

**Mothers' lived experience of 'giving
medicines' to children with severe and
profound intellectual disabilities**

A thesis presented to the University of Dublin for the degree of Doctor
in Philosophy

By

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Declaration

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Summary

Background

Children with severe and profound intellectual disabilities experience multiple chronic health conditions that require a large variety and number of medicines. Mothers take on the responsibility of 'giving medicines' on a daily basis with their child with severe and profound intellectual disabilities. There is a dearth of literature pertaining to this phenomenon and therefore the impetus for this research was borne out of not only a personal interest but a clear lack of recognition and understanding of the essence of mothers' lived experience. No comparable work was located and this research study was developed to illuminate the topic.

Aims and objectives

The overall aim of this study was to explore mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities. The range of activities mothers undertake were identified and associated challenges highlighted. It was clarified how mothers learn to 'give medicines' and the meaning of the phenomenon was explicated in order to demonstrate an understanding that might have implications for both families and children with severe and profound intellectual disabilities and healthcare professionals providing services also.

Methodology

A hermeneutic phenomenological approach guided by the work of van Manen (1990) underpinned this research study and focused on interpreting and understanding what it means for mothers to 'give medicines' to their child with severe and profound intellectual disabilities. On gaining ethical approval, purposeful sampling was adopted to include 15 mothers of children with severe and profound intellectual disabilities who experienced the phenomenon. Multiple in-depth face to face interviews and participant diaries were utilised for data collection. Van Manen's method for thematic analysis was used to analyse the data and extrapolate the key essential themes.

Findings

The findings provided an integration of the views of participants whether gathered through interview or diary. Findings presented were supported with direct quotations to reinforce the issues under consideration. A total of 20 essential themes were identified through the process of hermeneutic data analysis and presented using the five existential dimensions endorsed by van Manen (1990). An array of activities was evident in terms of 'giving medicines' with insight given into the key relationships mothers experience in their role and the resultant impact these have on daily life. Furthermore, the challenges mothers experience in 'giving medicines' and knowing and learning key associated skills were expounded. Both the physical and emotional bodily experience of 'giving medicines' was explored with dominant feelings identified. The dimension of 'time' provided an understanding of mothers daily lives with the concept apparent in all of the mothers undertakings. Being organised was identified as paramount to coping with the unpredictability of care. Additionally, the material 'things' that influenced mothers' experience of 'giving medicines' were associated medicine equipment, documentation and the cost of medicines. A richer, deeper understanding of the phenomenon was depicted and it was determined that mothers experience of 'giving medicines' to their child with severe and profound intellectual disabilities is a relentless and challenging, yet invisible element of caring.

Conclusions

This study provides insight into the phenomenon of mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities. The adoption of hermeneutic phenomenology and presentation through existential dimensions makes it possible to understand the phenomenon as a human experience shared by the participants. It has captured what the lifeworld of these mothers looks like and has identified the challenges experienced by them in 'giving medicines'. The findings and in-depth discussion and interpretation of these resulted in identification of implications and recommendations for research, education, practice and service provision. Through addressing the gap in understanding and exploring the meaning of this phenomenon it may be useful in developing care for mothers and children with severe and profound intellectual disabilities.

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Finally, I would like to dedicate this study to my 'boys', Rich, Charlie and Harry.

List of Abbreviations

A & E	Accident and Emergency (emergency department)
AED	Anti-epileptic drug
ANP	Advanced Nurse Practitioner
CNS	Clinical Nurse Specialist
CP	Cerebral Palsy
DCYA	Department of Children and Youth Affairs
DES	Department of Education and Skills
DOH	Department of Health
DOHC	Department of Health and Children
DSFA	Department of Social and Family Affairs
GOI	Government of Ireland
GORD	Gastro oesophageal reflux disease
GP	General Practitioner
HPRA	Health Products Regulatory Authority
HSE	Health Service Executive
ICGP	Irish College of General Practitioners
IQ	Intelligence quotient
JEJ	Jejunostomy feeding tube
LTI	Long Term Illness
MHRA	Medicines and Healthcare products Regulatory Agency
MOCHA	Models of Child Health Appraised
MODRIC	Manipulation of Drugs Required in Children
MMP	'My Medication Passport'
NG	Nasogastric tube
NHS	National Health Service
NIDD	National Intellectual Disability Database
NMBI	Nursing and Midwifery Board of Ireland
NMC	Nursing and Midwifery Council
PEG	Percutaneous Endoscopic Gastrostomy
PEG-J	Percutaneous Endoscopic Transgastric Jejunostomy

PRN	Medicines only taken when the need arises
RCGP	Royal College of General Practitioners
RCN	Royal College of Nursing
SESS	Special Education Support Service
SNMREC	School of Nursing and Midwifery Research Ethics Committee
UK	United Kingdom
US	United States of America
WHO	World Health Organisation

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Chapter One – Overview of the Study

1.1 Introduction

The purpose of this study is to gain insight into mothers' experiences of 'giving medicines' to children with severe and profound intellectual disabilities. This chapter provides the introduction to this thesis, within which the background to the study is provided. This includes a discussion on terminology, the current context and the incidence of children with severe and profound intellectual disabilities. This chapter first considers the background to the study and how the term 'intellectual disabilities' has been defined and applied, primarily to clarify the group of children whose needs are of concern to this study and to identify key emergent themes. The phrases "severe and profound intellectual disability" and "medication management" are also scrutinised. What some of the literature tells us about the presentation of intellectual disabilities, associated health issues and the prevalence of severe and profound intellectual disabilities is also considered. This sets the context for exploring further aspects of importance to the topic at hand and identifies gaps and best practice in meeting the needs of mothers and children with severe and profound intellectual disabilities in subsequent chapters. In writing this thesis it was decided that use of the 'first person singular' would facilitate the detailing of my thoughts and choices and therefore is used throughout.

1.2 Background and Context

This study is necessary because there is a dearth of research in the area of children with severe and profound intellectual disabilities and in particular the phenomenon of interest. In Ireland, recent figures report, there are a total of 10,032 children with intellectual disabilities registered on the National Intellectual Disability Database (NIDD) (Hourigan *et al.* 2018) with 1,106 of these classified as having a severe or profound intellectual disability. This represents nearly 36% of those registered on the NIDD under the age of 20. Furthermore, the rate of new-borns and children with intellectual disabilities who have life-limiting conditions and complex physical healthcare needs have

also increased significantly (Milligan 2010, D'Amore *et al.* 2011, Health Service Executive (HSE) 2018). This growth is as a result of increased life expectancy, ongoing developments in healthcare knowledge, drugs, advanced medical care, technology, parental efforts and availability of varied facilities for education and living (Nakken & Vlaskamp 2007, McConkey *et al.* 2007, HSE 2009, McCarron *et al.* 2011, Simkiss 2011, Nicholl *et al.* 2013). Medical innovations and health initiatives have led to a decline in the infant mortality rates worldwide. Many of these children have rare syndromes, multiple and complex needs and require high levels of assistance and support (Eddy 2013, Gates & Mafuba 2014). Consequently, many children are becoming increasingly dependent on equipment or technological devices to sustain their life or optimise health. This dependence can involve a myriad of equipment, technology and medications, managed by parents at home (Davies & Carter 2013a).

Chronic health conditions experienced by children with severe and profound intellectual disabilities are accompanied by numerous challenges because of the prolonged period over which children take medication and sometimes the large number of drugs they take (Kalyango *et al.* 2012). Children with complex needs receive 5 times the number of medications than do typical children (Fiks *et al.* 2012) that can include a variety of medications; protein pump inhibitors for gastro oesophageal reflux, prokinetic agents for dysmotility, anti-constipation agents, bronchodilators, anti-epileptics, spasmolytics, sleep medications and behaviour medications such as stimulants, antipsychotics or anxiolytics (Hogg 1992, Kapell *et al.* 1998, Zijlstra & Vlaskamp 2005). As well as prescription medicines, complementary and alternative medicine use is common in this population to enhance wellbeing rather than treat specific symptoms (Wood & Finlay 2011).

1.3 Research rationale

Medication management is a critical but complex responsibility of the mothers of children with severe and profound intellectual disabilities. These children often require potent pharmacological interventions especially at end of life to relieve distressing symptoms (Lau *et al.* 2009). There is some evidence suggesting family caregivers feel

inadequately prepared to manage medications (Schumacher *et al.* 2008). However, this was established in a general adult population requiring hospice and end of life care. Other prior studies have explored aspects of health care at home to include such areas as medication management by caregivers within the elderly population or adults with intellectual disabilities but not with children (Travis *et al.* 2000, Travis *et al.* 2003, Travis *et al.* 2007, McCarron *et al.* 2011, Flood 2016). Medication management skills have been reported in the literature but usually as a particular task of direct care to which caregivers are expected to adhere (Buelow & Smith 2004) and again this is within the adult population. While some research studies exist on medication management from the perspective of professional caregivers and families, this literature again mainly relates to the adult requiring end of life care (Lau *et al.* 2009), the older person with dysphagia (Smith *et al.* 2003) and use of a gastrostomy tube for administration alternatives in adults (Wright & Kelly 2012). Some research refers to informal carers of older care recipients with little attention paid to parents who manage medication in the home for the child with severe and profound intellectual disabilities (Francis *et al.* 2002, 2006). Literature outlines some elements of medication management in the adult population such as the appropriateness of medications (Smith *et al.* 2003), making clinical judgements (Francis *et al.* 2002), the role of the pharmacist (Smith *et al.* 2003, National Health Service (NHS) 2014) and associated risks (Oulton & Heyman 2009). These adult studies while acknowledging medication management roles, fail to identify frequency with which these tasks are undertaken, the nature of involvement and the challenges associated with medication giving in this population.

Along with the transfer of care to the home setting, in recent decades the assumption of primary responsibility for 'giving medicines' lies with the parent (Woodgate *et al.* 2015). It is accepted the most frequent activity undertaken by nurses in practice is medication administration (Keohane *et al.* 2008). Therefore, it can be concluded that parents assuming caregiving roles of children with severe and profound intellectual disabilities requiring medicines undertake medicines administration regularly in daily life. While management of a child with severe and profound intellectual disabilities requires a multi-element approach, one of the key tasks associated with care is that of medication

giving. Informal caregivers have become increasingly important in recent years as they take on expanded roles of coordinating care (Lau *et al.* 2010).

The impetus for this research is an acknowledgement that much of the medication management of children with severe and profound intellectual disabilities takes place in the family home and is led by the parent, predominantly the mother. In order that a child with severe and profound intellectual disabilities is cared for at home, parents are taking on long-term complex nursing skills 24 hours a day and are confronted with new and unexpected experiences, one of which is 'giving medicines'. Mothers must therefore develop their skills to administer and manage medications at home. This may require a high level of cognitive processing that involves applying knowledge of disease and medications (Smith *et al.* 2003). In addition, other skills in opioid use may include responding to side effects, interpreting response to medications and medicating on a round the clock basis (Letizia *et al.* 2004).

Though it is evident previous research has focused on many aspects of the caregiver's role, limited attention has been given to the role of informal carers in management of medication with children. There is a clear gap in the literature pertaining to the experience of 'giving medicines' to children with severe and profound intellectual disabilities and detail of the specific experience for mothers. In light of the complex nature of care delivery for this group of children, it is necessary to explore mothers' experiences of the task of 'giving medicines'. This topic has not been explored, either nationally or internationally and little is known about the task of medication management or administration with children with severe and profound intellectual disabilities. Nor is it known how mothers effectively manage medication in the home, manage prescriptions, storage of medications, administration, dealing with multiple symptoms relating to the child's health status or what skills or training they need. Issues that are not discussed in the literature but have been identified anecdotally by mothers in clinical practice include; difficulty in administering medication, difficulty with interpreting written information and assessing relevance or importance of package inserts, communicating with various health professionals and perceived lack of

medication review. In a previous study I undertook (Nicholl *et al.* 2013), it was found that equipment used in the home of children with complex needs always included medication related equipment such as medication devices or additional medicine related equipment.

With increasing numbers of children with severe and profound intellectual disabilities, there is a new interest in this cohort of children as lifespan is longer. Despite the overall small numbers of children with severe and profound intellectual disabilities, the impact of care for these children in terms of health, family wellbeing and functioning is enormous. In an emergent field of care provision, it is imperative that the focus sharpens and some of the issues that are of concern to parents and children alike are addressed. Developing a deeper understanding of mothers' experience of 'giving medicines' is an important step in managing medications and homecare for children with severe and profound intellectual disabilities. It may also facilitate the goals of care. An understanding of the process of medication management is essential for development of appropriate services that respond to the needs of the parent and child. Additionally, it will provide much needed information for key health professionals such as nurses, pharmacists and prescribers in assisting mothers caring for their child with severe and profound intellectual disabilities.

Much of the literature demonstrates mothers' interest in the topic area over fathers' interest despite there being opportunities for both to partake in research studies. Many of the studies cited in the literature review were open to both parents to partake and yet mothers were the dominant participants. Baumann & Braddick (1999) highlighted that fathers of children with disabilities worry about their children and want the best for them but tend not to take on the main caring role. Some fathers were very involved in the daily care of their child, particularly if they did not work outside the home and are integral to the family support system but even those fathers involved in research studies affirm mothers to be the primary caregiver (Baumann & Braddick 1999, Carpenter & Towers 2008, MacDonald & Hastings 2010, Hobson & Noyes 2011, Flippin & Crais 2011, Marsh *et al.* 2018). However, it was noted that children with an early diagnosis of intellectual disabilities tended to have more involvement by the fathers (Davys *et al.*

2017). Interestingly, key differences are cited between mothers' and fathers' experiences of parenting a child with disabilities with mothers more concerned with day to day tasks and interpersonal communications and fathers interested in ensuring their child was viewed as normal (Pelchat *et al.* 2003). Therefore, considering the available evidence, it was decided mothers may best address the phenomenon under investigation as they are usually the primary carer. In researching my chosen topic of mothers' lived experiences of 'giving medicines' to their child with severe and profound intellectual disabilities, I wanted to get closer to and unearth the essence of what it is like for mothers to experience 'giving medicines'. Furthermore, I wanted to gain a deep description and understanding of this lived experience.

1.4 Aim and Objectives

The aim of this study was to explore mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities.

In order to meet this aim, specific objectives were identified:

- To explore the experiences of mothers of children with severe and profound intellectual disabilities 'giving medicines';
- To identify the range of activities mothers of children with severe and profound intellectual disabilities 'giving medicines' undertake;
- To develop an understanding of how mothers learn about 'giving medicines';
- To identify any issues experienced by mothers of children with severe and profound intellectual disabilities 'giving medicines';
- To explicate the meaning of mothers living with 'giving medicines' to children with severe and profound intellectual disabilities as a basis for understanding and interpretation by others.

1.5 The research design

Various research designs have been adopted in previous research studies in the area of severe and profound intellectual disabilities, mainly qualitative in nature using semi-structured interviews. According to van Manen (1990, 1997) hermeneutic

phenomenology seeks to help people understand a phenomenon from the perspective of those who have experienced it, but largely with the emphasis on analysis or interpretation of texts. Differentiations between phenomenology and hermeneutic phenomenology can be made when historical and methodological perspectives are examined (Sloan & Bowe 2014). Hermeneutic phenomenology closely aligned with my values and research goals and the rationale for this choice is further explored in Chapter Three. As little is known about the subject area and the study is concerned with increasing the knowledge base, hermeneutic phenomenology and the in-depth exploration of the lived experience of 'giving medicines' was the preferred research design. Examples of such studies using hermeneutic phenomenology and similar data collection techniques are those undertaken by Nicholl & Begley (2012) which explored mothers' lived experiences of caregiving for a child with complex needs and Somanodhan & Larkin (2016) who examined the lived experience of caring for children, adolescents and young adults with Mucopolysaccharidoses. Van Manen's (1990, 1997) approach integrates both interpretive and descriptive features. Acknowledging the researcher and not bracketing beliefs was essential and this approach supported recognition of my beliefs. Adopting van Manen's (1990) approach gave structure to the research process with his six guidelines or research activities to approaching hermeneutic phenomenology evident throughout the research process.

1.6 Terminology used in this study – Choosing Definitions

It is important, when presenting a study that a precise definition of key terminology is offered as there is usually no opportunity to clarify the various concepts with the author and if unclarified may lead to divergent connotations (van Mil & Henman 2016). Therefore, key terminology adopted within this study are further explained; intellectual disability, severe and profound intellectual disability and 'giving medicines'.

1.6.1 Intellectual Disability

Intellectual disability is the most common form of developmental disability in children (Eddy 2013). The World Health Organisation (WHO) Working Group on the Classification of Intellectual Disabilities for ICD-11 has proposed a new term, intellectual

developmental disorders, recognising intellectual disabilities as both a health condition and disability (Foster *et al.* 2015). The ICD-11 defines intellectual developmental disorders as a group of developmental conditions characterised by significant impairment of cognitive functions, associated with limitations of learning, adaptive behaviour and skills. The WHO (2018) define intellectual disability as “a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. Disability depends not only on a child’s health conditions or impairments but also and crucially on the extent to which environmental factors support the child’s full participation and inclusion in society”. While many terms exist for intellectual disability, this is the one favoured within Ireland, the United Kingdom (UK) and much of the academic literature.

One criterion used for determining the presence of intellectual disability is a standardised measure of intellectual functioning (intelligence quotient, IQ). An average score would be 100 while a significant impairment is measured through this rating as two standard deviations below average, which is an IQ of below 70. Those children scoring below 75 are thought to have an intellectual disability with those below 34 deemed to have a severe to profound intellectual disability. According to the WHO (2015) intellectual disability can be categorised according to the classification; mild, moderate, severe or profound (see Table 1).

Table 1: Classification of Intellectual Disabilities (WHO 2015)

Classification	IQ	Abilities
Mild	50-70	Communicates effectively and lives relatively independently with minimal support in the community.
Moderate	35-49	Individuals, who with lifelong support will have significant relationships, communicate, handle money, travel on public transport, make choices and understand daily schedules.
Severe or Profound	<34	Individuals who are totally dependent on those around them and will require lifelong help with personal tasks, communication, and accessing and participating in community facilities, services and activities.

Those children with a severe intellectual disability would usually have limited language skills, poor social skills and attend a special school while living with supports in the community environment. Children with a profound intellectual disability would typically display multiple disabilities and be heavily dependent for daily activities requiring high support in daily life. While a child's level of intellectual disability can be defined by their IQ, the types and amount of support the person needs is often more diagnostic than a number (Eddy 2013). There is general agreement that children with severe and profound intellectual disabilities require additional supports and that these need to be individualised. Furthermore, the care requirement for children with severe and profound intellectual disabilities is commonly seen to extend over longer period of times, from infancy through to adulthood (Hollander & Prince 2008, McIntosh & Runciman 2008, Ling 2012).

1.6.2 Severe and Profound Intellectual Disabilities

A clear articulation of the concept of children with severe and profound intellectual disabilities is necessary in contextualising this study. A plethora of terms exist for children with severe and profound intellectual disabilities with many of these children linked with the concepts of 'complex' and 'multiple' needs, used by various disciplines interchangeably (see Table 2).

Table 2: Terms often associated with Children with Severe and Profound Intellectual Disability

A child with(name of the condition)	Medically extreme catastrophic children
A child with disabilities	Medically fragile
A child with severe neurological disability	Multiple and complex needs
Children with complex needs	Multiple disabilities
Children with complex and exceptional healthcare needs	Multiple impairment
Children with medical complexity	Polyhandicap
Children with multiple impairments	Profound multiple disabilities
Child with severe neurologic impairments	Profound and multiple disabilities
Children with special health care needs	Profound intellectual and multiple disabilities
Complex care needs	Profound intellectual multiple disabilities
Complex health needs	Profound and complex disabilities
Complex intellectual and sensory disabilities	Severe intellectual and motor disabilities
Developmental disabilities	Severe and profound intellectual disabilities
Global developmental delay	Severe multiple disabilities
High support needs	Special needs
Having complex needs	The medically fragile child
Having a complex medical condition	The technology dependent child
Having special needs	Medically extreme catastrophic children
Learning disability	Medically fragile
Learning difficulties	Multiple and complex needs
Life limited	Multiple disabilities
Life Threatened	
(Ware 1996, McPherson <i>et al.</i> 1998, Samuel & Pritchard 2001, Neff <i>et al.</i> 2002, Ware 2004, Thurgate & Warner 2005, Nicholl 2007, Cohen <i>et al.</i> 2011, Foster <i>et al.</i> 2015, Allshouse <i>et al.</i> 2018, Brenner <i>et al.</i> 2018a, Rousseau <i>et al.</i> 2019)	

This is especially evident in the literature reviewed in Chapter Two with great variety in terms adopted by different authors. According to Hewitt-Taylor (2008a) children with complex needs refer to a group of children requiring complex interventions that are ongoing as opposed to requiring acute intervention. Several definitions and alternative terms are in existence for the term “complex needs” (Bellamy *et al.* 2010) and not all children with complex needs have an intellectual disability.

Nicholl (2007) investigated terminology adopted by 46 nurses working in Ireland when referring to children with life-limiting illness. The questionnaire yielded evidence that a wide range of terms are used in practice. Terms adopted often refer to the child’s diagnosis, the chronic nature of their condition and the limitations of their condition. The study findings advise that terminologies differ as no one term may reflect the complex nature of the child’s needs. More recently, Brenner *et al.* (2018a) undertook a

systematic concept analysis of children's complex care needs identifying key attributes, antecedents and consequences of the term. What is evident in this analysis is the multi-dimensional health and social care needs of those children with either recognised conditions or without an agreed diagnosis.

Nonetheless, the number of children with disability is often difficult to ascertain due to definitional ambiguities. Overall, from exploring the literature it is evident that there is a lack of consensus on terminology and yet is important that there is a shared understanding of terms for description of this group of children for the purposes of ascertaining prevalence rates, strategic development and provision of care and service delivery (Nicholl 2007, Bellamy *et al.* 2010, Bishop *et al.* 2015). Each sector whether it is health, education or social care appears to use differing definitions tailored to reflect their own priorities. Sattler (2002) suggests severe intellectual disability manifests in major developmental delay with individuals often having the ability to understand language but who otherwise have limited communication skills and require the support of family to meet their self-care needs. Comparably, those who experience a profound intellectual disability cannot live independently and require intense supports for self-care with limited communication abilities and multiple physical impairments (Sattler 2002, Pawlyn & Carnaby 2009).

Rankin & Regan (2004) usefully identify the essence of complex needs as denoting both: breadth - multiple needs (more than one) that are interrelated or interconnected and depth of need - profound, severe, serious or intense needs. In this study the preferred term of severe and profound intellectual disabilities (Information Services Division 2006, Scottish Executive 2007) was chosen as it was unambiguous with clear criteria that could be adopted in the sampling process. The child has severe or profound disabilities in at least three of the disability categories or the child has severe or profound disabilities in at least two of the disability categories plus he/she is in need of at least two types of resources (Table 3). In either case, the impairments and needs of these children are sustained, lasting for more than 6 months and are on-going.

Table 3: Defining Severe and Profound Intellectual Disabilities

Disability Categories: The child has severe or profound disabilities in at least <u>three</u> of the disability categories	Resource Types: plus in need of at least <u>two</u> types of resources
<ul style="list-style-type: none"> • Motor impairment • Hearing impairment • Visual impairment • Cognitive impairment • Speech and language impairment • Behaviour problems • Feeding problems • Additional chronic health needs 	<ul style="list-style-type: none"> • Therapy services • Additional educational resources • Nursing care needs • Social care resources • Mental health services
<p>(Information Services Division 2006, Scottish Executive 2007)</p>	

A similar definition to this is adopted in Ireland by the Special Education Support Service, SESS (Department of Education and Skills (DES) 2018) indicating that children with severe and profound intellectual disabilities are likely to be severely impaired in their functioning in respect of a basic awareness and understanding of themselves, of the people around them and of the world in which they live. The SESS (DES 2018) also suggest children with severe and profound intellectual disabilities exhibit a wide and diverse range of characteristics, including a dependence on others to satisfy basic needs such as feeding and toileting, difficulties in mobility, problems with generalising skills from one situation to another, significant delays in reaching developmental milestones and significant speech and/or communication difficulties. However, the chosen definition encompasses the elements suggested by Rankin & Regan (2004) which made it useful in operationalising it and in identifying those that met the inclusion criteria. What is evident is that a consistent definition can be difficult to obtain and operationalise. Cohen *et al.* (2011) proposes that clinical and research initiatives would benefit from one uniform definition that is clear, reproducible and comparable across studies.

1.6.3 'Giving Medicines'

The medication use process is complex and includes prescribing, transcribing, documenting, dispensing, administering and monitoring (Crouch & Chapelhow 2008,

Brack *et al.* 2013). In exploring formal definitions, medication management is defined as facilitation of safe and effective use of prescription and over-the-counter drugs and as a comprehensive intervention which encompasses the knowledge of nurses and midwives (and that of other health care professionals) and the activities that are performed to assist the patient in achieving the greatest benefit and best outcomes involving medications (Bulechek & McCloskey 2013). Additionally, medicine administration is expressed as preparing, giving and evaluating the effectiveness of prescription and non-prescription drugs (Bulechek & McCloskey 2013). However, all of these formal definitions allude to the role of the nurse or health professional in the administration process and not the caregiver.

Together for Short Lives (Armitage 2014, p.3) adopt a more holistic definition and state “the entire way that medicines are selected, procured, delivered, prescribed, administered and reviewed to optimise the contribution that medicines make to producing informed and desired outcomes of (patient) care”. This definition offers more clear guidance on what the key elements of the medication management process entails. Medication administration by caregivers has been conceptualized to include; information seeking and sharing, safety issues, scheduling logistics and polypharmacy concerns (Travis *et al.* 2000, 2003). In an effort to ensure ease of understanding by participants and without wanting to be overly prescriptive, within this study the informal term ‘giving medicines’ was adopted and this included anything related to the process such as accessing, managing and administering medications. The term ‘medicines’ could relate to prescription, over the counter and nutritional supplements. Essentially, the term encompassed any activity the participants engaged in that related to medication administration or management. This phrase and its suitability were discussed at length with an expert panel prior to being adopted for the study.

1.7 Prevalence of Intellectual Disability in the Child Population

It is estimated that 15% of the total world population experience disability while the prevalence rate is often suggested to be around 1% (Maulik *et al.* 2011). However, following completion of a systematic review spanning 2010-2015, McKenzie *et al.* (2016)

argue that it may be anything from 0.05 to 1.55% and while not concretely suggesting a downward prevalence trend this may be considered in future analysis. Still, figures for those children experiencing disability worldwide are vague and can vary considerably (WHO 2012). Numbers of children surviving with disabilities have risen due to increased knowledge and capability to treat premature infants and genetic disorders (Teare 2008) in addition to increased survival rates following serious illnesses (Burns *et al.* 2010, Fraser *et al.* 2012, Pinney 2017). The survival rate of preterm babies is rising but aligned with this, the disability rate also appears to be increasing suggesting these children have more long term neurological deficits and intellectual disabilities (Bracewell & Marlowe 2005). Neonatal care has improved and in turn contributed to the survival of children with intellectual disabilities and developments in health care have increased the lifespan of children with genetic disorders (Parkes & Clarke 2006). The numbers of individuals with profound intellectual disabilities is increasing in the developed world as a result of advanced medical input and the availability of complex equipment and medication (Nakken & Vlaskamp 2007, Pinney 2017). The UK report an estimate of up to 6,000 children living at home who are technology dependent (Glendinning *et al.* 2001, Pinney 2017) while in Ireland, there are a total of 1,106 children categorised as having a severe or profound intellectual disability (Hourigan *et al.* 2018).

1.8 Causes of Severe and Profound Intellectual Disability

Intellectual disability still remains one of the disorders for which the cause is still poorly understood (Battaglia & Carey 2003) and often unknown (Parker *et al.* 2010). However, causes can be categorised as resulting from genetic problems, problems during the pre or perinatal period, childhood injury or disease. Research indicates that intellectual disability can be caused by a wide range of aetiologies including biological, environmental and social factors (Pawlyn & Carnaby 2009). A scan of the literature for biological causes may yield results for those children with moderate intellectual disabilities while some of the more obvious syndromes present a moderate intellectual disability such as Down Syndrome (Pawlyn & Carnaby 2009). Notably, biological causes are rarely found in children with mild intellectual disability. However, two thirds of cases of severe intellectual disability are caused through biological factors. Genetic factors

have been estimated to cause around 50% of all severe intellectual disabilities with chromosomal disorders accounting for 20-25% such as Down Syndrome (Foster *et al.* 2015). Another 20-25% have other identifiable disorders or syndromes with some having progressive metabolic or degenerative disease (Foster *et al.* 2015). Smith (2010) identifies chromosomal abnormalities such as trisomy, microdeletions, simple gene disorders or mitochondrial disorders as the most common causes of intellectual disabilities. Other conditions that lend themselves to severe intellectual disability also identified by Smith (2010) include; cerebral palsy, microcephaly, infantile spasms and cerebral insults such as meningitis or trauma.

The most common non-genetic biological cause of intellectual disability is cerebral palsy (Pawlyn & Carnaby 2009, Smith 2010). Metabolic causes account for about 1-5% of intellectual disabilities but can be effectively treated through dietary restrictions or enzyme replacement therapies (Foster *et al.* 2015). Some biological causes are effectively treated for example, phenylketonuria screened for in newborn babies enabling early treatment while other biological causes such as rubella can be prevented by rubella immunisation.

Specific aetiologies of intellectual disability can carry more defined risk profiles (Davis *et al.* 2014). Specific health problems are varied between aetiologies but a range of common chronic health difficulties can include: sensory problems, poor nutrition, constipation, thyroid dysfunction, gastro-oesophageal reflux disease (GORD), poor bone health, epilepsy, cardiovascular and respiratory difficulties (Van Schrojenstein Lantman-de Valk & Walsh 2008, Smith 2010). Environmental factors that may contribute to intellectual disabilities either antenatally, perinatally or postnatally include congenital infections such as rubella or toxoplasmosis, teratogens such as alcohol leading to fetal alcohol syndrome (Zoorob *et al.* 2014), drugs, birth asphyxia, neonatal brain injury (Hayward & Adappa 2014) or complications of prematurity. Some of these factors are direct causes of disproportionate increases in the incidence of intellectual disabilities in developing countries (Katz & Lazcano-Ponce 2008).

1.9 Presentation of Severe and Profound Intellectual Disability in Children

The age at which intellectual disability presents is dependent upon the severity and presence of specific disorders or syndromes coupled with parental observation and alertness (Foster *et al.* 2015). Presentation at birth tends to be obvious with recognisable malformations or syndromes such as Down Syndrome. Within the first year of life slow motor development is sometimes the most obvious feature of intellectual disability and associated hypotonia or “floppiness” (Sheridan *et al.* 2014). More notably, individuals with profound intellectual disabilities are usually unable to walk, feed independently or communicate verbally (Sullivan 2008), require prescription medications (Simon *et al.* 2012, Caicedo 2016) often requiring high levels of assistance in daily living.

Children with profound intellectual disabilities often have more than one disability and usually will have difficulty communicating (Mencap 2012). It is common for these individuals to have sensory or physical disabilities coupled with mental health problems and complex health needs (Mencap 2012, Royal College Nursing (RCN) 2013a). Children with intellectual disability have an overall risk of developing medical complications associated with their physical disabilities and almost all of these children require regularly administered medication (Nakken & Vlaskamp 2007, Caicedo 2016). The combination of disabilities can also affect behaviour. With each individual condition a specific symptom profile may exist with unique identifying symptom experiences (Malcolm *et al.* 2010, 2011).

Children with profound intellectual disabilities possess limited motor function (Nakken & Vlaskamp 2007) and experience significantly more health problems than the general population (Davis *et al.* 2014). They also have an overall risk of developing medical complications and almost all require regularly administered medication to include; anti-epileptic drugs (AEDs), sleep medication or anti reflux medication (Hogg 1992, Kapell *et al.* 1998, Zijlstra & Vlaskamp 2005). A US quantitative study by Caicedo (2016) explored health, functioning and health care service use by children with medically complex technology dependence. Data was collected pertaining to 84 children who met the

inclusion criteria. Of a total 44 children with severe intellectual disabilities, 41 were prescribed daily medications with 26 of these children taking 6 or more per day.

Apart from cognitive and motor dysfunctions the number and severity of associated characteristics augment the difficulties these children experience. Health problems can include; respiratory, gastrointestinal conditions, and epilepsy with an increasing number of children regarded as technology dependent due to their need for oxygen, suction equipment and feeding tubes (Dunworth-Fitzgerald & Sweeney 2013). Visual impairments are more common than hearing impairments mainly due to increased survival rates of premature babies. Usually individuals with severe and profound intellectual disabilities will require extensive supports for daily living and care is particularly challenging (Phelvin 2012).

The impact of health conditions on supporting children with profound intellectual and multiple disabilities was explored by Zijlstra & Vlaskamp (2005). A review of medical records was undertaken for 48 children attending three centres for special education in Netherlands. Prevalence of medical conditions was high and included such things as gastrointestinal feeding issues, seizures, pulmonary problems, orthopaedic issues and general malaise. These medical conditions often determined children's attendance at school or engagement in specific activities on a daily basis with many children missing these activities.

Diagnosing intellectual disability in childhood is challenging and defining and measuring childhood disability can be a perplexing task (Smith 2010). Infancy to adolescence is a period marked with developmental changes and the evolving characteristics of a child can make the task of assessing function more complicated (Smith 2010, Mountstephen 2011, Meggitt 2012). Furthermore, the multiplicity of disabilities associated with these children can make assessment and diagnosis particularly challenging. Additionally, the configuration of unique levels of functioning can be so varied, a standardised assessment process is not always helpful (Nakken & Vlaskamp 2007). The symptom profile of children with severe and profound intellectual disabilities can be broad with a wide range of symptoms existing that remain largely unexplored in the literature

(Malcolm *et al.* 2008, 2009). Characteristics impacting on the child include onset, timing, pattern and severity of symptoms that present (Siden *et al.* 2010). The younger the child the more difficult it can be to diagnose and with the dynamic physical changes and acquisition of physical and mental skills in the early years, it can be complicated. Approaches to diagnosing intellectual disability include observation, developmental screening checks, noting discrepancies in the appearance of skills and use of diagnostic assessment tools (Health Service Executive 2006a, 2006b, WHO 2012).

More recently, the prevalence of health problems present in children with severe or profound intellectual and motor disabilities were examined in a Dutch study (van Timmeren *et al.* 2016). A wide range of health problems were identified with 99 participants displaying a mean of 12 problems. Highest prevalence rates were found for constipation, visual impairment, epilepsy, spasticity, deformations, incontinence and reflux. These problems resulted in all of the children requiring medication to treat one or another symptom.

Often the health needs of children with intellectual disabilities overshadow other needs such as communication, play, socialising and learning. Hewitt-Taylor (2008b) discovered the importance of these other needs in one to one interviews with parents of children with complex health needs. These parents stressed that their child's efforts to communicate were frequently not valued and because of physical needs, play and socialising was more arduous. Additionally, others often placed more priority on health activities over other activities while parents cited their desire for support and encouragement around the areas identified. Hewitt-Taylor (2009a) also reported from this study on the gaps in the provision of transport, play, leisure and retail facilities for these children. Suitable provision of facilities and opportunities were proposed by parents and the need for recognition that attitudes can influence how children and their families feel included in society.

The presentation of severe and profound intellectual disabilities impacts on the interventions required for the individual child. The most useful approach for children with intellectual disabilities consists of multi-disciplinary efforts aimed at many aspects

of the child's life such as education, social and recreational activities, management of behavioural issues and associated impairments. Medication is not of any benefit in treating the core symptoms of intellectual disability as no drug has been found to improve intellectual function. However, medication is often required in treating co-morbidities and directed at specific symptoms such as epilepsy, gastro-intestinal issues or neuropathic pain. A continuum of services may be required to maintain or improve health and functioning of children with severe or profound intellectual disabilities. These services can include: specialised medical and nursing services, therapeutic services, family support services, equipment and medical supplies and other related services such as early intervention, special education and transportation (McPherson *et al.* 1998). Additionally, it is essential that children are supported to enjoy opportunities that other children experience such as play and leisure, social activities and accessible education (Hewitt-Taylor 2009b, 2010).

1.10 Children with Severe and Profound Intellectual Disabilities - Service Provision

As survival rates of children with severe and profound intellectual disabilities improve, supportive and sometimes palliative care is required for extended periods of time (Downing *et al.* 2012, Brown & Clark 2015) resulting in additional responsibility placed on hospital systems to resource those who require medical input and technology dependence. A multi-agency approach where different agencies and professionals work together to provide a holistic service is one that has been discussed widely in the literature since the 1990's (Cigno & Gore 1999). Wang & Barnard (2004) suggest that in order to cut hospital costs and the burden of care on hospitals, children are sent home to their families resulting in greater demand for community-based delivery of care. Expectations have increased regarding the extent of care that can be provided in the home, although, according to the HSE (2014) development of this model of care has not kept pace with demands.

The preferred site for care provision for children with intellectual disabilities is the home (Olsen & Maslin-Prothero 2001, Carter *et al.* 2016) and while this has positive benefits for both the child and family, recognition of the care burden on parents needs to be

acknowledged (Scott 2000, McCann *et al.* 2015). The most recent figures available from the NIDD advise that 98% of children with intellectual disabilities in Ireland live at home with their parents (Hourigan *et al.* 2018). The evidence is abundant in demonstrating that positive improvements in quality of life are envisioned when children with disability live at home (Wang & Barnard 2004). The trend in care has shifted away from institutions to the child's home which in turn places a considerable responsibility on the family (Condliffe 2006). It is assumed that children with disabilities and possible technology dependence will be cared for at home with little or no choice afforded to parents in terms of an alternative to homecare (Carnevale *et al.* 2008, Lindahl & Lindblad 2011, Mendes 2013). It is recognised that home care provision is 'beset with problems' (Hewitt-Taylor 2005a) including financial difficulties, delay in discharge, lack of family privacy among others (Kirk & Glendinning 2004) and can become a protracted process.

