had been so quick and out of the blue. No history, there was nothing I could have done, should have done. Nothing I didn't do. It's just luck of the draw. So that was that day and then we had to drive all the way back to (home) and process all that and then go home and tell everybody.

I: You were going home to tell everyone.

R: We were going home to tell everybody then and of course, my husband was writing down stuff and I'm trying to process it and we were still getting it mixed up. So as I say, my three kids then. Two girls are at home, my son. So I rang them all and I says, "Look, [son] you need to come home for the weekend. We're all going to sit down together. I'm not doing this ten times. We'll sit down and we'll talk about it and I'll tell you what they said." So he came up for the weekend and told them what had been said. I would be the fixer of the family, I'm the one that does for everybody. Drives everybody everywhere, lifts and look after my dad. He found it a bit of a struggle now, he's 82 and as I say, I'd be the one that does for him.

I: You're looking after him.

R: Well, I don't look after him. He's quite mobile and he still drives and he goes to the pub and he does all that, but he doesn't drive any distances, I do all that. My sister has learning disabilities and she lives with him. So she's not processing it as we would, but she's getting there. They're all getting there. It's still surreal because it's really only been April, May, June. Eight weeks, nine weeks. So it's just been so randomly quick and then work and colleagues and friends, but I just meet people and they're like "Tricia we've heard you're not well, but you look great." "I have a tumour." I just say it as it is and deal with it. You deal with it now, I don't care I've told you now what's wrong with me. If I had a broken arm you'd be asking me how it happened. If I fell over and how did I break my arm, I'm telling you now.

I: It's the facts you're telling them and deal with it how you may?

R: Deal with it how you may, it's your problem how you deal with it. I'm dealing with it my way. I suppose I am dealing with it. I still find it a bit, "Okay." I'm not going down the whole route of, "Why me?" Why not me? It is me so I have to deal with it as best I can. I'm a very positive person, I'm going to fight this. Whatever it takes.

I: You were saying it wasn't anything you had done or you hadn't done or could do or whatever. Were they questions you asked the doctors when you were there?

R: Yes. Could it have come from anything? First of all, I was worried was it secondary, but it was a primary tumour. Didn't come from anywhere else because they did scans and that would have been probably one of my fears that it was somewhere else and had gone to the brain. Being a "healthcare professional" you don't like to hear these things, but no, he was happy and he was happy that he got it all as well because one of the other doctors had told us that he only got 80% of it and we were like, "Why would he only take 80%?" Then the surgeon spoke to us himself and he was like, "No, no I did it. I know I got everything that you could see." but this is why now the radiation and the chemo is for any residue and we'll see just to make sure everything's got.

I: You're trying to process all of that when they're telling you.

R: Yes. As I say, it's still surreal and I suppose going home at the weekends and trying to be normal when I know it's not normal, nothings normal at the minute. It's just not. I've never been sick, I've never been off work or I've never had to take time off work. It's the whole process of doing that as well, social welfare and sick money and sick leave and making sure that all that is in place. It's all the red tape as well. I had to get a medical card. I had to go to the social welfare for my sick pay, go through work for sick lines and it's doing all that while you're sick, but it's knowing what to do. Only for I have friends who've been through other stuff and I'm big in the union as well so, I know what I'm entitled to, but people that don't know, huge, huge problems. I have salary protection, I have critical illness protection and I would have done all that through the union and through my work, but I know people who have had cancer and have had nothing and nobody to tell them what forms to fill in and what way to go. Have had no money while they've been out sick or have had to go back to work previous to them being well enough to go back to work. Where I know, if I choose to retire I can do so on my full pay because I have salary protection. So it's a lot to have riding on your head worrying about money when you shouldn't need to. You should be thinking about getting well or just looking after yourself. I was lucky enough to have all that in place.

I: You were aware of all of that.

R: Yes. I work through [union], they do all our 'healthcare professional' insurance and stuff like that. He came out to the house, did all my forms, but I would have a good working relationship with him anyway through the union. As I say I'm lucky.

I: There's people who would probably struggle with it.

R: I know people who have had nothing and had to get money from their parents just to survive while they're going through cancer treatment. So for that people need to be made more aware. I said to the Corn Market fellow, I'll be your poster girl now. Everybody will have salary protection. They'll all be signing up. I know especially, for younger people starting out, you don't think. "I'll never be sick." It's out of the blue, you just don't know.

I: Yes you were saying things like, it's random and it's surreal and it's happened to you.

R: Yes. The most surreal thing that's ever happened to me I think, I can easily say is this because as I say, just one day sitting there and next thing a week later. "You have a tumour." I keep meeting people, "You look great are you sure you're sick?" I do try, you have to get up you have to have a shower, get dressed, slap on a bit of makeup and go out. Even if you sleep all evening and pass out for the rest of the day, get up and make an effort.

I: So since you left [hospital] that's your routine. You're making sure you're getting up during the day?