The type of interventions and equipment in use with children with complex needs would traditionally have required hospitalisation often within intensive care settings (Hewitt-Taylor 2005a). However, long-term it is considered inappropriate for children to stay in hospital because while health needs may be met, developmental and psychosocial needs are unlikely to be (Neufeld *et al.* 2001). Moreover, parents are not always satisfied with hospital-based care (Phua *et al.* 2005). A cross-sectional study with a sample of 40 parents of children with cerebral palsy (CP) and 90 parents of able-bodied children demonstrated satisfaction rates were lower in those parents of children with CP who are often less able-bodied (Phua *et al.* 2005). The associated higher dependency needs of these children and poorer communication mechanisms often meant hospital staff failed to understand the child's needs.

Living at home and experiencing a 'normal' home environment is well documented in the literature (Wang & Barnard 2004). However, a fragmented system of home care delivery currently exists (Kirk & Glendinning 2000, 2002, 2004). Home delivery of health care has been shown to be a cost-effective alternative to in-hospital care (American Academy of Pediatrics 2002) but can risk placing a financial burden upon the family (Appierto *et al.* 2002). In a case study presented by Brombley (2008) care at home was deemed to be not only better, but also clinically beneficial and cost effective without

adding financial burden to the family. Despite the obvious psychological benefits of home care for the child and family and the sense of 'normality' that ensues, often it is beleaguered with problems such as lack of support, lack of funding and lack of collaboration between community services if available (Noyes 2002). These need to be considered to ensure quality care (Hewitt-Taylor 2005a). A number of children who are deemed to be medically stable and may be discharged from hospital to their home environment, spend unacceptably long periods of time in acute hospital environments awaiting appropriate discharge care packages. The requirement for complex multi-agency care packages to be established requires co-ordination, planning and additional investment (Murphy 2008). Pordes *et al.* (2018) broadly identified three models of care delivery for children with "medical complexity"; primary care centered, co-management centered and episode based models. However, they found they were hindered in establishing which model yielded positive outcomes due to the difficulty in using a common definition and a lack of standardised outcomes of care.

Investigating community care provision, Carter (2005) undertook a participant inquiry research study with data generated by children with complex health care needs and their siblings accessing the 'Diana' team, an established service providing ongoing care and support for children in the community. Qualities a 'Diana' nurse should possess were identified and equally qualities not valued were highlighted with much of the findings very positive. A variety of factors including lack of support, poor communication and poor inter-disciplinary working, make enabling home care for children with complex needs challenging. Additionally, Farasat & Hewitt-Taylor (2007) evaluated a student practice placement where two students accessed homecare practice placement experience with children with complex needs through a private service provider. It was established that these placements were beneficial for student nurses and would enhance the availability of skilled staff providing in home services in the future. More recently, Carter *et al.* (2016) explored how nurses can facilitate transition of children with complex needs from hospital to home. Interviews were undertaken with nine nurses and 37 professional stakeholders. Findings reflected the ways in which nurses facilitated transition of children and the journeys the nurses took in developing the skills, knowledge and networks required to support the transition. The place of care

being the home, was significant in this study where the home was seen as a transformative environment for undertaking caring practices in which the family could exist and be nurtured together.

Typically, a child with severe and profound intellectual disabilities may be receiving care through multiple agencies, some statutory and some voluntary and may have interactions with many members of the interdisciplinary team. Currently, there are three possible models of care delivery in existence in Ireland for these children; the child receives continuous care in a children's unit in hospital, the child is discharged to the family home and receive services through voluntary organisations such as Jack and Jill Children's Foundation or the child is discharged to the family and receives homecare from the statutory authorities such as the HSE (Normand & Revill 2010). Within this study, commissioned by Jack and Jill Children's Foundation, it was evident that homecare delivery was more cost effective than hospital delivery but more importantly, the wellbeing of families and their children was greatly enhanced with home care delivery, without the health or wellbeing of the child being compromised. More recently, a service evaluation of Jack and Jill Children's Foundation identified the significance of the specialist nursing team working with children and their families (Coventry University 2017). Insights into the nurse's role working in partnership with the child and family were evident as well as empowering families to take on expert caring roles.

WellChild, a UK charity introduced a network of community nursing posts across England, Scotland and Wales in 2006 with the aim of working to improve provision of community nursing care for children and focuses on coordination and planning for discharge of children with complex needs from hospital and supporting the child and family in the home (Johnson & Coad 2008, Carter *et al.* 2010, Coad *et al.* 2015). This service has been positively evaluated by both WellChild nurses and parents accessing the service and revealed how the WellChild nurse plays a key role in supporting parents as they develop strategies to help them address the questions they have (Whiting 2017).

While coordinated care within the community has been talked about, the reality is that community services are fragmented and limited in delivery (Bewley 2002, Coventry University 2017). The development of community nursing for children in Ireland has been virtually non-existent with few new developments in recent years, while in the UK a variety of community children's nursing services exist (Eaton 2001, Whiting 2017). Community nursing is seen as an enabler in the lives of children with complex needs as these services can prioritise, advocate for families, influence policy makers and manage changes in an evolving public health arena (Condliffe 2006). Hewitt-Taylor (2008b) presented a case study describing an adolescent with multiple health needs, who clearly wished to reside at home with her parents but with adequate supports, so she obtained the services she required without compromising on such things as parental exhaustion. While quality of support was identified as important, insight into the intrusiveness of having someone present constantly was also offered.

The provision of multi-agency support is widely promoted (Kirk & Glendinning 2000, Danvers *et al.* 2003, Townsley *et al.* 2004, Carter *et al.* 2007, Whiting 2014a, 2017). However, much of the research proclaims details of poor practice in this provision. Kirk & Glendinning (2000) reported that parents co-ordinated services as health professionals failed to do so. Similarly, Hunt *et al.* (2003) reported that parents identified poor continuity of services between multiple care providers. In order to reveal examples of best multi-agency working practice with families and children with complex needs, Carter *et al.* (2007) explored examples using appreciative inquiry with families and healthcare professionals. The study resulted in best practice statements that explained what works and covered issues around information, decision making, communication, accessibility, collaboration, respect and sharing a common vision. Findings suggested it is imperative that parents have an opportunity to receive support from other parents who understand their lived reality and also that a long term co-ordinator is involved in the support process.

1.11 Summary of Chapters

This thesis comprises seven chapters. Chapter One focuses on the introduction to the thesis, introducing and contextualising the study and the rationale for same alongside identifying the meaning of key terms and concepts. Chapter Two concentrates on existing national and international research and identifies recurrent themes from the literature further providing the context for the study. Each theme is discussed and literature scrutinised in order to inspect what was understood in the themes. Chapter Three identifies the key features of the philosophical framework that underpins this research study. Hermeneutic phenomenology and its tenets are explored in the context of this study and the rationale for choosing van Manen presented. Chapter Four delineates the methods employed for the study. An explanation of how the study was conducted is offered and the reasons for choosing the population and associated sample. The mechanism for the gathering of data and how it was subsequently analysed is also considered. A discussion on ethical issues pertaining to the study is proffered and the ethical integrity of the study is explored. Chapter Five focuses on the presentation of the findings through use of van Manen's (1990) framework for thematic analysis. Chapter Six provides a discussion on the key findings and the interrelation between what is currently published in the topic area and the findings extrapolated within this study. Chapter Seven concludes with a final summary of how successfully the research question was answered and draws on the implications of the study. It also offers recommendations for consideration in the future on research, policy, practice and education.

1.12 Conclusion

This chapter has provided the context for the study. The background of the study was introduced highlighting detail relevant to this study and explained the key concepts adopted. The aim and objectives were also set out and justification given for the purpose of this study. The prevalence of children with severe and profound intellectual disabilities, causes and presentation was explored. Service provision was also considered in providing background. A brief synopsis of each chapter has also been offered giving an

outline of what is forthcoming in this thesis. In the following chapter a thorough literature review pertinent to the study is discussed.

Chapter Two – Review of the Literature

2.1 Introduction

Given the many perspectives from the literature, this review will focus on literature specifically aimed at contextualising the topic at hand. Chapter One has already emphasised the terminology adopted and given context on the prevalence, causes and presentation of severe and profound intellectual disabilities. It also positions current service provision for this cohort of children. This chapter reviews the literature to date on topics pertaining to the research aim which is to explore mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities. Detail on the search strategy adopted is included and an overview of the related literature is proffered. Subsequently, overarching themes and associated sub themes are further explored and this also highlights the lack of specific research on the topic at hand.

2.2 Placing the literature review in this study

A review of the literature identifies characteristics that are known to impact on the subject being investigated (Ritchie *et al.* 2014) and therefore is important in defining the aims and objectives of the study. According to Creswell & Poth (2018) the literature review element of a research study accomplishes several purposes, sharing with the reader the results of other studies closely related to the study being undertaken, fills in the gaps and provides a framework for establishing the importance of the study. It also serves as a benchmark for examining the results of the study with that of other studies. Creswell & Poth (2018) also acknowledge that an initial review may help orient the researcher to the research and help focus the aim and objectives.

Adopting a hermeneutic approach emphasises engagement with the literature which in turn increases understanding and allows insights to be developed. Indeed, van Manen (1990) talks of the hermeneutic manner of reviewing literature, turning to "the tradition of one's subject so that the work of others turns into a conversational partnership that reveals the limits and possibilities of one's own interpretive achievements" (p.76). Furthermore, Smythe & Spence (2012) suggest the purpose of the literature review is not simply to position pre-articulated knowledge, to demonstrate a gap in the literature

or as a means to argue for on-going research, but the key purpose of such an endeavour in hermeneutic phenomenology is to provoke thinking. In this instance, in keeping with a hermeneutic phenomenological approach, the literature review is an important step in keeping attuned and articulating a pre-understanding of the phenomenon. Additionally, it is important to be able to contextualise the study as well as provide in-depth review of the topic. Consequently, Chapter One focusing on context was an important prelude to the literature review presented here in Chapter Two.

2.3 Search strategy

In keeping with the chosen research design of hermeneutic phenomenology, this preliminary literature review confirmed an absence of similar studies on the topic of children with severe and profound intellectual disabilities both nationally and internationally. The advice of a specialist subject librarian was sought and a search of the literature was undertaken using databases including: CINAHL, Medline, PsychINFO, PubMed, Embase and Cochrane database of Systematic Reviews. These databases were selected as they were relevant to the topic area. Depending on the database being searched, controlled vocabulary terms were used to search for relevant literature. MeSH terms were used with PubMed, Medline, PsychINFO and the Cochrane database while Emtree terms were used with EMBASE and subject headings in CINAHL. Truncation or wildcards (*) allowed for a greater number of searches to be undertaken. The results were narrowed using the Boolean operators AND/OR. Key search terms and derivatives of these search terms included; intellectual disability, mothers, giving medicines, medicine administration and medicine management (see Appendix 1 for search terms). Relevant searches were undertaken to incorporate major texts and publications from Ireland and the UK. A search of reference lists of relevant studies was also undertaken to identify additional studies.

Generally, literature from 1990 to 2018 was sourced though earlier literature was used where appropriate, when the evidence was relevant to this study. Voluntary organisation literature was accessed such as Together for Short Lives and Jack and Jill Children's Foundation. Searches were also undertaken using the names of key

researchers in the field and 'related articles' functions available on databases. The electronic database search was supplemented with a comprehensive search for grey literature including descriptive studies and available guidance. The search established a small amount of grey literature through databases including OpenGrey System for Information on Grey Literature in Europe, OpenSIGLE and the Open University dedicated grey literature site. In assisting the research process, methodological literature was sourced throughout the course of the research study. During data analysis a further in-depth search of the literature was undertaken to confirm the emerging findings with those reported in national or international studies. Finally, a manual search of the reference list of any included study was undertaken so as to ensure nothing was missed.

2.4 An overview of the literature

Internationally, many studies have been undertaken in the area of children with complex needs often assuming the reader will recognise they are also talking about children with severe and profound intellectual disabilities also. These studies include those that focused on the needs of both the families and children with complex needs or children with severe and profound intellectual disabilities (McCann *et al.* 2012, 2015, Coad *et al.* 2015). Many studies have been undertaken in the field of intellectual disabilities especially in the adult arena. However, much of the literature in the area of children with severe and profound intellectual disabilities is limited with the variety of terms identified in Chapter One evident in the literature. Studies tend to focus primarily on the needs of children with specific diagnoses or chronic illness (McConkey *et al.* 2007, Compas *et al.* 2012), the needs of the family and child and general responsibilities (Hewitt-Taylor 2008a, Green 2007, McCann *et al.* 2012, 2015, Coad *et al.* 2015), the need for respite (Hartrey & Wells 2003, Redmond & Richardson 2003, MacDonald & Callery 2004, Merriman & Canavan 2007, Department of Health and Children (DOHC) 2010, Ling 2012), quality of life issues (Ellzey *et al.* 2015, Johaningsmeir *et al.* 2015) and parental burden encompassing caregiving, stress, financial problems, difficulties accessing care, deterioration in family structure and marital breakdown and coping skills (Leiter *et al.* 2004, Condliffe 2006, Green 2007, Elias & Murphy 2012, Nicholl & Begley

2012). There appears to be more published literature in recent years in the field possibly due to the recognised increase in survival rates of this group of children.

The number of children with intellectual disabilities who are technology dependent is increasing worldwide and life expectancy has also increased with more children living far longer than originally anticipated (Davies & Carter 2013b). While longer life expectancy and the advent of improved home-based care is a positive development for children and their families, it creates particular specific demands on the family. When delivering home-based care parents repeatedly take on the challenge of managing their child's care hour to hour, often undertaking health care interventions such as medication giving and assessing clinical status (Davies & Carter 2013b).

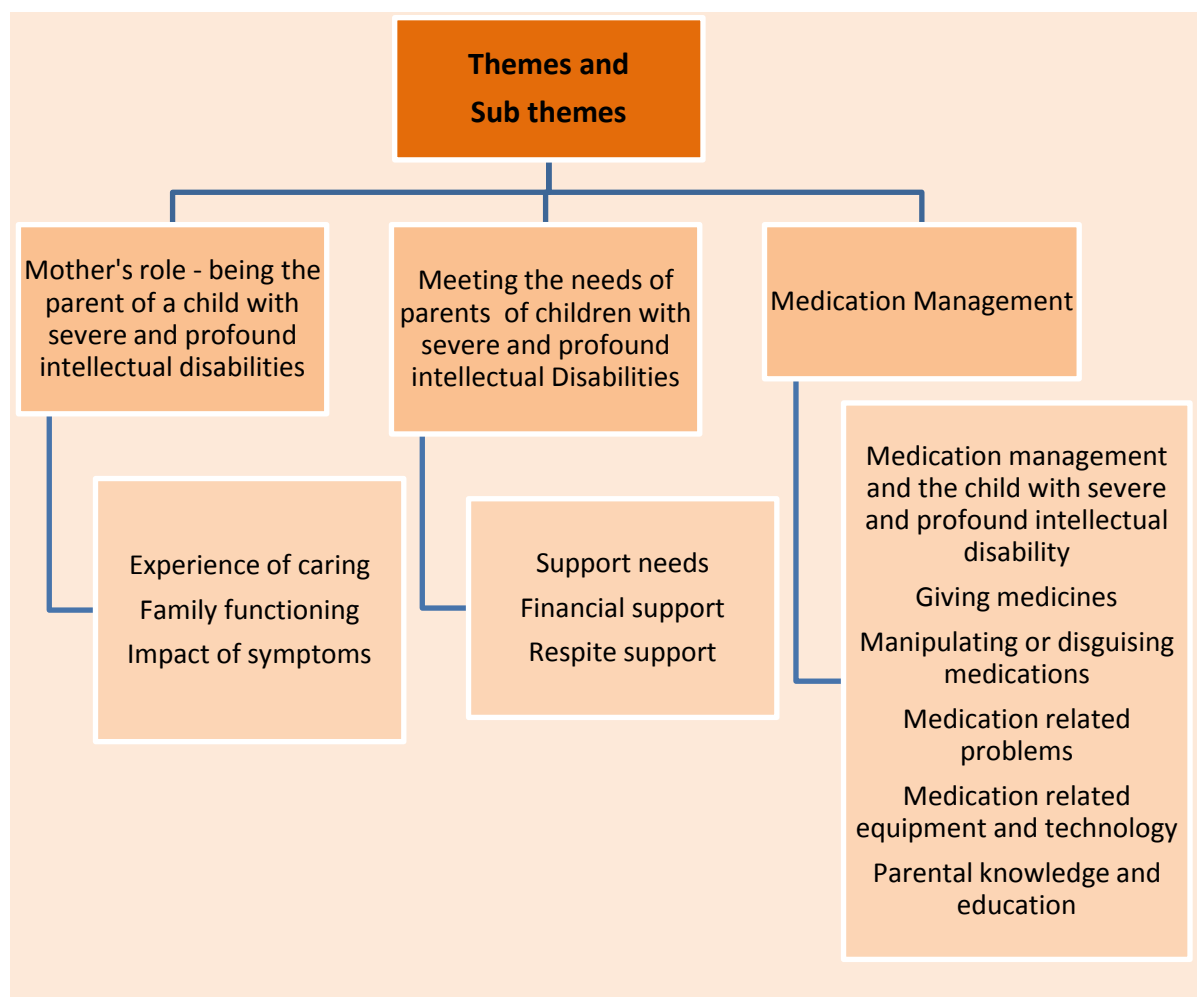
Most studies relating to medication related issues in adult populations address such topics as non-adherence, polypharmacy, inappropriate prescribing and the challenge of medication related problems linked to chronicity of conditions (Elliott 2006, Haslbeck & Schaeffer 2009). Poor home medication management practices include poor storage practices, lack of medication administration schedules, use of drugs from multiple prescribers and non-adherence (Sorenson *et al.* 2006). An earlier study which again explored family caregivers experience of medication management, established it was often difficult to obtain the medications from the pharmacy if the care recipient could not be left alone (Ranelli & Aversa 1994, Ranelli & Hansen 1994).

Within this review of the literature, three emergent overarching themes and key areas considered in-depth within this literature review are; mothers' role - being the parent of a child with severe and profound intellectual disabilities, meeting the needs of parents of children with severe and profound intellectual disabilities and medication management. Twelve related sub themes are distinguished also and explored further (see Table 4 for more detail).

With regard to the mothers' role and meeting the needs of parents, the bulk of the literature adopts a qualitative research design gathering data through individual

(Glendinning & Kirk 2000, Kirk 2001, Redmond & Richardson 2003, Kirk & Glendinning 2004, Foundation for People with Learning Disabilities 2005, Heaton *et al.* 2005, Kirk *et al.* 2005, Steele & Davies 2006, Hewitt-Taylor 2008c, 2009b, Koshti-Richman 2009, Nicholl & Begley 2012, Mendes 2013, Bourke Taylor *et al.* 2014, Whiting 2014a, 2014b, Coad *et al.* 2015, Carter *et al.* 2016) or focus group interviews (Diehl *et al.* 1991, Gravdal-Kvarme *et al.* 2016). The majority of these studies were descriptive in nature with a few adopting grounded theory and just one hermeneutic phenomenology (Nicholl & Begley 2012). In addition, one study adopted ethnography and the use of Photovoice as a means of data collection (Woodgate *et al.* 2015) and one used participant diaries (Nicholl & Begley 2012).

Table 4: Themes and sub themes



Quantitative research design saw questionnaires adopted in some studies (Cornish *et al.* 1996, Case 2000, Brett 2004, Hewitt-Taylor 2005b, 2005c, Tadema & Vlaskamp 2009, Toly *et al.* 2012) while child records were also accessed as a method of data collection by Zijlstra & Vlaskamp (2005). Llewellyn *et al.* (1998), Roberts and Lawton (2001), Green (2007), Cadell *et al.* (2012), Hunt *et al.* (2013) and Carter *et al.* (2015) assumed a mixed methods approach. A variety of participants were accessed in all studies with mothers (eight studies) being most commonly accessed and fathers (five studies) less so. Many of the studies had family participation which saw mothers and fathers partake (12 studies). Other study participants included significant others, service workers, nurses, teachers and voluntary organisations. Sample sizes varied from between 7 to 133 families and 2 to 71 individuals. These studies were undertaken within Ireland, the UK, Europe, the United States of America (US), Brazil and Australia. On the whole, the methods adopted within the studies that were reviewed and the resultant findings were consistent.

In considering the theme of medication management, again qualitative research design was the favoured choice with data gathered through individual (Goldstein & Rivers 1996, Birchley & Conroy 2002, Francis *et al.* 2002, Lau *et al.* 2009, Dunworth-Fitzgerald & Sweeney 2013, Ramos *et al.* 2015) or focus group interviews (Venables *et al.* 2015, Erickson *et al.* 2016, Gibson *et al.* 2017). Similar to the previous theme, qualitative research studies were descriptive in nature and none acknowledged use of hermeneutic phenomenology. Some studies adopted a quantitative approach using questionnaires (Smith *et al.* 2003, Hewitt-Taylor 2004, 2005b, 2005c, Kirk 2008, Kuo *et al.* 2011, Bourke-Taylor *et al.* 2013, Caicedo 2016, Aboneh & Chui 2017). One study used a case study approach (Epitropakis & DiPietro 2015) while two further studies used retrospective chart review and audit (Feudtner *et al.* 2005, Flood 2016). A mixed methods approach was adopted in two studies (Nicholl *et al.* 2013, Richey *et al.* 2013). Data for the studies in this theme was gathered from a variety of sources; care recipients, caregivers, families, hospice providers, managers, nurses, nursing teams, pharmacist, medical practitioners and child records. Sample size was varied with anything from 6 participants to a review of over 10 million child records. Again, these studies were undertaken within Ireland, the UK, Europe, the United States of America, Brazil and Australia.

The three identified overarching themes and associated sub themes are now further explored setting the context for this study.

2.5 Mother's Role – being the parent of a child with severe and profound intellectual disabilities

This overarching theme examines the literature pertaining to being the parent of a child with severe and profound intellectual disabilities and explores; the experience of caring, family functioning and the impact of child symptoms on the role of the mother.

2.5.1 Experience of caring

While all children are dependent on their parents in every domain of daily living (Tadema & Vlaskamp 2009), for children with severe and profound intellectual disabilities there are more non-normative requirements of the caregiver role creating a level of burden beyond that experienced by other parents (Nelson 2002, Leiter *et al.* 2004, Heywood 2010). For the majority of families raising a child with severe and profound intellectual disabilities becomes a lifelong responsibility placing immense burden on families (Coad *et al.* 2014). Central to this burden is the assumption that parents, particularly mothers, will assume a health provider role, undertaking activities that may previously have been provided within a healthcare setting (Leiter *et al.* 2004). Often the role of the caregiver is relentless and intense in nature (Bourke-Taylor *et al.* 2010). Days could be laced with unpredictable care requirements (Heaton *et al.* 2005) with mothers of children with severe and profound intellectual disabilities reporting fewer 'typical days' than other parents (Crowe & Michael 2011). Children with severe and profound intellectual disabilities often require complex home care (Green 2007) and this can place high time demands on parents (McCann *et al.* 2012). However, it must also be recognised that families also acknowledge the positive, deep and enriching experiences of parenting a child with complex needs (Carnevale *et al.* 2008, Dybwick *et al.* 2011, Whiting 2013).

As care transitions from health care institutions to the home setting, the role of parents has intensified (Swallow *et al.* 2011). Finding time to do anything other than care in

terms of employment, leisure activities or social interaction is difficult (Brandon 2007, Carnevale *et al.* 2008). The feelings of being overwhelmed by the scope of caring and the relentlessness of responsibility can be incredibly stressful (Carnevale *et al.* 2008). Inevitably, one of the parents usually ends up as full time carer and therefore, financial concerns can be a great source of worry and frustration (Diehl *et al.* 1991). Caring for a child with intellectual disabilities impacts upon a family's daily life physically, financially, socially and emotionally. Furthermore, it can have overwhelming effects on the entire family, parents, siblings and extended family. It is well documented that mothers feel the bulk of the burden of care, experience stress, financial problems, difficulties in accessing care, deterioration in family structures and marital problems (Condliffe 2006, Nicholl & Begley 2012). However, it must be noted on the positive side, it can increase family functioning, enhance cohesiveness and encourage connections with support groups (Green 2007, Reichman *et al.* 2008).

Caring for a child with severe and profound intellectual disabilities requires a lifetime commitment by parents (Department of Health (DOH) 2001) and while historically children with severe and profound intellectual disabilities were cared for in institutional organisations, the concepts of normalisation and inclusion has led to community care (Condliffe 2006) with the preferred site for care provision for children with complex needs being the home (Olsen & Maslin-Prothero 2001). While this has positive benefits for both the child and family, recognition of the care burden on parents needs to be acknowledged (McCann *et al.* 2015). Mothers with medically fragile children experienced feelings of exhaustion particularly following discharge of their child from hospital (Hodgkinson & Lester 2002, DOH 2004). Likewise, sleep deprivation, insomnia and high levels of anxiety are experienced by parents of children with severe disabilities living at home (Heaton *et al.* 2006, Kielty *et al.* 2015). Evidence indicates that the daily burden of routine and continual responsibilities can result in physical and emotional over burden for carers (Thomlinson 2002).

While much literature explores the preparation of parents for technical care-giving, it is important to consider the psychological impact on parents who must perform clinical tasks on their children (Glendinning & Kirk 2000, Hewitt-Taylor 2005a). This undertaking

is often overlooked and the conflict between nurturing and providing nursing care is one that should be considered (Hewitt-Taylor 2005a). Using a grounded theory approach, Kirk (2001) undertook interviews with 23 mothers, 10 fathers and 44 health professionals to gain insight into the experience of caring for children with complex health care needs and supporting them and their families in the community. Interestingly, the initial assumption of responsibility by parents was not negotiated with professionals but borne out of parental responsibility and desire to have their child at home. Similarly, professionals indicated that parents were not really given a choice in accepting responsibility and it was an expectation that they would take their child home and care for them accordingly. Therefore, this resulted in role negotiation only happening post-discharge as both parents and professionals gained experience and found what worked for them. In a later article on the same study, Kirk *et al.* (2005) reported data on the parenting role versus the nursing role they undertake. All participants acknowledged their parenting role as having two dimensions to include nursing. However, they affirmed that their primary role was to be a parent and they differentiated their caregiving role from their nursing one.

Raising children with profound intellectual and multiple disabilities is considered to be extremely difficult for parents (Tadema & Vlaskamp 2009). Parents (mix of mothers and fathers) of 133 children with profound intellectual and multiple disabilities completed a questionnaire exploring the care load, burden and support of Dutch parents (Tadema & Vlaskamp 2009). Findings concluded that these children were dependent on their caregivers and required intensive care in daily life activities. Recurrent health concerns increased this burden of care on parents, with home care supports and respite care valued positively. Interestingly, family support was not valued as highly as respite or home care support and this may be due to the fact that these are formal structured supports and not delivered in an ad hoc fashion.

An Irish study explicated the meaning of caregiving for 17 mothers of children with complex needs (Nicholl & Begley 2012). Through use of in-depth interviews and diary keeping by the participants, it was indicated that care can be divided into three differing worlds; in the home, outside the home and travelling between the home and outside.

Within these worlds 4 categories of caregiving were identified; normal mothering, technical caregiving, pre-emptive caregiving and individualised caregiving. Nicholl & Begley (2012) therefore propound that professionals need to embrace a greater understanding of what it is like for mothers to care for these children.

Heaton *et al.* (2003) in their research study focused on the experiences of families of technology dependent children using one or more medical devices on a daily basis and examined care routines and the instances of technical care. A sample of 36 families including parents, children and siblings engaged in interviews detailing their daily time schedule. Routines varied depending on the device, diagnosis and fluctuations in their child's health status. Technical care was mainly provided by the mother and highlighted associated difficulties such as combining this caring role with work, sleep disruption, social isolation and the negative impact on siblings engaging with school and social activities due to the constant disruption. In a subsequent article, Heaton *et al.* (2005) argued the rhythm and routine varied across families and was determined largely by the type and complexity of equipment the child used and whether technical care was required on an ongoing basis and through the night-time. While the children required and benefited from the technology, the need to oversee its use, especially in the night time left parents suffering regular sleep disruption.

Additionally, Green (2007) explored the perceived benefits and burdens of mothering a child with disability surveying 81 mothers and interviewing 7 of these. It was concluded that the burden of care could be segmented into objective (physical) burden and subjective (emotional) burden. Participants were more likely to talk of their financial stresses and time constraints rather than the emotional distress they might feel. Furthermore, the extra effort parents commit to, in raising a child with severe and profound intellectual disabilities was to the forefront of an ethnographic research study where 68 parents were interviewed and/or partook using the Photovoice method of using digital cameras to take pictures that represented their everyday life (Woodgate *et al.* 2015). Parents reported their role as labour intensive requiring readiness to provide care at any time, day or night. As a result, parents were left with little or no time to address their own needs that did not involve caring for their child. Caring for a child with

severe and profound intellectual disabilities can also take a physical toll on parents with some experiencing sleep deprivation (Meltzer & Mindell 2006), anxiety, stress and depression (Woodgate *et al.* 2015). Likewise, parents have reported experiencing physical health issues such as headaches and exhaustion related to their child's difficulties and the necessity to attend to their needs in the night (Sawyer *et al.* 2010, Moveliuss & Hemmingsson 2014).

2.5.2 Family functioning

The effect of caring for a child with severe and profound intellectual disabilities on the family cannot be underestimated. Parents are required to accept responsibility without giving up, make key decisions and co-ordinate care in the midst of normal family life (Wilson *et al.* 1998). Many factors can affect family functioning and it is notable that unlike healthcare staff, parents have no time off-duty, and their homes are disrupted by medical equipment, disturbed sleep and visits from a range of healthcare professionals (Glendinning & Kirk 2000). Adjustments are made to everyday life in order to accommodate the child's needs within family life (O' Brien 2001).

Emotional demands on parents caring for a child with severe and profound intellectual disabilities are often neglected by healthcare professionals (Narramore 2008). The need for emotional support has been recognised especially around the time of diagnosis when grief reactions can be triggered (Thurgate & Warner 2005, Harnett 2007) and when loss of expectation for a "normal newborn baby" are experienced. Stress is often experienced by parents especially in the early days when their baby may be admitted to a neonatal unit with serious illnesses associated with their disability (Narramore 2008). Parents of children with disability can also have higher depression scores (Olsson & Hwang 2001, Bemister *et al.* 2014). However, Fowlie & McHaffle (2001) suggest that the severity of the disability does not reflect how stressed a parent might be and for some parents the emotional stress can lead to a recognised mental health illness. This is supported by Emond & Eaton (2004) and Radriguez & King (2009) who assert parents of children with life limiting conditions often have their mental health compromised. Despite all of the challenges experienced by parents of children with severe and profound intellectual disabilities, parents sacrifice their emotional and physical

wellbeing for the sake of their child (Kars *et al.* 2008). Woodgate *et al.* (2015) also reported that parents were emotionally committed to their children and were hesitant to entrust care to others as they may not provide the same level of care as they do.

Toly *et al.* (2012) examined family functioning in a longitudinal study, during two interviews over a 12 month period with 82 primary caregivers who were mothers of technology dependent children. It was identified the task of providing long term care in the home of a child who is dependent on technology can be daunting for mothers as they assume the majority of the caregiving role. While some of the children of these parents reduced the volume of technology dependence over the 12 month period some increased their requirements adding additional burden to the family. Family functioning was assessed and following the second interview, 39% of participants were displaying depressive symptoms thought to be directly related to the severity of the child's illness and this impacted on family functioning. Authors concluded that the duration and burden of caregiving coupled with technology dependence were influential factors in these findings.

2.5.3 Impact of symptoms

Symptoms a child displays can have an impact on the child and the wider family networks (Hunt *et al.* 2003). Steele & Davies (2006) explored the multidimensional impact that caring for a child with a progressive life limiting condition displaying worsening symptoms had on families, including the emotional, physical, financial and spiritual impact on their lives. A grounded theory approach gathering data through both observation and interviews with eight families (mix of mothers and fathers) yielded evidence that parents of children with neurodegenerative life threatening illnesses required help in alleviating some of the issues but did not always get this help or certainly not in a useful manner (Steele & Davies 2006). It was identified that professionals and family members needed to recognise the effort involved for the parents and find ways they could assist them.

Parents' perceptions of their child with complex needs were further discussed by Hewitt-Taylor (2008b). Fourteen parents (12 mothers and 2 fathers) participated in a

research study exploring parents' perceptions of their child's experience of communication, play, socialising and learning. Parents felt that while the impact of symptoms meant health needs being met were important, they often felt their child's efforts to communicate were unheard and undervalued. Additionally, play and socialising were more challenging because of physical need but also because of the priority service providers placed on these elements. Inclusive experience of education was also identified with mixed opinions on their experience of this.

In summarising this overall theme of mother's role, being the parent of a child with severe and profound intellectual disabilities, it is evident that while the experience of caring can be a positive and enriching one (Carnevale *et al.* 2008, Dybwick *et al.* 2011, Whiting 2013) it can also bring with it increased burden (Coad *et al.* 2014). Mothers are responsible for taking on the relentless role of caring placing huge demands on them (Leiter *et al.* 2004, Bourke-Taylor *et al.* 2010). The impact of caring has been noted to take its toll on mothers in many ways, physically, financially, socially and emotionally (Diehl *et al.* 1991, Kirk 2001, Heaton *et al.* 2003, Condliffe 2006, Green 2007, Tadema & Vlaskamp 2009, Nicholl & Begley 2012). The effect on family functioning was also considered with high emotional demands placed upon mothers and families (Narramore 2008). Factors affecting family functioning were highlighted by Glendinning & Kirk (2000) such as disturbed sleep, disruptions at home by visiting health professionals and no time off their caring duties. Additionally, Toly *et al.* (2012) identified the task of caring for mothers of children requiring technology in daily life as daunting and found they experienced high depression scores. The impact of symptoms experienced by the child was also seen to impact on mothers providing care (Hunt *et al.* 2003, Steele & Davies 2006, Hewitt-Taylor 2008b).

2.6 Meeting the Needs of Parents of Children with Severe and Profound Intellectual Disabilities

Meeting the needs of parents of children with severe and profound intellectual disabilities is the focus of this second overarching theme further divided into the sub themes; support needs, financial support and respite support.

2.6.1 Support needs

A common theme in the literature is the perceived lack of adequate services and supports afforded to parents and children (Bourke-Taylor *et al.* 2014, Coad *et al.* 2015, Woodgate *et al.* 2015). Caring for a child with severe and profound intellectual disabilities who needs technical support for daily life and high levels of care can result in adverse impacts on the primary caregiver, usually the mother. These caregivers are particularly at risk if supports and necessary resources are limited or unavailable (Noyes 1999, 2002, Roberts & Lawton 2001). Llewellyn *et al.* (1998) recognised that parents of children with intellectual disability require support and acknowledge that the growing interest in this area is due to these services wanting to be responsive to parent identified concerns. In this Australian mixed methods study, the views of 52 parents, 40 mothers and 12 fathers, 32 significant others (identified by parents and usually a family member or friend) and 38 service workers (workers who were helpful to them in their parent role) were considered through completion of a survey and interviews. Survey items explored areas such as child care, social and community living and domestic skills. From the parents perspective the greatest gaps existed in accessing community resources, and meeting people or making friends. Exploring work options were also identified with parents signalling pessimism about their employment choices when combined with their caring role. Interestingly, service workers perceived greater need on almost all items compared to the needs identified by parents themselves.

A UK study sourced data from 40,000 database records and also undertook nine focus group interviews with parents of children with a range of disabilities (Roberts & Lawton 2001). The majority of children required extra assistance or supervision in multiple aspects of daily living. Causal factors included cognitive difficulties and physical limitations. Parents requested that professionals recognise and offer explicit acknowledgement of the extra care they deliver to their child with disabilities. In a similar study also exploring the needs of parents, Diehl *et al.* (1991) undertook nine focus group interviews with 80 primary caregivers (71 females and 9 males) of children aged between birth and 21 years old who had chronic debilitating conditions. Family issues were identified as one of the key themes whereby the intensity of care needed by

the child impacted on family relations. Husbands and wives rarely did things as a couple with any spare time spent with siblings. Sibling jealousy was also cited as an issue.

Redmond & Richardson (2003) in an Irish study explored mothers' views of the usefulness of financial, practical and emotional supports afforded to them. Seventeen mothers of children with severe and profound intellectual disabilities under the age of 4 were interviewed. Again this study reinforced that mothers are engaged in a stressful but skilled caring role and want to continue doing so in the home environment. However, they indicated that the process of gaining information was haphazard, uncoordinated, unreliable and sometimes inaccessible with needs not being met by either intellectual disability services or health services. All participants highlighted suggestions for service improvements and signalled their desire for more support at home and the need for home-based respite care.

The influence of medical conditions of children with profound intellectual disabilities on the professional support they received in centres for special education was investigated in the Netherlands (Zijlstra & Vlaskamp 2005). Reviewing medical files, daily records and daily communication records between parents and professionals for 48 children accessing three centres, it was established that not only major medical conditions such as those requiring hospitalisation but also minor medical conditions had an impact on the ability of the child to engage in activities and therapies. As a result of such minor conditions, such as an increase in body temperature or the drowsy state of the child, professionals may decide not to undertake activities without exploring alternatives, therefore resulting in many 'empty' hours in the day.