R: Oh yes, I haven't done any of this lying about. At the weekends when I go home now, my husband doesn't let me do a lot. It is, feet up on the sofa and he'll bring me whatever I want, but I'll make dinner and go out and get pedicures and have lunch with the girls. We go out for dinner. I still try and do something every weekend that's what I would normally do because I know come next week, I know that tiredness is going to start kicking in. It floored me yesterday. I just slept all day. Every time I sat down I fell asleep, but that's part of the process. I'm accepting of that, I know I'm going to be tired and I know I have to just rest and stop. I suppose the kids are all grown up. My daughter's 33 and has five children of her own and my youngest girl is 23 and has one and one on the way and my son is 32 and has one little girl. So they're all busy. So there's seven grandchildren and one on the way, but as I say, I would have done a lot of babysitting for the five grandchildren. So I don't do that anymore. While I'm there I do a bit because they're babies as well. They're all under seven. It's not that I wouldn't trust myself, but if anything happened because I can't drive, I just wouldn't be on my own with them because you need to have your full wits about you with little ones.

I: Absolutely and the energy needed.

R: Absolutely and they wear you out. I go and visit them at the weekends and do all that, sit on my knee and they're all aware granny has a bad leg.

I: Is your leg still sore?

R: My leg is numb.

I: It's numb, but you're able to walk?

R: Yes. It's not numb, the sensation is like a dead leg, but I can still walk. I do have to concentrate on it. I can't wear flip flops or loose shoes, hence the lovely Sketchers. That's all I wear these days. I do wear different ones if I am going out, but I have to be aware of them. Something tighter or lace up. Heels are gone and driving has gone.

I: When did they tell you that?

R: Well, anything with a seizure you're not insured and you have to be a year free of seizures afterwards as well. So probably about two years I'd say before I can drive, which is devastating because that's my car and my independence. That's probably more annoying than the fact that I have a tumour. It's my independence and I'm not driving that long in the bigger scheme of things. I'm only driving since 1999. So not that long really.

I: You were saying you usually Drive everyone else around-

R: Take everybody, yes, but it's their turn now. They're all doing payback. It's great. I have a great bunch of friends, a small circle of friends, but they're great and the family are good and my husband's great. He works in IT. We only got married a year and a half ago.

I: Oh congratulations!

R: I've been divorced from my first husband. We're separated 22 years. My youngest girl was only one when we separated so that was over yonks ago. Then I met [husband] five years ago and we got married a year and a half ago. So that is also a bit like, you wait all this time to meet a good person and the right person and look at you now. Which is tough as well, it's tough on him. It's tough on him, he's English and he hasn't got a big circle. He's got family outside [county in west of Ireland], his ex. It's hard for him and every now and then we have a little blow up because I'd be like, "We have to talk, I want to know how you're feeling and how you're dealing with this. I need to know that you're okay when I'm not there." "I'm fine, I've been through this before." "You haven't been through it with me." His dad died of leukaemia when he was 42 and he has four brothers. His mum brought up five boys on her own. Well, they were nearly grown up at that stage, he would have been the second

eldest and he was only in his 20s when his father died, but this is his, "I've been through it before." "I know, but you haven't been through it with me and that was different, it was leukaemia, totally different." "No, I'm fine." and that's how he deals with it, but I'm like, "You need to talk to me and you need to let me know how you feel." He's not a chatty, this is how I feel kind of person. He's quite emotional, he gets upset.

I: Does he say why he's upset?

R: No. Well, what he said is he would take this from me if he could. He doesn't want me going through this, he would rather go through it. He's that kind, he's just so good and so genuine, which part of me thinks, "We've only just got where we need to be. Why now?" Not why me, but why now? 20 years' time would have been fine.

I: You have only just started your time together.

R: Yes, but we'll get there. We've a lot to do yet.

I: Does he come here to visit you?

R: No because he is off the weekends when I'm at home. So he can work from home on a Friday when I get home and then he's off Saturday and Sunday. So I'm at home all weekend and then during the week my daughter comes up or my son comes over. So they do during the week, he does the weekends.

I: I was wondering if being around the hospital either upsets him or makes him talk more or anything.

R: No. He doesn't mind that, it's the fact that he wants to be at home all weekend and not doing work at the weekend. That's the way it was worked.

I: It's nice to have.

R: It is and he takes me to the hospital on Monday morning and collects me on a Friday and then we have Saturday and Sunday as well. So we can either be around the house or go off ourselves and do something. So it's good to have him at the house for the weekends.

I: So you may be reading it from him that it's tough for him, rather than him-.

R: Telling me. Yes, I don't know, does he think he's protecting me by not telling me how he feels or protecting himself? I don't know. As I say, when I did push

him he just got upset and I don't want him upset when I'm not there either, but he probably is.

I: You think.

R: Yes, as I say he's quite emotional. The least wee thing if I'm upset, he'll cry. That kind of way.

I: He's probably very sensitive is he?

R: Very sensitive. I'm probably tougher than him. Whereas, my I'll cry at the drop of a hat, sad ads on the telly or things I record, which I probably shouldn't watch when I'm upset. I'll be blubbering like a poon.