Being mindful of fragmented service provision, Hunt *et al.* (2013) on behalf of the organisation Together for Short Lives, set out to establish how well the needs of children with life-limiting conditions and their families were being met by the organisation. They examined specifics such as the cost of the service provision as well as its impact. This mixed method study gathered data using questionnaires, interview and focus groups with children, families and professionals and identified the need for coordinated care on

a 24/7 basis with smoother access to services. It was also established that professionals require development of their skills responsive to the needs of the children and families.

More recently, a UK study undertaken with 34 parents investigated the experiences of parents of children with complex health needs in relation to help and support they receive when caring for their child (Whiting 2014a, 2014b). Parents identified their need for people (family, friends and professionals) to support them and secondly, processes and resources with a clear indication for respite requirements. Open access to an acute children's ward was also requested as it can be a valuable out-of-hours support. As the immigrant population rises in the UK, an exploratory hermeneutic study, undertaken by Gravdal-Kvarme *et al.* (2016) identified 27 immigrant parents (18 mothers and 9 fathers) caring for a child with complex health needs and through interviews established that these parents experienced personal health and quality of life challenges. Similar to Whiting (2014a, 2014b) inhibitors of health and quality of life were identified such as lack of respite support, lack of social support and language barriers. In order to promote quality of life it was recommended that service providers have a key role to play in supporting these parents and a co-ordinator of care may assist in ensuring needs are met.

It is clear that providing ongoing care for a child with complex needs can be wearing and appropriate supports for families on a daily basis and not just when a crisis occurs, can alleviate some of the pressure felt by parents (DOH 2004, Hewitt-Taylor 2005a). Practical supports are essential for families especially those parents of children with severe to profound intellectual disabilities who usually care for their child 24 hours a day, seven days per week (Narramore 2008). Such practical supports can include assistance with care, reassurance in the home, direct access to child health services and bypassing emergency departments. Furthermore, early support can allow parents achieve better coordination of care for their child with severe and profound intellectual disabilities (Narramore 2008).

Highlighting professional roles in supporting parents, Case (2000) analysed the efficacy of service provision for 114 parents of children with disabilities sampled from across the

UK. The findings of the completed questionnaire highlighted deep parental concern regarding professional attitudes towards them and their children, neglect of parental knowledge, lack of supports enabling coping and fear for future supports. Results indicated that professionals continue to control the parent-professional relationship, which is in conflict with much of the literature on facilitating family centred care. The Foundation for People with Learning Disabilities (2005) undertook research with 22 families of children with intellectual disabilities and concluded more positively, that professionals visiting the home were appreciated in all cases. However, the practicality of providing such supports is onerous requiring key decisions on where to provide the support, who should provide it and who will pay for it.

Kirk & Glendinning (2004) suggest that while care needs are high, especially for those who are technology dependent, community based supports have not kept pace with this rate of development. They acknowledge that multi-agency services are often poorly planned, inadequately co-ordinated and often represent a complex web of support. Few studies have addressed how parents can be supported to undertake specific nursing interventions when their child requires technical care. In providing supports, it is imperative professionals listen to parents of children with disabilities. Koshti-Richman (2009) ascertained from a group of 20 parents of children with disabilities that being listened to undoubtedly enhanced interactions and made experiences positive, helping parents feel like they were involved. Respect for parents' opinions by professionals meant parents respected the opinions of professionals as well.

Within Brett's (2004) study which surveyed teachers, special support staff, nurses and parents, it was understood that the hardest decision for parents was asking for help but if they did so they coped better. This study resulted in development of an education programme for school nurses to deliver a training package for education staff working with children with complex needs. Parent support groups have also been found to be useful and can provide reassurance to parents especially when they feel isolated and alone and that no one else has experienced what they are going through (Emond & Eaton 2004). Additionally, the role voluntary organisations play in supporting parents of children with life limiting disorders was explored through a national postal survey of 147

voluntary organisations providing for children with such disorders (Cornish *et al.* 1996). A wide variety of services were provided by these voluntary organisations to include information giving, emotional support and counselling, child and family support and a telephone helpline service. However, Cornish *et al.* (1996) acknowledge the role of voluntary organisations as partners in care with statutory services requires further exploration and debate especially in light of the unstable funding arrangement for voluntary organisations and the expansion of the sector.

More recently, Carter *et al.* (2015) undertook a mixed method study exploring the role of trained family support workers employed by a voluntary, charitable organisation in the UK, Rainbow Trust Children's Charity. Findings revealed that these family support workers were instrumental in embracing families through supporting needs and promoting resilience, befriending and bonding with families through developing knowledge and building trusting relationships. Furthermore, accompanying and enduring alongside families in different settings, situations and crises was evident. This contribution was seen as a provision of support not provided by other services such as undertaking the ironing, washing, shopping, taking siblings to school and generally listening.

Parents of children who are technology dependent report being satisfied that their child witnesses social and emotional normality (Diehl *et al.* 1991) while enabling their child to receive some education is also reported as a vital agenda of parents (Elder 2001). Eight mothers' perspectives of caring for a school aged child with disability in the UK were explored by Bourke-Taylor *et al.* (2014). Participants identified a multitude of challenges related to issues surrounding the child, maternal characteristics, the family, services and the community. Emotional distress and mental health issues were reported also. Additionally, Coad *et al.* (2015) explored perceived met and unmet needs of 51 families (74% mothers, 13% fathers and 13% other family members) of children with life-limiting illness in the UK. Findings indicated that children and their families felt medical and nursing needs were well met but supplementary provision was needed for broader financial, emotional and social supports. Furthermore, Coad *et al.* (2015) advise

optimising support services is essential in order to provide conditions that facilitate them in their caring task.

Mendes (2013), in a US study adopted a qualitative approach undertaking interviews with seven parents (4 mothers and 3 fathers) to establish the components for supporting ideal home nursing care. Parents achieving competence in technical assessment, clinical decision-making and problem-solving skills was of paramount importance and an acknowledgement that caring went far beyond just technical caregiving. Parents also felt that it was essential they maintained control of decisions and their rights and wishes were respected especially by those who provided supports within the home.

2.6.2 Financial Support

Financial costs of having a child with severe and profound intellectual disabilities are an important factor to consider in meeting the needs of parents. Often, the financial reality of caring for this child cohort is an incidental finding of research studies and not considered as a major priority (Randall 2017). A large cross sectional study undertaken in the US examined 38,886 children with special health care needs (Kuhlthau *et al.* 2005). It was established that reduced employment to care for their child and other out of pocket expenses are commonplace with this cohort of parents. Financial support can be offered through ensuring parents have applied for relevant funding (Kuhlthau *et al.* 2005). In Ireland, this would be carers allowance and any other eligible benefits that may alleviate financial worries. In addition, adaptation of the home environment can be financed through a disability grant and would allow families to make some necessary adaptations (Citizens Advice Bureau 2018).

Cadell *et al.* (2012) described the financial stress experienced by parents of children with life-limiting illness in another US/Canadian study. Despite in many cases, having reasonable household income, finances were affected by the time required in caregiving, such as attending appointments, meetings and seeking supports or resources. Financial instability was also experienced as a consequence of medical and equipment expenses, travel to and from hospital and time away from work. Within the

Irish media, financial supports are further explored with speculation concerning these children and how a decade of economic austerity has impacted on children with intellectual disabilities with suggestions that particular challenges make them and their families more susceptible to poverty (Flynn 2017). Erosion of the intellectual disability infrastructure in Ireland is cited in the literature and suggests that children and families accessing these services in particular have been disproportionately disadvantaged by economic recession (Gartland 2007, Disability Federation of Ireland 2010, Flynn 2017). Despite some indicators that better outputs are evident, radical resource cuts due to the Irish financial crisis have led to longer waiting lists especially for those requiring niche specialist input such as children with intellectual disabilities (Thomas *et al.* 2014).

2.6.3 Respite Support

Given the high demands of caring for a child with severe and profound intellectual disabilities, respite is of particular importance in meeting the needs of parents. Research has highlighted how parents feel imprisoned in their own homes as a result of the complex mechanism of travelling outside the home with their child and associated equipment (Kirk 1998, 1999, Brinchmann 1999, Neufeld *et al.* 2001). Respite care can relieve parents from this for periods of time and enable them to have a good night's sleep. However, many studies have found that securing respite care can be difficult and when received, it is on a limited basis (Diehl *et al.* 1991). Due to the increase in home-based care for these children, the issue of respite support is high on international and national agendas (Merriman & Canavan 2007, DOHC 2010). In Ireland, while the Disability Act (Government of Ireland, GOI 2005) does not address respite care as a specific issue, it does indicate the need for each individual with intellectual disability to have an independent assessment of need which is likely to propose respite care provision as one of the required supports. While parents may be reluctant to use respite care, they do find it beneficial (Eaton 2008) and formal in-home care was the preferred form of respite for carers in many studies (Hartrey & Wells 2003, Redmond & Richardson 2003, MacDonald & Callery 2004). It was also evident that where possible this should be flexible and available locally (Ling 2012).

A gap in services such as respite is a major issue for families who are often required to learn complex nursing skills and take on 24 hour responsibility (Townsend & Robinson 1999, Ross & Parkes 2004) with access to respite care often difficult and fraught with bureaucracy. Terres (1999) compared users and non-users of respite care describing how 70 families of children with disability gained access to respite. While all participants knew about respite only 38 families actually used it and these families had children with significantly more complex disabilities requiring a lot of support. Those who did not use respite identified the difficulties they had come across when trying to gain access and this inability to access respite was their reason for not using it. A phenomenological approach was adopted in one Irish study on respite service provision to explore the views of two mothers of children with learning disabilities (Hartrey & Wells 2003). While some of the benefits of respite were felt, for these two mothers the personal significance of caring was evident. They indicated their experience of separation and feelings of guilt and emotional stress when using respite. Therefore, it is essential that respite care providers support parents to view the use of respite as a sign of caring and thereby alleviate such feelings.

One UK study reported using an ethnographic approach involving 43 participants who were mothers, grandmothers, fathers, grandfathers, nurses and social workers (Macdonald & Callery 2008). A developmental map of caregiving over time was constructed from retrospective accounts of parenting a child requiring complex care from infancy to young adulthood. The requirement for respite and the form of respite provision changed over time with the increasing complexity of care leading to an increase in demand for respite. Similarly, Power (2008) undertook qualitative interviews with 25 carers accessed through various organisations in Ireland, one of which was specifically for families of children and adults with intellectual disabilities. Additionally, he engaged six representatives from these carer organisations in interviews. Family carers all had children with intellectual disabilities ranging in age from late teens to 30 years old. Findings showed there was limited flexibility, choice and availability in meeting family preferences, which was not just symptomatic of a funding shortage but required supportive attitudes and flexibility in meeting the demands of these families.

Residential out-of-home respite remains unpopular for many but not all parents want in home supports on a daily basis as this can intrude on an already disrupted family life (Valkenier *et al.* 2002). While respite support is seen as an important resource for families (Neufeld *et al.* 2001, Olsen & Maslin-Prothero 2001) obtaining suitable respite care can be problematic and difficult to resource especially at short notice (Ling 2012). Of particular concern is the inability of parents to access respite care in a consistent manner that meets the needs of the child and family. The Irish Hospice Foundation (2011, 2013) have explored the area of respite for children with life-limiting conditions and have developed a national needs assessment aimed at paving the way for individualised, high quality, appropriate respite service provision for all children, irrespective of geographical location or family circumstances. What is evident from this national document, is that a range of respite programs need to be developed in a structured and co-ordinated way to meet the rising demand.

To summarise, this overarching theme explored the needs of parents of children with severe and profound intellectual disabilities and identified issues in terms of support needs, financial and respite supports. The specific needs of parents were identified recognising that they require a variety of supports in order to cope in daily life (Llewellyn *et al.* 1998, Roberts & Lawton 2001, Redmond & Richardson 2003, Kirk & Glendinning 2004, Zijlstra & Vlaskamp 2005, Bourke-Taylor *et al.* 2010, Hunt *et al.* 2013, Coad *et al.* 2014, Whiting 2014a, 2014b). Furthermore, the financial costs of having a child with severe and profound intellectual disabilities were pondered with reduced employment for parents commonplace (Kulthau *et al.* 2005, Cadell *et al.* 2012) and the impact of Irish economic recession evident (Disability Federation of Ireland 2010, Thomas *et al.* 2014, Flynn 2017). Additionally, respite was identified as a key support for mothers of severe and profound intellectual disability albeit not always easily accessible (Terres 1999, Hartrey & Wells 2003, Macdonald & Callery 2008, Power 2008, Ling 2012, Irish Hospice Foundation 2011, 2013).

2.7 Medication Management

With regard to the third overarching theme of medication management, it is important to acknowledge the complexity of the task and process. This theme considers various key issues under the sub themes; medication management and the child with severe and profound intellectual disability, giving medicines, manipulating or disguising medications, medication related problems, medication related equipment and technology and parental knowledge and education.

2.7.1 Medication management and the child with severe and profound intellectual disability

Studies have examined aspects of medication management by caregivers in the general adult population (Travis *et al.* 2000, 2003) and it is acknowledged that medication management may require a high level of cognitive processing involving application of knowledge of disease and medications (Smith *et al.* 2003). Some of the central tenets of medication management include; information seeking, information sharing, safety issues, scheduling logistics and polypharmacy concerns (Travis *et al.* 2000, 2003). A qualitative study undertaken by Lau *et al.* (2009) involved interviewing 23 family caregivers of those requiring hospice care and 22 hospice providers. Key findings included the necessity to have teamwork skills encompassing the ability to communicate and coordinate with other caregivers. In addition, organisational skills included the ability to acquire, store, track and discard medications. The ability to recognise and respond to common symptoms was also a key finding. In terms of medication knowledge skills, this included the ability to apply the basics of pharmacology, understanding the difference between brand and generic names, time to peak drug effect and difference between short and long acting drugs. It was determined that medication management is an important family caregiving responsibility that encompasses a complex set of cognitive, problem solving, interpersonal skills and processes.

Administering medicines to children with severe and profound intellectual disabilities is a part of everyday life and is multi-faceted and often complex. Nurses have indicated

medication management as a core intervention when working with adults and children with profound intellectual disabilities in Ireland (Dunworth-Fitzgerald & Sweeney 2013). Within this study, 10 nurses identified administration of medication and monitoring of side effects as a time consuming task for which they needed a good understanding of medications particularly when medications changed often. The role of the nurse encompassed considerable knowledge of medications in order to be aware of drug interactions and side effects. The ordering, storage, monitoring and administration of regular and as required medications were all cited as elements of medication management intervention.

In a US study, family caregivers of people with intellectual disabilities have identified multiple problems in the medication management process (Erickson *et al.* 2016). This descriptive qualitative study explored issues utilising five focus groups with 30 caregivers (mix of family and support staff) and identified lack of continuity of care and accuracy of medication records, poor communication between healthcare professionals and caregivers and also poor caregiver understanding and training on medication related topics. Findings provide key insights into the problems that exist and suggest the need for interventions to address each of these challenges. Similarly, in an Irish study, Flood (2016) explored medication use in residential care for older people with intellectual disabilities. While this was an adult population with intellectual disabilities, some similarities exist with the child populations. A baseline audit was undertaken of prescription records for all 129 people residing in the residential centre. Issues such as combinations of multiple medications use and medical complexity were evident. It was also acknowledged that while medication administration may seem a 'simple' task, that given the medical complexity of individuals it is often more complex than fully understood and the presence of swallowing difficulties or cognitive impairment in the recipient may complicate administration.

2.7.2 Giving Medicines

The giving of medicines to children with severe and profound intellectual disabilities can be a complex process intertwined with difficulties. Any administration of medicines to children must be considered in relation to the individual child's capacity to take the

treatment and the impact it will have on them (Glasper *et al.* 2010). Several routes of administration are used with children (Watt 2003a, 2003b) whether a disability exists or not (see Table 5).

Table 5: Routes of Medication Administration

Route	Explanation
Oral	Including anything swallowed to the stomach or via nasogastric (NG) or nasojejunal tubes or percutaneous endoscopic gastrostomy tube (PEG tube).
Sublingual/buccal	Allowed to dissolve under the tongue or in the cheek.
Topical	Including application into eyes, ears, or insertion in rectum.
Transdermal	Through slow release patches adhered to the skin.
Inhalation	Including via mask, nebulisers, breathing tubes and spacer devices.
Intravenously	Administered into a vein or artery, usually by a doctor or nurse.
Subcutaneously	By injection under the cutaneous or subdermal skin layers.
Intramuscularly	By injection into the muscle layers.

Considerable care has been taken to ensure children do not experience unnecessary routes of administration such as injection or intravenous care. The prescribed route of administration is dependent on the availability of the medication, condition being treated, speed of action of the medication and the child's tolerance to the route of administration (Macqueen *et al.* 2012). In children's nursing the majority of parents are encouraged to participate in the administration of medication to their child (Macqueen *et al.* 2012) and this is supported by the Nursing and Midwifery Council (NMC) (2007, 2008). The Nursing and Midwifery Board of Ireland (NMBI) (2007) also support this, providing standards for service user education that are accessible and understandable.

In a Brazilian study, Ramos *et al.* (2015) set out to identify the feasibility of home care for children with special health needs and the associated difficulties experienced by mothers. This descriptive qualitative study ascertained from 10 mothers, that giving medicines sometime presented as easy while sometimes difficult. Difficulties included forgetting to give medicines, the bad taste of the medicine and the unwillingness of the child to accept the medicine. In overcoming such difficulties, Ramos *et al.* (2015) recommend that nurses have a key responsibility in educating mothers regarding this task.

More recently, Aboneh & Chui (2017) focused on quantifying and comparing unmet need for prescription medications and care coordination for subgroups of children with special health care needs in the US. Secondary data analysis of a national telephone survey was utilised in drawing comparisons between children with and without medical complexity. It was established that children with medical complexity had significantly more unmet need for prescription medications and care coordination compared to non-medical complex children. It was also determined that children with medical complexity had more requirements for medications and were at higher risk of medical breakdown if medication needs were not met. Aboneh & Chui (2017) suggest that good quality care coordination with formal training of nurses in medication management and involvement of pharmacists may enhance care for these children.

One of the fundamental difficulties in giving medicines relates to the issue of dysphagia, a disorder of swallowing usually resulting from physical impairment or neurological disorder (Calis *et al.* 2008). Gastrointestinal dysfunction among individuals with intellectual disabilities is significant (Kelly *et al.* 2009) with approximately 1 in 3 individuals with intellectual disabilities experiencing dysphagia (Howseman 2013). Moreover, about 99% of children with severe cerebral palsy will have dysphagia (Calis *et al.* 2008). While eating and drinking constitute one of the many physical difficulties that a child with severe and profound intellectual disabilities experiences (Pawlyn & Carnaby 2009), much of the literature centres on this issue in the adult population (Jackson *et al.* 2008, Kelly & Wright 2009, 2010, Bennett *et al.* 2013). Poor muscle tone and body posture alongside difficulties in chewing and swallowing can make eating and drinking difficult. Calis *et al.* (2008) established that proactive identification of dysphagia in children with cerebral palsy and intellectual disability was warranted and that structured mealtime observation was a feasible option in this process.

For the majority of individuals the most convenient and acceptable method of taking medicines is by mouth (Blair & Standing 2011). Some children with severe and profound intellectual disabilities will have a need for non-oral feeding by gastrostomy while other children will remain oral feeders but at the risk of aspiration and reflux (Catto-Smith & Jimenez 2006, Dunworth-Fitzgerald & Sweeney 2013). Many of these children who have

gastrostomy tubes in situ for feeding purposes find these can then be used for administering medicines, bypassing the need for administering by mouth (Glasper *et al.* 2010). This in turn means identifying alternative approaches to administering tablets and capsules, such as crushing, dispersal and disguise (Wright & Kelly 2012). Additionally, as approximately 30% of individuals with intellectual disabilities have epilepsy, rescue medication administered buccally or rectally is something many mothers have to familiarise themselves with and little is known about this experience. The various routes of medication administration for children with severe and profound intellectual disabilities are explored further in Appendix 2.

2.7.3 Manipulating or disguising medications

Many medicines given to children with severe and profound intellectual disabilities do not come in the required dose and a fraction of the medicine may need to be measured. When medicines are not available in liquid preparations, crushing and disguising by adding to food can occur for ease of administration (Richey *et al.* 2012). Arguably, this manipulation could affect the dose and stability of the medicines rendering them ineffective (Crawford 2012) and posing potential risks (Donnell & Nunn 2011). Subsequently, the medication may not be covered by the product licence. Use of medicines outside of the specifications described in the licence represents off-label or off-licence use (WHO 2007). Tablet splitting to fractionalise a dose can lead to variability in fragment weights and medicine weight losses (Verrue *et al.* 2011, Elliott *et al.* 2014). The literature also suggests that dose variations can occur using dispersible products. Broadhurst *et al.* (2008) determined that when aspirin was dispersed in water and the dose fractionalised, the dose withdrawn was less than that prescribed.

All medicines are approved by the Medicines and Healthcare Products Regulatory Agency (MHRA) in the UK and the equivalent Health Products Regulatory Authority (HPRA) in Ireland which issues a marketing licence for the product. However, a cautious approach is adopted when agreeing to licence medicines for use with children where there is scientific uncertainty or potential risk concerns (MHRA 2012). Furthermore, this means in practice a large number of medicines used in child health care are 'off-label' (Crawford 2012). This can mean that the product has only been approved for adults or

approved for one particular route of administration. This in turn can mean the adaptation or manipulation of a medicine by crushing or diluting may not be approved by manufacturers (Crawford 2012).

If a product is not specifically marketed for paediatric use, it is unlikely to be available in a suitable formulation for children and therefore requires manipulation (Nunn & Williams 2005). The Manipulation of Drugs Required in Children (MODRIC) study undertaken in the UK (Richey *et al.* 2011, 2013, Alder Hey Children's NHS Trust 2013) investigated the manipulation of medicine forms to administer the correct doses to children in general. The study had several components including observation of drug manipulation in ward areas, a questionnaire to nurses nationally, risk assessment and in turn development of a national guideline. This study investigated drug manipulations occurring in clinical practice in three UK sites and a postal survey to sample paediatric nurses who conducted manipulations and insight into their experiences and views. The observational element identified 310 manipulations, of which 62% involved tablets, 21% were intravenous drugs and 10% were sachets. Of the 54 observed manipulations, 40 involved tablets with 65% being cut and 30% dispersed to obtain smaller doses. The questionnaire completed by 153 nurses, identified manipulations take place in practice but are not supported by data and raise questions regarding safety, policy and practice. While none of the sites were specifically for children with disabilities, these children may well have been consumers of care within each of the sites and the researchers identified that the majority of manipulations took place in specialist practice with more highly dependent children with complex healthcare needs. The resultant guideline presents the available evidence on manipulation of medicines to achieve a proportional dose and aspires to illustrate interventions that may avoid the need to manipulate medicines.

It can also be argued that disguising medicines or administering medicines in a covert manner is unethical as the child is being led to believe they are not receiving medications. However, the decision to do so must be in the best interests of the child and usually takes the form of using food and drink to administer (Crawford 2012). Disguise of medications is used widely in the field of intellectual disabilities (Halder *et al.* 2012) and especially with children with severe intellectual disabilities whereby it is

imperative that the medicine is taken, for example, AED for seizure management. However, covert administration means that the child unknowingly ingests an agent. Nunn (2003) recommends that medicines should be made in a palatable form for children. As parents tend to know their child best, their involvement in medication giving is imperative and they will know what works well and not so well for their child when it comes to administration.

According to Venables *et al.* (2015) sensory perceptions relating to colour and smell were problematic for children with taste being identified as the most significant barrier to children taking oral medications and texture being a major problem for those with intellectual disabilities. This UK study recognised the perspective of 8 doctors, 6 pharmacists and 5 nurses partaking in 4 focus group interviews to explore problems with oral medicines prescribed to paediatric patients. Difficulties with taste and texture resulted in challenges with medication adherence while it was acknowledged children often experience problems with the tablet size or large dose liquid volume. Manipulation of drugs to obtain correct doses and forms is commonplace for children; cutting transdermal patches, splitting and crushing tablets, dissolving tablets in water and taking a portion and cutting suppositories (Venables *et al.* 2015). Mixing medicines with foodstuff was a significant concern of pharmacists within this study who recognised the pharmacokinetic effects of such manipulations potentially altering pH of drugs especially when mixed with orange juice. Venables *et al.* (2015) also considered non-sensory outcomes from their study. Difficulties with special or unlicensed medications were indicated with parental understanding of medicines also a concern.

Disguise of medicines is directly related to medication refusal which can be a challenge for children with severe and profound intellectual disabilities especially when many of these children require medication compliance due to treatment of complex conditions. Epitropakis & DiPietro (2015) devised an individualised medication compliance protocol for 6 children with severe intellectual disabilities who were inpatients in a US neuro-rehabilitation unit. These protocols addressed issues commonly seen in this cohort of children; increased and decreased sensitivity to taste, smell, touch and texture, oral aversion and distorted comprehension. Using a process of applied behaviour analysis

and positive reinforcement the consistent implementation of medication compliance protocols was successful in these 6 cases over a four week period.

In Diehl *et al's.* (1991) study, foremost among needs was the requirement for appropriate balance of medications and dosages and ease of administration. Caregivers felt it was a balancing act between different doctors' advice and respecting the daily functioning and comfort of the child. Information about medicines was often offered in a piecemeal manner from a variety of different sources. Caregivers also expressed the need to know the short and long-term effects of medicines and how they would interact with other medications.

2.7.4 Medication related problems

Medication related problems have been identified in the literature and were found to contribute to the stress experienced by carers in some studies (Ranelli & Aversa 1994, Ranelli & Hansen 1994). Goldstein & Rivers (1996) examined 20 informal carer's experiences in the UK and established that carers reported experiencing a range of medication related problems such as scheduling difficulties, compliance problems and difficulties organising medications so it was taken properly. Some carers took responsibility for all of the medication practices while others only partook in some medication practices and it was a shared responsibility. Responsibilities were influenced by the cognitive and physical abilities of the care recipient. The need for organised and routine approaches to managing medication was highlighted in terms of time management and also completion of specific tasks. Furthermore, Kuo *et al.* (2011) who undertook secondary analysis of a national survey of 10.2 million children with special health care needs in the US, highlight the importance of securing prescription medicines in a timely manner, such as AEDs for seizure management in order to prevent high resource use such as preventable admission to hospital for avoidable seizure management.

Maintaining a continuous supply of medicines was also identified as a challenge by Smith *et al.* (2003) in a UK study. A total of 184 carers of older care recipients described concerns about liaising with doctor surgeries, pharmacies and monitoring the need for

further medication supplies in the home. Surgery prescription ordering systems were laden with bureaucracy, prescription details needed to be checked to ensure products supplied were correct requiring constant vigilance and careful checking. Transport to and from surgeries and pharmacies was problematic and time consuming and burden increased if it was necessary to query the accuracy of prescription. Some positives existed in the experience of carers with surgeries and pharmacies. These included sending the prescription by fax to the pharmacy or client's home, home delivery of medications by pharmacy staff and willingness of pharmacists to lend small supplies until repeat prescriptions were made available (Smith *et al.* 2003). Furthermore, practicalities of administration were highlighted within this study. Remembering to administer the medications was reported as a difficulty as was, opening containers, applying particular formulations and the frequency of dosing regimens which were required on an ongoing basis throughout the day.

Francis *et al.* (2002) interviewed 184 carers of older care recipients and found their role stretched beyond just organisation and practical tasks of medication administration, to necessitating making clinical judgements for example, deciding on timing of doses or how much to take and how often and identifying potential and actual side effects. These are activities that informal carers cannot be expected to be equipped to do. Responding to the changing health status of the care recipient requires the carer to make ongoing judgements. Medication management for many carers within this study meant daily life was affected. Other carers merely absorbed the medication related activities into the daily routine or adjusted daily routines to accommodate the activities. Carers' comments made it apparent that medication related activities were an integral part of their caring role.

Risk was also a medication related concern in the literature. Effective medication management is essential to ensure safety, however, errors can occur at any stage in the medication management process (Armitage 2014). The majority of medication errors reported relating to children were dosing errors (Wong *et al.* 2009, Ghaleb *et al.* 2010). Adverse drug reactions were considered by Kanneh (2011) with an acknowledgement that almost 10 percent of children admitted to hospital will experience these reactions.

Much of the literature on medication management is related to the hospital setting and linked to errors and risk (Murphy & While 2012). However, this does not consider those children with severe and profound intellectual disabilities that are cared for at home and often warrant new medicines or new prescriptions to be administered in the home environment. A review of the literature by Alomari *et al.* (2015) explored factors involving nurses, families and healthcare systems that impact on medication errors in paediatric patients. One of the contributing factors for parents was the communication failure between them and professionals with many parents not receiving written information on medications or how to administer these at home from either GPs (General Practitioner) or pharmacists.

2.7.5 Medication related equipment and technology

The term technology dependence is used widely in the literature and can refer to low tech such as a stoma or high tech such as ventilator dependency (Wang & Barnard 2004, Nicholl *et al.* 2013). Many children who require technology dependence use more than one device and rely on substantial nursing care provided by either a trained lay caregiver such as the mother or a qualified nurse. Characteristics of technology dependence are diverse with children requiring some or all of the following; ongoing or intermittent ventilation, tracheostomy, oxygen therapy, enteral or parenteral feeding, drug therapies and in addition, possibly experiencing some form of disability.

The proportion of children being discharged from hospital requiring medical technology was investigated by Feudtner *et al.* (2005). This US retrospective cohort study acknowledged the requirement of some children for technology dependence due to their physical conditions. One hundred randomly selected charts were reviewed for their discharge data and data extracted into a specially designed data collection instrument that recorded several variables of which technology use and medication orders were of specific interest. Not all of the 100 children would have had severe and profound intellectual disabilities but an array of conditions were detailed some of which included epilepsy related conditions. Children having special health care needs accounted for 58% of those participants. A quarter (26%) of all the participants used some form of medical

device such as gastrostomy (10%) or nebulisers (7%). The majority of participants (82%) were discharged with multiple medications, two or more prescribed to 61% of participants with five or more prescribed to 12% of participants. One parameter highlighted in these findings is that of the burden of administration of these medications as 12% of the participants required between 10 and 22 daily medication administrations. A variety of medicines were recorded with many requiring AEDs and anti-gastrointestinal reflux drugs.

In a later UK study, Kirk (2008) obtained a profile of children and young people in the UK who needed the ongoing support of medical technology. Data was retrieved through 28 community children's nursing teams who had 591 cases on their books. The most prevalent technology in use by over 60% of children was a gastrostomy feeding tube followed by intravenous drug therapies (14%) and tracheostomy (14%). At least 25% of children required one or more pieces of technology with 27% of children being technology assisted for six or more years. According to Kirk (2008), this data highlights the need for future planning and supports and with some children in adolescence, transition to adult services a need for consideration.

Equipment related issues with children with severe and profound intellectual disabilities are cited frequently within the literature with technology referring to anything from suction tubes to syringes or postural chairs (Diehl *et al.* 1991, Kirk & Glendinning 2002, 2004, Moore *et al.* 2010, Nicholl *et al.* 2013, Bourke-Taylor *et al.* 2013, Caicedo 2016). Boosfeld & O'Toole (2000) indicate that caring for children with complex needs in the hospital setting is an inappropriate use of hospital resources and care should be provided in the community. In recent years attention has been drawn to the impact of technology and equipment in the homes of many children with severe and profound intellectual disabilities (Moore *et al.* 2010). It is generally accepted that technologies and equipment are a permanent feature of care and are used for prolonged periods of time (Kirk & Glendinning 2002, 2004). Adopting technology requires training on how to use equipment, sourcing and securing the equipment and finding recommended equipment to meet the child's needs. Obtaining equipment and supplies can be an additional stress factor for parents (Hewitt-Taylor 2005a). Supplies can be unreliable and difficult to

obtain causing inconvenience. Accurate estimation of volume of equipment required can also change depending on the child's condition and this can be difficult to explain to suppliers (DOH 2004).

The breadth of equipment adopted for use at home is becoming more extensive as child needs become more complex (Hewitt-Taylor 2008a). Nicholl *et al.* (2013) undertook a mixed method study exploring the range of technologies in use with children with complex needs and the challenges faced by parents when using these. This two phase study involved data collection from 9 nurses providing care to children with severe and profound intellectual disabilities in the home and 177 parents of these children. A broad range of equipment was found to be employed with an average of 22 pieces of equipment used by each child. A proportion of parents (69%) used medication equipment devices such as syringes and tablet crushers while 67% of parents had a specific medication storage cupboard.

In a similar smaller UK study, Bourke-Taylor *et al.* (2013) used an anonymous questionnaire with 29 families of children with cerebral palsy and associated deficits to yield findings on equipment and technology purchases these families were required to make in order to assist these children in their daily lives. Various pieces purchased were documented to include medical equipment. Each participant required anything from 1 to 15 pieces of medical related equipment which included medication equipment. However, this study did not highlight the specific pieces of equipment that were being adopted for medication giving. More recently, Caicedo (2016) identified medical technology devices used by 84 children with medically complex technology dependence. In order to sustain or monitor bodily functions 74% of children required medical technology devices with an average of 4.2. devices per child, the bulk of which related to breathing and eating.

Within Kirk & Glendinning's (2004) study exploring what services might be developed to support these families it was determined that parents performed multiple roles undertaking regular clinical procedures such as administering intravenous medication. They also made complex judgments based on their child's condition and acknowledged

the impact technology dependence had on their own sleep with disruption common due to the need to administer medications and other treatments throughout the night. Additionally, Venables *et al.* (2015) highlighted not only the difficulties requiring disguise of medication, but the supply of medicines and liquid measuring devices such as syringes, can also be problematic with the NHS in the UK not always freely providing these pieces of essential equipment.

2.7.6 Parental Knowledge and Education

Much of the literature addresses parental knowledge and education in a broad context. Yet, it is applicable in the context of 'giving medicines' and the associated skills required to do this. Knowledge is not just required in terms of the specific medications as Elias & Murphy (2012) suggest caregivers need be taught and should demonstrate competency in clinical tasks such as care of feeding tubes, often used for medication administration and other medication management. In achieving this, a systematic approach to care coordination is required with clear advanced planning to achieve this education. Considerable training and supports are required for parents to be able to develop the skills, knowledge and confidence to care for their child in the home (Boosfeld & O' Toole 2000). This often requires visits to the home by professionals in order to identify and address practical problems before discharge home from hospital.

The purchase of medications was addressed in one study where Birchley & Conroy (2002) interviewed 25 parents of children regarding medicines purchased over the counter. Only 3 of these participants were aware of possible side effects of medicines and indicated they would note the side effects through observed reaction in the child. These participants suggested that over the counter medicines were unlikely to cause harm. Conversely, research has shown that there is a belief that prescription medicines are stronger and therefore carry more risks (Bissell *et al.* 2000). When medicines are dispensed by the pharmacist, parents are usually supplied with an information leaflet for each medicine but these are not always read (Crawford 2012).

Directly associated with not reading information leaflets is the issue of health literacy as it may also influence the development of medication management skills (Lau *et al.* 2009). Comprehending drug labels and other printed materials for administering medications is important while communication with health providers may also be affected by health literacy because of differences in educational backgrounds. More understanding on this would assist providers to better tailor care delivery and inform future development of training interventions (Lau *et al.* 2009).

In addition, knowledge related to professionals has been cited within the literature with variance among the level and quality of training given by professionals (Diehl *et al.* 1991). This can relate to the need for parents to be assertive and informed when talking to professionals as they often did not listen or appear competent when talking to the caregiver. Within this study professionals who did a good job were deemed the exception and caregivers expressed the need for competent professionals to deliver good quality care and to avoid fragmentation of care. Likewise, parents felt they were judged by professionals and other individuals in their life despite doing everything they could to protect their child (Woodgate *et al.* 2015). The need for good communication is highlighted and seen to enhance how parents cope with various situations relating to the care they give their child (Avis & Reardon 2008, Midson & Carter 2010, Coad *et al.* 2014).

A common factor that impedes discharge home from hospital for children with complex needs is the lack of availability of skilled staff who can support the family and help care in the home. Hewitt-Taylor (2004, 2005a) reports on a survey regarding education and training for staff who care for children with complex needs outside the home environment. This study provided insight into service providers' views on staff education needs. Questionnaires were completed by 21 managers and incorporated the needs of registered nurses and care staff who are not nurses. Technological needs of caregivers were identified with less emphasis on the non-technical tasks although some did mention the reality of everyday life for this cohort of children and the need to address psychosocial needs of parents.

Parents of children with severe and profound intellectual disabilities are often trained to undertake healthcare interventions within the home environment (Case 2000, Read 2001, Brett 2002a, 2002b, Condliffe 2006). An exploratory study in the US described paediatric nurses experiences of medication teaching with carers in the children's hospital setting (Gibson *et al.* 2017). Six focus groups yielded information on medication teaching being an opportunity to promote successful transitions to home. It was also acknowledged that medication teaching was challenging in the hospital environment and not always representing what it may be like at home with many parents finding it difficult to retain important information due to the stress of having an ill child. Other challenges included nurses not being confident in their knowledge of some medications, poor relationships with caregivers and lack of resources. A key recommendation was the need to remove the barriers to medication teaching in order to ensure smooth transition for caregivers. Education of those other than parents is also recommended. Brett (2002a) posits it is possible to design and deliver training and education to staff other than healthcare staff such as education staff on healthcare interventions traditionally carried out only by nursing staff.