I: It's nice to cry with something.

R: Yes, get it out. I do, I have my odd cry every now and then.

I: That's what I was going to say, if you don't mind me asking. Since all of this has started, have you been upset much?

R: Yes. Not much, I think enough. I don't mean that like you have to be upset a certain amount of times. For me, it's working, talking to people. As I say, I have a great bunch of good support and I can talk to the people that I can, genuinely and openly and lots of them are 'healthcare professionals' and they know the medical side of it, but they're friends as well and they know how I am feeling. So that kind of way, we've been friends for so long and then there are people who, out of the blue want to be my friend again. It's like, "Oh, you're just nosey. So I'll tell you nothing."

I: Some people just want the gossip.

R: Yes that's it. I know who they are.

I: So you have people you can be upset with.

R: Yes.

I: I was wondering, in the hospital space on a ward. Do you feel you have the space to be upset if you want to?

R: Yes I think so. There's quiet areas and I don't feel the need here. I suppose because it's clinical, it's more black and white. Since I've been here it's been all good. I'm happy to be getting the treatment and Dr Fall is happy with the way the treatment's going and I suppose medication is one of the things that-, not annoys me, but I know the steroids is giving me this bloated face and I don't

like that because I've just spent the last two years at Slimming World and that's all my good work gone, but I'll start again after. It's a by-product of what's going on.

I: Of getting treatment.

R: Yes it's part of it, I know that. They're reducing the steroids again today so they are. So hopefully this will come down another bit.

I: That's connected is it, the steroids come down.

R: Well, steroid treatment and I am classic. This face. They say you get a 'moon face'. Swell and around the back of your neck, but I know that from steroids anyway, from working with-, being a 'healthcare professional', I know it's part of it and it goes.

I: So the medication would have been something that frustrated you or upset you.

R: Not upset me because I know I have to have it because the steroids are reducing the swelling on the brain as well, which is reducing the lack of feeling in my leg because it's left side right side weakness. I know all that it's just, "Oh god, do I have to get fat again?"

I: You know all of this, but you can still feel things beyond the logic of it.

R: Yes. It's knowing the logic and then it's like, "But do I have to go through this again? Do I have to lose it again?" Steroids will give you an appetite as well and I'm at home justifying, "I'm sick I can eat what I like. I want that I'm going to eat it, why not?" I'm just a huge believer in do what makes you happy. If it's have a glass of wine, have a glass of wine. My husband is like, "You're not drinking wine Tricia." "I am going to have a glass of wine and I don't care what you say and you're going to pour it."

I: What's keeping you happy?

R: What's keeping me happy? I suppose the support I'm getting from friends and family, my husband and the fact that I've always been optimistic anyway. Keeping things real I suppose, as real as I can. Thinking it's shitty, but do you know what there's worse things happening as well and I've things to look forward to. I've got weddings coming up and my brother's going to come over from Wales. He keeps on saying he's going to come over just for a day trip.

“Why would you come for a day trip from Wales? Come to (home) and see the whole family and spend a weekend.” “No, no I’m going to do a ninja job.” he says, “I’ll flit in one day on the ferry and go home again.” “Okay, whatever makes you happy?” I suppose pulling back a bit from organising everybody. Sort yourselves out, I’m pulling back. My two daughter’s would be quite niggly at each other. [daughter] is 33 and [daughter] 23. Two different generations. They are arguing a lot at the moment. So I’m like, “Girls come on, sort yourselves out. I don’t need this stress really. So it’s still ongoing. They’ll get there, but I’m not getting involved. I try not to get involved. I still have my little bit of input, but I try not to. There’s no point in me fighting with them. Let them sort it out.

I: You’re kind of self-preservation is it? You’re trying to mind yourself?

R: Yes than getting stressed because it upsets me when I know that they’re sisters and they’re family. One’s as stubborn as the other you see, they’re just two stubborn girls. As I say, I’m pulling back because this is not doing my head any good or my emotions. So you sort yourselves out.

I: So it’s looking after yourself.

R: Yes and I know I have to do that. I know I have to step back and let them at it. Let them off. They’ll sort it. They will sort it, they’ll have to sort it. My son sort of gets caught in the middle as well. That’s the way they are at minute, but they’ll come around. They’ll have to, they’re family and they will, they’ll come around eventually, one of these days.

I: How are they getting on in terms of you being up here and your diagnosis and everything? How are they coping?

R: I think they’ve all been on Google, which is not good.

I: They searched the diagnosis on Google is it?

R: Google will always fire up the worst scenario first. I told them, “Don’t go near Google.” “Too late mum.”

I: What makes you think that they were on Google?

R: Oh, they’ve all said it.

I: Did they tell you what’s on it?

R: No. The two older one's would have come to the oncology department with me over in Beaumont the first time I met [doctor] about the chemo and all that and where that's going. Of course, they wanted-, my son wanted me to ask about prognosis. So I didn't really want to. So I did ask and he goes, "Do you want to know?" "Not really." He said, "Then I won't tell you. I don't work on that kind of statistics anyway. I like to see how we go. We'll talk today and half way through the treatment we'll talk again," which his next week and he says again that the end, "But I can certainly tell you if you want to know." "Not particularly." Damien was kind of like-, I says, "No, it's me. If I want to know I'll ask. You can just wait." but then of course, Google. I think they'd been on Google the day after I got the diagnosis of a tumour. So how they deal with it is how they deal with it. They're in their 30s, they're big enough to process. They do find it difficult definitely. I'm their mum and they think I'm going to be around forever. Please God, I'll be around for a while yet. Yes I suppose they deal with it however they deal with it and that's as much as I can hope for at this stage. I'm not there to tell them how to deal with it. I can only deal with how I feel at the minute and because it's been so quick, it's still difficult to process.

I: To wrap your head around.

R: I suppose being here all week it's the medical side of it and then going home at the weekends it's home life. It's a big divide.

I: That's fascinating, can you talk more about that?

R: I suppose coming here on a Monday and especially, being on the ward as opposed to being in the Lodge. I've talked to some of the girls that are on the bus about being in the Lodge. They're all in the Lodge, I think I'm the only one that's on the bus that's on the ward. Where they would talk about meeting in the evenings and having a bit of a social get together over in the Lodge. Whereas, on the ward it's more clinical. You get your tablets at a certain time you get your dinner at a certain time, you get your treatment at a certain time and everything it structured and for me during the week that's fine. I'm happy enough doing that. I think it maybe takes some of-, what's the word? Not your independence, it helps me deal with it I think a bit during the week because it's

structured or maybe it's a way of not dealing with it because it's structured and this is the time you get your tablets and this is the time you get your dinner. Whereas, at home then I am dealing with everybody's emotions and everybody's dramas. Times are different and visitors. Home is different, where here is clinical. This is my treatment and I can deal with that. I think if I was at home and having to travel to get my treatment every day and deal with emotions and deal with dramas, I think that would be hard. Whereas, I find this good. I can read if I want, I can sleep if I want. I can go for walks, but I know that at a certain time I'm going to have my treatment and I'm going to have my tablets. It's fine and then at home over the weekend, I can deal with what I have to deal with in that two and a half days. So when I go home after all this treatment I don't know how I am going to be.

I: I was just thinking that when you're finished with the structure that here gives you.

R: Yes. Then it's reality. I don't know, would you find the hospital environment reality? It is reality I suppose, but not your home life. It's just not your life, it's a different way of being. It's just different because it's the hospital environment and it's the ward environment.

I: Yes and you don't really have to think about anything other than getting up for your breakfast and having your day planned out for you.

R: If you want to stay in bed all day you can. Whereas, I don't. I get up and I get dressed where everybody else on the ward doesn't. I am the only one that will get dressed on the ward. Everybody else stays in their pyjamas or in their beds, but I get up every day. Have my shower, get dressed and even if I don't do much to me that's how I cope because I wouldn't sit around at home without getting up and getting dressed.

I: That's a really interesting description of it. I haven't thought of it in that way. Here almost minds you. You're being held for those five days and then you go home.

R: Yes and you have to have a normal life at home or not. Come this weekend, if I'm tired I may not get dressed, but I'll have that choice. I have the choice here as well not to get dressed if I don't want to, but I do because I think this is what

you said you'd be doing, this is you. You wouldn't generally not get dressed unless you're having a day when it's a miserable day and you think, "Right, sofa day today. Let's just have the pyjamas and old movies." which is good too, but I do find the ward situation as opposed to the home situation different and talking to the girls that are in the Lodge, they come and go and they do their own thing. A lot of them go to James' for their treatments as well. I think I'm the only one on the bus from (home) that has all my treatments here.

I: Everything is happening here.

R: Which is good.

I: Yes.

R: I'm quite happy here and people keep saying to me, "How do you cope up there five days?" It flies.

I: I could imagine being on a busy ward-, I suppose it's not as busy as some wards, but it's still hustle and bustle, but it doesn't bother you.

R: Not at all, it's fine. I enjoy the crack. I'm a people watcher anyway. The stuff that goes on in that ward, I'm keeping a diary as well.

I: Are you?

R: I am. From the day I came in I said, "Right I'm going to keep a diary from the first day until whenever." So I am writing down every day and I keep reading back and thinking, "Oh god, yes that happened that night." There's a few characters on the ward.

I: Do you write about your feelings in the diary?

R: Some pages. Yes, it's more that I can look back down the line and think where did this start from and just keeping it for that. I suppose looking back and seeing how I was and were there dark days or not? There's been no dark days yet I have to say.

I: No dark days as in days when you're feeling down is it?

R: Really down, miserable, poor me. Thank god, no. Dark moments I suppose. Not even dark, moments when it's been okay that wasn't good. I have a good cry or think this is not good, but then it's like, "Okay it's not good, but do you know what, it's not the worst thing. I'll get there."