This final overarching theme explored medication management for mothers of children with severe and profound intellectual disabilities. Such issues as complexity of giving medicines were addressed (Macqueen *et al.* 2012, Calis *et al.* 2008, Catto-Smith & Jimenez 2006, Wright & Kelly 2012, Dunworth-Fitzgerald & Sweeney 2013) and the manipulation or disguise of medicines (Nunn & Williams 2005, Richey *et al.* 2011, 2012, 2013, Halder *et al.* 2012, Venables *et al.* 2015). Medication related problems were identified also, such as scheduling or timing difficulties, maintaining a continuous supply of medicines, practical tasks of organising medicines and concerns about risks (Goldstein & Rivers 1996, Francis *et al.* 2002, Smith *et al.* 2003, Kanneh 2011, Alomari *et al.* 2015). Additionally, the requirement for medication related technology and equipment in the home was examined (Kirk & Glendinning 2004, Feudtner *et al.* 2005, Kirk 2008, Hewitt-Taylor 2008a, Nicholl *et al.* 2013, Bourke-Taylor *et al.* 2013). Parental knowledge and education was also probed and it was determined that a level of knowledge is required in the 'giving medicines' process (Birchley & Conroy 2002, Hewitt-Taylor 2004, 2005a, Lau *et al.* 2009, Gibson *et al.* 2017).

2.8 Summary and Conclusion

The aim of this chapter was to review national and international literature pertaining to the subject under consideration. Within the literature reviewed in this chapter on children with severe and profound intellectual disabilities, both quantitative but mainly qualitative studies have been undertaken with parents and professionals. Three overarching themes and twelve sub themes were identified and further explored. Studies have approached such issues as parenting a child with severe and profound intellectual disabilities and broadly meeting their needs. Literature also contextualises the issue of 'giving medicines' and considers routes of administration of medicines alongside medication related problems and associated equipment. Examining the mothers role in being a parent of a child with severe and profound intellectual disabilities is also considered but with the highlighted studies not delving deep into the intricacies of care related to 'giving medicines' but more so, broadly addressing caregiver burden.

In linking the literature to the aim of this study, the experience of mothers 'giving medicines' to their child with severe to profound intellectual disabilities warrants further attention. Therefore, my intention is to use a hermeneutic phenomenological approach to develop a greater understanding of this phenomenon. This will be achieved through multiple interviews and diary keeping with mothers of children with severe and profound intellectual disabilities. While a few Irish studies have been undertaken, these explore the concepts of nursing resources, palliative care, respite and supports (Redmond & Richardson 2003, Hartrey & Wells 2003, McConkey *et al.* 2007, DOHC 2010, Irish Hospice Foundation 2011, 2013, Nicholl & Begley 2012). However, the implications for mothers caring for their child with severe and profound intellectual disabilities are less considered. While previous research has emphasised the care assumed by parents and family members, this research study differs from others and will focus on one element, the experience of 'giving medicines' from mother's perspectives and identify the range of activities undertaken. It will also identify any issues experienced by mothers of children with severe and profound intellectual disabilities 'giving medicines'. The following chapter, Chapter Three will explore the philosophical underpinnings and methodological issues for this research study.

Chapter Three – Philosophical and Methodological Issues

3.1 Introduction

This chapter is concerned with the philosophical underpinnings of this research study and also deliberates upon the methodological issues that were considered. The distinction between method and methodology needs to be clarified at this stage. According to van Manen (1990) methodology refers to philosophical framework and the fundamental assumptions and characteristics of a human science perspective. Research methodology consists of a complete approach aligned to the answer for the given research question and as a foundation it assists in understanding the effectiveness of methods when applied (Polit & Beck 2017). In many ways methodology is the theory behind the method or could be described as the justification for employing a particular research design. The method should be attentive to the implications of a particular philosophical perspective and therefore, techniques and procedures adopted must harmonise with the methodology or philosophical framework (Polit & Beck 2017). Additionally, the adopted method in undertaking a research study should help to answer the research question.

This research study focuses on interpreting and understanding what it means for mothers to 'give medicines' to children with severe and profound intellectual disabilities. Thus, hermeneutic phenomenology, the science and art of interpretation would appear logically to provide an appropriate philosophical underpinning. Therefore, this chapter begins with an exploration of hermeneutic phenomenology, the various prominent philosophers and the evolution of modern hermeneutics which is important in setting the context for choice of method. It is imperative that an understanding of the philosophy behind the approach is sought. An exploration of how van Manen (1990) was deemed to be the most appropriate framework to guide this study is also presented. There a number of features that are common within qualitative methodologies involving broad questions on human experiences, use of sustained contact with people in their natural environments and generation of rich, descriptive data that helps understanding

of experiences and attitudes. One of the methods lying within the qualitative realm is the field of hermeneutic phenomenology which underpins this research study.

According to Gray *et al.* (2017a) the research design can offer a blueprint for conducting a research study and refers to the researcher's overall design for answering the research question. There are two main approaches to collection and analysis of data: qualitative and quantitative research. Lavery (2003) contrasts quantitative research that emphasises prediction, control and measurement, with qualitative research, that emphasises discovery, description and meaning. Historically, those research designs that could not be scientifically explained, such as qualitative research, held no place in research (Streubert & Carpenter 2011). However, in recent years humanistic qualitative approaches have gained much recognition and wide respect as an authentic approach to research studies. This upsurge is particularly important in the study of human interaction and experience. A qualitative approach uses an emergent design that may evolve as the researcher makes ongoing decisions or reflects on what has already been learned (Polit & Beck 2017).

3.2 Hermeneutic Phenomenology

Hermeneutic phenomenology, informed by van Manen (1990, 1997) aspires to help people understand a phenomenon from the perspective of those who have experienced it. This approach propounded by van Manen most closely aligns with my own values and research goals. Van Manen (1997, p.1) asserts that "one does not pursue research for the sake of research but because of a prior interest". Both personally as a mother and professionally as a nurse, this topic area whetted my appetite for further examination as I had experienced at first-hand in my personal life what it was like to 'give medicines' to my own children but also while working with children with severe and profound intellectual disabilities. This inspired the development of my research aim: to explore mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities. This aim fits well with this method of research and therefore, I chose to adopt hermeneutic phenomenology.

The work of the German philosophers, Husserl and Heidegger proclaimed the development of two branches of phenomenology, epistemological (descriptive) and ontological (interpretive) respectively. Hermeneutics falls into the latter and is derived from the Greek word *hermeneuin* which means to interpret (Heidegger 1962, Moran 2000). Historically, hermeneutics can be traced as far back as interpretation of Holy Scripture and drawing out the meaning of a given text. The work of Heidegger (1962), Gadamer (1976) and Ricoeur (1976) provided a basis for development of hermeneutics with the latter two being primary exponents of hermeneutics. According to van Manen (1990) hermeneutic phenomenology is attentive to philosophies that underpin both hermeneutics and phenomenology. Hermeneutic phenomenology is concerned with the life world or human experience as it is lived and it attempts to unveil the world as experienced by the subject through their lifeworld stories (Kafle 2011). Creating meaning is the focus of hermeneutic phenomenology and there is an intention to illuminate details within experience that may ordinarily be taken for granted. This in turn helps achieve an understanding about a phenomenon (Heidegger 1962). Unlike epistemology, hermeneutic phenomenology rejects the idea of suspending personal opinions (Kafle 2011) and is focused on subjective experience of individuals.

Under the umbrella of phenomenology, many interpretive frameworks have been adopted with the aim of seeking out relationships and extrapolating meaning with much debate on what makes research phenomenological (Norlyk & Harder 2010). A hermeneutic phenomenological (interpretive) approach is promoted as a philosophy of the nature of understanding a particular phenomenon and the scientific interpretation of phenomena appearing in a text or written word. Similarly, it is often described as the art of interpretation (Kakkori 2009). Ricoeur (1976) suggests the interpretive process in hermeneutics is a series of analytic steps and acknowledged the relationship between epistemology (interpretation) and ontology (interpreter). Crist & Tanner (2003) promote interpretive discussions where within a research team interpretations can be debated, adding depth and insight to the topic. Hermeneutic phenomenology moves beyond description and seeks meanings that are entrenched in everyday experiences (Lopez & Willis 2004). A study becomes hermeneutic rather than just descriptive when its method is taken to be interpretive (Dean & Black 2015). A significant difference between

hermeneutic phenomenology and other interpretations is that this method does not require the researcher to bracket their own preconceptions but sees them as embedded and essential to the interpretive process (Polkinghorne 1983, van Manen 1997).

Hermeneutic phenomenology has been widely used in enabling understanding of the meaning of lived experiences in health research (Caelli 2000, Ortiz 2009) and has become popular (Mackey 2005), applied in many different ways and of high value in understanding the patient experience (Miller 2002). A major challenge when attempting to understand hermeneutic phenomenology is the complicated and often cryptic philosophical language that is adopted in the literature (Miles *et al.* 2013). Various concepts exist in hermeneutic phenomenology; being in the world (*dasein*), fore structures, lifeworld existential themes and the hermeneutic circle. These will be explored further with regard to their relevant foremost proponents. Philosophers aligned to the origin of ontology and hermeneutic phenomenology are Martin Heidegger (1889-1976), Hans George Gadamer (1900-2002), Maurice Merleau-Ponty (1908-1961), John Paul Sartre (1905-1980) and Paul Ricoeur (1913-2005). For the purpose of this work Heidegger, Gadamer and Merleau-Ponty's work will be explored more closely as these were key influencers of van Manen's stance on hermeneutic phenomenology (van Manen 1990, 1997).

3.3 Heidegger

Martin Heidegger, a 20th century German philosopher, was most famous for developing hermeneutic phenomenology. He rejected the theory of knowledge and adopted ontology, the science of being (Reiners 2012). While complex in his explanations in written material, he influenced the thinking of the major philosophers and has contributed to the development and adoption of hermeneutics in not just nursing but human science, the humanities and arts (Horrocks 2000, 2002). The translation of his texts from German to English has been difficult and has made some phrases more complex and difficult to understand. While a student of Husserl, Heidegger (1962) was significantly different and this was evident in his early work where he focused on theology. He developed hermeneutic phenomenology by extending hermeneutics

through studying the concept of being in the world rather than merely knowing the world. Heidegger (1962) focused on the term '*dasein*' otherwise known as '*the mode of human being*' which essentially was the meaning of a human in the world. This German word is derived from *da-sein*, which literally means *being-there* and refers to 'presence' or 'existence' and is a fundamental concept of Heidegger's work. Heidegger sought to use the concept of '*dasein*' to uncover the primal nature of '*being*' and indicated that '*dasein*' is always 'being engaged in the world'. Heidegger emphasised the importance of elucidating the everyday aspects of lives and noted that when individuals talk about everyday experiences they are talking about 'being' although they may not be aware of it. This level of everyday understanding is referred to as pre-ontological (Heidegger 1962, 1996).

Heidegger (1962, 1996) developed the hermeneutic method focusing on the interpretation of the meanings of human experience. He believed that understanding or knowing is a basic form of human existence. According to Heidegger (1962) pre-understanding is a structure for being in the world and suggests that meanings are present before we understand and that we cannot set aside these meanings. Interpretation is key to hermeneutic phenomenology according to Heidegger (1962) with him suggesting that every encounter involves an interpretation influenced by the person's background. Heidegger (1962) also speaks of a given set of fore-structures or pre-suppositions that cannot be eliminated. This fore-structure involves a prior awareness usually unnoticed and not yet described or acknowledged. There are three components of fore-structure including forehaving, foresight and foreconception. Heidegger (1962, 1996) suggests forehaving means intention and indicates the fact that in interpreting anything, an individual has a sense or idea of what is being interpreted. Foresight then means to look at something in an effort to comprehend the unifying character that holds the totality of intention together. The third forestructure, foreconception, typically refers to being able to conceptualise the object or recognition of the structure of the object being interpreted. Therefore, in hermeneutic phenomenology interpretation occurs in a unified manner exploring the total phenomena under investigation.

Heidegger (1962) recommends that one's history cannot be removed or bracketed and therefore one must become as aware as possible about one's interpretive influences and these in turn become an integral part of the researcher's understanding of phenomena. Heidegger goes so far as to say that one's past enables the phenomenon to be seen as a whole. Heidegger also proposed the concept of the 'hermeneutic circle' to envision a whole in terms of a reality that was situated in the detailed experience of everyday existence by an individual (the parts). The hermeneutic circle refers to the idea that one's understanding of a phenomenon as a whole is determined with reference to the individual parts and vice versa (Heidegger 1996, van Manen 1997). Thus, interpretation must be found within the context in which it is viewed and the researcher must be cognisant of this context continually changing throughout the research process. This concept of the 'hermeneutic circle' constitutes reading, reflective writing and interpretation in a rigorous fashion (Lavery 2003) and this metaphoric circle used during interpretation of the data demonstrates the fluid movement between the parts and the whole of the text (Cohen *et al.* 2000). The interpretive process is achieved in full through the hermeneutic circle which moves from the parts of experience to the whole of experience and back and forth again to increase the depth of engagement with and understanding of texts (Lavery 2003). Interacting and understanding the phenomena at hand encompasses three key stages in data analysis; naive reading, structural analysis and interpretation of the whole (Dreyer & Pederson 2009). The concept of the hermeneutic circle from Heidegger's phenomenology informs van Manen's (1990) method of thematic analysis that will be used in the interpretation and analysis of this research study.

Additionally, Heidegger (1962) views language as an integral part of hermeneutic phenomenology and the interpretive process seeks to bring understanding of phenomena through the use of language. The meaning of words is important because use of language is a primary source of expressing meaning (Cohen *et al.* 2000). Heidegger's (1962) view was that language and understanding are inseparable aspects of humans being in the world and therefore need to be considered together in deriving meaning of phenomena.

3.4 Gadamer

Hans-Georg Gadamer a 20th century German proponent of hermeneutic phenomenology was foremost in its enrichment. He was a student of philosophy in Germany greatly influenced by the earlier works of Husserl and Heidegger and was a student and colleague of Heidegger for a time. He moved to extend Heidegger's work into a practical application. According to Gadamer (1998), phenomenology becomes hermeneutical when its method is taken to be interpretive and principally oriented to the explication of texts. Gadamer studied under Heidegger and asserted that he was stifled in his own writings by Heidegger. Therefore, Gadamer chose to develop a philosophical hermeneutics and focused on the early Greek philosophers. Gadamer (1975) similar to Heidegger contests that individual prejudices or presuppositions are impossible to eliminate from one's perceptions and suggests the process of eliminating them is unnecessary and interpretation becomes limited without the researcher's own experience.

He took two focal positions; prejudgement (one's preconceptions that are part of our linguistic experience and that make understanding possible) and universality (the persons who express themselves and the persons who understand are connected by common human consciousness which makes understanding possible). Gadamer (1990) considered that through pre-understandings, understanding is made possible and if an individual does not recognise their pre-understandings there is a risk that they will fail to understand or misjudge meaning. Gadamer agreed that text should be read with an open mind keeping in view the larger significance of the text as opposed to criticising narrow or selected statements. Gadamer also supports Heidegger's view that language and understanding are inseparable aspects of humans '*being in the world*'. Inquiry using Gadamerian hermeneutics (his term for his philosophy) becomes dialogue rather than individual phenomenology and sees the interpreter and the phenomenon being studied, combined together.

Gadamer (1975) also talked of horizons being a range of vision that includes everything seen from a particular vantage point and being able to see beyond what is close at hand. This '*fusion of horizons*' signals the viewpoint of the researcher and the participant that

spirals into a new understanding. For the fusion process to be established the researcher must be ready to be open and hear the story of another making interpretations from the linguistic sources. These insights are said to occur at each stage of the research process, data collection, transcribing, interpreting and writing (Miles *et al.* 2013). An essential element of Gadamer's work is the notion of questioning and he suggests it is an essential aspect of the interpretive process as it helps make new horizons and understanding possible (Lavery 2003). Gadamer believed that understanding and interpretation are bound together and interpretation is always an evolving process. He also viewed bracketing as impossible and absurd (Annells 1996).

3.5 Merleau-Ponty

Merleau-Ponty (1962, 2012) built upon the work of Husserl and then Heidegger. In his work *Phenomenology of Perception*, the suggested goal of phenomenology is to rediscover first experience. According to Merleau-Ponty (1962) "the world is already there before reflection begins" (p. vii). Therefore, the goal of Merleau-Ponty's work is to help us view experience in a new light without a reliance on categories of pre-reflective or reflective experience. Intentionality meaning consciousness is always consciousness of something, was a term adopted and the primary focus of Spiegelberg's (1965) and Merleau-Ponty's (1962, 2012) work. Intentionality applies the principle that every mental act is related to some object (Moran 2000) and implies all perceptions have meaning (Owen 1996). Van Manen (1990) supports this notion propounding that all thinking is thinking about something. Therefore, intentionality is the total meaning of the object or idea which is always more than what is given in the perception of a single perspective (Kafle 2011). Merleau-Ponty (1962, 2012) also discussed the concept of bracketing and emphasised the researcher must be aware of their own intentionalities in a research study, in turn assisting in the explication of what is meaningful about the phenomenon being investigated. Consistent with Heidegger, Merleau-Ponty emphasised considering one's own preconceived ideas and history in the interpretation of a phenomenon.

Embodiment is deemed an essential element of human existence according to Merleau-Ponty (1962, 2012) who suggests that through understanding existential behaviour, human embodiment can be better understood and explained. Merleau-Ponty (1962, 2012) proposes that in being in the world, humans experience it through their body. The worthiness of Merleau-Ponty's writings in nursing is evident in the utilisation of the four existentials belonging to the fundamental structure of the lifeworld; lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality). All of these existentials together can demonstrate a fusion of the hermeneutic circle and can be differentiated but not separated while serving to form an intricate unity which is called the lifeworld (Merleau-Ponty 1962, 2012, van Manen 1997).

3.5.1 Lived space

Spatiality is an important concept closely related to perception and embodiment (Merleau-Ponty 1962, 2012). It is defined as more of an interaction with the other person than just physical space alone and connects all things. Interestingly, Mackey (2005) suggest 'lived space' positions the person in a location. Both Merleau-Ponty (1962) and van Manen (1990) propounds there is a difference in how we feel in a space that may be our home compared with an impersonal space such as work.

3.5.2 Lived time

'Lived time' or temporality is not merely viewed as a succession of seconds, minutes or hours but in relation to things or a situation (Merleau-Ponty 1962, 2012). According to Merleau-Ponty (1962) and van Manen (1990) 'lived time' refers to subjective time as opposed to objective clock time while Mackey (2005) says understanding can only be achieved if grounded in time. For example, 'lived time' can speed up when enjoying things and seem to drag when we are bored or waiting.

3.5.3 Lived body

Embodiment or 'lived body' was a phrase adopted by Merleau-Ponty (1962) and related to how individuals experience the world through the body. Merleau-Ponty (1962) suggests we are always in our bodies and that when we meet people, we reveal and conceal things about ourselves both consciously and unconsciously. Body language comes to the fore and can change depending on the encounter.

3.5.4 Lived relation

'Lived human relation' or relationality pertains to the relation we maintain with others in an interpersonal space that we share with them and includes how we experience the world (Merleau-Ponty 1962, 2012, van Manen 1990). We meet people in a corporeal way such as shaking hands or communicating in a particular way. It can be argued that all life revolves around dealing with relationships.

3.6 Van Manen and this study

Although many philosophers have offered valuable insights into how one may develop a deep understanding of texts, many do not offer a method for doing so. Nevertheless Gadamer (1990) suggests that to reach understanding, methodical direction through use of a systematic approach is required. Interestingly, Cohen *et al.* (2000) suggests that hermeneutics avoids method and does not have a step by step method or analytic requirements. However, hermeneutics does demand a dynamic interplay between research activities, from choosing the research question to describing the phenomena through the art of writing. Regardless of which philosophical approach that is assumed when conducting hermeneutic phenomenological research, the aim remains the same: to gain deeper understanding of the meaning of everyday experience (van Manen 1997).

Max van Manen, a Canadian educator, has been developing his hermeneutic approach to phenomenology in recent years. Van Manen (1997) clearly recommends that a methodical approach helps guide an inquiry. The originality of van Manen's (1990) approach lies in the translation of the epistemological foundations of the philosophy of Merleau-Ponty and Gadamer into a research methodology that attends to lived

experience. This type of approach demands an individual's understanding from their experience. Therefore, choosing this approach will enable me to achieve a greater understanding of what it means for mothers to 'give medicines' to their child with severe and profound intellectual disabilities while also taking into consideration the sociocultural and historical traditions that contribute to the unique experience.

Van Manen (2014) adopts phenomenology of practice to describe and communicate methods that give meaning and his approach can be used to clarify phenomena in many disciplines such as pedagogy, psychology and indeed nursing with it widely cited in health literature. At the University of Alberta the program associated with phenomenology of practice has produced graduate papers for all fields of professional practice and is widely commended in nursing research. Van Manen (2014) also propounds the relation between being and practice and with this in mind has aided the evolution of phenomenology from a philosophy to a method or phenomenology of practice. Van Manen (2001) provides guidelines for phenomenological researchers and suggests that to really understand phenomenology, one must actually "do it".

My desire for this study is to interpret the essence of phenomena rather than just describe it, so that led to my choice of hermeneutic phenomenology. I also personally believe it would be impossible to bracket out my interpretation of the phenomenon and so this study will fuse the horizon of my beliefs and experiences with that of the participants. To achieve this, this research study is guided by van Manen's (1990) methodological approach for doing practical phenomenological research. This approach, applying a research method is one known as "new phenomenology" (Crotty 1996) and includes acknowledgement of the place of the researcher's personal experience. Van Manen's approach incorporates both interpretive (hermeneutics) and descriptive (phenomenology) elements, that is "phenomenological text is descriptive in the sense that it names something and hermeneutic text is interpretative in the sense that it mediates" (van Manen 1997, p. 26). When van Manen adopts the term 'phenomenology' it refers to both descriptive and interpretive components (1997).

Crotty (1996) contends that researchers should not claim Husserlian or Heideggerian influences on research that uses new phenomenological methods. With this in mind, I have ensured that I acknowledge van Manen's influences, but focus on his interpretation and guidance for this research study. His approach is embedded in the Dutch school as it is a combination of descriptive and interpretive phenomenology (van Manen 1997). Van Manen's (1990, 1997, 2014) viewpoint on hermeneutic phenomenology is comprehensive and covers an expansive range of practices under its umbrella. Several key concepts have already been outlined earlier in this chapter in line with their foremost proponents. However, it is important to acknowledge the concepts that van Manen (1990) considers in his approach; explicating pre-understandings, dialogue and language, existential lifeworld and the hermeneutic circle.

3.6.1 Explicating pre-understandings

Van Manen (1990) acknowledges that knowing too much about a phenomena we want to investigate can be problematic especially if not acknowledged by the researcher. Therefore, our pre-understandings and assumptions predispose us to interpreting the nature of a phenomena before coming to grips with the significance of the research question being adopted. Similar to Heidegger he does not embrace the view of bracketing and suggests that knowledge gained from pre-understandings should be explicated and brought to the fore but not forgotten. Therefore, van Manen (1990) suggests it is imperative that pre-understandings are made explicit prior to commencing a research study. Acknowledgement of my previous experience, knowledge and beliefs and how these may influence me in all phases of data collection, analysis and interpretation is imperative according to van Manen (1997). Therefore, I do not seek to suspend or eliminate my beliefs. In order for me to be aware of my own prejudices and beliefs, I will explicate these through writing a journal. The purpose of this journal is real exposure and awareness of my own experiences in working with children with severe and profound intellectual disabilities and what it was like to 'give medicines'. My preconceived notions, opinions and expectations will be brought to the fore. My personal reflections noted in a journal since commencement of the study will help me illuminate my own experiences. I will find these notes invaluable as a reminder of earlier

thought processes, initial impressions of concepts and participants and as a cue to the continuous evolution involved in producing this thesis.

3.6.2 Dialogue and Language

Van Manen's (1990, 1997) approach is seen to follow Gadamer, as language is suggested to reveal contexts understood by both researchers and participants. Van Manen (2014) offers several ideas on how to collect experiential descriptions from participants to include conversational interviewing and writings. This method places an emphasis on dwelling on the phenomenon through a reciprocal process of dialogue with the participant and reflection on their experience. In this instance, it is anticipated that my relationship with the participant will be subjective in nature and transactional with knowledge being constructed through interaction between the participant, me and the interview questions. This co-construction of understanding will capture a description of the lived experience of the participant. Therefore, conversational interviews will be adopted in order to align with this concept, with listening an important part of my role as researcher. Furthermore, through diary keeping, an additional dialogue will enhance understanding.

Van Manen (2001) reminds us that phenomenology is the application of language to a phenomenon and focuses on writing as a form of interpreting. Heidegger (1962) describes phenomenology as "to let that which shows itself be seen from itself in the very way in which it shows itself from itself" (p. 58). In using van Manen's approach of achieving rich description and interpretation, the written text in the analysis will describe the essence of the lived experience of mothers 'giving medicines' to children with severe and profound intellectual disabilities. The process of data analysis is as important as the outcome due to the fact data are reported in words. During the process of analysis and writing up the findings, researcher bias has the potential to affect the results as often the researcher interprets the meanings from his or her own perspective, therefore indicating the importance of language. The challenge of writing phenomenological research is to "be allusive by orienting the reader reflectively to that region of lived experience where the phenomenon dwells in recognizable form" (van

Manen 2002, p. 238). Van Manen (2001) also suggests the textual approach the researcher takes in the phenomenological study should largely depend on the nature of the phenomena under investigation.

With language and writing an important component of the chosen approach, van Manen (1990) focuses on the significance of writing, “the process of writing and rewriting...going back and forth between the parts and the whole in order to arrive at a finely crafted piece that often reflects the personal signature of the author” (p. 132). Through systematically working through texts the researcher identifies topics that are integrated into higher order themes that address the overall research question (Braun & Clarke 2006). In order to attribute meaning to the data, van Manen (1990) offers three approaches to the analysis of phenomenological data or isolation of thematic statements; detailed or line by line reading approach, the selective or highlighting approach and the holistic or sententious reading approach. Van Manen (2001) also suggests the textual approach the researcher takes in the phenomenological study should largely depend on the nature of the phenomena under investigation. Therefore, my use of language and the way of writing will highlight something about the essential nature of the lived experience.

3.6.3 Existential lifeworld

According to van Manen (2014) there are five existential themes that are fundamental to the lifeworld of all human beings regardless of their historical, cultural or social situation. These enable phenomenologists to reflect on how people experience the world (van Manen 1990) and are helpful in aiding the process of phenomenological questioning, reflection and writing. These existentials originated in Merleau-Ponty’s work considered earlier in section 3.5: ‘lived space’, ‘lived time’, ‘lived body’ and ‘lived human relation’ (Merleau-Ponty 1962, van Manen & Adams 2010). However, more recently, van Manen (2014) introduced a fifth existential, ‘lived things’. ‘Lived things’ or materiality refers to how things are experienced with respect to the phenomenon under exploration, impressing the importance of material things and how they may help us gain certain insights. These five existential dimensions will be adopted in presentation of the findings and further within the discussion and interpretation.

3.6.4 Hermeneutic circle

Van Manen's (1990) method of thematic analysis is informed by Heidegger's (1962) concept of the hermeneutic circle. In a research study adopting van Manen's (1990) stance, both the researcher and participant work together to bring life to the experience being explored. Being able to move back and forth between van Manen's (1990) six activities will see the authentic adoption of the hermeneutic circle within this study. The fluidity of the six guidelines allows for free movement in the circular process. Being aware of and using the hermeneutic circle brings about a fusion of horizons aided through acknowledgement of pre-understandings, adopting a framework of analysis and using a variety of sources of information such as both conversational interviews and diary keeping within this study. Additionally, I will adopt van Manen's (1990) process of thematic analysis and be attentive to the art of writing resulting in explication of the essential nature of the lived experience.

3.6.5 Van Manen's guidelines

Adopting van Manen's (1990) approach brings structure to the research process. Although van Manen (1990) does not approach hermeneutic phenomenology with rules he does provide six guidelines or research activities to approaching hermeneutic phenomenology and these are what will guide my design and data analysis process (see Table 6).

Table 6: Summary of van Manen's (1990) six guidelines

Guideline	Explanation of Each Guideline	Stage in the Research Process
Turning to a phenomenon which seriously interests us and commits us to the world	This includes orienting to the phenomenon, formulating the research questions and explicating assumptions and pre understandings.	Development of appropriate research question.
Investigating experience as we live it rather than as we conceptualise it	Is influenced by how data is gathered and recommends conversational interviews.	Data Collection – choosing appropriate type of data collection.

Guideline	Explanation of Each Guideline	Stage in the Research Process
Reflecting on the essential themes which characterise the phenomenon	Refers to what it is that renders a particular experience significant. Offers 3 approaches to analysis. <ul style="list-style-type: none"> - detailed reading approach, - the selective or highlighting approach - and the holistic reading approach. 	Data Collection and process of thematic analysis.
Describing the phenomenon through the art of writing and rewriting	Suggests clear understanding of the phenomenon is determined by writing and type of writing used.	Thematic analysis, presentation of findings and discussion.
Maintaining a strong and oriented pedagogical relation to the phenomenon	Refers to the need to remain focused in the phenomenon. Revisiting the research question as a reminder is important.	Revisiting research question and aim. Data collection, thematic analysis, presentation of findings and discussion.
Balancing the research context by considering parts and whole	Ensuring that the whole is balanced with the parts when writing and rewriting.	Thematic analysis and presentation of findings.

These guidelines are seen as sufficiently broad to allow flexibility in emphasising or minimising one step or another, depending on the emergent data. While van Manen did not intend these guidelines to be a prescriptive, linear method for conducting hermeneutic phenomenological research, it was aimed at providing some methodological structure (Mills & Birks 2014). Each guideline identified by van Manen (1990) harmonises with steps in the research process. The guidelines identified are dynamic and not to be viewed as sequential.

3.6.5.1 Turning to a phenomenon which seriously interests us and commits us to the world

Within this guideline, orienting to the phenomenon and developing an appropriate research aim is essential. According to van Manen (1990), lived experience is the start and ending point of phenomenological research and that an individual's lived experience gathers hermeneutic significance as they reflectively gather them using memory. Lived experiences have temporal characteristics in that they can only be reflected on as past experiences with their meaning never fully grasped in their fullness because they pertain to past experiences. The intention of this study is to transform the lived experience into a textual expression of its essence. I have oriented myself to the phenomenon as someone with a great interest and experience in the topic area. These personal experiences continue to be documented in my reflexive journal. This journal is important as I am not bracketing pre-understandings but making them explicit.

Van Manen (2001) explains that phenomenological inquiry is always a project of someone, in the context of a particular circumstance, whereby making sense of a certain aspect is the overall aim. Essentially, this step requires formulation of an appropriate research question that we can connect to as researchers. For this study, I have intentionally chosen to interview mothers of children with severe and profound intellectual disabilities and my research question became: 'what is the lived experience of mothers in 'giving medicines' to children with severe and profound intellectual disabilities?'. Van Manen (1990) propounds that questions posed must be explicit, focused and formulated in a manner to encourage rich description of the experience. Throughout the research process and considering van Manen's guidelines, I will continually maintain my 'gaze' referring back to this question in order to ensure that the methods being adopted continue to be appropriate to answer the question.

3.6.5.2 Investigating experience as we live it rather than as we conceptualise it

I am maintaining a reflective journal on my own personal experiences relating to the topic in order to orient myself to the phenomenon under study. It is my intention that the participant and I become partners in the process of understanding the lived

experience under enquiry. Interviews will commence the data collection process enhanced by participants' willingness to diarise daily experiences.

3.6.5.3 Reflecting on the essential themes which characterise the phenomenon

Van Manen (2001) highlights that a true reflection on lived experience requires a thoughtful, reflective grasp of what it is that renders a particular experience its special significance. Therefore, phenomenological research distinguishes between appearance and essence. This suggests the way in which the researcher approaches the analysis of a transcript is important. Therefore, when reviewing a transcript I intend to reflect deeply on what the participant was saying and what constitutes an aspect of lived experience. The significance will be indicated through the essential qualities of the experience that will be made evident on reading and listening and subsequently will aid the development of the findings.

3.6.5.4 Describing the phenomenon through the art of writing and rewriting

In using van Manen's (1990) approach of achieving rich description and interpretation, the written text in the analysis will describe the essence of the lived experience of mothers 'giving medicines' to children with severe and profound intellectual disabilities. The process of data analysis is as important as the outcome due to the fact data are reported in words. During the process of analysis and writing up the findings, researcher bias has the potential to affect the results as often the researcher interprets the meanings from his or her own perspective. Therefore, it is my intention to document my thoughts in my reflexive journal throughout the research process.

3.6.5.5 Maintaining a strong and oriented pedagogical relation to the phenomenon

Van Manen (1997) recognises the difficulty of undertaking research and the risk of getting distracted. During the sometimes difficult and tedious process of data analysis, maintaining a strong and oriented relation with the topic is important. My genuine interest in the subject at hand is advantageous to the continuation and completion of the project. Often it can be easy to become immersed in the stories of participants and become distracted from the study as a whole. As distraction can lead to becoming side-tracked, my personal reflections through journal writing will be important and focus my

attention if I am swayed. Being aware of my thoughts and maintaining my self-reflection should enable me to stay focused on each individual's experience.

3.6.5.6 Balancing the research context by considering parts and whole

The act of reflecting deeply, writing and the process of re-writing can result in the researcher becoming immersed in the finer details. Van Manen (1990) recognises that often the researcher needs to take a step back and balance this immersion with the bigger picture or 'whole'. This in turn allows the experience to be seen in its entirety as well as in detailed description of its aspects. This will become clearer as the write up of findings develop and the hermeneutic circle is reflected.

3.7 Conclusion

In delineating what hermeneutic phenomenology is or is not, it was established that the underpinnings of hermeneutic phenomenology are quite complex and required the exploration of early and modern works in the field. Methodological applications are dynamic and evolving each decade with different philosophers having different interpretations of hermeneutic phenomenology as both a philosophy and a method. What was established was that phenomenology as a research method is a rigorous, critical and systematic way of investigating phenomena. Because of the existence of multiple interpretations, I had to familiarise myself with the various philosophies and ground the study in the approach I feel will offer the most rigorous and accurate interpretation for the chosen phenomenon. It is important to acknowledge that appraisal of Heidegger, Gadamer and Merleau-Ponty and their hermeneutic phenomenology is not exclusively about the philosophy but about bringing together relevant philosophical viewpoints to establish a methodological framework to guide this study.

While upholding the ideas of epistemology and ontology, both Husserl and Heidegger also promoted the transcendental and eidetic (descriptive) and hermeneutic (interpretive) stance. Both viewpoints present subtle differences and therefore this has led to two distinct research traditions (Lavery 2003). Descriptive phenomenology is an earlier form of phenomenology and involves such steps as bracketing, intuiting,

analysing and describing (Lopez & Willis 2004) while interpretive phenomenology is used to ascertain meaning of a phenomenon without bracketing researcher biases and prior engagement with the topic under study. There are many perspectives of hermeneutic phenomenology presented in differing paradigms; interpretivist (Heidegger), constructivist (Gadamer) and post positivist (Merleau-Ponty). While diverse in their interests and interpretation of what phenomenology is, Merleau-Ponty (1962) identified the four qualities of description, reduction, essences and intentionality as being characteristics common to different schools of phenomenology.

In this instance, I have indicated why hermeneutic phenomenology is the chosen approach. I have chosen to adopt van Manen's (1990) framework and have evidenced how it has developed and summarised the six step guidelines to approaching research. The following chapter, Chapter Four serves to inform the reader of the method adopted and how the research process was operationalised.

Chapter Four – Methods

4.1 Introduction

In this chapter, the methods chosen to investigate the topic of mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities are rationalised and explored. The choice of research method is justified by reference to relevant literature. The methodological process will be detailed to include research design, reflexivity, chosen sample and sampling technique, recruitment and access. Data collection and analysis are detailed while in the final part of this chapter, ethical considerations and integrity of the study are addressed.

4.2 Research design

As indicated in Chapter Three, a hermeneutic phenomenological approach has guided this qualitative study focusing on interpreting and understanding what it means for mothers to 'give medicines' to children with severe and profound intellectual disabilities. This design was deemed most appropriate as it allows for the experience of participants to be described and interpreted and appeared to fit the overall research aim. Adopted within this study, van Manen (1990) devised a methodological outline for doing hermeneutic phenomenology which involves a dynamic interplay between six guidelines which were explored in the previous chapter.

4.3 Research Aim and Objectives of the Study

The aim of this study was to explore mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities. This aim was derived not only from a personal and professional interest but a search of the literature demonstrated there was limited attention given to the role of informal carers in management of medication with children and in particular children with severe and profound intellectual disabilities. The aim was reflective of an issue in need of address.

In order to provide an answer to this aim, specific objectives were identified:

- To explore the experiences of mothers of children with severe and profound intellectual disabilities 'giving medicines';
- To identify the range of activities mothers of children with severe and profound intellectual disabilities 'giving medicines' undertake;
- To develop an understanding of how mothers learn about 'giving medicines';
- To identify any issues experienced by mothers of children with severe and profound intellectual disabilities 'giving medicines';
- To explicate the meaning of mothers living with 'giving medicines' to children with severe and profound intellectual disabilities as a basis for understanding and interpretation by others.

In keeping with hermeneutic phenomenology, it can be argued that the work of understanding had already begun, through identification of objectives directly relating to the subject under scrutiny or *turning to a phenomenon which seriously interests us and commits us to the world*.

4.4 Reflexivity in the chosen approach

In qualitative research, acknowledgement of the influence a researcher has is imperative (Carolan 2003). Reflexivity refers to the entanglement of researchers with the methods they adopt in researching phenomena. It can be described as the process in qualitative research whereby the researcher continuously reflects on how their own actions, values and perceptions impact upon the research setting and affect the data collection and analysis (Gerrish & Lacey 2012). In order to ensure rigour the researcher must be able to account for their role and be reflexive. Schwandt (1997) suggests reflexivity is an important component of the researcher's toolkit especially where the researcher and the research are so closely intertwined. It is also suggested there are two aspects to reflexivity; acknowledging that the researcher is part of the study setting and context and secondly, involves a process of self-reflection about one's own biases, preferences and inclinations about the research (Schwandt 1997). Reflexivity serves to enhance the quality of a research study and is a useful measure. All knowledge is deemed to be

affected by social conditions and includes the observer and the observed (Hesse-Biber & Leavy 2011) which in this case is the participant and me.

In this research study, I see reflexivity as a way of 'coming to terms' with the complexity of my presence within the research setting and have developed insight into my work as a result. Holliday (2016) acknowledges the importance of avoiding futile attempts at eliminating the researcher effect but instead setting about understanding these effects. Maintaining a reflexive approach ensures a critical review of the researcher role and how this may impact on the research process or outcomes (Newton *et al.* 2012). Prior to commencing interviews with participants, it is essential to recognise the need to either bracket or reflect on one's own experiences and identify anything that might hinder one's ability to listen and hear the participant experience in an authentic manner (Mills & Birks 2014).

Finlay (2011) suggests instead of bracketing, the researcher critically engages with their own subjectivity. When investigating lived experience, the researcher's experience of the phenomenon must be considered. Van Manen (1990) supports the notion that by becoming aware of their own experiences the researcher can use them to orientate towards the phenomenon and in turn becomes part of the research process. In keeping with hermeneutic phenomenology, I chose not to bracket my own possible effect on the research study. Reflexivity ensures the researcher considers their own personal biases and how they influence the topic under research (Mason 2018). Through active reflexive practice a transparency can be brought to the research and aids demonstration of how knowledge was formed. This transparency can enable ethical issues to be highlighted and the power relation between participant and researcher considered. It also adds to the rigour of research as it enables others to develop an understanding of how the research was undertaken.

From the outset, I spent time thinking, writing and talking about why this topic was of interest to me and how I had experienced 'giving medicines' both in my professional capacity with children and in my personal capacity as a mother. I developed an awareness that while I had experience of 'giving medicines' to children with severe and

profound intellectual disabilities, this was in my professional capacity and it was very much 'my' experience. Having awareness enabled me to keep it in mind when interviewing mothers and by using the same guiding framework for all interviews I attempted to halt any researcher bias arising.

I commenced writing in a reflective journal at the start of the research process making note of how I felt about the topic and process, highlighting any thoughts or connections I had. I took note of what was seen, said and done in the process, as well as interpretation of meaning in written memos throughout the study. I also made memo notes within NVIVO during the analytical process. I found keeping a reflective journal useful especially after completion of interviews or after reading submitted diaries. I noted things like connections I was seeing between transcripts, experiences and early emergent themes. On reading transcripts, I referred to notes I had made in my journal and tried to remain open about the possible meanings and themes. As each theme emerged I would refer back to transcripts ensuring that the theme I was indicating was in fact evident in the participant experience and was not one developed from my biases. This was part of reflecting between the parts and the whole of the text as advocated by van Manen (1990).

During the analytical process, I remained focused on understanding each mother's perspective being mindful that my experience could not merge with their experience. In adopting van Manen's framework (1990) for exploring lived experience, I acknowledged my role as co-creator in the research process where the meaning of the experience is created through my own immersion with the data and text. According to van Manen (2014) writing forces the researcher into a reflective attitude which in turn enables them to remain focused on the meaning of phenomenon, an important facet of my chosen research design.

4.5 Sample

Population refers to all individuals who conform to a certain set of criteria (Polit & Beck 2017). When choosing a study population, it is regarded as a subset of the target

population from whom the sample should be taken (Gerrish & Lacey 2012). The accessible population for this study were mothers of children with severe and profound intellectual disabilities. Sampling is an important step in any research study, inevitably affecting the findings and permitting analysis of an accessible population (Polit & Beck 2017). A sample refers to the selected group of people with whom to conduct a study (LoBiondo-Wood & Haber 2014).

In this instance, non-probability sampling was adopted in order to study the population of interest. This type of sampling serves to deliberately select participants that reflect the required features of the population under research (Ritchie *et al.* 2014). Purposive sampling is used in qualitative research and selected participants can inform or represent the central phenomenon of the study (Palinkas *et al.* 2015). Patton (2002) states that 16 different forms of purposive sampling exist and choice depends upon the research question and resources available. In the case of phenomenological research, such purpose is that the participant selected can provide good personal accounts of the lived experience to be studied (Gerrish & Lacey 2012) and will be able to inform a detailed exploration of the central themes (Bryman 2012). In this instance, homogenous purposive sampling (Holloway & Wheeler 2015) was used, purposively seeking out mothers of children with severe and profound intellectual disabilities who have lived experience of 'giving medicines'. This was the chosen sampling type based on the aim of the study and the existing knowledge on the topic. In order to obtain material relevant to the study aim, Van der Maren (1995) stipulates that participants must have had the experience themselves and be able to remember it and create a narrative. This study demanded a personal commitment in terms of sustained activity through multiple interviews and possibly diary keeping and therefore it was important that participants had an interest in sharing their experience.

The sample for this study was drawn from an approximate population of 1106 children with severe and profound intellectual disabilities in Ireland (Hourigan *et al.* 2018). In phenomenological research it is customary to use small numbers as the ultimate goal is to achieve a rich understanding of a lived experience and not produce findings that are generalisable (Mason 2018). The sample size of a phenomenological study can range

from 5 to 25 participants (Creswell & Poth 2018). Van Manen (1990, 1997) does not indicate a specific sample size for his method and prefers the term 'example' over 'sample' expressing that examples of experiential descriptions should be evident. Van Manen (2014) goes so far to say that there is no rule of sample size for phenomenological research and does not advocate the use of the term data saturation as this suggests looking for patterns which is not the objective of phenomenology. Rather phenomenology can illuminate a singular theme in an experience and does not necessarily count how many times certain words appear in text (van Manen 2014). Therefore, I chose to adopt a sample size of 15 participants taking cognisance of the need to reflect deeply on each transcript and consequently not wanting too many that could then lead to shallow analysis. This sample size was deemed appropriate for phenomenological research as it allows for greater depth of investigation with larger amounts of information being obtained due to multiple interviews and diary keeping.

4.5.1 The Sampling Process

4.5.1.1 Gaining access

The sample was accessed through six service providers providing services to children with severe and profound intellectual disabilities in the Republic of Ireland. Prior to final selection of organisations and submission of formal applications for ethical approval, I commenced tentative dialogue with these, giving a brief background to the study aim and what may be required. I found this beneficial in clarifying interest from organisations at an early stage and feel it may have enhanced my ethical applications as issues that may have been problematic were clarified prior to submission. Rules of access were clarified for organisations and the ethical application process commenced with ethical application forms submitted to the School of Nursing and Midwifery Research Ethics Committee (SNMREC), and subsequently to three of six organisations. The three remaining organisations while they reviewed the research proposal and associated appendices, accepted ethical approval from the base University as they did not have their own ethics committees. All six granted ethical approval to progress with the research study (Appendix 3).

4.5.1.2 Inclusion criteria

The criteria used to define a population for a research project has implications for the interpretation of the results (Polit & Beck 2017). To be eligible for this study, participants had to be mothers of children with severe and profound intellectual disabilities aged between 2-18 years of age who need medication administered on a daily basis. Following consultation with a paediatrician specialising in neuro-developmental disabilities and a paediatric pharmacist, it was decided that no stipulation would be made as to how many medicines a child was receiving in order to be included. Both experts expressed the opinion that each child was likely to be receiving more than two medicines and most likely requiring varying routes and methods of administration.

4.5.1.3 Exclusion criteria

Those people excluded from this study were:

- Mothers who did not have a child with severe and profound intellectual disabilities;
- Mothers of a child with severe and profound intellectual disabilities aged between 2-18 years of age that did not experience administration of medication on a daily basis;
- Those who did not wish to have their name disclosed to one specific organisation after participation in the study (naming of participants was a requirement of one organisation who then ensures the participant is not invited to partake in research studies for a 5 year period thereafter).

4.6 Recruitment and Access

Purposive sampling was adopted with the sample population being mothers who were 'giving medicines' to their children with severe and profound intellectual disabilities. The sample size was 15 participants. Six sites were accessed for recruitment of a suitable sample (Appendix 4). Each site (with the exception of site four) had an appointed gatekeeper with one site having three gatekeepers due to the service layout. Access to potential participants was through these gatekeepers. The gatekeeper role was crucial in accessing participants with some being more receptive to their role than others. Positive

influences of a gatekeeper can be invaluable in facilitating a research project and is well documented in the literature (Gerrish & Lacey 2012, Macfadyen & Rankin 2016).

I met with each gatekeeper before commencement of recruitment, so that they were clear of what was required of them and to clarify any questions they might have. Following discussion with each gatekeeper, sealed information packs were given to them for distribution to potential participants who fulfilled the inclusion criteria. On selection, the gatekeeper then posted these packs to each potential participant. Individuals who were interested in participating were asked to complete an expression of interest slip, with contact details and return it in the stamped addressed envelope provided. On receipt of this, I then made contact with potential participants to move the process forward. During this initial phase between January 2015 and January 2017, 50 information packs were distributed. As site four was an organisation placing an advertisement at my request, there was no gatekeeper appointed. The communications officer placed the advertisement on the website and this indicated that interested participants could contact me directly. On making this contact, each participant was then forwarded an information pack before agreeing to participate in the study. In total, 15 participants were successfully recruited to the study (see Appendix 4).

4.7 Data collection procedures

Van Manen (1990) suggests that *investigating experience as we live it* is influenced by how data is gathered while Polit & Beck (2017) outline that the success of any study depends on the quality and implementation of the chosen data collection methods. Often multiple data sources are used in hermeneutic phenomenology which was the case in this research study. Van Manen (2014) offers several ideas on how to collect experiential descriptions from participants to include interviewing and writings. In addition to interviews, participants were also asked to keep an account of happenings in relation to 'giving medicines' in a diary. This was an additional source of information and complemented the interview findings.

4.7.1 Interviews

The most common form of data collection in hermeneutic phenomenology is conversational interview (van Manen 1990, Priest 2002). Phenomenological interviews are in-depth in nature (Miller 2002) and are usually unstructured but may be semi-structured adopting open ended questions (Liamputtong 2010) that are carefully chosen to elicit the desired information. The interview is aimed at gathering and exploring narrative materials to develop a comprehensive understanding of the phenomenon of interest, developing a conversational relationship with the participant to understand the meaning of an experience (Brinkman & Kvale 2015). Individual interviews are an effective means of gaining insight into people's experiences of a given phenomenon (Ryan *et al.* 2009).

In this instance, I chose one to one, face to face multiple interviews, unstructured (1st interview) and semi-structured (2nd & 3rd interview), digitally audio recorded with each participant. This approach allowed for in-depth exploration of the topic. A summary of participants and the data collection method each one participated in are provided in Appendix 5. Multiple in-depth interviews were used as a vehicle for developing a conversational relationship with the participant about the meaning of the experience. In this way, I was able to understand the experience by listening to the words of people who lived it daily. Returning to participants for second and in some cases third interviews, this permitted an in-depth review of what was previously said and further clarification on key issues.

Additionally, sensitivity was shown in choosing dates and times that suited participants, something recommended in the literature (Price & Nicholl 2013, Dempsey *et al.* 2016). The interviews were conducted over a 17 month period through February 2015 to July 2016 and were held at locations agreeable by both parties. Some were neutral venues and most were held in the participant's home. Interviews allowed the participants and I to relive their original experiences as they related them. My sincere interest in the topic area allowed me to be present in the moment, regardless of venue. Participants felt safe enough to share their stories with me. Mothers were encouraged to describe their lived experience of 'giving medicines' and share their stories, anecdotes and thoughts. Open

ended questions formed the basis for questioning and were carefully worded so as to avoid imposing predetermined responses. The line of questioning placed the participant in the role of expert in the topic area.

In this instance, I used an unstructured format in the first interview and thereafter a semi-structured format. The initial interview commenced with a non-leading opening statement “tell me about your experience of giving medicines to your child with severe and profound intellectual disabilities”. This interview was non-directive and conversational in style adopting a ‘grand tour’ approach. In contrast, subsequent interviews were semi-structured allowing for clarification to be sought. Several questions were asked of the participants to raise issues of importance and to facilitate comprehensive discussion. These were prepared in advance and based upon what participants had discussed in the initial interview with clarification sought. This commenced the process of *reflecting on the essential themes which characterise the phenomenon*.

It is important to note that in a phenomenological interview the interviewer and the interviewee are partners in the process of discovery. Thus, formulating some questions before the interview is essential to ensure clarity throughout the interview. The interview is a delicate balance between asking open ended questions to foster a conversational style interview and allowing silences to help the participant proceed with their story. In this instance, I adhered to this notion by using one open ended question in the initial interview and questions for subsequent interviews were derived from the interview data (Appendix 6). In developing an interview guide it was important to stay close to the experiences as lived by the individual, by asking concrete open questions about specific instances. The goal of a conversational interview was to establish trust and build a rapport with the interviewee and create an atmosphere amenable to self-disclosure (Brinkman & Kvale 2015). Prompts and probes were established at the outset so they could be used to clarify information or elicit a fuller response at interview but were not always required (Appendix 7).

In data collection, although I could not predict with any certainty the number of interviews that would be needed to achieve an understanding of the subject matter; I anticipated that I would meet with participants on two to three occasions over a 6-9 month period. Aside from the time period being associated with the practicalities of interviewing, transcribing and arranging further meetings, the time lag facilitated a more holistic view of the participants' lives covering more than just one period in time. It also allowed participants the opportunity to diarise experiences over the time period. Equally, I was concerned that repeated revisiting of the participants and repeated conversations would see new understanding go on indefinitely and I would not know when to end data collection. Ultimately, I had to trust that through the collaborative process with the participant, we would know when it was time to halt data collection. This became transparent in all of my interviews and participants were clear about whether they had more to offer or whether they felt they had exhausted all conversation about the subject at hand.

According to Mills & Birks (2014) phenomenological interviews can last from 45 to 90 minutes or longer. A total of 28 interviews were completed within the study, five participants engaging in one interview, seven participants engaging in two interviews and three participants engaging in three interviews, while seven participants engaged in diary keeping. Interviews in this study lasted from 27 minutes (interrupted and recommenced) to 57 minutes. In most qualitative research, it is essential to have a full record of interviews undertaken (King & Horrocks 2010). It was important to audio record the interviews as the participants' words needed to be presented verbatim in the analysis to ensure meaning was preserved. A back up recording of each interview was taken also using a smartphone and deleted once the digital recording was uploaded securely. The audio files were also imported into qualitative analysis software NVIVO 11 to aid in data management. All participants agreed to have interviews digitally audio recorded. Additionally, supplemental biographical and contextual data along with medication details were collected prior to commencement of the initial interview.

4.7.2 Diaries

In addition to interviews, participants were also invited to keep an account of happenings in a diary, with regard to 'giving medicines'. This was an additional source of information and complemented the interview findings. Diaries have been used as a single source of data collection and as one method among others, with participants of all ages (Jacelon & Imperio 2005, Alaszewski 2006, Nicholl 2010). The terms journal, log and diary are used interchangeably in the literature (Hayman *et al.* 2012). A diary as research tool is often described as a kind of self-administered questionnaire (Robson 2002).

In this study, diaries were adopted in order to record participant experiences as they were happening, in their natural contexts. Verbrugge (1980) first identified journaling as a primary source of data collection and it is now seen as a successful method of examining specific experiences in natural contexts (Simmons-Mackie & Damico 2001). Swenson (2004) argues that a diary as method of data collection can be used with other methods of data collection in an effort to enrich information gathered from interviews. In this study, the aim of diaries was twofold: to collect data that would enrich and confirm the data already collected during interviews and to clarify and seek responses to questions inadequately explored during interviews. Diaries were an adjunct to interviewing and aided and informed the interview process. The resulting rich data was used to explore participant situations in the interview process and to confirm the findings in subsequent interviews.

I encouraged participants to use solicited diaries within this research study. These types of diaries are written with the researcher in mind (Elliott 1997). I provided any equipment necessary to maintain a diary such as a diary and pen. Diaries can vary from structured to unstructured (Moule & Goodman 2009). I adopted an unstructured approach but used prompts in the instructions to encourage each participant to document their experiences that were significant to them relating to 'giving medicines' to their child with severe and profound intellectual disabilities. It was important to remind participants there was no right or wrong way of documenting their experiences. In designing the diary, it was essential that it was not so big that it would be off-putting for the participants and that instruction was clear but succinct. When the initial draft

was completed, four experts (comprising a children's nurse working in the sector, a parent, an academic and a children's nurses/experienced researcher) reviewed the diary for readability, use of jargon or complex language and colour (see Appendix 8 and 9). Coloured paper was adopted as this is seen to boost response rates (Cowman 1997). As pink and peach are colours that seem to have greatest effect (Hartley & Rutherford 2003), peach was adopted for the diary. I was cognisant of the great deal of responsibility placed upon the participant in asking them to keep a diary. However, the entries, the volume and number of times were all self-determined by the participant.

4.8 Design of the Information

The design of the information pack received much attention. This was due to the fact that participants selected needed to have adequate information regarding the study to make an informed choice. Once drafted, an expert panel of four people (as described in section 4.7) reviewed the information pack for clarity, jargon and content (See Appendix 10). The information pack (Appendix 11) contained the following items:

- Covering letter
- Participant Information leaflet
- Expression of interest slip
- Informed consent form
- Self-stamped addressed envelope

All titles on the pages were in bold type in order to identify for the participant what the significance of the next section would be, which is perceived as a valid method of keeping the participant interested when reading information (Gerrish & Lacey 2012). Sub-headings were adopted in the participant information leaflet for ease of reading. Advice from the expert panel included the use of non-jargon style language, which was adhered to. Each pack gave clear instructions to the participant on what was to be returned. A self-stamped addressed envelope was used as this is seen as a method of boosting response rates as there is no cost involved for the respondent (Parahoo 2014). The participant invitation letter, which was clearly visible, was an attractive peach colour

with the title and instructions in bold print. The response envelopes had only a label with the return address and a stamp on the right hand upper corner.

4.9 Data collection procedure - The interview process

Data collection using interviews and diaries was undertaken over a 17 month period through February 2015 to July 2016. The interview process is further explored here.

4.9.1 Gaining Consent

Any participant who returned the expression of interest slip was contacted by phone to discuss consent and participation in the study outlining in more detail what was required of them. All participants were offered an initial meeting and they could then decide if they wished to participate. However, no participant availed of this and following discussion over the phone they all agreed to participate. Formal consent was clarified then at the first interview. Initial dates were arranged at the participants' convenience and for their own comfort interview locations were dictated by individuals and I travelled to meet with them. Interview venues varied, nine participants were interviewed in the home and six participants were interviewed at locations of their choice, usually a hotel lobby or a coffee shop near where they lived. The purpose of the study was reiterated and any questions answered. Confidentiality agreements regarding digital audio recordings and transcripts were offered and anonymity assured through use of codes. Any names or places mentioned in interviews would be anonymised during transcription and writing and pseudonyms adopted where relevant. Participants were reminded that they could withdraw without question from the study at any time, without having to explain their decision, or suffer any adverse effects. Within the consent form participants were offered an opportunity to tick a box so they would receive a copy of their diary entries and a copy of their interview transcript. At the outset, some participants clearly acknowledged their desire to keep a diary while others indicated their preference not to keep one.

4.9.2 Preparation for Interviews

Before commencement of interviewing, I ensured I had composed a non-leading opening question that would commence the conversation, “tell me about your experience of giving medicines to your child with severe and profound intellectual disabilities”. This interview was conversational in style primarily led by the participant. My role was one of active listening and less of asking questions, other than to encourage conversation or clarify comments. I was unable to predict the length of interview but in some cases whole days had to be allowed for getting to and from geographical locations countrywide. I ensured I allowed enough time for travelling to and from the chosen venue with Google Maps becoming an important element of my researcher toolkit. With nine of the interviews taking place in the participants’ home I was conscious of personal safety and adopted Lone Worker Guidelines (Trinity College 2017). In doing so, I ensured at least one person knew of my whereabouts (general location, not specific to ensure confidentiality) and following the interview I would let this individual know it was complete and that I had left the venue. Another important component of my toolkit was a digital audio recorder which I had chosen because of its high recording quality and convenience of use with no restriction on length of recordings. The transcription process was, in turn, facilitated by these high quality recordings.

4.9.3 The First Interview

Prior to the first interview, I contacted participants the day before to confirm they were still agreeable with the arrangements. This was important for me before I travelled, but for the participant also as the nature of their caring role often meant that unpredictable caring needs took precedence over other activities such as interviews. Participants were also reassured they could text me the morning of the interview if anything urgent had come up and they needed to postpone or cancel. One interview was rescheduled due to a child being hospitalised but all others went ahead as scheduled.

Prior to commencement of the formal part of the interview, a ‘getting to know each other’ dialogue took place chatting about such things as the weather, where I had travelled from and often the participant seeking information about me which put them at ease. Participants usually offered tea and refreshments and preparation of these led

to further dialogue before the interview commenced. Seven of those interviewed at home also had their child present in the house and they either remained in the room while interviewing or other family members cared for them while interviewing took place in a separate space. I also met two of the participants' husbands and chatted with them but both absented themselves when interviews were taking place.

Six participants were interviewed at other locations of their choice, usually a hotel lobby or a coffee shop near where they lived. Three of these six participants rarely left the home and welcomed the opportunity to get out. As well as verbal consent, written consent was obtained and two copies were signed. One copy was held by the participant and one held by me. Generally, the first interview was very much getting to know the participant and their story. While the recording might have been an hour, usually at least two hours was spent with each participant. Either side of the interview itself, there was tea-making, refreshments and general conversation which aided the process of engagement and disengagement, an important component of the whole interview process according to Edwards & Holland (2013). On completion of the first interview plans were made for me to make contact three months later with a view to arranging a second interview. Once transcription had been undertaken, if indicated, the transcript was posted to the participant.

[4.9.4 The second and subsequent interviews](#)

Process consent was adopted and therefore, as well as ongoing verbal consent, written consent was obtained again and two copies were signed, with one being held by the participant and one held by me. When contacted seven of the participants agreed to partake in another interview while the remaining eight felt they had no more to contribute and may have already submitted a diary with entries as well. All second interviews commenced with my enquiring as to how things had been since the previous interview. Participants would then usually respond with how their child had been and how medication changes might have impacted. At this point I would have identified key issues from the previous interview transcript and sought clarity on these or further information and was assured that the participant was happy with the transcript details. Being able to refer to the previous interview made participants comfortable and they

slipped into the conversation easily. For the most part, participants were content with their transcripts with the odd exception where they had used swear words when talking of their frustrations.

The fundamental difference between the first and second interview was the initial telling of their story did not happen in the second interview as this had already been told. Therefore, the second interview was more structured with clear questions arising from the transcript or diary transcript. This was important in developing a clear understanding of the topic and affording me the opportunity to start interpreting the findings. Four of the seven participants who undertook a second interview expressed that they felt they had no more to add in a third interview while three requested that I contact them again after another three months to arrange a final third interview. These interviews led to a natural closure of the process and again were led with clear questions that had arose from their previous interview transcript. Participants felt they had nothing additional to add and I felt I had nothing new to ask. At this point, I indicated I would only be in touch if I needed to clarify anything when analysing the data. However, I emphasised that they were free to contact me if they had any queries. Again, once transcription had been undertaken, if indicated, the transcript was posted to the participant.

Following every interview I listened back to each recording ensuring I had missed nothing and the quality was good. Recordings were then uploaded via a secure server for transcription. The participant name was coded by number to ensure anonymity and confidentiality. A professional transcription service was used with one professional transcriber assigned to transcribe each interview. A confidentiality or non-disclosure agreement was signed by this individual and the company to ensure no data would be compromised. An agreement was made with the transcriber that uploaded interviews would be transcribed and made available to me within five working days. They were accessed by me again through a password protected secure server. Once accessible, each transcript was read and checked by me while listening to the recording and any changes or clarifications made where words were not heard by the transcriber in order to ensure accuracy. Additionally, I screened transcripts for any potential identifiers such

as names or hospital details. Each transcript was assigned a code when being submitted to the transcriber for example, Participant 1 – P1 and then a corresponding A, B or C to indicate if it was the first, second or third interview. In this way the confidentiality of each participant was maintained. I held a schedule of interviews in Microsoft Word with the corresponding codes. I personally transcribed diary entries that were returned to me and coded and cleaned these for identifiers also. Once this process was undertaken, transcripts were posted to participants. Some participants did not make contact regarding receipt of these while others sent me texts to inform me they had received them and found reflecting on the transcript had placed a spotlight on a topic they had not given a lot of thought to previously. On completion of data collection, I posted an individual thank you letter to each participant indicating how grateful I was for their participation (Appendix 12). I also indicated a potential timeframe for completion of the study and at that point I would forward them a summary of the findings.

4.10 Data collection procedure - Diary keeping

All participants were offered the opportunity to keep a diary of their experiences of 'giving medicines' to their child. While not wanting to be prescriptive or risk stifling participant contributions, I provided prompts in the instructions to encourage each participant to document experiences significant to them. The content of entries, volume and number of times were all determined by the participant. Ten participants agreed they would like to keep a diary but only seven actually kept one with the remaining three forgetting about it or feeling they had nothing more to add after the interview. All ten were given a diary and pen at the first interview with an introduction to what this was about and the purpose of it. They were also given a stamped addressed envelope and asked to return the diary after eight weeks and before I made contact regarding a second interview. This allowed them some time to reflect on what they might include but also allowed me sufficient time to transcribe the entries and prepare questions for the second interview. All seven returned the diary by post and without prompt, some with multiple diary entries and some with minimal diary entries.

4.11 Reflection on the data collection process

A total of 28 interviews and seven diaries were completed. My nervousness waned as I became confident in the interview process. My first interview was my shortest and lasted only 27 minutes. It was a good test of my ability to engage with the interview process but also the unpredictable nature of interviewing as it was interrupted a number of times by visitors to the house. During the data collection process, I was unsure whether or not I would recruit enough participants and if I would know when to halt my study when enough data was gathered. This was a needless worry as it became evident that I had generated sufficient high quality data. On completion of the last two interviews, it was my feeling that further data collection would not enhance the findings any further and at this point no new or different concepts were emerging. Diary submissions were also completed at that stage and therefore, a natural ending to data collection occurred. Conscious of the notion that understanding is not static and the hermeneutic circle could go on indefinitely, I also had to keep in mind the burden of participation for individuals who had already given so much of their time. Throughout the data collection process, I journaled my reflection in my 'pink' notebook. This notebook travelled with me everywhere in my handbag and I documented my thoughts on initial interviews, post interview thoughts or reminders of omissions that I should have addressed. This journaling of my reflections became part of the data collection process and I would read back on the entries prior to undertaking subsequent interviews. I also found this reflective process enhanced my performance as an interviewer. I found it useful in devising questions for subsequent interviews and participants seemed reassured to hear others might be experiencing what they were.

4.12 Data analysis

The data analysis phase of this research study represented the stage at which the essence of the phenomenon of interest was being understood (Priest 2002). The analytical process is central to any research study but within hermeneutic phenomenology often due to ideological stances by some phenomenologists, specific analytical steps are not focused upon. Phenomenological data analysis has received considerable attention by methodologists in recent years and a number of approaches

do exist (Spiegelberg 1965, 1975, Paterson & Zderad 1976, Colaizzi 1978, van Kaam 1984, Giorgi 1985, van Manen 1990, Streubert 1991, Moustakas 1994). Regardless of the particular phenomenological approach taken, all hermeneutic phenomenological analysis uses a process of close and repeated engagement with the data. It is important to remember that the complexities and intricacies of the phenomenon need to be captured and reported in ways with which others can understand and engage (Grbich 2007). Furthermore, the analysis centres on generating themes influenced by researcher engagement with the text. Langdridge (2007) acknowledges the important role of the analyst in constructing meaning within hermeneutic phenomenological research. Bearing this in mind, this study was guided by van Manen's (1990) methodological approach for undertaking practical phenomenological research.

4.12.1 Van Manen's method for thematic analysis

It has been said that the method of hermeneutics is that there is no method (Gadamer 1975). Yet, van Manen (1990) propounds that there is indeed a history of traditions, a body of knowledge and insights associated with the field of hermeneutics and with this in mind he has developed what he describes as methodological themes or features which influence researchers' development of the research methods. Van Manen's method for thematic analysis involves discovering, interpreting and reporting patterns and clusters of meaning within data (van Manen 1990, 1997, 2007, Ritchie *et al.* 2013). Through systematically working through texts the researcher identifies topics that are integrated into higher order themes that address the overall research question (van Manen 1990, Braun & Clarke 2006). The phases I adopted in the data analysis process are summarised in Table 7 and detailed further below.

Table 7: Phases of Data Analysis

Phase of Data Analysis	Van Manen's (1990) guidelines
Transcribing, reading and re-reading	<i>Turning to the nature of lived experience</i>
Constructing a qualitative database	<i>Turning to the nature of lived experience</i>
Selective reading approach - creating initial	<i>Investigating experience as we live it</i>

Phase of Data Analysis	Van Manen's (1990) guidelines
themes	
Holistic reading approach - creating essential themes	<i>Reflecting on the essential themes which characterise the phenomenon</i>
Writing	<i>Describing the phenomenon in the art of writing and re-writing</i> <i>Balancing the research context by considering the parts and whole</i>
Adopting an existential approach	<i>Describing the phenomenon in the art of writing and re-writing</i>

4.12.1.1 Transcribing, reading and re-reading - Turning to the nature of lived experience

Analysis during the interview and diary keeping process was ongoing. Following each interview or return of diary, transcription was undertaken (see Appendix 13 for sample interview transcript and Appendix 14 for sample diary transcript). This is the process of converting material into text and is a necessary precursor to data analysis (King & Horrocks 2010). Thereafter, following transcription, each transcript was analysed one at a time in the same way. Between interviews, an initial analysis of transcripts was undertaken with reading and re-reading undertaken several times. Reading also took place while listening to the audio recording to become attuned to the parts of the interview that cannot be transcribed, such as the emotions communicated. This was important in developing an understanding and identified what was and was not said. This was also helpful in identifying aspects for further clarification or development. It was beneficial not only in that individual participant's next interview, but in other subsequent interviews for example, *other participants have identified that.....how do you manage this issue?* This was important in ensuring subsequent interviews were focused. When reading these transcripts, I made notes to myself, prompting further question development for the next interview. Additionally, diaries that were received were also reviewed and data from the diary was referred to in subsequent interviews with the participant in order to clarify or gain a deeper understanding of the concepts discussed.

My field notes and reflexive journal were also important tools that were analysed on a continuous basis with the aim of enhancing the data collection and analysis process.

4.12.1.2 Constructing a qualitative database - Turning to the nature of lived experience

An important instrument in supporting me in managing the data for analysis was the construction of a database adopting NVIVO 11. While there are a range of computer assisted qualitative data analysis packages on the market, I adopted the Computer Assisted Qualitative Data Software Analysis package, NVIVO. This refined package allows for “in vivo” coding or naming a category directly from a participant’s own words (Bringer *et al.* 2004). There has been much debate about using computers to organise and manage qualitative data and what is clear is that these do not undertake the analysis for the researcher (Wong 2008, Durand & Chantler 2014). Being mindful of van Manen’s (1997) stance suggesting there is no need to use a software package I felt it would be helpful for storage and more importantly the retrieval of relevant sections and quotes which would in turn aid the development of my essential themes. In order to ensure I stayed true to van Manen’s guidelines I devised a document that reminded me of van Manen’s six research guidelines (activities) or components and where they fitted in the NVIVO process (Appendix 15). This aided me in ensuring transparency of each step and assisted me in clearly identifying the various elements of data analysis (Bringer *et al.* 2004).

4.12.1.3. Selective reading approach - creating initial themes – Investigating experience as we live it

In order to attribute meaning to the data or *reflect on the essential themes which characterise a phenomenon*, van Manen (1990) suggests three methods for isolating thematic statements; detailed reading approach, the selective reading or highlighting approach and the holistic reading approach. The selective reading approach involves a comprehensive scrutiny of the text reading it several times with the aim of revealing statements or phrases that seem essential to the experience being described (van Manen 1990, p. 93). I chose to adopt the selective reading approach examining sections and paragraphs that seemed relevant, highlighting key segments. In the selective reading approach, the researcher reads the text and asks what statement(s) or phrase(s)

seem particularly essential or revealing about the phenomenon or experience being described. I found this approach helpful without over analysing individual words, a central tenet of the detailed reading approach. The following excerpt is an example of how this selective reading approach was undertaken in this study, examining particular paragraphs. For every transcript, I asked what a paragraph says about the mother's experience of 'giving medicines' to their child with severe to profound intellectual disabilities and as a statement or series of statements it captures important elements of the phenomenon. I then created keywords (those underlined) which in turn would become the essential themes.

... (child) is on 17 meds daily and he's on them numerous times a day. So in the morning he's on 12 medications and a Flixotide inhaler as well, or a nebuliser if he's unwell. So, mornings, you want to be organised. So I draw up all my meds the night before. He goes to school at quarter to nine in the morning, so I need him to have his meds before he's going on the bus. (P7B)

(This tells me of the burden/being on call, how time consuming this process can be and the need for organisation)

This process of selective reading allowed me develop multiple initial themes (codes). According to Saldana (2009) a code is a phrase or a word that symbolically assigns essence capturing attributes for a portion of language based data. By assigning themes (codes) to the data it enabled me to organise what the participants were saying in a logical manner. Within this selective reading phase, I stayed true to the wording used within the transcripts and gave themes tentative titles that were either using the words of the participants or words closely linked to the words of participants. I identified 78 initial themes over a period of time (see Table 8).

Table 8: Selective Reading Phase – Initial Themes

Selective Reading Approach – Initial themes	
1.	Administration
2.	Alleviate distress
3.	Alternative route
4.	Always on call
5.	Average day
6.	Avoid doing things or going places
7.	Being mammy
8.	Caring alone
9.	Changing medications

Selective Reading Approach – Initial themes	
10.	Childs pace
11.	Collaborative decision making
12.	Concern
13.	Confidence
14.	Conflict
15.	Control
16.	Cost of medications
17.	Decision making
18.	Dentist
19.	Difficulty giving the medication
20.	Documenting
21.	Drugs and food
22.	Easy life
23.	Effect on child
24.	Equipment
25.	Expert
26.	Expiry date
27.	Fear of changing medications
28.	Fear of the future
29.	Fear of transition to adult services
30.	Fear of using meds
31.	Frustration
32.	Getting help at home
33.	Going by the clock
34.	Guilt
35.	Handing over to another person
36.	Hospital relationships
37.	If he wasn't on medication....
38.	Isolation
39.	Just part of life
40.	Knowing
41.	Learning
42.	Life is difficult
43.	Making mistakes
44.	Masking the taste or Disguise
45.	Medicine shortage
46.	Naivety
47.	Not a big issue to give medicines
48.	Organised
49.	Overwhelming
50.	Precision
51.	Preparing medications
52.	Prescriptions
53.	Public Health Nurse
54.	Recommendations
55.	Relationship with child
56.	Relationship with GP
57.	Relationship with pharmacist

Selective Reading Approach – Initial themes	
58.	Resignation
59.	Sadness
60.	Schedules
61.	Seeking advice
62.	Seeking information
63.	Sending meds to school
64.	Sending to respite
65.	Siblings
66.	Side effects
67.	Sourcing
68.	Staying in hospital
69.	Storage of Meds
70.	Stressful and helpless
71.	Support
72.	They wouldn't have a clue
73.	Time consuming
74.	Transition to adult services
75.	Travelling
76.	Unlicensed drugs
77.	We've tried everything
78.	Worry

4.12.1.4 Holistic reading approach - creating essential themes - Reflecting on the essential themes which characterise the phenomenon

In addition to the selective reading approach, I adopted the holistic reading approach where the text was viewed as a whole and notable phrases that captured the fundamental meaning of the text were identified. By adopting a two pronged approach of selective and holistic reading, it varied the depth of analysis. For the holistic approach van Manen (1990) advocates seizing and expressing the main meaning or significance of the whole transcript, sometimes in one sentence. I undertook the holistic approach to examine each participant experience and compare it to the other participants within the study. To operate this approach, I went back to the transcript for each participant and the themes generated within the transcript and wrote a short paragraph to express each participant's experience (see Appendix 16 for example). Within the selective reading approach, I often felt that the whole transcript was highlighted so therefore, the holistic reading approach meant it was vital to capture the important elements of the experience. Adopting this holistic reading approach based on my initial identification of themes, I developed 26 essential themes through reorganising, renaming, merging and distilling related constructs and initial themes already identified in the selective reading

approach. This clustering simply meant arranging related themes in groups so that sections that seemed to relate to each other were grouped together. Further analysis saw themes further clustered and renamed into 20 meaningful essential themes (Table 9).