- I: What are you thinking then with your meeting with [doctor] next week? Have you rethought your previous decision not to ask for a prognosis or are you still on the same-?
- R: No I'm still there. I don't particularly, unless something drastic happens and I think, "Right, I'm going to need to know. Now, is there things I need to put in place?" Even with Corn Market, the insurance, I have to make a Will, but a year ago I was still thinking I have to make a Will. Before all of this. Not that I have anything to leave anybody or any huge amounts to do with, but the likes of salary protection and all that comes with benefits. So you have to make a Will, but that would have been part of what I was forward planning anyway. When I was doing it all anyway and it's one of those things that you put on the long finger and you think, "I'll never need a Will." but again, it's like salary protection, everybody needs to have a Will made at some stage.
- I: I was just even thinking to even go about-, like you were saying, it's a process organising salary protection and stuff, as you can tell I haven't, but to set up salary protection, you're thinking one day in your head I might need my salary protected because I might be sick. So it's similar to a Will and that someday I might need this.
- R: As I say a Will is the next thing, but it's not because of this, it was just something that was going to have to happen anyway.
- I: It was already something you were thinking about. So your son or your family hasn't been on at you to ask again. It's not the same thing again coming up to this meeting.
- R: No. We're not even sure I suppose, it's half way through so my daughter and my husband, I don't know about Damien, whether he'll come across or not, but there'll be three of us there. So I always like to have a few of us that we can pass information back and forward, "Did he say that, are you sure? I thought he said something else." but he's very good so he is. He's a bit black and white I suppose, he tells it as it is, but he's good, he's nice. He's young.
- I: What's your preference for communication styles? That's just something I am looking at as part of this project.

R: I suppose as honest as possible. There's no point in wishy-washy. We did get some wishy-washy things in [hospital]. As I say that one doctor who told us that they only got 80% of the tumour. Another day, he came out with something like, "You won't be sick." "Are you sure I won't be sick?" "Well, you might be sick." and I'm like, "Are you a doctor or what are you?" You're supposed to be a consultant, say it as it is. So we didn't really have much dealings with him. For me personally, say it as it is, let us process. If it's going to be hard maybe pre-warn us that it's not good news or it's difficult or whatever, but be honest. I think you can only process information that's straight up. How do you process a wishy-washy answer?

I: Yes, you're right.

R: You can't. Anyway Dr [radiation oncologist] has been great. She was in with me this morning, "You're going to lose your hair." "Thanks."

I: She said that.

R: Yes. I was like, "Okay." "Yes, probably by next week you'll start to lose it."

I: Okay and had you asked?

R: No, not today. I think I was just out of the shower so she must have known. Do you know what again, it will either come back or we'll do something else with it.

I: Is it something that's on your mind?

R: No. My daughter's a hairdresser anyway and as I say, I have good growth so I can handle it either way, long or short. It's a bit grey now, that I would never have had grey hair.

I: I can't see it.

R: An inch there.

I: It must be the light, I can't see anything. It just looks brown.

R: It's fine. I text [daughter] then and I says, "Looks like we're going to need a wig." but I don't even know if I want a wig. I might just go with scarves, but I have my stepson's wedding coming up in July that I plan to be at on 18th July. It's my last week of treatment.

I: Is it on the weekend?

- R: No, it's on the Monday. I think they got a good deal for it being on a Monday and it's school holidays, kids are off anyway. So Monday works for us now, anyway. So she knows I won't be here for the Monday treatment, but I have to be here for Tuesday.
- I: So it's possible for you to just maybe skip a day?
- R: Yes. As I say, that's my last week anyway. So even if it's Tuesday, Wednesday, Thursday of that week instead of Monday, Tuesday, Wednesday.
- I: Oh I see, it's not a full week anyway.
- R: No, it would have been my last week of treatment. So I think it's only three days that week anyway. So fine.
- I: That's okay yes so, you're thinking maybe of getting a wig for that if you need it?
- R: No. Well, I won't know until the week previous. I know I won't be looking for a wig, but-
- I: So many people say that.
- R: I don't think I will, but you never know. I might just want longer hair.
- I: Exactly yes and so many people's opinions change on it was well. Do like you're saying probably, the week before is the time to make the decision.
- R: Well or the week before that even. As I said to [daughter], "We might need to go and look at wigs." and she says, "Right." So I'll see her at the weekend and we'll see what she thinks because she's always done my hair anyway. I don't know how she'll feel about getting rid of it. I don't know if she'll process that well or not because I have a fuckin' scar here as well, it's like an S-shape.
- I: Can you feel it is it?
- R: It's there, it's where he did the surgery and it's still not properly healed because it's only been five weeks since the surgery. So I don't know whether she would want to do it or go to somebody else to get it done, but then I don't want a bald head either with a dirty big scar across the top of my head. So I will leave my hair the way it is at the minute and see. I know she said it will come out, but it may only come out around the radiation site as well.
- I: I haven't met anyone who has lost all their hair.
- R: I have. One girl on the bus and it happened in her first week.

- I: Is she getting treatment like yours?
- R: No. She has breast cancer.
- I: No, anyone in this study who I've met getting treatment to the brain, theirs has only gone-.
- R: At the site.
- I: Yes that's it. I haven't seen anyone lose all of their hair.
- R: I don't want a bald patch here either and hair everywhere else.
- I: People find great ways of-, just even a comb back or side, it covers it.
- R: I can go the other way with my hair or [daughter] can cut it. I don't mind a shorter cut, but I'll be more grey then.
- I: You're not able to dye it.
- R: I'm not able to dye it, no. I think you can put a semi-permanent in. We had that lady up yesterday, the feel good. She was saying you can put semi-permanent in, but then because this is still not healed properly, I don't know about putting hair colour on.
- I: You'd probably be best asking one of the nurses, they'd be able to tell you because I know someone had a question about it before and they asked the nurse specialist and she was able to advise on that.
- R: Yes so, I might do that.
- I: There's so much going on it sounds like.
- R: I know. To me there's so much to take in for something that happened two months' ago. You're supposed to process something like this for years. Then everybody has to start somewhere.
- I: You've been expected to really get to grips with everything very quickly.
- R: Yes in a short space of time.
- I: Is there any time where you feel up to speed with it?
- R: Most of the time. I suppose my-, I don't like using the word 'darker moments', moments would be 3 o'clock in the morning when I can't sleep and when you're lying there and thinking, "Right what now? What do I have to do now? How am I going to get to sleep?"
- I: You wake up.

- R: Yes for a while there I wasn't sleeping. I'd be waking from two, maybe to six and try and stay away from the phone or the tablet and not putting the light on to read because Nigel doesn't sleep well either. This is when I'm at home. He doesn't sleep well, the least wee movement and he's awake and I am trying not to wake him and then he tells me he's been awake anyway, "Why don't you talk to me?" "Because I didn't want to disturb you." So the two of us are lying there awake not wanting to disturb anybody. It's crazy, but most nights I'm okay now. There's still the odd night I'll wake up and think, "Right, this has to be done. What if you get on well and you need to-, will you write letters to the kids and plan my funeral or-?" music for my funeral and things like that. Then I think, "Stop it, you don't need to be talking about that or thinking about that." Then it will creep in again. It's like niggling there saying, "Oh, but you do. You need to think about these things." If this does happen it's a process as well, but generally no. There are times it will sneak in and I think about it and talk myself out of it.
- I: Okay so that's how you manage with those thoughts.
- R: Yes. I can, "No, you don't need to be thinking about that just yet." but it's there and you know what you want done or you think you know what you want done.
- I: So you do go with the thoughts a bit then.
- R: A bit because again, it's a process and you just don't know. No more than this coming out of the blue. Things could happen, it might just not go away and it's something that needs to be dealt with as well, but I generally don't think about those things for very long when I get back into my own way of thinking then.
- I: Your optimistic way of thinking you were saying.
- R: Yes and even when I am thinking about them, I'm not thinking in a bad way. It's not doom and gloom, it's celebrate what you have done and what you've achieved. That kind of thing. I've got great kids. Great grandkids. Great family. Great friends. Celebrate that.
- I: So it's not that doom and gloom part it's you're looking back and seeing this great achievement.

R: Yes, I've worked hard to get where I am and went through a lot of dark days to get out of them. So I have no relish to go back to them so, I'll keep the happy head on me.

I: Thanks for telling me that.

R: As I say, a lot of dark days, a lot of tough days so there was, but I came out this side of it.

I: Even getting through those nights that sound so difficult, in itself is an achievement.

R: I think most people will tell you if they're having bad times, it's the middle of the night when they can't sleep and everything seems like, "This isn't good." but as I say, I'll chat away to myself. Tell yourself you've done well, you still have so much to do, places to see. Last year I was away five times. That was a fluke, a complete fluke. I was in New York for St Patrick's Day. I know, my husband paid for that for me for my birthday. Five girls went away to New York for five days. That was great. We won a trip to Paris, me and him. So we went to Paris at the end of May and then we had already booked to go to Portugal with my dad and my sister. So we took him to Portugal and then myself and my husband, we try and get away ourselves. So we went to the Canaries in September and then with the union, I was in Lisbon in October. So I was away five times last year.

I: That's fantastic and it spread out lovely.

R: Yes the whole year. That was definitely a fluke though. The Paris trip we won, I did a Valentines competition at Shannon Airport and won a trip to Paris. So that was good. Last year was good, did a lot of travelling last year. This year, not so much. We had planned-, the week this happened we were supposed to go to Portugal.

I: You cancelled.

R: The apartment was fine because it was on bookings.com so we didn't lose anything on that, just cancelled that. The flights was EasyJet and we contacted with them and within two days they had us, not refunded, they had us a voucher for redoing the flights. So they say within six months, but if I'm not

allowed to fly within the six months we'll contact them again and just let them know and see what they can do for us. I'm hoping to go away.

I: The month that you're off from work is it?