Table 9: Summary of Data Analysis

Selective Reading Approach 78 Initial Themes	Holistic Reading Approach 26 essential themes <i>(Selective reading initial themes collapsed and merged)</i>	Holistic Reading Approach <i>(sub themes developed as part of 26 essential themes)</i>	Holistic Reading Approach 20 essential themes <i>(26 essential themes further collapsed, renamed and merged to develop 20 overall essential themes - these also absorbed sub themes)</i>
Alternative route	Alternative route	Alternative routes of administration Easier with different route	Challenges in 'giving medicines'
Always on call Going by the clock Support	Always on call	I'm always on call Preparing medicines	Always "on call"
Avoid doing things or going places Caring alone Easy life Just Part of Life Life is difficult	Avoid doing things or going places	Adapting your life Just Part of Life	Adapting "my life"
Administration Organised Schedules Recommendations	Being organised	No sub theme	Being organised
Changing medicines Childs' pace	Changing medicines	Stopping - starting medicines	Challenges in 'giving medicines'
Cost of medicines	Cost of medicines or equipment	No sub theme	Cost of medicines or equipment
Difficulty giving medicines Drugs and food Making mistakes Masking the taste or disguise Not a big issue to give medicines Storage of medicines Average day	Difficulty giving the medicines	Challenging Disguise and masking Ease of giving Hard to get in medicines Hate giving medicines Refusal Shortage of medicines Side effects of medicines Sourcing products Storage of medicines and equipment	Challenges in 'giving medicines'

Selective Reading Approach 78 Initial Themes	Holistic Reading Approach 26 essential themes <i>(Selective reading initial themes collapsed and merged)</i>	Holistic Reading Approach <i>(sub themes developed as part of 26 essential themes)</i>	Holistic Reading Approach 20 essential themes <i>(26 essential themes further collapsed, renamed and merged to develop 20 overall essential themes - these also absorbed sub themes)</i>
		Tablets Take opportunity to get medicines in Worry and nervous	
Documenting	Documentation	It's all in my head Keeping a document or diary Keeping a record	Documentation and keeping a record
Of changing medications Of the future Of transition to adult services Of using medicines If he wasn't on medicines Alleviate distress	Fear	Of changing medicines Of the future Of transition to adult services	Feelings experienced by mothers
Concern Confidence Conflict Frustration Guilt Isolation Naivety Overwhelming Resignation Sadness Stressful and Helplessness Worry We've tried everything	Feelings	Effect on child Frustrating Guilty Harrowing Isolated Nervous Overwhelmed Resignation Sad Sorrow Stress Upset Worried	Feelings experienced by mothers
Equipment Medicine shortage Sourcing medicines	Getting equipment	No sub theme	Associated equipment
Control Getting help at home Handing over to others They wouldn't have a clue	Handing over to another person	Retaining control Effect on siblings Getting help	Getting help while retaining control
Expert Knowing	Knowing-Instinct	No sub theme	Just knowing

Selective Reading Approach 78 Initial Themes	Holistic Reading Approach 26 essential themes <i>(Selective reading initial themes collapsed and merged)</i>	Holistic Reading Approach <i>(sub themes developed as part of 26 essential themes)</i>	Holistic Reading Approach 20 essential themes <i>(26 essential themes further collapsed, renamed and merged to develop 20 overall essential themes - these also absorbed sub themes)</i>
Dentist Expiry date Learning Seeking advice Seeking information Unlicensed drugs	Learning about medicines and giving	Gathering information Getting advice	Learning about giving medicines
Collaborative decision making Decision making Public health nurse	Making decisions	Collaborative decision making Doctors making decisions Having a partner to help in decision making Independent or solo decision making Not being included in decision making Supported decision making	Decision-making
Effect on the child Side effects	Negative effect on child	No sub theme	Negative effect on child
Precision Preparing medicines	Preparing medicines	Being Precise Being prepared	Preparing medicines
Prescriptions	Prescriptions	No sub theme	Prescriptions
Being mammy Relationship with child Siblings	Relationship with child	No sub theme	Relationship/bond with the child
Relationship with GP	Relationship with GP	Frustration with GP Satisfaction with GP	Supportive and unsupportive relationships
Hospital relationships Staying in hospital	Relationship with hospital	No sub theme	Supportive and unsupportive relationships
Relationship with Pharmacist	Relationship with Pharmacist	Frustration with Pharmacist Satisfaction with Pharmacist	Supportive and unsupportive relationships
Sending medicines to respite Transition to adult services	Respite	Frustration with respite Satisfaction with respite	Supportive and unsupportive relationships
Sending medicines to school	School	Frustration with school Satisfaction with School	Supportive and unsupportive relationships
Time-consuming	Time consuming	You're talking about the day is gone	Time-consuming

Selective Reading Approach 78 Initial Themes	Holistic Reading Approach 26 essential themes <i>(Selective reading initial themes collapsed and merged)</i>	Holistic Reading Approach <i>(sub themes developed as part of 26 essential themes)</i>	Holistic Reading Approach 20 essential themes <i>(26 essential themes further collapsed, renamed and merged to develop 20 overall essential themes - these also absorbed sub themes)</i>
Travelling	Travelling	No sub theme	Physical space
		Alternative routes of administration Easier with different route	Effect on siblings (new essential theme – was a secondary node)

4.12.1.5 Writing – Describing the phenomenon in the art of writing and re-writing

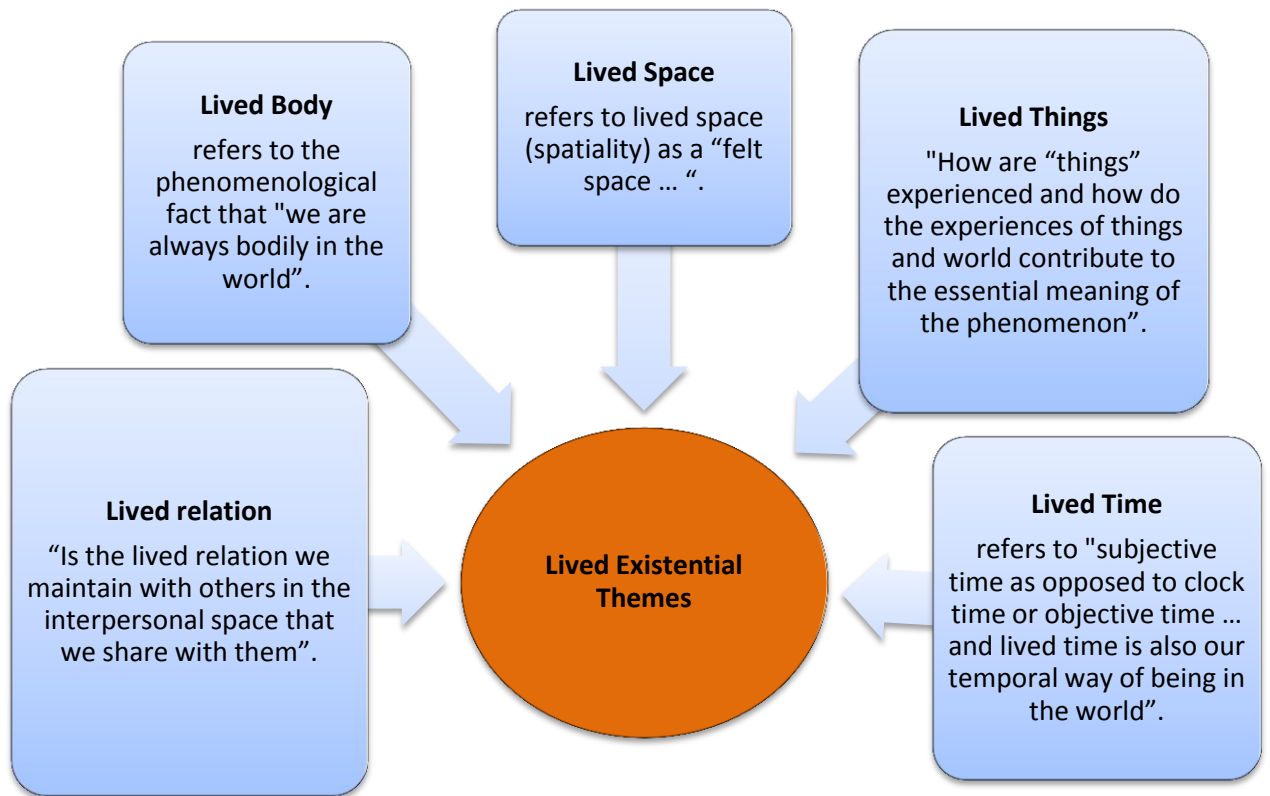
In analysing the data, I found writing aided my understanding and as I translated the participant experience into shared essential themes, I gained a clearer understanding of the phenomenon. Writing invited further reflection as I reflected on meaning and searched for the right words to describe and interpret the experience of these mothers. As the cycle of writing and re-writing continued during the research process, there was constant revising and refining of thought. Ideas that were formed during data collection and transcription became clarified during writing and re-writing and in reading and re-reading. Within this phase of the analytical process, I acknowledged my experience with the phenomenon, my insights gleaned from the interviews, listened to the interviews over and over and reread the transcripts. Constant questioning and reflection of the emerging themes allowed a deeper understanding of the lived experience. Finally, all the information was integrated into a cohesive and coherent text presented in the next chapter as findings. This *description of the phenomenon through the art of writing and rewriting* was essential as was *balancing the research context by considering the parts and whole*. I ensured that writing took place in conjunction with returning to the original transcript and reading the full text in order to ensure that what was being expressed was truly as the participant described it. Essential themes are presented in such a way that the most important elements are being expressed with themes adopted in order to structure the presentation of quotes and the findings text.

Van Manen (1990) advises that the task at hand is to hold onto the themes by capturing in statements their main thrust. In distinguishing what constitutes an essential theme, I referred to van Manen (2001, p. 107) and his explanation “in determining the universal or essential quality of a theme our concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is”. Therefore, I adopted the stance that if the phenomenon under review lost its fundamental meaning without a particular theme, it was then considered essential.

4.12.1.6 Adopting an existential approach - Describing the phenomenon in the art of writing and re-writing

Van Manen (1990) suggests alternative ways of structuring a study findings to include; thematically, analytically, exemplificatively, exegically or adopting your own approach. Van Manen (1990) also endorses an existential approach to presenting the findings, reflecting on the transcripts and seeking out the fundamental existential themes of which there are five. I decided to use the five existential dimensions common to all beings in everyday situations. My decision to adopt these existentials came about when I reflected on existence in the lifeworld and I deemed this important in presenting the findings of this work. These existentials guided my questioning, reflections and writing. Selective and holistic reading of the transcripts were undertaken using reflection to explore the fundamental lifeworld existentials. Van Manen (2014) has highlighted five fundamental existential themes which are present in all phenomenological human science research; ‘lived space’ (spatiality), ‘lived body’ (corporeality), ‘lived time’ (temporality), ‘lived human relation’ (relationality) and ‘live things’. These existentials can be used in seeking out meaning and I used these to frame the presentation of findings (Figure 1).

Figure 1: Lived Existential Themes (van Manen 2014, p. 302-310).



Before applying lifeworld existentials I needed to decide how to go about this process. Instead of taking each transcript and examining to see individual lifeworlds, I decided to take one lifeworld existential dimension and used it as a lens through which I would examine all essential themes I had identified within transcripts. This process allowed exploration for each lifeworld equally across transcripts. It was important that no hierarchy was adopted in applying the lifeworlds and was not based on size or order of importance (Rich *et al.* 2013). While existentials can be differentiated, they form what van Manen (1990) describes as an intricate unity or 'lived world'. This was what I defined as the last element of data analysis. Within this phase, I identified essential themes and sample quotes that fitted with each existential dimension (see Table 10). This assisted in framing the final portrayal of findings.

Table 10: Summary of essential themes linked to existentials and associated sample quotes

Holistic Reading Approach - 20 essential themes	Lived Existential Themes	Sample quotes (for context only)
Challenges in 'giving medicines'	Lived body	<i>"If I don't stir that medicine up enough, and he gets a bit of it, he'll stop eating it. Now it only happens... it rarely happens, but he'll stop eating it. So I don't know how much of it he's after getting. So I can't, even if it looks like he had none of the smoothie, I can't give him another one because I could be overdosing him in it."</i> (P5B)
Always "on call"	Lived time	<i>"I'd just love to have a sleep in".</i> (P10B)
Adapting "my life"	Lived time	<i>"We've gone out in an evening but we're always back, or we're back at eleven or twelve or whatever the time is, rather than an overnight."</i> (P15A)
Being organised	Lived time	<i>"X is on 17 meds daily and he's on them numerous times a day. So in the morning he's on 12 medications and a Flixotide inhaler as well, or a nebuliser if he's unwell. So, mornings, you want to be organised. So I draw up all my meds the night before. He goes to school at quarter to nine in the morning, so I need him to have his meds before he's going on the bus."</i> (P7A)
Cost of medicines or equipment	Lived things	<i>"it was also money driven, because the liquid is €16 for 100ml bottle and if she goes onto 40 four times a day, so you're talking 160ml a day at €16 for 100ml, and they're not on the medical card because it's a non-standard item."</i> (P2A)
Documentation and keeping a record	Lived things	<i>"it's just usually in me head. I've got a memo board now, but it's all usually in me head."</i> (P10A)
Feelings experienced by mothers	Lived space	<i>"My biggest worry is that he'd become reliant on it and he'll start waking for it. So I have a three night rule, where I'll give it to him three nights but then on the fourth night he's not getting it".</i> (P6A)
Associated equipment	Lived things	<i>"I had to go and explain it to the public health nurse, who didn't seem to comprehend what exactly was going on, which I personally find staggering."</i> (P7B) (referring to sourcing particular equipment)
Getting help while retaining control	Lived relation	<i>"people don't realise the amount of time it takes. Even my own family now. Some of them wouldn't have a clue. They're nearly all teachers. They're brilliant but they wouldn't have a clue what it's like, of what it's actually like to take twenty or twenty-five minutes at a time. "</i> (P10A)
Just knowing	Lived body	<i>"I think it was just life experience. You just get to know. We know him so well I suppose at this stage. We know exactly - I suppose we know him better than</i>

Holistic Reading Approach - 20 essential themes	Lived Existential Themes	Sample quotes (for context only)
		<i>we'd ever know our other kids."</i> (P10A)
Learning about giving medicines	Lived body	<i>"nobody said to me, "Do you know how to put in an NG tube?" Nobody said, "Have you any questions about administration of medicines via an NG tube?" Nobody has ever, ever, in 18 years asked me how I'm managing the administration of (child) medicines. Ever. You just get given a prescription and that's it".</i> (P2C)
Decision-making	Lived relation	<i>"So it's me, (nurse) and Dr. X, the consultant and the three of us, as a team, decide what next thing to do, even though X (consultant) is in charge and makes the decisions. He really has always listened to me."</i> (P2A)
Negative effect on child	Lived relation	<i>"when he wakes up in the night, or if he has discomfort whether it be from the stoma or whatever, he might be sleeping then, and you'd love to be able to let him sleep in peace and let him wake naturally."</i> (P10B)
Preparing medicines	Lived time	<i>"I crush the Vitamin D tablet; I'm thinking out loud here, the Kepra tablet. I've already put the 30ml of peppermint water and yoghurt, honey and her 5ml of Potassium Citrate into the bowl. I thicken them up and then I don't add the Vitamin D and the Kepra until just before I feed her. And I don't know why I do that. I just have this idea that I don't want the Kepra interacting with other stuff for the 20 minutes it takes me to get her up. It's probably stupid, but that's what I do. So I have it mostly ready and thickened - but only thickened slightly - otherwise, by the time I have her up it will be rock solid. And I'll have to loosen it and then it's a bigger volume."</i> (P2A)
Prescriptions	Lived things	<i>"Prescriptions are probably the bane of all our lives".</i> (P7A)
Relationship/bond with the child	Lived relation	<i>X (child) spent the first few years in hospital, in and out of ICU. I saw him at death's door. I don't want to him to ever feel sick. So if I can do anything to make him feel a bit better then I will do it.</i> (P7A)
Supportive and unsupportive relationships	Lived relation	<i>"My GP is really only for getting scripts...." I'd phone her secretary first, so I would. Yeah, but she knows us very well over the years. She'd pass on the message straight away. I might be waiting a few days for her to get back to me, but you know, that's fine. She's very busy, you know?" "They'd be very approachable, and they'd know us so well now at this stage".</i> (P12A)
Time-consuming	Lived time	<i>"And to acknowledge the time-consuming, that people</i>

Holistic Reading Approach - 20 essential themes	Lived Existential Themes	Sample quotes (for context only)
		<i>don't realise the amount of time it takes. Even my own family now. Some of them wouldn't have a clue.” (P10B)</i>
Physical space	Lived space	<i>“if you're away for a few days then that's a different ball game. You would obviously be bringing... the lunch box comes with us, with all the bits and pieces and obviously a big block of syringes as well”. (P15A)</i>
Effect on siblings	Lived relation	<i>(Daughter) is five, has often commented on it...“can I help you Mammy?” ...because (child) was here when she was born I suppose she knows no better, she's after growing up with that, this is life for her... like, if I was in the bedroom and (child) was having a seizure she'll call me “Mammy, (child) having a seizure. (P1A)</i>

4.12.2 Summary of Data Analysis

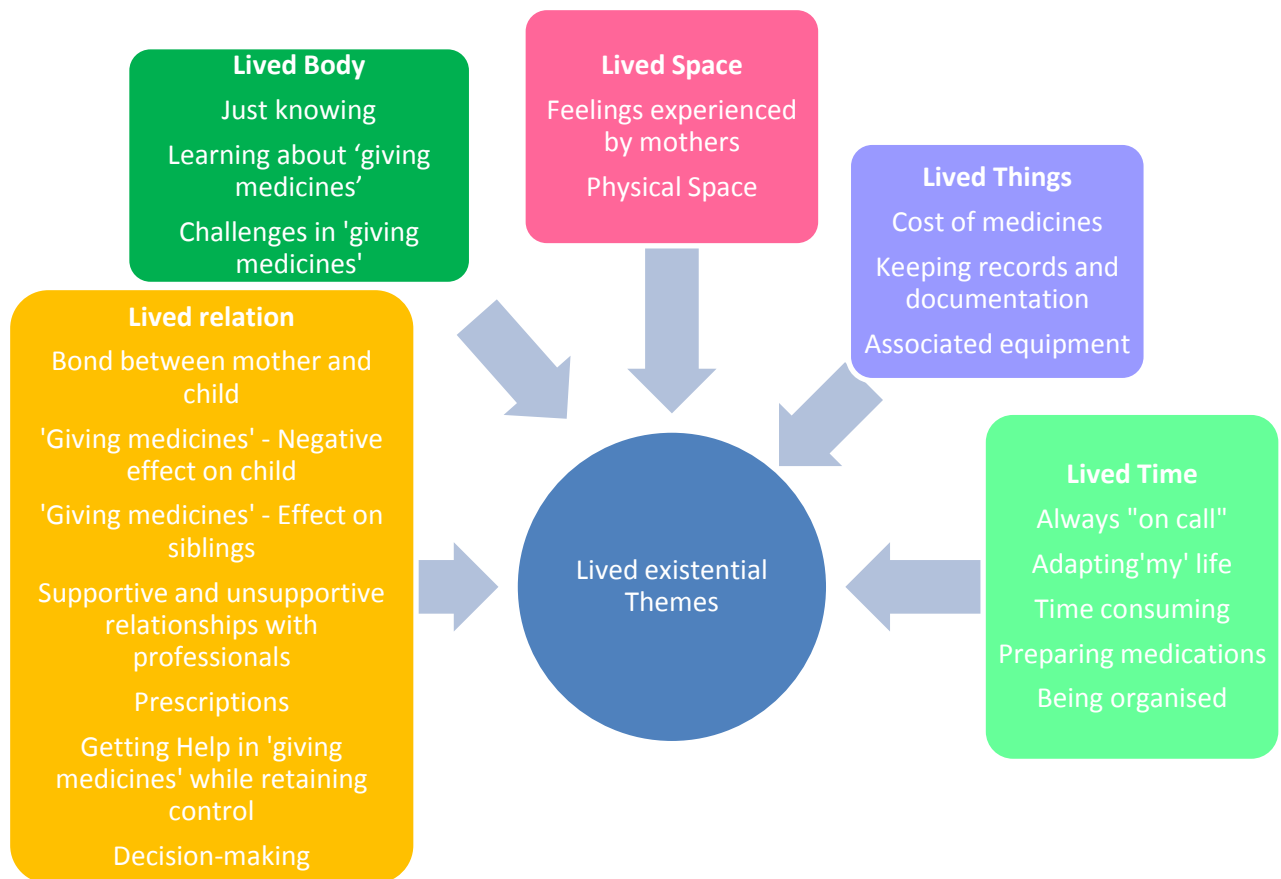
Throughout the data analysis process, feelings that were roused in me were documented and provided an audit trail to allow me revisit where I was and where I planned to go, keeping me oriented at all times. Frequent contact with my supervisor and colleagues in order to reflect on the research process was essential to maintain concentration on the project at hand and to ensure my writing was strong, well oriented, rich and deep. *Maintaining a strong and oriented pedagogical relation to the phenomenon* and revisiting the research question was of paramount importance at this stage. Having entered into ongoing relationships with the participants through multiple interviews, this allowed for frequent contact with people who clearly met the inclusion criteria and they kept my interest very much 'alive'. For me, this motivation meant my interest did not falter along the way. In addition, Koch (2006) recommends the inclusion of evidence of decisions made, otherwise known as a 'decision trail'. I have included evidence of decisions made in the material presented in this section as part of data analysis. This evidence of decisions made is important in confirming how I undertook preliminary analysis and identification of themes to how I identified the final essential themes.

Balancing the research context by considering parts and whole was important. Although analysis began following the initial interview and continued thereafter, the 'parts'

reflection allowed these stories to be gathered together as a 'whole'. The hermeneutic circle was evident throughout the phases with no beginning or end or top or bottom evident in this circular process. Reading and rereading the transcripts, considering one's understanding of the whole, writing about the phenomenon, scrutinising the parts again, writing some more before once again considering one's position, was a process that continued throughout the production of this thesis. The adoption of both a selective and holistic reading approach allowed for achievement of a balanced view of the transcript resulting in a reading of both the whole and the parts. I was constantly aware of the interplay between the parts and whole textual composition.

I was especially attentive when writing my findings and took a step back and looked at the whole so as not have missed any parts. In the end, the whole that was identified was determined by me as the researcher and author of the thesis. However, I attempted to demonstrate how mothers' lived experience showed itself in each interview. Aspects or qualities of a phenomenon were written and interpreted as essential themes and the findings were presented across all interviews as a whole by overarching essential themes. In adopting van Manen's lifeworld existentials for the presentation of findings, the final thesis sees findings presented as reflected in Figure 2. Together, all themes represent the participants' unique experience of 'giving medicines' to their child with severe and profound intellectual disabilities.

Figure 2: Lived existential dimensions with themes identified



4.13 Ethical considerations

The key principles of good ethical practice are consistently stated within research literature and various codes, frameworks and guidelines have been produced. Bryman (2012) notes that the main elements in ethical discussion have not changed over the last few decades but suggests that the ethical issues have become more central to the discussion on research methods of a particular study. Ethical principles are used as a framework to guide the researcher through the research process ensuring the highest possible standard in every aspect of the research. Any research that involves human subjects as sources of data has ethical implications. The researcher has an obligation to ensure that the appropriate body sanctions the research and ensure that the rights of the participant are protected at all times (Gray *et al.* 2017a). The researcher should be aware of ethical policies and procedures in their area of practice (Gerrish & Lacey 2012).

In this instance, ethical approval was received for all sites both through the SNMREC and each individual site. Three of the sites required completion of their own individual ethical applications while the remaining three sites required confirmation of ethical approval from the SNMREC. For the purpose of this study, I adhered to the ethical principles outlined by the NMBI (2015); respect for persons/autonomy, beneficence and non-maleficence, justice, veracity, fidelity and confidentiality.

4.13.1 Respect for persons/autonomy

This right implies that as a human being the participant is treated autonomously and has the right to self-determination (Gerrish & Lacey 2012). The participant has the right to choose whether to participate in the study and their choice will be free from coercion (LoBiondo-Wood & Haber 2014). This right also allows the participant to withdraw from the study without penalties (Gray *et al.* 2017a). Another requirement of autonomy is the provision of adequate information about the study (Gray *et al.* 2017a). When recruiting, I enclosed a participant information leaflet, which provided information on all aspects of the study. It provided detail on the purpose of the study and the proposed procedures for data collection, what was required of them if they participated and their rights. I ensured that the information provided was sufficient for the participant to make an informed decision. The participant information leaflet had to maintain the guidelines provided by the ethics committees and was written in plain language in a user friendly style without jargon. Careful consideration was given to ensure the information could be read and understood in line with the National Adult Literacy Agency guidelines. Therefore, an expert panel of four people reviewed the information pack for clarity, jargon and content. Information was further outlined after participants expressed an interest in participation and was undertaken by telephone in all instances. It was important for me that prior to committing to data collection the participant comprehended what was required of them and what participation entailed.

All participants had my mobile phone number throughout the study and if they required any further information they were able to contact me at the number or email address supplied. The participant could speak freely at all times and they were in control of the conversation. They understood that if at any stage they felt uncomfortable they could

pause or stop the interview and withdraw without explanation. All of this detail was outlined within the informed consent form and indicated in more detail within the participant information leaflet. Before each interview and handing over the diary, participants were fully informed of their rights as illustrated in the informed consent form. Although clearly indicated in the information leaflet, I was conscious that some participants may feel they had to participate or the support they received by the organisation may be jeopardised. Therefore, I reassured each participant that there would be no negative consequences from their participation in the study and that I was not an employee of their support organisation.

Throughout the study, I had to determine the extent to which I would make an effort to contact participants. For example, on completion of the first interview I followed up with a phone call to make arrangements for a second interview after a 10-12 week period had lapsed. In some instances, the phone was left unanswered and no messaging service was available. However, usually the participant would return the call. In one instance, I was unsure if the unanswered phone was indicative of a withdrawal from the study. On discussion with my supervisor it was agreed that I would make one more attempt to contact the participant after which I would withdraw further efforts. Over the course of the study, one participant who participated in a first interview, did not return my call and no second or further interviews were scheduled with that individual.

4.13.2 Beneficence and non-maleficence

The principles of non-maleficence and beneficence are based on the right to protection from harm and discomfort. Non-maleficence means that an individual should not intend or permit harm to another person (LoBiondo-Wood & Haber 2014). Therefore, research that can result in direct harm to subjects should not be undertaken. Beneficence suggests that an individual should act to prevent or remove harm to another person (Gray *et al.* 2017a). In research, harm and discomfort can be physical, social, emotional and economic (Gray *et al.* 2017a). It is the role of an ethics committee to ensure that participants are protected from harm. In this study, it was a requirement that ethical approval be sought from the SNMREC and the proposed research sites. This proved to be a turning point for me in terms of refining the study and gaining clarity on critical

scientific and ethical issues. I applied to the first site and after some minor adjustments to the form, ethical approval to proceed with the study was granted. As this site adopts a standardised research ethics form recognised by Trinity College and underwent a rigorous ethical approval system, I then submitted this form to the chairperson of the SNMREC for chairperson approval. Permission to proceed with ethical approval was granted from the chairperson of the committee. My second and third proposed sites adopted a different ethics form and therefore a separate application was made to those committees with approval being granted. The remaining three sites recognised ethical approval from the base University and therefore only required a copy of ethical approval granted from the Chairperson of the SNMREC.

4.13.3 Justice

This right stems directly from the ethical principle of the right to fair treatment. This principle highlights that people should be treated fairly (Parahoo 2014). One area in which violation of this principle could occur is in the sample selection (Parahoo 2014). Participants should be selected in order to fulfil the criteria in a study and not because of easy availability, manipulability or friendship with the researcher (LoBiondo-Wood & Haber 2014). To eliminate such injustice, participants for this study were selected using purposive sampling. A gatekeeper was appointed, as appropriate at the organisations and they were briefed on the study details and requirements of the sample. They were then provided with the information packs for distribution. I had no knowledge of who the packs were administered to unless they made contact with me expressing an interest in partaking in the study.

4.13.4 Veracity

Veracity involves the concepts of truth and absence of deception (NMBI 2015). Participants have the right to be told the truth and not deceived about any aspect of the research study. I strived to maintain an open and honest relationship with participants from the outset. This was achieved from the beginning by disclosing all relevant information to the participant about the study and their involvement. The importance of trust and openness cannot be underestimated and the participant must feel safe (Curtis & Drennan 2013).

4.13.5 Fidelity

Fidelity has trust at its core and in general requires the researcher to ensure that all actions are in good faith, agreements are fulfilled and promises kept. This concept is closely aligned to that of justice also. It necessitates a commitment by the researcher to ensure the participant is protected and has an understanding of the risks involved in participation allowing them to make an informed choice (NMBI 2015). Gaining informed consent was of paramount importance to the researcher. Initial consent was obtained in written form and two copies were signed by all participants with one being held by me and one being held by the participant. While, on their own they do not constitute informed consent, the forms provided documentary evidence that consent was given. The informed consent form included the title of the study and reiterated the voluntary nature of participation and the individual's right to withdraw at any time. Participants were also given the chance to ask and have their questions answered prior to commencement of data collection. While it is essential to plan and ensure the participant is well informed it is difficult to plan for what may be unearthed in an interview. Therefore, process consent was an integral part of the data collection process. While initial written consent was achieved prior to each interview, verbal and written consent was renegotiated at every stage of participant involvement. Continuous dialogue and reaffirmation was required throughout.

4.13.6 Confidentiality

This right allows the participant to determine the extent and circumstances under which private information is shared with others and concerns privacy and anonymity also (NMBI 2015). A person's attitude, beliefs, opinions and records are all regarded as private information. When private information is disclosed without individual's consent an invasion of privacy is said to have occurred (Curtis & Drennan 2013). By participating in this study and completing the informed consent form (Appendix 11) the participant agreed to share the information from both the interview and diary records with me. Furthermore, action had to be undertaken to ensure the identity of the participant was concealed and all data was securely stored and only accessible by relevant persons. As this was a qualitative study complete anonymity could not be assured as the participants were known to me. Therefore, it was imperative that outside of the research

relationship the participant identity remained unknown. I adopted a recruitment process whereby participants' involvement in the study was only known by them and me. However, one organisation involved in recruitment required the names of participants to be submitted to the research data officer on completion of the study. This was to ensure that participants were not recruited for additional studies in the following five year period. This was included within the consent form for that site (Appendix 17) and participants reminded, before participation in the study was agreed.

Identifying characteristics were removed from transcripts and each participant was assigned a code when being submitted to the transcriber and also identified using a pseudonym for the purpose of reporting the findings. Given the diversity of geographical locations and the chance that identification could occur, I also removed references to named places and hospitals. Additionally, names of staff, family and friends were removed. Rare or unusual characteristics or contexts peculiar to the individual were also removed as were biographical details that may contribute to identification of the individual.

In addition, the digital audio recorder and transcripts were stored in a locked cabinet within my work office, where I was the only one with access. The informed consent forms, names and addresses of the participants and diaries were stored in a separate locked cabinet in the same office. Computer held records of transcripts and data analysis were held in a secure file that was password protected and stored in accordance with the Data Protection (Amendment) Act (GOI 2003). These strategies were detailed in the participant information leaflet and discussed with participants prior to commencement of data collection. A professional transcription company was used to transcribe the digital interview recordings. The company used was compliant and registered with the data commissioner. A non-disclosure agreement was signed prior to commencement of transcription.

4.14 Integrity of the Study - Quality and Rigour

Quality and rigour are the words adopted in phenomenological method design. As phenomenology does not draw on numerical data, it is often considered a “soft science” (Mills & Birks 2014). Quality of research is imperative and I endeavoured to ensure that authentic reflections of mothers’ experiences of ‘giving medicines’ to children with severe and profound intellectual disabilities were portrayed. Rigour signifies the measures the researcher took to confirm guidelines were accurately followed and that conflicting factors were removed to permit dependable and trustworthy conclusions (Gerrish & Lacey 2012). However, there is no consensus in the literature on the best way to ensure rigour in qualitative research (Koch 2006, Whitemore *et al.* 2001, Polit & Beck 2017, Pereira 2012). The need for structure to be in place to address the merit of a qualitative approach in research is well documented and it is claimed that a study is credible when it presents authentic descriptions that those who experience the phenomenon can recognise (Lincoln & Guba 1985). If a reader can evaluate a study through reviewing an audit trail then trustworthiness or rigour can be established (Koch 2006). Validity of interpretation in qualitative research is contingent upon the end product demonstrating how interpretation has been reached (Mason 2018). Van Manen (1990) asserts that rigour in a research study comes from being able to illustrate the connections between philosophical framework and findings as an interpretive process. De Witt & Ploeg (2006) concede that one set of criteria may not suit all types of qualitative research and that diversity exists. In this instance, I chose to adopt the framework proposed by de Witt and Ploeg (2006) who developed a “framework of expressions” (p. 227) for establishing rigour in relation to interpretive phenomenology. These expressions of rigour are balanced integration, openness, concreteness, resonance and actualisation and are further explained within Table 11.

**Table 11: Criteria for the Integrity of this Study
(De Witt and Ploeg 2006, Gerrish & Lacey 2012)**

Criteria for the Integrity of this Study	
Balanced Integration	Congruence between the philosophy, subject matter and the researcher. Balance between the philosophical integration and voice of participants.
Openness	Opening the study to scrutiny. Accountability. Orientation the phenomenon.
Concreteness	Usefulness of study findings for practice.
Resonance	Richness and the felt effect of study findings upon the reader.
Actualisation	Potential or future realisation of the study findings.

Complex language is often associated with phenomenology and through adopting practical expressions of rigour as opposed to philosophical language; it enables the application of a framework in an understandable manner (de Witt & Ploeg 2006). The information provided about the research process and the way in which the findings are portrayed and presented in this thesis form the basis for supporting the integrity of this study.

4.14.1 Balanced Integration

It is suggested that in qualitative studies where thematic analysis is adopted, all procedures that are employed to generate findings must be dependable, reliable and trustworthy (Polit & Beck 2017). The characteristics of balanced integration are necessary to address the misinterpretation or superficial inclusion of philosophy and in this instance was achieved through ensuring van Manen's (1990) tenets were considered and incorporated into every stage of the study. Ensuring prolonged engagement with participants and undertaking multiple interviews as advocated by van Manen (1990) assisted this process. The exploration of the adopted philosophical framework in Chapter Three demonstrated my understanding and an account of how this was applied in the methods in Chapter Four was also important.

A personal reflective journal was used in this study to capture interactions and reactions to maintain self-awareness as the study proceeded. Consulting participants to ensure interpretations reflect intent is critical. Bradbury-Jones *et al.* (2011) recognise

participant feedback as an important facet of phenomenology while van Manen (1990) clearly appreciates that once themes start to emerge, they can become objects of reflection in follow-up hermeneutic conversations between the researcher and participants. At each interview I found I was taking back my early identified themes to participants and they would concur with draft descriptions of the essential themes. This process was imperative as I knew my themes were valid in a sense when participants gave them the phenomenological nod of acceptance. It also reassured me that I as researcher was not wholly reliant on my knowledge but had taken cognisance of the participant especially throughout data analysis. The guidance of my research supervisor also reassured me in identifying relevant essential themes. I was confident that the themes fit with the phenomenon under investigation. All themes were deemed credible, an important facet of rigour (Koch 2006, Ritchie *et al.* 2014) and representative of participants' lived experience of 'giving medicines' with a joint construction of interpretations evident. In presenting the findings, I ensured that the philosophical concepts used in the study methods and findings were sufficiently intertwined. A harmony between themes and verbatim excerpts was upheld throughout, through ensuring all themes were supported by relevant quotes and excerpts.

4.14.2 Openness

Being transparent about the research process is imperative in all research studies (Mills & Birks 2014). I have achieved this in outlining the research process adopted and the various steps in Chapter Four. Openness is crucial regarding the purpose of the research, the orientation toward the phenomenon of inquiry and is required to be sustained by the researcher throughout the research process. It requires a systematic accounting for decisions and ensures evidence if the study is scrutinised by others. Consistency of the data is ensured when another researcher can follow the decision trail in the study and interpret the data in a similar manner, the interpretation does not have to be exact but it should not be contradictory (Sandelowski 1995). Building a path for other researchers and readers to follow, allows for the discussion of the theoretical, methodological and analytic choices through the course of the study. I ensured I maintained an audit trail and this enabled me review the development of data from start to finish, thus decreasing the chance of inaccuracies existing (Giacomini & Cook 2000). Furthermore,

transparency of the findings was promoted through supporting essential themes with participant quotes and excerpts. This was accomplished by completing a written audit trail throughout the research process and keeping a reflexive journal.

4.14.3 Concreteness

Concreteness is described by van Manen (1997) as 'lived throughness' in that the reader of the text is able to associate a phenomenon in the frame of reference of everyday life. Concreteness is demonstrated through the study design and its strong orientation to the phenomenon. During the writing and rewriting phase I ensured concreteness by associating themes in terms of possible experiences in the reader's own life. It was also important to develop key implications for practice arising from this study and recognise any study limitations, which are outlined in Chapter Seven.

4.14.4 Resonance

This expression refers to the experiential effect of perusing the findings upon the reader (van Manen 1997). The reader should be able to transfer the information gleaned from the study and find it meaningful and applicable to their own experience and it should resonate with them. I tried to ensure resonance was achieved by writing in a way that the experiences of the participants may correspond with experiences from the readers own life. Resonance is evident during analysis of the findings and the use of thick description in the presentation of such findings. In analysing the data gathered, key recommendations have been developed and dissemination of these will be important in ensuring this study is viewed in the context of the field of children with severe and profound intellectual disabilities. It is also essential that findings can be understood outside the context of the current study. This was evident in conference presentations already undertaken in presenting some of the key findings.

4.14.5 Actualisation

The final expression of rigour pertains to the future realisation of the resonance of study findings. De Witt & Ploeg (2006) recognise that a phenomenological interpretation does not end when a study is finished. Actualisation means that study findings will not only be

presented by the researcher but will be interpreted further by future readers of the research findings. In presenting the findings, opportunities for interpretation will be suggested through the implications of the findings. Within this study the generative possibilities begin with discussion of the findings and interpretations presented. The resultant implications for practice present the potential of this study. While actualisation is the final outcome criterion referring to the generative nature of the study it is difficult to record actualisation. However, I have presented the findings at peer reviewed conferences and these have been well received yielding further interest in the subject area.