R: I'm off work until I decide to go back, which may be never. Between the end of this treatment and the start of the chemo.

I: So you have that month in between.

R: A month so, I will see if I am allowed to fly. Yes so, we're hoping. Even just to get away for a week me and him because he loves the sun and it regenerates him. Getting away to the sun, I think it will be good for us to get away. We'll see, if I'm allowed to fly we'll go.

I: Will you be on chemo then for-?

R: Six months.

I: Six months after this. Okay and how do you feel about that?

R: Fine. I don't care what I have to do. There was even the notion that if it comes back, it could mean more surgery, depending on when it comes back or if it comes back or how soon it comes back. It could be a different type of chemo. If it comes back sooner rather than later, it will be a different type of chemo. If it comes back later, it could be more surgery, which is okay as well.

I: So it depends on the different options depending on if, when, what way or something.

R: Yes because it is an aggressive type of tumour the doctor is very sure that it will come back in some form in time, but it depends on the time. As he said, if it's sooner rather than later it will be-, they'll look at options and it could be a different chemo.

I: You'll go for surgery?

R: I'll go for whatever. Whatever, clinical trials, send me anywhere.

I: Did they talk to you about any of that?

R: They have said that if clinical trials would I be interested? So, yes.

I: Does this all happen in the same meeting?

R: Yes probably.

I: There seems to be so much.

- R: Yes there is a lot to process when you talk to them and it's different people as well. Different members of the team would maybe come up with different-, with the clinical trials, when I was in [hospital] they were in and out to me sort of because they would have been in daily to me through the surgery and all. A different doctor would say, "There may be different trials that come up. Would you be up for it?" and I'm like, "Yes." and I did a blood test for one clinical trial for the Royal College of Surgeons and that was fine, it was just blood tests to be part of a trial for that. So that doctor has already said, "If more trials come up would you be interested?" and I'm like, "Yes."
- I: So your name's there if a trial comes up, sign you up.
- R: Yes, depending on your criteria I suppose. If you fit. I'm happy enough to go with whatever. As I say, if it's more surgery that's needed go for it. If it's-, I don't care. I'm up for anything to fight this.
- I: Yes and after surgery, do you feel-?
- R: I don't generally do well after anaesthetic.
- I: Is that what they're saying or would you be up for surgery again, is it the anaesthetic?
- R: No, no. He didn't even say, "Would you be up for surgery again?" He was like, "You may need surgery again." and I'm fine with that, that's whatever. Even if I don't do well after anaesthetic, I've never done great after anaesthetic. I maybe take two days to recover, where somebody might take a day or half a day, but that's fine as well. I'm aware of it and I know.
- I: Yes, like you say you'll do what you have to do.
- R: Absolutely. Absolutely and up for anything. Whatever it takes.
- I: Is your husband of the same thinking?
- R: Oh yes, he's completely the same. We've such a lot to do yet. Lots of places I haven't seen.
- I: I know, I can't believe you only married a year and a half ago.
- R: October, it will be two years now in October.
- I: I've covered all my questions that I wanted to ask you.
- R: I probably rambled on too much.

- I: Oh no, absolutely not. Thank you so much for being so generous with your information and your story. So brave, thank you so much. When you were saying that you were able to cry, I was wondering how are you able to talk about it and keep yourself together.
- R: As I say, I have done crying and I am sure I'm no finished crying. I went home last week-, I would be a big fan of-, I love Casualty and Holby City and in Holby City of course, there was a big story line where one of the doctors had cancer and he died and of course, I recorded it and sat down to watch it. Nigel was working upstairs and I sobbed, but I think a lot of it was release as well and I just sobbed and sobbed and I thought he's going to come down the stairs now in a minute and think she's lost it, but it was all to do with the story line as well because I'd been following it, but I know part of it was a release as well and when it was done it was done and I was like, grand clean your face now, go and pour yourself a glass of wine and I was fine.
- I: So it's the release?
- R: Yes, it was all that. He wasn't there and I thought, now I can do this and I'm not upsetting anybody by having this good old cry and I suppose, part of me was telling myself it's the story line, knowing that it wasn't all the story line and that was fine too. It had to be done. A good old laugh or a good old cry. Yes so, I think I'm doing okay. My friends all tell me that being so optimistic I'm doing well and keeping them-, I try and put a thing up on Facebook every day, a positive thing in the morning and I send-, me and the kids are on a Viber chat. So first thing in the morning it's, "How are you all?" Tell them a bit of crack that happened over night in the ward. So yes, all good.
- I: The stuff you put on Facebook, what's that?
- R: It's usually just a positive saying or a picture with a positive attitude on it or something. Generally just that.
- I: Yes, every day something positive.
- R: Something positive for me, but if it's not right I wouldn't put it up. Something that's a wishy-washy thing just for the sake of putting it up. It has to suit me and has to be something that's mine.
- I: Yes and your friends are watching that.

R: Yes and they'll answer, "Good on you 'Aoife'. You'll kick this." and that kind of thing. And the diary, it's good for me and I suppose it's something I would probably want the kids to read and [husband] as well, later. Maybe not, it might just be for me. I haven't decided yet. I'll decide when I look back on it because I'm always one for keeping diaries and looking back on them.

I: Yes and just seeing where you were at, at that time.

R: I haven't really ever kept focused diary. This is probably the first time to be specific, but I wanted the start of the treatment to go to wherever. It's not necessarily going to finish in six weeks when I'm finished here. I'll keep it going. Friends of mine-, I follow some blogs. I don't like blogs as such. I don't know why, it's personal to the person. I think putting it up on Facebook and I think, "No, keep it to yourself for now." While it's good to see what people are going through, "No, I'm not going to follow you for too long."

I: Is it specific to people who are on treatment?

R: There's one, one of my friends at work, her sister-in-law is going through chemo at the minute and she has a blog up. I did start following it, but it's a bit too depressing. I think while it's personal to you, if you're down and you're putting it up and someone's reading it and you're having a bad day and you've put up that you've had a bad day and why you've had a bad day. It's like, "I don't want to read that today."

I: Especially, when you need to focus on being-.

R: Which is why I would probably only put up one positive or if I find something else that's positive, I'll put that up as well during the day, but whatever's going on in my head can stay in there for now and I can process it. Be it good or bad.

I: Like the processing, you were saying that something doesn't come to you at once. You know the way you were saying this whole journey, this whole diagnosis, any piece of news you get, you don't process it all of a sudden it's a gradual thing.

R: No because I like to have a couple of us there, there's always been two or three of us with the doctor or with nurses or with whoever, you can bandy back and forward what they said and make sure that you actually heard what they said because there's nothing worse than thinking, "He said that." "No he didn't, he

said something else.” and I’m like, “Oh yes so he did, now I remember.” and it’s when you hear it said back through a few others, then you can work on that.

I: Okay and you’re processing that together or sharing information.

R: Then they’re there as well. They’ve been there, they’re not getting it third hand or they’re not getting a watered down version of it or if it’s just me that’s heard something and I’m like, “Actually, I’m not going to tell the kids.” where [husband] would be, “They need to know today.” which the day he was with me when he got the diagnosis, he says-, I’m like, “I’m not telling them until over the weekend.” “No, they need to know now. They’re sitting at home waiting to hear what was said.” and I’m like, “I’m not telling them over the phone. That’s not right.” “Well, at least tell them you’ve got news and they need to all get together.” That was that day. So we contacted them and said, “We need everybody together, let’s meet up.” and told them a little bit, but not much over the phone. Once we got together it was everything, it was like ‘spew’. As I say, that’s how I work anyway. That’s how I deal with things and always have.

I: You gave them the information and they know what you know.

R: Yes they know what’s been said and we can work on it together then and they can ask me stuff and how I feel and I can ask them how they feel.

I: It sounds like very organised?

R: I don’t know is it organised or is it selfish? It’s our way and I suppose we’ve always been like that because of stuff I went through previous. I think (as a result of professional background). So I did a lot through talking and I am a firm believer, get it out there. That’s the only way of processing stuff because once it’s out there and said you can work on it.

I: Has your training as a healthcare professional-, you’re in a medical setting now. You’re in a health system. Has your training as a healthcare professional fed into it at all?

R: It’s very different being a patient and being a healthcare professional. It’s very different. I’m like, “But I know what to do with that.” but you’re not allowed to. “Give me my tablets, I’ll sort it out.” and I’m conscious as well that there’s ladies on the ward that aren’t good on their feet or they’re playing with their drips and I’m thinking, “Stop.” There’s one lady up there and she’s not allowed

to drink, she's 'nil by mouth' and we keep catching her drinking out of bottles of sterile water or drinking from the tap. "You can't do that." "You're not my minder." So I am trying to-, but it's difficult and you don't want to see anybody getting sick or falling. So I do a little bit. "Don't be drinking." "I'm just cleaning my mouth out." She's so funny. That's why I like to be on the ward because I like to people watch. It passes the day as well, it's great.

I: That's really interesting the 'healthcare professional' versus patient.

R: Yes, I suppose it can be difficult to pull yourself back. Allow yourself to be a patient.

I: Are you letting yourself be a patient and to sit down?

R: Yes. You need to have to tell yourself, "Stop, you're not at work. Sit back and rest." but I am getting there, I'm a good patient.

I: Well that's everything. Thank you so much for everything. Is there anything I've missed out on?

R: I don't think so. I'll probably think of something again.

I: Maybe write it down and you can let me know if we meet again.

R: I'll be here for another four weeks. Even the last week if you want to meet?

I: No pressure, only if you want to, but I would really appreciate that.

R: If you want to in the last week and see where we are.

I: Yes. That would be fantastic if you don't mind. Just to see how treatment went and everything's gone in the last six weeks that would be great, but no pressure. You can change your mind if you feel like you want to.

R: No that's fine, absolutely.

I: Thank you so much for your time.