4.15 Conclusion

This chapter has focused upon the methods and procedures utilised to gather data. It has provided justification for this qualitative study in which a hermeneutic phenomenological design was chosen informed by the work of van Manen (1990). Rationale for the choice of data collection methods has been exhibited. It has also shown how the research was conducted and the ethical guidelines that were adhered to. The research process and data analysis framework was displayed and justified with van Manen's (1990) six guidelines adopted and interpretation evident. The integrity of the study was also presented. The following chapter provides details of the findings elicited through using the aforementioned methodology and clearly indicates the findings arising from the data analysis process adopted.

Chapter 5 – Presentation of Findings

5.1 Introduction

In Chapter Four the research method adopted in this study was presented. The purpose of the research method was to elucidate a deeper understanding of mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities. This chapter is concerned with the received data and its analysis and interpretation. Using the method of analysis outlined in Chapter Four, section 4.12, this chapter presents key findings from the research study. For the presentation of findings, the views of all participants are integrated whether data were gathered via interview or diaries. Where possible, direct quotations are used to reinforce the issues under consideration. It provides an outline and interpretation of the findings elicited from the study, embodies the experience of mothers and will include: the pertinent characteristics of the participants, associated demographics, participants' stories and presentation of essential themes aligned to existential dimensions.

For the participants' comfort they chose the interview venues and I travelled to meet with them. Nine participants were interviewed in the home and in 7 of these interviews the child was present in the house when the interview took place. I also met 2 of the participant husbands and chatted with them but both absented themselves when interviews were taking place. Six participants were interviewed at locations of their choice, a hotel lobby or a coffee shop near where they lived. Three of these 6 participants rarely left the home and welcomed the opportunity to get out of the house for a while.

5.2 Demographic Data

Demographic data was gathered as part of the data collection process in order that the research be placed in the particular context it was gathered. This data encompassed information about the participant and their children as this was deemed relevant for the study and was an important component of setting the context. The sample included 15 mothers of children with severe and profound intellectual disabilities. Ten participants lived in urban areas and five in rural areas. Six of the mothers worked outside of the

home either on a full or part-time basis. Thirteen mothers were married while two were single mothers. The children ranged in age from 2 to 17 years old, 10 were males and 5 were females with 9 experiencing profound intellectual disabilities, 5 severe intellectual disabilities and 1 severe to profound intellectual disabilities. Various causes of intellectual disability were identified across the sample. The number of medications each child was prescribed was between 5 and 17 with anything from 6 to 33 drug administrations, primarily undertaken by mothers on a daily basis. Children were prescribed many medicines with the most commonly prescribed medicine an AED, with 16 branded medicines prescribed for seizure management. Additionally, a benzodiazepine and sedative were also given for seizure management. Furthermore, 5 branded benzodiazepines were used in total for the purpose of sedation. Four antibiotics were prescribed while other prescriptions were varied with children prescribed a diversity of medicines. Ten supplements were prescribed to the children in this study. A variety of formulations were prescribed including; solid form, liquid, nebulised, halved tablets, patches, rectal, buccal, topical preparations and nutritional supplements. Mothers had been caring for their child from birth to their current age, up to 17 years in 3 cases. A more detailed participant profile is presented in Appendix 18 which offers some insight into the lives of these individuals and helps contextualise this research study. Table 12 provides a summary of the participants' children. Medication brand names instead of generic names were often cited by participants. However, a more detailed list of medications adopting both generic and brand names, where relevant are provided in Appendix 19.

Table 12: Summary of Participants' Children with Severe and Profound Intellectual Disabilities

Participant number	Mothers' name	Child name	Child gender	Age	Diagnosis	Degree of Disability	Number of Medicines Prescribed	Route of admin
1	Catherine	Aaron	M	13	Global developmental delay	Profound	9	PEG Buccal Neb
2	Gillian	Ava	F	17	1P36 Deletion syndrome.	Severe to Profound	16	Oral Buccal Rectal Neb

Participant number	Mothers' name	Child name	Child gender	Age	Diagnosis	Degree of Disability	Number of Medicines Prescribed	Route of admin
3	Olivia	Marie	F	4	Ponto Cerebellar Hypoplasia with cask	Profound	11	Oral Buccal Neb PEG
4	Jane	Barry	M	14	Global developmental delay lissencephaly and pachygyria	Profound	8	Buccal PEG
5	June	Robbie	M	13	Down Syndrome and Autism	Severe	9	Oral Injection
6	Grace	Eoin	M	10	Chromosome disorder 29 (24.2-31 deletion).	Profound	11	PEGJ Rectal
7	Liz	Jake	M	10	Down Syndrome and Chronic infantile neuro cutaneous articular syndrome (CINCA)	Profound	17	Neb Injection PEG
8	Anna	Tom	M	5	Anoxia at birth resulting cerebral palsy, quadriplegia and epilepsy	Profound	17	JEJ Rectal Buccal Neb
9	Martha	Max	M	16	Autism	Severe	6	Oral Injection
10	Pam	John	M	17	Deletion of the long arm of chromosome 5	Profound	6	Oral Buccal Neb
11	Mags	Sophie	F	9	Brain haemorrhage resulting in complex difficulties	Severe	5	Oral Injection
12	Sadie	Todd	M	11	Lissencephaly	Profound	6	Oral Buccal
13	Helen	Shay	M	17	Down syndrome and Autism	Severe	6	Oral
14	Lynn	Emma	F	14	Quadriplegic cerebral palsy	Profound	13	PEG Absorption
15	Siobhan	Niamh	F	2	Pyrovate Dehydrogenase Deficiency (PDH)	Severe	7	Oral Rectal PEG Neb

5.3 An Illustration of experience

In order to position the findings of this study, a profile of one participant and her child is provided to illustrate the contextual features of experiencing 'giving medicines'. All names adopted in the presentation of findings are pseudonyms and bear no resemblance to real names of participants or their children. Pseudonyms are directly linked to the participant profiles presented in Appendix 18. Any locations cited have been anonymised also. Before presenting an excerpt of one interview, in an attempt to set the context of this study, a description of the participant and her child is offered. Furthermore, Appendix 20 addresses a brief reflection setting the scene for a first interview that I undertook with this particular mother. This excerpt presented below best demonstrates key themes relevant to this research study and are elaborated on at a later stage.

5.3.1 Participant Profile (P8) - Anna and Tom

Tom is a 5 year old boy who experienced anoxia at birth resulting in development of a profound intellectual disability with associated cerebral palsy, quadriplegia and epilepsy. He is oxygen dependent and contracts pneumonia regularly. He is also Jejunal fed with no suck, swallow or gag reflex and requires suctioning frequently throughout the day. Tom is incontinent and immobile requiring 24 hour care for his daily activities of living. Anna is a stay at home mother who cares for Tom on a continuous basis. She also has a 2 year old boy and her husband goes out to work Monday to Friday. Tom attends a special school, but as he needs full nursing care and the school can only provide this 2 days per week he only attends for 2 mornings when his health status is stable. He receives respite care for 3 nights every 7 weeks and also requires a nurse at night time from 11pm-7am. Tom is prescribed 17 medications, requiring 13 daily and 4 PRN medications depending on his health status. He has a total of 33 drug administrations per day (not including PRN medications) using a variety of routes of administration; jejunal, rectal, buccal and nebulised. Many of these drugs are modified for administration requiring crushing, halving, mixing or further measurement. Tom takes a number of anti-epileptic medications to include; Topomax, Kepra, Epilim, Frisium, Diazepam, Stesolid and Midazolam and a range of other medications; Glycopyrolate (for secretions), Baclofen

(for muscle relaxation), Zantac (for gastro-oesophageal reflux), Zoton (for gastro-oesophageal reflux), Melatonin (for sleep), Zithromax (antibiotic for prophylaxis), Salbutamol (for bronchodilation – eases breathing pattern for Tom) and saline nebs (for clearing airway). Tom and his mother Anna have a clear bond and he responds to her voice, often with a smile.

5.3.2 Excerpt - A Day in the Life of Anna and Tom (Participant 8)

It's busy. Now, I have a nurse at night time so I take over in the morning. So, from seven o'clock on he gets medicines. It seems like round the clock to be honest. So, at seven o'clock he'll get Glycopyrolate for his secretions and then he has a bit of a break when he comes off his feed. He could break from his feed for about two hours. Then he could get his bath and his physio at that time and then at nine o'clock it kicks off again. He gets two or three medicines at nine o'clock and then at ten o'clock he's back on his feed. Then he has a bit of a break. The feed goes continuously and then he's on medicines then again at twelve o'clock. Two medicines at twelve. Then he'll have nebs then as well at that time. The Salbutamol and a saline neb at twelve. That brings us up to lunchtime. At two o'clock he'll get another medicine. Then he's finished his feed at three o'clock; he's on a break. So at that stage he's taken off his feed and he has Zoton, liquid Zoton for his tummy. Then he gets a break for himself and myself, which is about two hours. It goes quick enough. He then starts again at five o'clock - three other medicines.

I suppose I'm a bit like clockwork now. The medicines he needs, he gets. You just have to keep a clear head on you for doing them up. We do have a little bit of a system but I have a two and a half year old as well. So in between him pulling out of you, and I guess then Tom- if he's a bit more unwell, he might need more medicines, or if he's needing a lot of suction...some hours can very busy. But we have a cupboard designed here behind me for all the medicines. We keep them all locked away from the little lad. It's busy, and between getting them and just keeping stock of the medicines, stocking up the cupboard and going to the chemist on a daily basis.

He was five months when he first came home, so they would have brought us into their medicine room and I think initially they would have drawn them up and then they'd give

them and then they'd show us how to give them. When it came to the stage of him going home they brought us into the medicine room and we prepared the medicines and then gave it to him. I suppose that was all very well, but when it came to his first night at home, I can still remember it and the next day. I felt like I'd stepped into a pharmacy and it was all so new to us. So like - lining everything up and making sure, and checking his chart and then checking again. It was a really slow process. Now, we're just a little bit like clockwork. As busy as it is, - I mean you still have to remind yourself to look. There's times where one medicine seems to run into the next. But in the beginning it was quite daunting. I wouldn't say it wasn't. One of my nurses described me as being a bit kind of shell-shocked by the whole thing. It was...for any parent going through that in the beginning. It's overwhelming really, because you know you've got to mind your child, do all the nursing and then along with giving him the medicines and making sure you're giving them at the right time, because he's getting so many, to try and space them out because he was peg fed initially and he just didn't tolerate feeding and medicines that way. So, we have his Jej instead...

We've got our GP, but the GP will always refer us to the hospital. In the hospital you're not always going to get your consultant onto the phone, or the team. So we are linked into the palliative care team and, while they're good, there's times where I can't really sit on a phone to be honest. Even at that, I mightn't even get an answer, so there's lot of times where you're taking matters into your own hands and you would love somebody a little bit more of a link like that. That when you're in it, you feel there's times where you're a bit isolated. If only you had somebody who could just help you out. Sometimes when you're in the hospital and they put the ball back in your court, while it's all very well, sometimes you want someone just to kind of guide you and just tell you to do this, try that.

We have a pharmacist in (location) that we use and (pharmacist) there is fantastic. They're very helpful. We're lucky like that. They link with his GP for prescriptions and then the GP needs to link with the hospital just to find out. But yeah, they know us as well as a family now at this stage. I'm in the pharmacy, sometimes it feels like every second day. If Tom goes to school people would say, "Well, you've got three hours." But it's never really

like that to be honest because it's ring the pharmacy. Go up and collect his medicines and then go to the medical centre and collect the syringes or the other supplies that he needs. So yeah, I don't even have to say who I am on the end of the phone. They know my voice.

An odd time. You know, people will say, "Oh take time out for yourself. "Or I'll say, "I won't ring the chemist today" and they're the days that just hit you in the face. "Why didn't I ring?" I mean (pharmacist) is very good, the lady who owns the pharmacy. I have her mobile number. She's given it to me. Christmas is always the difficult one because all the suppliers are telling us, "Oh, check what you have and make sure you've got well enough to keep a stock in." But because even though I know what his medicines are well, sometimes they change. The doses will change quite a bit, frequently as well, depending on his seizures and visits to the hospital and how well he is. So you're keeping an eye on that as well and an odd medicine can slip through the list. I can be out and think, "God, I need to get this and that." The chemists are usually pretty good but there's been times where you'd need to ring the hospital ...well you kind of learn as you go. It's hard to know sometimes with Tom what side effects there is, because obviously he doesn't communicate. So sometimes it's hard to know. They might say to me, "How would you think if we increase?"

I guess just if there was somebody we could call on for giving medicines. Somebody more specific really, that was at the end of a phone and could - I definitely think for families coming home initially with a child, with a young baby like Tom you need somebody specifically in the house. Like it's a massive undertaking. When I look back now I don't know how we did get through it. To kind of sort the family out, to set up a little mini pharmacy in your home and to how you're going to manage and how you're going to do it and just to instill confidence in you to do it. Because if we go anywhere it's always, "Ok, what's he due now? Do we give the medicine now? Do we pack it up after?" You know, you're constantly thinking about that, so I think just a little bit more back-up, to have somebody at the end of a phone. And even now, when you are used to giving him medicines, but then there is always that, "What if we can't get something? What are we doing that's right? Do we need to change this? Does he need more of this, less of this?"

You know, there's always questions from one end of the week to the next, that it would be helpful to have somebody...

But that's it when you have a child like Tom, and my two and a half year old - nothing wrong with him. And you can stand at a school door waiting to collect him and talk to other mothers about "What did you do? Do you do this?" You can get loads of practical advice. But when you've somebody like Tom and you're in the home, you're not in the hospital and then obviously you want to bring them home because it's a better quality of life for him - that is the one thing that you're really stuck for. Trying to find the time to get on the phone and when you are on the phone you're either onto an answering machine or somebody can't give you a direct answer. So it would be great to have more of a link with really.

Nobody really told us to do it... But from being in (hospital) and seeing what they did - initially they actually gave us some copies of their daily sheets and then with carers in the beginning, they couldn't give the medicines so we used to do them. Then the agency used to have a report that you'd fill in on his nightly care. You'd tick the medicines but it was nearly seven pages long, what you'd do. So by chance we came across this monthly chart, so you've got all the medicines for the month in one chart, and we just initial as we'd give it. Now, it can change from one month to the next - his doses and what he's on and extra medicines can be added in, but we allow for that. It's just a safety net to be honest.

...well my husband is great at doing all that. He'll update it and print it off once a month for us. Then usually every month there's an update on that too. Then that's not to say if he's had a hospital admission or a visit a week into the monthly chart, then we could be writing over it and changing it. From one month to the next you just don't know what changes are going to arise.

With Tom there can be a lot of paperwork and there's a lot of notes and visits to the hospital, so sometimes I feel like I need a secretary as well to keep up with all this. But this medicine chart is just one page for one month. So you get to the end of the year and

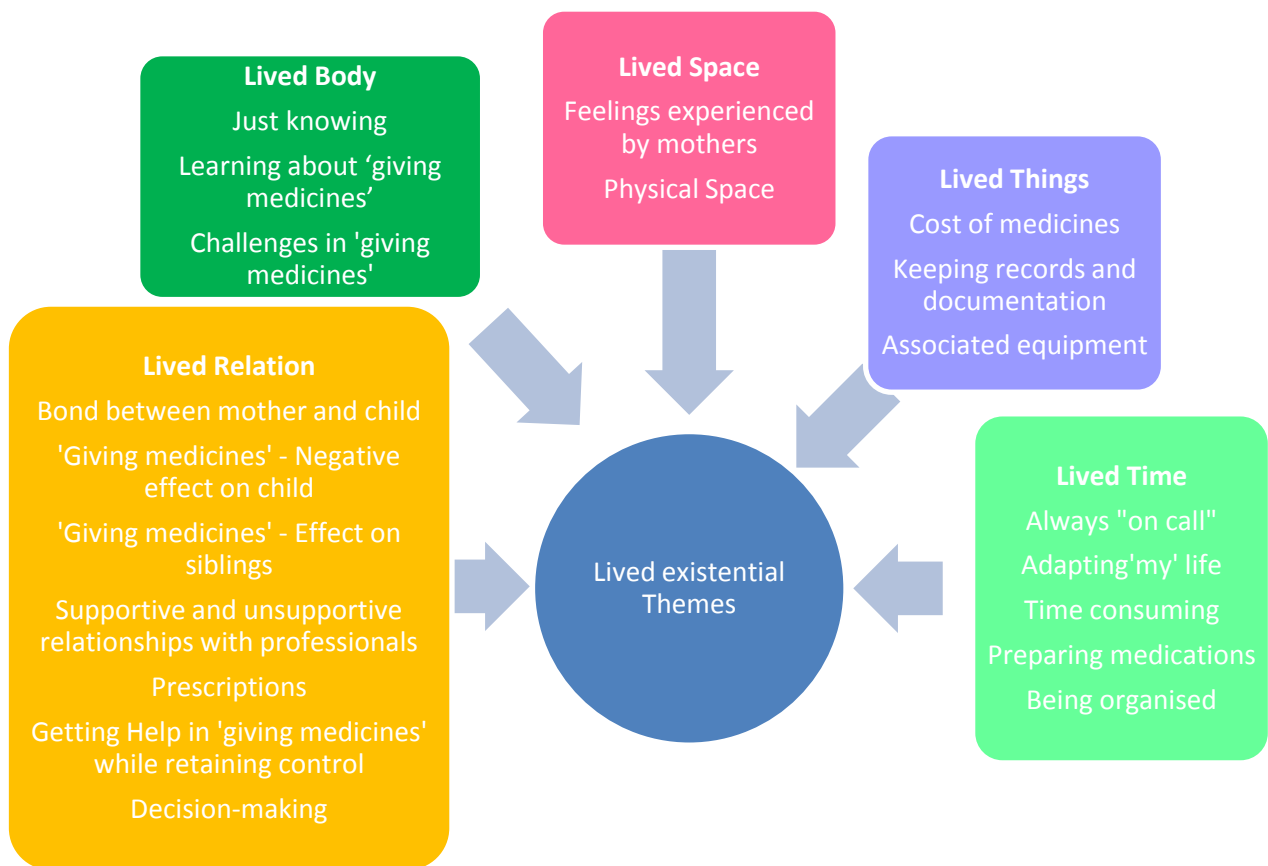
you've 12 pieces of paper as opposed to 52 pieces of paper. So that's a lot easier because obviously we've got to go back on it for other years if we're checking what he was on and what antibiotics he's had reactions to. (P8A)

5.4 Adopting Lived Existential Themes

This story depicts the essence of one mother's experience of 'giving medicines' to her child. In considering the subject of 'giving medicines' it can be clearly seen that this impacts on many elements of daily life outside of just the physical act of giving medicines. In turn this story represents the five existential dimensions (van Manen 2014) alluded to in Chapter Four section 4.13, that underpinned the analytical and interpretive process and allowed for meaningful expression of mothers' experiences of 'giving medicines' to their child facilitating a deeper reflection on each theme.

A total number of 20 essential themes (codes) were identified through the process of hermeneutic data analysis outlined in the previous chapter and are exhibited adopting the five existential dimensions delineated. Each existential dimension is displayed with relevant themes presented in turn and illustrated with verbatim material from the mothers themselves (see Figure 3 for an illustration of key themes identified).

Figure 3: Lived existential dimensions with themes identified

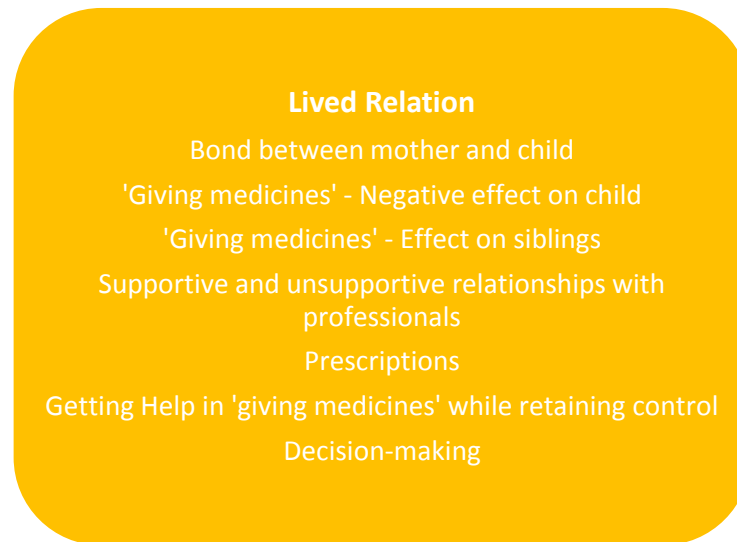


5.5 Lived relation – The importance of relationships for mothers who ‘give medicines’

The first overarching existential theme explored was ‘lived relation’ proffering insight into various relational aspects of participants’ day to day experience of ‘giving medicines’ to their child with severe and profound intellectual disabilities. This yielded the greatest number of themes with seven identified (see Figure 4). The findings show that mothers do not describe their experience in isolation from their child, but contextualise every experience in direct relation to their child. Therefore, the first relationship to be examined is that of the mother and child and the unique bond between them. The mothers described dynamics in terms of those relationships with both healthcare professionals and others which were supportive and less supportive. Mothers’ relationships with others can affect their daily life and experiences as reflected in this study. The seven themes (with two sub themes) of ‘lived relation’ were identified as; bond between mother and child, negative effects on the child, the effect on siblings,

supportive and unsupportive relationships with professionals, prescriptions, getting help in 'giving medicines' while retaining control and decision making.

Figure 4: Lived relation



5.5.1 Bond between mother and child

In documenting the findings of this research study the unique bond of a mother and child is central. This study while exploring the mother's experience of 'giving medicines' cannot ignore the child as the experience I'm exploring involves a mother's experience with their child. Everything a mother undertakes in daily life when caring for their child is underpinned by an innate sense of love and a unique bond requiring lifelong adjustment. All themes that emanate from this study will be contextualised on the basis that the mother and child are viewed as a unit. Both physical and emotional factors affect the relationship between mother and child and while the average child grows to gain independence and learn new things, this is not always the case with children with severe and profound intellectual disabilities. Understanding the child's cues can take time and may only be achieved by those who are closest such as the mother. This was something clearly evident in all interviews and visible in interactions in seven interviews where the child was also present in the room or in another room in the house while interviewing the mother. Being a mother involves a complete change in how life is lived, from a practical sense of how time is spent and from an emotional perspective in how she feels and thinks with the child often becoming the most important thing in her life.

Motivations change in order to take care of the child and what was evident in this research study was the all-consuming nature of this role.

One participant, the mother of the youngest child in the study, held her sleeping daughter on her knee during the interview and tended to her needs both during the interview and between pauses. The gentle touches with her child was evidence of the strong bond between them. Eight participants whose children were not present during interview showed me pictures of their child unprompted and smiled when talking of them. Another participant discussed the complexities following her son's birth and the need for him to be hospitalised for his first 9 months of life and then his subsequent return to hospital a number of times in his early years. The relief she felt on getting her little boy back home was evident in her facial expressions and she showed determination in voicing his needs.

Jake spent the first few years in hospital, in and out of ICU. I saw him at death's door. I don't want to him to ever feel sick. So if I can do anything to make him feel a bit better then I will do it. (P7B)

Additionally, the bond between mother and child was evident in the stress, worry and concern voiced by participants and their wish to protect their child from illness. Participants' desire to ensure their child was not suffering and their advocate role for their child was evident in all of the interviews. One participant acknowledged she wanted her child to be comfortable;

I'm at the stage with Marie I just want her to be comfortable. I used to joke about different medications and I'd be thinking, why are they not giving her what she needs? Why are we worried about her liver and her kidneys when nothing else actually works? Let's just make her comfortable. (P3C)

Another indicator of a strong bond between mother and child was the decision by four participants not to send their child (often described as their baby) to respite to be cared for by others. In presenting the remaining 19 essential themes, the bond between mother and child is evident throughout.

5.5.2 'Giving medicines' - Negative effect on child

While the feelings experienced by participants are addressed later, one major concern for all was the negative effect of medicines on their child. One participant mentioned the complexity of interactions as her child was on 17 daily medications requiring her to be vigilant and watch for side effects or negative interactions. Another participant who has been caring for her child for 17 years became upset when she reflected on the number of medications her child was taking (16 in total) and yet these didn't always reduce seizure activity or give her adequate pain relief.

she's had so many changes with epilepsy meds and now with this pain thing, I just feel really sorry for her ... I can't believe I'm suddenly feeling upset... I'm giving this child so many pharmaceutical drugs, I'm putting all these things into her body and I've no idea how she feels ... (participant crying) because she can't articulate it. (P2B)

Another participant admitted that there were always going to be side effects but you didn't always know what they would be;

for every drug you give there's... there are side effects, and what are they going to be? She's never had any side effects, as such, from any of the medications. But there's always that worry there. You read through the list of side effects that they've found, and you think, "is this going to be the one that she's going to have some major reaction to? (P14A)

5.5.3 'Giving medicines' - Effect on siblings

It was not only the effect of 'giving medicines' to the child that was emphasised but how this affected siblings within the family. Three participants reflected upon the impact of 'giving medicines' on a daily basis on siblings and how it affected their lives. One participant, who has another daughter as well as her child with profound intellectual disabilities, discussed how her and her husband had never asked anything of their daughter in terms of help or assistance and that they wanted her to feel like a sister and not a carer. However, as she has grown older she herself has asked to help and wants to know how to 'give medicines'.

we always said we don't want (daughter) life to be interrupted or for her to feel that she is a carer or a minder. She is her sister and that's all she needs to be...it's herself that has, you know..."I'll do it. Show me how to do it." She has prompted

us to... "I'll do it" or "I'll stay with her. I can do it." And that's the way we wanted it. We wanted her to be comfortable with it. Not for us to. "Will you not do it? (P 14A)

Conversely, another participant talked about how her son had not shown interest in 'giving medicines' but she had asked him to do it as he was now a young adult and she wanted him to take some responsibility;

I usually give the Midazolam. Now I have started saying to (son), "I want you to give it now." (P10A)

Another participant talked of going away for a day and leaving her child in the care of her older daughter who is 20 years old. As this was her first time to care for a full day, this participant acknowledged the interest her daughter displayed and willingness to ensure everything was correct.

she sat down with me the night before and said "Ok, let me just make sure that I'm absolutely clear what I have to give Ava in the morning." And she is a very bright girl and I have 100% faith in her to be careful with Ava. So yeah, she gave Ava all of her medicines that day. (P2A)

Similarly, another participant chatted about her youngest daughter having a connection with her brother because he was already there when she was born and therefore she did not know a life without him.

(Daughter) is five, has often commented on it..."can I help you Mammy?" ...because Aaron was here when she was born I suppose she knows no better, she's after growing up with that, this is life for her... like, if I was in the bedroom and Aaron was having a seizure she'll call me "Mammy, Aaron is having a seizure"... (P1A)

One participant considered the positive influence of siblings when it came to 'giving medicines' in particular;

they help distract. I'm constantly saying, Quick! Sing a song. Sing a song to Marie. There's various songs Marie likes or they know what station to put on the TV. They know what station she doesn't like...they're very good at distracting her. Certain sounds they make, make her laugh. And we could have meds in her mouth and we just need her just to laugh for a second for it to just go down. They try and help out that way. (P 3A)

The negative effect on siblings was also raised and especially for younger siblings who may not have understood the reasons for 'giving medicines'. One participant described how distressing the process of 'giving medicines' was and it was compounded further by the effect it was having on siblings.

they find it stressful now with the medication. And particularly in the last few months it's been stressful for them. My six-year old was here and she was telling my husband, "Stop Daddy. Marie doesn't like it" because we were so stressed trying to get it into her. (P 3A)

5.5.4 Supportive and Unsupportive Relationships with professionals

Mothers of children with severe and profound intellectual disabilities meet many professionals mainly in healthcare on an ongoing basis. All the participants identified those professionals either singular or collectively, that impact on their lives in a supportive or less supportive manner, in terms of 'giving medicines'; GP, pharmacist, hospital, school and respite facilities. All of those professionals with the exception of the school who was seen as supportive only, had both supportive and unsupportive elements for consideration.

5.5.4.1 Supportive Relationships

Supportive relationships refer to those interactions between the mother and others whereby they experienced positive outcomes and found these relationships as key elements in aiding their daily activities and helped them cope with the challenges of caring for their child. The relationship with the GP was identified by all participants in terms of them linking with the GP for child related queries on illness, getting prescriptions or seeking advice. Participants indicated that having the support of a helpful GP was key in aiding them to cope on a daily basis. This relationship was seen as fundamental in providing seamless care and the satisfaction of mothers with this care was evident at interview;

We've a fabulous GP ...that knows us so well. It's great in that sense, that we have their support really. (P 10A)

Similarly, the relationship with the pharmacist was central to the daily activities relating to 'giving medicines' and a good relationship resulted in a happier mother. Participants specified the pharmacist knowing the child and family, provided a level of support that mothers relied upon and indicated that the pharmacist often went beyond their job to help them out.

they shouldn't be underestimated...I do feel they go that extra mile, and there's a little bit more kind of personal touch there, and nothing's ever a bother to them. Even if they have to call you back... We know them so well; I don't think I have to say my name if I ring up. They know my voice on the end of the phone. ...they liaise in between the doctor, and the doctor's surgery is only down the road, so it's great just to come up. They'll either go down and get it if I can't get out of the house. (P 8B)

A good quality relationship with the GP has been emphasised by all participants as multiple contacts are made regarding various daily issues from seeking prescriptions to getting letters or rewriting drug Kardex for trips to school or respite. Being able to approach the GP easily and getting appropriate support was highlighted also;

I'm just very lucky. She (the GP) was the one in the beginning when I went in and I said I was concerned about him when he was.... I've always had a great relationship with her. She's been brilliant. I suppose I never feel she pawns me off. So when I went in when he was only, I think two weeks, and I went in bawling crying of course, saying, "Oh, I know things aren't right". I just felt straight away, she said, "Look -". She listened to me. She didn't say, "Oh, you're just anxious" or whatever. So, I've a great relationship with her. (P 10A)

Accessibility to key health professionals was signalled as imperative by all participants. The importance of access to the GP was indicated and not having to wait to be seen with an acutely ill child is something that is vital to mothers especially due to the risk of infection for the child;

All I had to do was ring up (secretary) yesterday and say, "can somebody just listen to Emma's chest and look in her ears and see if she has an infection brewing?" And they will. They'll always fit her in. It's not a big deal and I'm never made to feel like "We can't do that" or "No, you'll have to wait." Then just they facilitate you and they take you on board...They're very accommodating. (P 14A)

Additionally, accessibility to the hospital and avoiding accident and emergency (A & E – emergency department) with their child was something highlighted by three participants. Attendance at hospital always ran the risk of the child picking up another infection when they were already vulnerable. Having direct access to the ward in order to avoid this happening was viewed as essential;

I have the nurses down in (hospital) ... there's a plan in place that if Marie is unwell, that I can bring her down and bring her straight up to them. Avoid A&E. (P 3A)

Positive interactions with the GP and associated clinic staff was deemed crucial even when mothers felt they were constantly making demands on the GP over and above what other private patients might command as their child might need far more GP visits.

I like my GP. I'm also acutely aware that Ava is on a medical card. He gets paid very little per month per medical card holder, and in the past year he has been writing prescriptions for Ava incredibly regularly. He and his receptionist have done an awful lot of work for her. And yet every time I phone, and I'm onto them a lot because her Oromorph - her prescription for that has to be done every fortnight. Every time I phone them I never get the impression that they're silently rolling their eyes in the background. (P 2C)

The act of repeated storytelling was mentioned by six participants in terms of having to explain their child's condition on each hospital or pharmacy visit or to new staff in any healthcare interaction. Even if ringing the GP clinic or hospital for a prescription, the explanations required were time-consuming. The introduction of hospital passports by some hospitals has been seen as a positive intervention and removes the need for repetition as one participant described;

(hospital) have now introduced these - they're like care plans, they're folders. And all of Eoin's details are in that with all his meds and his prescriptions. So that's only a new thing the liaison nurse gave me, which has proved great now, because the last time we went in an ambulance, you could just hand the folder and say, "There is everything."... instead of explaining your life story, you can just hand the folder. So that would include all his meds in that as well. (P 6A)

Using the same pharmacy and ideally the same pharmacists was found to be helpful in ensuring a consistent approach and to avoid repeated storytelling about their child. The

relationship with the pharmacist was cited as being significant with one participant conceding “*your new best friend becomes your pharmacist*” (P 15A). Treating the mother as more than just a customer was important to participants and knowledge of their lives other than their carer role was another indicator that the pharmacist cared beyond just being the provider of medicines.

I think it's really important to have a good relationship, and over the years the pharmacists in this particular pharmacy - you get to know them very well and then they go. Somebody else comes in...in this particular pharmacy they couldn't be nicer...I walked in the other day to get more Oromorph and Potassium Citrate ...and the pharmacy manager called me over and gave me a family and friends 20% off discount card. Another day I walked in and the pharmacist handed me a little Vichy sample gift set. So they know something of my life and they go out of their way to be nice to me, and they're very efficient at getting stuff in. (P 2C)

As all of the children could not do without medications for example, AEDs and there was always the possibility of running out or not having the correct stock in the house, flexibility and willingness to give medicines and receive the prescription retrospectively were evident indicators of satisfaction with pharmacists.

the pharmacist is around the corner, that knows us so well...even if we don't have a script, sometimes we can just go down and say, "We need something for John", and straight away they'll give it to us. They know we'll always get the script again. So it's great in that sense, that we have their support really. (P 10A)

The support of an efficient pharmacist was very important and learning from each other was also indicated by all participants. When participants have a child with severe and profound intellectual disabilities, the support of the pharmacist is fundamental in getting to know the medicines and how to administer them;

I need an efficient pharmacist backing me up. And they're learning from us, because this latest drug she's been put on - they've never used it before...they've given me guidance, advice, help, because I've gone to them for it. (P 2C)

The consistency in pharmacists providing a fast and efficient service was highlighted as often children had medication changes requiring new prescriptions and collection of new drugs within a short timeframe. Furthermore, the importance of the pharmacist understanding the time constraints of these participants was evident and they would go

out of their way to ensure they did not add to the daily burden experienced by participants. The majority of participants admitted that pharmacists were very helpful and would deliver to the house and communicate between other professionals, for example, GP and hospital teams.

They were very, very helpful ... they would bring things to the house and they would explain things and verify things for me, and if I was unsure about something they would say, "Leave that with us" or "We'll check with the hospital" or "We'll check with doctor for you." They're very good. They're very, very good. (P 14A)

The pharmacist was found to be helpful in supplying a print out of the list of medications, something necessary for associated schools and respite facilities or hospital appointments. Their expertise in sourcing medications did not go unnoticed and they were found to be accommodating in this regard as sheer volume of medications and difficulty in swallowing are key issues participants are dealing with in 'giving medicines'. Therefore, if the pharmacist could alleviate some of the issues of concern they would try to.

My pharmacist is very good and he was sourcing some liquid medication. I also explained to him about the volume. So, he eventually got us liquid forms of all her medication and in addition to that, he went one step further and he got me a stronger Frisium. Whereas we would have had to give her 15 mls every morning, he got me a double strength. (P 3B)

The awareness of safety was an evident role of the pharmacist in highlighting drug interactions and was found to be important because participants could forget that there may be interactions when new drugs are added in;

He will highlight, "Oh Marie on this other drug..." But when you're talking about ten or twelve drugs at the same time, it's easy to overlook it - that's something that can interfere. (P 3B)

Other supportive relationships included that of respite. Participants acknowledged that the burden of care was 24 hours per day full time with only three participants indicating they had any support structures outside of their own family unit. While four participants had chosen not to seek respite support, 11 participants availed of respite in some form. A respite stay was generally seen as a lifeline for these participants providing a break

from routine daily life and a consistent support albeit not often enough and often celebrations or events could not be attended by mothers unless they knew their child was in respite.

Going away is thanks to (the respite facility). That's the only way we've got away and it's a night here, a night there and a weekend. We got married there earlier this year so they were great for two nights away which was fine for us. (P 8A)

In a similar vein, 14 of the children attended school either full-time or part-time when health status permitted or when there was a nurse in place to administer the medications while there. The likelihood of the children requiring medications in the school environment was high as all of the children had complex health needs. On the whole, going to school for the child was seen as an important element of the day despite the planning and organisation required by participants. Similar to respite, participants found they had to be organised around a number of medication related issues and not just hand over the medications but be prepared with prescriptions also and give clear advice on how medications were to be administered.

I have to make sure that the school has the drugs that they have the prescriptions for the drugs, original prescriptions that the drugs are in date, so keeping an eye on expiry of everything and that they have the honey and the stupid coconut yoghurt, which is hard to get sometimes. (P 2A)

5.5.4.2 Unsupportive Relationships

Unsupportive relationships refers to those interactions between the mother and others whereby mothers experienced frustration and negative outcomes and found these relationships as key barriers to their daily caring role in terms of 'giving medicines', adding additional burden to their busy lives. Interestingly, those professionals who provided support also appeared unsupportive in some instances. Sometimes the onerous task of paperwork associated with the child was perceived by participants not only to be a burden on themselves but also on the GP;

he doesn't be happy when you're coming with all these forms and then there's PRN forms that has to be renewed every three months. (P 4A)

With GPs being very busy, two participants found that gaining access in the clinic setting

is one thing and usually positive but getting a GP to undertake a house call was very difficult. House calls were deemed necessary by these participants as their child required high levels of support and at least two adults, to be transported to the clinic setting along with associated equipment.

there's good and bad experiences with GPs, but on the whole they'll tell you they're too busy. They're overworked, and they don't have enough staff to come out. His first GP wouldn't come near the house, which is kind of shocking because Tom's not the kind of child that you can bundle into the car and bring them to the GP. (P 8B)

Some participants' experience of visiting the GP with their child is the foundation for more frustration than satisfaction with some GPs clearly not knowing how to interact with the child. One participant described it fittingly;

She's definitely no manner with Shay - because if he goes down, he could be standing in the middle of the room. He mightn't sit down for us. Or he'd be jumping up and down, or eating his fingers, and she'd say, "Stop that now Shay. Take your fingers out of your mouth." I look at her as if to say, "He's autistic. He hasn't a bull's what you're on about." (P 13A)

As all participants spend a significant portion of time getting prescriptions completed, frustration with the GP was also highlighted by participants and sometimes placed an unnecessary additional burden on them especially when prescriptions were completed incorrectly or a generic drug was prescribed instead of the correct drug name.

script for Desunin was printed wrong by the doctors. 200mg per day – should have been 400mg per day. So I will have to phone doctors and get the correct script (yet more extra trips to and from!!). (P 4D)

Three participants actually found by writing the prescriptions out on blank drug Kardex themselves was more useful and more likely to be legible especially where the GPs writing was difficult to read thereby meaning they had a more satisfactory experience.

I do write it myself because no one can read the doctor's. I write the medication down, the amount, the route, all the little boxes across and of course I actually have to nearly put a sticker on where he has to sign because he's so busy he doesn't know what box to fill in. (P 4A)

Sometimes the GP lacks awareness in assessing the bigger picture and can forget that

the child with swallowing difficulties will find having an antibiotic added to the medication list a hindrance. This is especially noticeable when it is prescribed in liquid format resulting in large volume for administration. Dissatisfaction with the GP was evident also with eight participants perceiving the GP to lack expertise in dealing with complex health issues. Sometimes the GP was considered to be only of use in writing prescriptions or administering flu jabs and beyond that, they would encourage you to contact the hospital instead, often appearing disinterested in the child;

...when you go into the GP, you basically get sent to (hospital) pretty much. The GP kind of looks at her file and "Ok. We'll send you on in there. (P 15A)

While on the whole the relationship with the pharmacist was found to be positive there were some challenges identified that participants found unsupportive, such as not having prescriptions ready despite being ordered. One participant's frustration was evident in her diary entries;

Visit to chemist today to collect food supplements, Nutrison and Fortisip. I ordered these items a few days before. Once again the order is not ready... Problem – ordered from wrong supplier. I will have to call again, next time I'm going! Also collected the balance of another med which chemist was short of on my last visit. This happens quite a lot. (P 4D)

Managing the medications with short shelf life was identified as a stressor for two participants especially when pharmacists did not seem to acknowledge the enormity of the situation with one specific example of a medication having a shelf life of three weeks once constituted. However, the participant was not aware it was ready for collection and as a result expiry was the following week;

we had picked up the thiamine ... and literally she had the week in date of it. Now, I know there are issues in terms of the shelf life is quite short on it...So anyway, they said it would be ordered in and we would be able to pick it up...my husband went in to pick it up. The Kepra had come in and they couldn't get the thiamine. There had been a problem with it, and the blame was laid on the supplier and basically blaming other people, not themselves. (P 15B)

This frustration over ordering or lack of ordering the medications leads to additional stress for participants and yet often the mother does not feel they have a choice in changing pharmacy as it would result in more travel and inconvenience for them;

you're trying to keep a good relationship, because obviously the pharmacist is a very important person, it's the only local one that's very close to us so there's proximity, it's only two minutes away. It's very convenient. (P 15B)

As all participants felt they knew their child so well and spent the most time with them, being listened to by the doctors and health professionals was important and identified as something that often did not happen;

...there's definitely a couple of teams where you don't feel you are listened to... it can be personalities. It can be lack of continuity of care, so you're getting different regs (registrar doctor), so you don't see them that often so nobody really knows... Plus they don't realise - I saw him at death's door. So they don't understand my fears. (P 7B)

Almost all participants talked about a time lag existing, between mothers making contact with the specific medical team or nurse and the time they actually returned a phone call or responded to a query. However, participants were resigned to this and did not usually expect to get an immediate response to queries despite them feeling it was urgent and warranting a quick response. This is very frustrating for participants especially when an immediate response is what is required by the mother and often necessitated the mother making solo decisions around care.

I'd phone her secretary first... She'd pass on the message straight away. I might be waiting a few days for her to get back to me, but you know, that's fine. She's very busy, you know? (P 12A)

Gaining access to the right personnel at the end of the phone was not always easy and answering machine recordings often went unresponded to. Even when phones are answered participants indicated their frustration at not getting to speak with someone who knows their child;

Everybody knows him; all the staff...So you look for number one, and then number two and number three is fine as well, but they're difficult to get. I'm finding it more difficult now to get in touch than it was say even a year or two ago. Everyone's on a tight schedule and they're only working so many hours and the phone is put on answering machine consistently. Then you're running around and you get no answer here and you get no answer there. Then you go through the main switch and you actually get a person on the end of the phone and you'll say, "Can you get someone to run up there and just tell them I'm trying to get

through?" It's just so difficult. (P 4A)

Going to respite was not without some difficulties and all mothers in receipt of respite agreed they felt frustrated with respite for a variety of reasons. One of the central issues revolves around ensuring the medication 'Kardex' that is required for respite reflects all medications accurately and is signed by the GP with clear instructions on how medications are to be administered. If it was incorrect unless the respite doctor was available, it would require a return to the GP for correction.

Because he goes to (respite facility) and every month I have to get scripts and that is the bane of my life, because I have to get (hospital) to give me a script. I need them to fax into (respite facility), or else I have to fax it. Then I have to go to my doctor. Then I have to drop it to the chemist. (P 7A)

The pressure to be prepared and have everything in order is enormous when respite is looming with specific emphasis on the accuracy of prescriptions. This was reflected in many of the interviews with medications and prescriptions required for respite being described by one participant as;

...the bane of all our lives... Some people call it "stresspite" because of the drugs. (P 7A)

Some participants found going to respite so stressful in terms of organisation that they dreaded when it came about as there was a perception that the checking procedures while necessary were tedious;

I dread the thoughts of it. I've thought about it, I haven't psyched myself up yet to start packing. I was just at the pharmacy this morning, and so with the new script, getting everything written up...I'll give them the script. I'll have all his meds. Then on the check-in day they'll go through the script, they'll go through the meds, make sure everything is written up the way it's meant to be written up. If they found something wrong they would get their GP in there to write up whatever way it was meant to be. (P 1B)

Another concern for participants was the preparation of the equipment associated with the medications and the medications themselves, necessary for respite. Attention to detail ensuring everything is included is essential and on return from respite a similar process was required. Participants concluded that for each medication a syringe might

be necessary and therefore you had to count out how many would be required in any one day (one participant estimated this would be 40 per day) and ensure they were included. Similarly, each tablet would be counted and many participants used their own inventory for medications. This was identified as a time consuming process;

...there are a lot of meds. Then you need to make sure there's enough in each bottle. Sometimes you've to put two bottles in. Then you need to count out things like tablets...Then there's syringes. You have to bring all your syringes because they're a charity so they don't get syringes...injections, even the box for the injection. (P 7A)

5.5.5 Prescriptions

Prescriptions were specifically highlighted by four participants and their concerns related to securing prescriptions and the role of the GP or pharmacist relating to this. One participant described prescriptions as “*the bane of all our lives*” (P7A). This participant was particularly frustrated at the communication systems between GPs, pharmacists and the participant themselves while also explaining it became more difficult when high tech scripts were required. Another participant accepted it was not just as simple as getting the prescription but you had to check it thoroughly;

if any doctor prescribes any drug I always ask what form it comes in because it's happened a few times in the past that somebody writes a script for a tablet and you go and get it from the chemist and it's in a form that she can't take, it's in a tablet that you're not supposed to crush or isn't crushable, that she can't swallow, so I always check the format that things come in. (P2B)

One participant suggests that the process of getting prescriptions should be streamlined and something that can be done between GPs and pharmacists directly.

I have to renew the script? I find that a pain. If the doctor and the chemist could do it between them, you know? But it means you physically have to go to the doctor and say "We need a script" and then we have to physically bring it back to the chemist. (P14A)

Another participant reinforced this by acknowledging how unwieldy securing prescriptions could be;

you might have to get a new prescription. So you've to go to the doctor, leave the thing in, go back, collect the prescription, go to the chemist, get it. Then if there's

the Kardex thing it's onerous, and if somebody scribbles on it you've to start again because they won't accept it unless it's pristine. (P9A)

5.5.6 Getting help and support in 'giving medicines' while retaining control

This fifth theme refers to mothers getting help in terms of 'giving medicines' and what was evident from this was how difficult it can be to get help or assistance outside of the main family unit. No regular babysitters could be used due to complexity of care and one participant described how her husband and children had "never gone on holiday together" (P 14A). Life was identified as being all about compromise. Getting help was identified as important but especially so during periods of transition such as returning home from a long stay in hospital. One participant admitted she would have not coped without the help and support of a voluntary organisation.

I had (organisation) helping me all the time. That's the only reason I'd say that I was able to manage, a great nurse...so that really helped the transition home. (P 7A)

Other than the occasional support from voluntary organisations, family members and friends were important people in the lives of participants especially if help was required but this was not available in some cases.

My Mum has learned a bit. I have a friend that helps me mind Marie from time-to-time. She has come and learned and she has actually brought her 16 year old daughter with her as back up. So, I think it's a great idea that the two of them know that if (friend) is giving her stuff, that (friends' daughter) can say, "Yes, Mam. You're doing it right." Between the two of them they've learned a good bit. (P 3B)

Only two participants recognised their husbands as being as good as them in terms of 'giving medicines' and in the absence of any other family supports, acknowledged they could even go away for a couple of days and leave their child in their capable hands;

He's as good as me. He can do all the medicines, the suction, change the tubing. Anything I can do, he's able to do and he's very willing. He's always been hands on. (P8A)

While many of the participants identified their husband as a great support, one particular participant acknowledged how supportive her husband was in terms of 'giving

medicines' but if she was going away and leaving him to care for their child she would have to make notes for him to refer to on how to administer.

I would have to definitely note down - more of the smaller things like what interferes with times and stuff. He wouldn't be as familiar as I would with things like that. It's just the timing of things he wouldn't know. (P6A)

Another participant conceded while her husband could give the medicines, his input beyond that was minimal;

(husband) would be able to give the meds provided I've left them all ready to go, but he wouldn't be able to come in and just say "well there's ten bottles of medicine for (child) and I'll give him his meds." He wouldn't know what to do. I'd have to leave them all ready in the syringes, ready to go, in a cup and say "there's Aarons' meds, he's due them at six o'clock, when his machine is finished there give him his meds" and that's the only way he'd be able to give them. (P1A)

Getting help was identified as not often easy to do, but sometimes necessary. One participant who found 'giving medicines' very difficult considered how she had to 'let go' and get her husband to help out, resulting in an improved team approach;

I am the main giver of medication and I was doing it and about two or three months ago I just had to say, "I can't give it anymore", because I just couldn't get it into her. My husband took over. He seemed to be calmer and he was managing. I'd say about two weeks into it then he was stressed big time. He just couldn't get it into her. We kind of do it as a team now. (P3C)

Seven participants highlighted they were very much on their own with just their husbands or partners to help out and therefore getting help was something that just did not happen. This was for the most part due to the complexity of care required by the child and the process of medication giving requiring a level of skill. Six of these participants used respite and planned any events or breaks to coincide with this period of time placing great trust in respite staff.

if I'm away the child has to be in respite, simple as that. You can't plan any nights away without respite. Or if he's in school, he's in school and obviously you get the few hours to go somewhere then but you'd have to be back. I don't know if I'd trust anybody else... You just can't make a mistake and I don't think I'd hand that responsibility to anybody else, to be honest. (P4A)

Comparably, one participant described life as being;

all about compromise. The nights we go out together she is in respite. Other nights, it's just "You're here or I'm here." We work it that way. You couldn't ask somebody to do it, and if something happened on their watch, they would be traumatised, and you would be traumatised. So it was just easier not to ask. Between us we work it, but God forbid anything happened to either of us. (P14A)

Sadly, one participant described how she is very much alone in the act of 'giving medicines' and has nobody to ask for help;

If I'm in bed sick I have to get up and do it. There's absolutely nobody because there's no family member. My husband's a farmer. He doesn't get involved in any of that. So there's nobody. (P4A)

In daily life, all mothers seek support at one time or another. Aside from getting help from family or friends, participants discussed seeking informal support in relation to 'giving medicines' and how this impacted on their lives. One participant indicated the importance of informal support through getting to know the school parents.

in terms of his medication, I get great support from a couple of other parents here and one of them is a nurse, and she's a good friend of mine. She's very good on just talking about medication and how, and different times and all that sort of stuff. So I get great support. The informal supports are there. (P9A)

In addition, social media was identified by five participants as a positive source of support, both in terms of problem solving and borrowing equipment. These participants were all members of a closed Facebook support group for children with severe and profound intellectual disabilities and often swapped relevant information.

it's great you can post up with the other extra special kids - we have a group - to see if I can get something. Things like syringes and stuff. Sometimes you can just not realise you're down to your last one, so it's good to have a supportive group around you with kids in similar circumstances. (P7B)

Being able to get advice was essential for participants. While some participants felt they could ring the GP and they were responsive, others looked to different sources for advice with one participant indicating it was a friend she sought advice from or a sister-in-law who was a nurse;

we have one very good friend. So we're best friends and she'd have such sound advice. She's a specialist in epilepsy. She's a nurse as well. She'd be, I suppose, our right hand woman. Then I've a sister-in-law that's a public health nurse, and she'd be very good as well. I'd always ring her, rather than ringing doctors I suppose. (P10B)

Another participant talked of her trust in the liaison neurology nurse and through building a strong relationship with her, found her to be a positive influence.

If it was an epilepsy drug that (name of hospital) was suggesting...I have a fabulous relationship with a neurology liaison nurse in (name of hospital) who's been there for years. She knows Ava, she knows me. (P2A)

Additionally, another participant conceded she was fortunate enough to have a brother whose a GP and while he lived abroad he was always only a phone call away. However, due to the complexity of medications many of these children are on, it is somebody who knows the child that is the important advisor.

I suppose my brother and my sister-in-law are both doctors, so we could link in with them. (husband's) Mum is also a nurse. But then when you get into these kind of meds, they're so specific. We're not just talking about Calpol or Nurofen - you know, really it needs to be somebody who knows what they're about, and a medical person. You wouldn't trust really anything, not when it's medications for your daughter. You want it accurate and correct, so it typically needs to be obviously someone - a medical person. (P15A)

This participant also recognised the role nurses from voluntary organisations played in their lives, whether direct caregivers for their child or regional advisors for the organisation. Conversely, one participant admitted she would only contact the hospital for advice as they knew her son so well.

Always (hospital) because they know him so well. Everybody knows him; all the staff, all the nurses and then you have one key nurse that deals specifically with the medication and the VNS. (P4A)

Having control over 'giving medicines' was something highlighted by all participants and was varied. Having some control while in the hospital was important for participants. One participant retained control on hospital emergencies and talked about how her son would present to A & E with prolonged seizure activity and the doctors would be trying

various medicines to halt the process. With each visit, this participant recognised what medication worked to halt seizure activity and therefore she requested a protocol be established for his treatment on arrival to A & E regardless of what doctors were on duty.

After several visits to casualty we realised it's the PhosPhenytoin that works and we asked the consultant for a protocol in writing to present in A & E. Now the team are drawing up the Phosphenytoin as we arrive from ambulance. It pays off to have a plan in place. (P6D)

Another participant expressed how she found it difficult when her child was in hospital as sometimes the staff appeared to be doing the wrong thing resulting in it being easier for her to just do it herself and retain control;

I found out it was better to do the Broviac myself because I went to A & E and nurses didn't know how to do it. They were drawing blood back up when it had been cleaned. (P7A)

Similarly, another participant acknowledged her desire to know exactly what medicines her child is given in hospital especially if it was anything different to her usual medications.

even if she was an in-patient, I didn't want them just giving her medicine without me knowing what they were giving her and why, and what doses and how often. I felt that I needed to be very in control. (P2A)

One participant mentioned how her husband is very good with their child and will remember the medicines but she still feels the need to have control and will text and remind him what he should be giving.

I have to say (husband) would be very good. He will remember the meds...but I'll still be ringing or texting to remind him. (P10B)

Likewise, other participants described how when their husband was 'giving medicines' they would always double check what he was doing and questioned how he did things as they were different to their own perceived standards.

I suppose in the back of my head I always feel I have to check what he's doing... I still have to check. When I looked back - I have a box there with all her daily stuff,

and there was red gooey stuff on the bottom and all sorts of stuff. Did he even close the lid on these bottles. (P3C)

Having some level of control was also important for one participant who sometimes went out for a walk or a run and left her husband or teenage daughter caring for her child.

I will leave the Buccal Midazolam on the worktop, just in case. It's just there. It's a reminder... that's the only thing I would do when I'm not here, is leave that out in plain view, so everybody knows where it is. (P14A)

When leaving their children with other carers, in this case nurses that provide care in the home, participants felt it was important to trust them but also retained some level of control by putting a checking procedure in place for checking medicines before administration;

you do have to be absolutely on the ball all the time if I'm having them (nursing staff) for a weekend, what I usually do is get them to draw up all the meds and check them with the next one coming on duty. So there's some kind of checking. Now sometimes, what I usually do is draw them up. So they're drawn up for that shift. If I have a nurse coming and I have time, and I haven't drawn up the meds, I sometimes line up the syringes. It sounds a bit OCD probably in a control freak kind of a way, but it actually, I think it lessens mistakes if you draw them up in the right syringes. (P7A)

One participant described how she sleeps poorly on nights when a new nurse is caring for her child or she is aware she may be disturbed during the night if a nurse has a query;

from time to time, we'd have new nurses stepping in. You sleep with one eye open on those nights, because obviously it's something completely different for them. Initially, they'll come and wake you during the night, and look, for your child you don't care. You just say, "Look, if it's a littlest of things, don't feel bad waking me, just to check if this is normal, or is this how this should go?" And if he's comfortable and I'm happy with him, I'll get back into bed and get an hour's sleep after that. (P8B)

However, on the other hand she also found it reassuring knowing you had someone taking over at night time especially when she felt very tired.

when it gets to 11 o'clock at night he's due more medications; you're tired, your

concentration kind of goes. So there is nothing like somebody fresh, a fresh pair of hands just going, "Now, get some sleep. I'll do that." So you're able to do the next 16 hours the next day. And especially, if they're the nurses we know, and that know (child). (P8B)

The fear of someone else making a mistake or not supplying equivalent care to the mother was a concern identified.

even down to crushing the medicines, and I'll be like, if it sticks to the tablet crusher, "Did the nurse really give him all that seizure medication." If he has a seizure, you're blaming, "Did he really get the correct dose? Did they measure it out like I would?" And as time goes on...You feel like you're nit-picking, but then you take it back, "Well no, you're not actually, because his life depends on this." (P8B)

The reality that these participants are very much alone with minimal daily support was evident throughout all of the interviews. One participant admitted that;

it would make life easier for us if there was other people around that would give the meds to her. But there isn't so... (P 11B)

5.5.7 Decision making

In keeping with 'lived relation' the importance of decision making was highlighted by all participants. Decision making is a fundamental component of the caring process in particular in relation to medicines whether this was relating to changing medications, dosages, routes of administration or knowing when it was necessary to give a PRN medication. Decision making was often an inconsistent process with participants making independent and collaborative decisions with hospital multi-disciplinary teams or conversely, being totally excluded from key decision making. Participants grappled with their existence in terms of how decisions they made affect others, namely their child. An overwhelming sense of responsibility for their child is depicted in participants' experiences. Constant decision making is evident in participant stories and this reflects consequences of choices made either alone or collaboratively. Being listened to by hospital multi-disciplinary teams was described by one mother;

So it's me, (nurse) and the consultant and the three of us, as a team, decide what next thing to do, even though (consultant) is in charge and makes the decisions. He really has always listened to me. I learnt years ago, that open discussion about

what I think Ava needs, and to a lesser extent, the ease with which I can give her the item, that decisions about Ava's epilepsy drugs have been made by this team of three, for years. (P2A)

The importance of this involvement in decision making was reinforced further with one participant indicating how significant the communications between the hospital consultant and nurses are because as a mother you are more familiar with your child and you are noticing the responses to medications.

it's kind of working more in tandem together; us, as parents at home on the ground, actually administering the medications and working with Niamh, seeing how she's responding, in tandem with the hospital and with the consultants and the nurses. I think it's really important to have that link because we're the people with the eyes on the ground who are actually seeing how she's responding. (P15B)

Devising plans with consultants was another element of decision making in which participants felt was integral in managing medications and participants acknowledged the consultant role in giving advice, typically at indicating if the risks outweighed specific side effects. One participant described how they required a plan to deal with acute bouts of irritability displayed by their child;

we had this plan in place with (hospital) that if this irritability strikes up, that we can increase Marie's Frisium by 2.5. So we were doing that and then I would get in touch with (hospital) and advise them of this increase and they would say, "Ok. Keep her on that and if it happens again, you can go up again". (P3A)

Supported decision making with multi-disciplinary teams at the hospital often provided reassurance for participants with another participant clearly depicting how it was important for her to get confirmation on decisions regarding medicines.

spoken to the nurses frequently on the phone line with all of the changes in the meds when get upped. So we would have discussed medication with them as we went along. But probably initiated by us, and then... kind of more reassurance, confirming that what we're doing is correct. (P15A)

Independent decision making was spoken about by all participants and some were confident in making these decisions. One participant suggested that her and her husband's decision was often a better decision than that of the hospital or doctors. It

was noted however in this case that the participant was herself a nurse and had a certain degree of familiarity with professional medication management.

We stopped giving John the prescribed dose of Baclofen as he was too drowsy. Later told GP who agreed with us (sometimes I find our decision can be better and at times we have to make the call whether to increase or decrease or omit meds). We always inform paediatrician afterwards who is very supportive. (P10D)

Another participant expressed the difficulties regarding solo decision making in the depths of the night when she was on her own and sleep deprived;

After sitting with my son for one and half hours I'm deciding whether to give him more sedative. He's up for school at 7am so it will make him groggy for schoolbut if I don't give him more I will be up for another 3 hours exhausted. It's a hard decision to make when you've only had 2 hours sleep. (P6D)

Participants relied on their own judgement as to whether the medication given was having a positive effect on their child or worthy of continuance with some participants keeping notes of perceived responses and behaviours. Decisions were often made in consultation with doctors but when the decisions require enactment, it was very much an independent decision.

(consultant) just said, "Start at 20, but you can go to 30, then to 40ml, four times a day." I started her on 20. I gave it about ten days, noticed no difference whatsoever, so I, on my own, made the decision to go to 30. And I, on my own, will make the decision to go to 40. (P2A)

Some participants grappled with solo decision making, with one participant revealing how a joint decision in which you were supported was an easier one;

His secretions had increased and I was thinking, "He had the Glyco, but when I give him the next dose of Glycopyrolate, will I increase it a little bit?" Then if you increase it a little bit, and then if he struggles with his sats. To maintain his oxygen levels up, then you think, "Oh, should I have made that decision? Did I make the right decision? Because then if he's starting to dip a little bit? So, there's a lot riding on it, really, and especially when you're at home. In the hospital, they'll ask you and you'll make a kind of a joint decision about it, but in the house, it's solo. (P8B)

Having the support of a husband or partner in making key decisions and providing emotional support was highlighted by two participants and having that support allowed

participants a little more confidence in their decision making.

I'll talk it out with (husband), because sometimes just talking it out between the two of us... if Robbie is sick and we say, "We're not going to give him his Methotrexate" once I don't have to make that decision on my own it's not so bad. So when you have that, like (husband) will say, "I think you're right" or "I think you should do that if you think that's best". (P5B)

5.5.8 Summary of 'Lived Relation'

What is evident in this existential dimension of 'lived relation', is the importance of various relationships mothers' experience and serves as a reminder of the central tenet of 'lived relation', that we maintain with others (anyone we have contact with) in the interpersonal space we share with them. The first theme pertained to the strong bond between each mother and their child and was evident in all of the interviews but especially so where the child was present and I had the experience of witnessing some participants in their mothering role. All of the participants voiced concerns and worries for their child and this was reflected again in the second theme when expressing their anxieties about the negative effect of 'giving medicines' to their child. Participants often felt helpless as their child could not express how they may have felt. Staying within the family unit, the third theme concerned the effect of 'giving medicines' on the child's siblings. Key findings to emerge in this theme surrounded siblings helping out in the administration process and other ways they became involved in the medication giving process.

Supportive and unsupportive relationships was the fourth theme to emerge with supportive relationships a necessary part of daily life. Having a point of contact that can respond to a phone call in an efficient manner was highlighted by all participants and having a knowledge and awareness of their child, their child's condition and the medications was important and seen as a basic expectation. All of the participants mentioned the GP as someone they felt needed to be accessible, approachable and supportive through offering advice as well as being attentive in writing prescriptions and filling drug 'Kardex' details. A real understanding of the child and their individual needs was a basic expectation by all of the participants. On the whole, a good relationship with an efficient pharmacist who provided individualised advice and support was the

favoured approach by all of the participants. The pharmacist was regarded as a key person with a role of responsibility in the 'giving medicines' process and someone who could positively influence the impact of 'giving medicines' on their daily lives. While participants found they had to be organised for school, the benefits of going to school for the child far outweighed the perceived need for organisation. Those unsupportive relationships conveyed in interviews and diaries were those that resulted in negative outcomes and were viewed as barriers to participants' daily caring role and often included the same people i.e. GP, pharmacist and respite. This theme encompassed issues associated with visiting the GP, the time lag between requesting advice and actually receiving it and the stress of respite when it came around. Frustration was evident in theme five regarding prescriptions. This theme illuminated the difficulties experienced by participants when communication systems between the GP and pharmacist did not always work and getting accurate prescriptions was sometimes difficult.

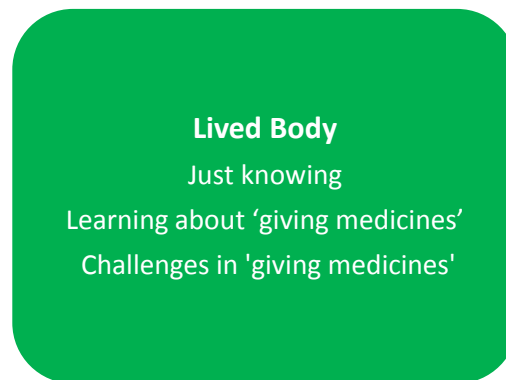
The sixth theme involved getting help and support in 'giving medicines' while still retaining control. Evidenced here was the difficulty or lack of assistance that was available to participants outside of their own family unit, usually their husband. Other sources of support highlighted were social media, voluntary services and hospital liaison nurses, when contactable. Maintaining control in terms of 'giving medicines' was key in hospital and when others were given responsibility, either husband or other. The final theme to surface was that of decision making and its fundamental contribution for participants in activating their caring role. The inconsistencies in decision making processes between participants and professionals were demonstrated with participants making independent and collaborative decisions on a daily basis.

5.6 Lived Body – Knowing, learning about and the challenges of 'giving medicines'

The second existential dimension deliberated on was 'lived body'. This reflected upon how the body was present in conversations relating to the topic at hand. The impact of 'giving medicines' was clearly inferred through discussion with the participants and related to both the bodily experience for the child and that of the mother. Themes to

emerge from 'lived body' were related to both the physical and the emotional aspects of the mothers' experience. Three themes were conceived (see Figure 5): Just knowing, learning about 'giving medicines' and the challenges in 'giving medicines'.

Figure 5: Lived Body



5.6.1 'Just Knowing'

This theme refers to participants 'just knowing' what was happening with their child whether this was by looking at the child or observing bodily behaviours and instinctively knowing that something was amiss, recognising changes that others may not discern. This was perceived to be especially important when it came to 'giving medicines' as participants felt you needed to know how to observe the effects of the various prescribed medicines. All participants expressed how they felt they knew their child so well with one participant indicating she was able to "read" her child;

knowing her so well, and knowing how she reacts to things and knowing where she's at, that takes somebody who is there with her all the time - consistency, and somebody who is able to read her and knows her so well. (P15A)

Equally, another participant declared she felt she knew her child better than her other children;

I think it's just life experience. You just get to know. We know him so well ...at this stage...I suppose we know him better than we'd ever know our other kids. We know every week. We can just tell exactly where he's at. (P10A)

Similarly, one participant described how she did not need her child to undergo clinical investigations to confirm a deterioration in his condition as she knew instinctively when something was wrong;

I know myself, I'm as good as an EEG. I don't need any EEG. Always going back the years when he was bad, if I rang (hospital) to say he's bad, they know he's bad and the first thing they say to me is come straight up. I know exactly the form, what's happening with him. (P4A)

Correspondingly, another participant in her diary notes described her 'knowing' what was normal for her child;

I also find myself reassuring nurses that this is Eoin's "normal" while their faces drop watching Eoin's sats (oxygen saturations) drop to 41% during a seizure. (P6D)

Another participant talked about the confidence with which she knows her role now compared to the early years and how her knowledge helped educate some of the nurses caring for her son.

There was a lot of getting to know Tom with us. I remember when it got to the stage when we were telling the nurses what to do, which I thought would never happen because in the beginning to us the nurses were just God. They just knew everything and we knew nothing. (P8A)

Furthermore, knowing referred to participants developing their knowledge relating to 'giving medicines' even when it seemed challenging.

it can be challenging at times... myself and my husband are very used to Niamh, so we've gotten to know her better, know what she can manage, and we've gotten more used to it ourselves as well and trying to figure it out. We've gotten used to knowing how the best way is to give the meds to her. (P15A)

5.6.2 Learning about 'giving medicines'

Learning about different medications was important to all participants. How this was achieved varied between reading the information leaflet that came with medicines to searching for information on the internet.

I'd look at the leaflet. That would be my first port of call. Then if I found something in it that, "Oh..." then I'd Google it. Or if I was having an appointment

with (doctor), I'd say, "Listen..." (P14A)

Another participant acknowledged she searched on the internet for information and similar to other participants was looking for information on how the medicine was to be given or what potential effects could be expected. This participant had only recently joined a particular Facebook group and used this now to gather information on her child's condition.

...we look it up a little bit online. That's where we get a lot of stuff from...just in the last few months I've joined this Facebook forum and there's sixty children now in the world with this condition. (P3A)

Learning about the intricacies of administering medications and the contraindications was something of huge importance to all participants. One participant talked of how her son had increased seizure activity and nobody could determine the reason until her husband went searching on the internet;

My husband tried to look at the changes our son had been through lately... It happened that we were giving our son Losec for his stomach about 10 days previous... after "Googling" Losec we learned it interfered with phenytoin levels. Our boy was 2 and we were learning from medical journals and drug websites. (P6D)

Learning did not just encompass the information and side effects of medications but also included learning how to administer the medications and using a variety of routes of administration. Doctors would usually advise what the medication is for and its function. However, beyond that, information and education was limited. All participants acknowledged the role the hospital had played in the learning process, watching what nurses were doing and often learning in hospital by 'accident';

I suppose I saw the nurses doing everything and it gradually went up from one to two meds to three meds to whatever. I was never told not to use a smaller syringe and I found out by accident one day when someone said it to me, "Oh you never use the smaller syringe". (P7A)

One participant admitted that while nurses might tell you how to do things, demonstrations were not always given and hearing and doing were two very different things.

Nobody ever showed me how to do that. They'd tell you. They'd tell you sure, but I mean telling you and doing it are completely far apart. I remember all right being handed a packet of them (medications) and being handed the syringes, your prescription in your hand and you don't even know when you're starting what these pills look like. (P4A)

All participants reflected on administering medication orally and the expectation that “obviously you're supposed to know how to do that. You disguise them in the food.” (P4A)

In addition, participants reflected on not knowing what order to give medicines and did it actually matter which was given first. Furthermore, there was a requirement for participants to gain knowledge on dosage and volumes of various medications. One participant summed up her confusion when being told of this and also her frustration when being told to crush tablets by her pharmacist;

My first experience was the nurse telling me about milligrams and calculating milligrams into mls and totally confused me altogether. When it comes to crushing the tablets, nobody showed me. I learnt myself. The pharmacist gave me a tablet crusher and I just had to figure it out myself. He said, "Dilute it in water." It's very difficult to crush and dilute it and try not to lose any of it when you're drawing it up. (P6A)

Depending on the medication prescribed and route of administration, sometimes participants were afforded more opportunity for education. This participant spoke of the need for her to learn how to administer an injection to her son and how the way in which she was taught was very helpful.

There's a little information pack and a step-by-step guide on how to draw it up. The CNS went through it with me and he did it in front of me. That was in hospital. Then the second time a nurse came out from the company...she went through it with me... She went through the kind of side effects and all that as well. So it was good. (P7C)

Interestingly, some participants described how they used their common sense and were practical and efficient about what was required of them in the initial learning stages admitting that they were not always taught how to do things.

I just became naturally clued into medicines when she was tiny. I used my own

judgment as to how to get them into her, but I would always check, either with the doctor or with the pharmacist, if I was given a new drug. Nobody ever sat me down and said 'Now, you're going to be giving lots of medicines to your little sick baby. (P2A)

However, such routes as rectal and buccal were never demonstrated by anyone and therefore participants had to learn these routes as they were required. The use of an NG tube was common practice in two instances where children did not have PEG insertions. This participant became angry when she reflected on her learning and explained that;

nobody said to me, "Do you know how to put in an NG tube?" Nobody said, "Have you any questions about administration of medicines via an NG tube?" Nobody has ever, ever, in 18 years asked me how I'm managing the administration of Ava's medicines. Ever. You just get given a prescription and that's it. Everything I've learnt, I've self-learnt. (P2C)

Another participant talked of how frightening it was to have this tube and all the elements of learning involved in using it.

The NG tube was a learning process. Just had to do it. Simple as that...very nervous. Hands shaking for the first time trying to get aspirates. And then checking the pH sticks - is that the right colour? There was days where I had to walk away from it because I simply couldn't get it and the more I pulled, the more stressed I was getting. (P3A)

Additionally, it was not just the element of administering the medications but with this type of route of administration, the tube could become dislodged and require re-insertion by the participant.

the NG tube had come out a couple of times, or it had to be changed and I suppose we were heading off on holidays and we needed to know how to do it. So, we did do it between us in the hospital and I held her while (husband) put it in. He was very upset about doing it to her. He said he wouldn't do it again, but on holidays, just towards the end of her holiday, the tip of the tube, the NG tube had come off. It got caught in something, so we put it back on with a plaster, some tape and that was doing us for a while and then the tube itself came out so we had to put it back in. So I suppose between the two of us we just calmed ourselves. (P3A)

Similar to NG administration of medications, PEG was also seen as a more complex route of administration. One participant acknowledged she learned how to administer using

this route by self-teaching;

Up to now I've learned myself how to do it. No one has sort of said "well this is the way you do this, that or the other." it's all new. How to learn to use a machine without beeping and air blocking and all that. And then you've to say "right, which way do I turn the button on this peg now to get this medicine in?" "Am I doing that the right way, should I be going that way or that way?" It's all trial and error, but over the years you learn it. (P1A)

Being alone in learning how to give medications was something reiterated a number of times by participants. One participant, whose child was the youngest at the age of 2, acknowledged that even in recent times she was still not taught how to do things.

I suppose just trial and error, and figuring things out ourselves, and obviously looking for Niamh's best interest as to what will make life easiest for her, and what could be most palatable, or certainly easiest for her to take. It's just been trying to figure it out, and our sole objective was to get whatever the medicine is into her in the correct quantity, but the easiest way possible. I suppose we've just figured it out ourselves. (P15A)

Participants admitted that they were often not told what might make things easier for administration with one participant chatting about how she could see the tablet was too big to administer whole and how she discovered a tablet splitter but no one had told her she could buy this or split the tablet. Another participant had learned through trial and error that her daughter required her tablets crushed in order to administer but no one had shown her how to crush tablets.

I remember before we got the crusher, using spoons. So I think somebody had to actually tell me, "You don't have to use spoons. There's a crusher." You'd put two spoons together and you'd crush it down. I remember doing that. (P14A)

Similarly, a participant talked of weighing the tablets when they required splitting as she wanted to be accurate in her measurements;

She has to take one and a half Frisium twice a day. So even chopping that tablet - I remember saying to them up in (hospital), "I can't weigh it. It doesn't come up on the scales. What do I do?" And they said, "It's just to the best of your knowledge, to the nearest 5 grammes if you can." So even at that, some days she probably gets more in the morning than she does in the evening. It's just trial and error. (P3A)

In terms of learning, one participant talked of being in shock coming home from hospital with her son;

when it came to his first night at home I felt like I'd stepped into a pharmacy and it was all so new to us - lining everything up and making sure, checking his chart and then checking again. It was a really slow process. I do remember quite clearly when he was first home, and standing at my kitchen counter with what I felt was like a pharmacy in my cupboard, and all the bits, and the chart to go with it. I thought, "How am I ever going to do this? You know it's part of his life. It's massively daunting, and nobody comes in and helps you, or tells you what to do. (P8B)

While two participants were nurses themselves and would have some knowledge regarding the medications and administration, both acknowledged they still had to learn some elements and were left to their own devices to do so.

5.6.3 Challenges in 'giving medicines'

The physical act of administering medications to this cohort of children is not without difficulty and was an issue at the centre of each individual interview yielding multiple concerns for participants. How a child fed was always implicated in the 'giving of medications' and impacted on this task. In all instances where the child took oral medications, for ease of giving, disguise or masking of the medications was undertaken in order that the child would be able to take them. The link between giving medicines and feeding was central and caused angst for many participants;

I feel we've probably spoiled a lot of her food from feeding her meds through her food, but it's the only way that we can get them in. (P3A)

Altering the texture of the food for giving medicines was mentioned by nine participants. Yoghurt is a frequently used food for administering the medicines and provides a thickened substitute to 'Thick and Easy'.

... her Kepra, her Potassium Citrate, her Pregabalin, or before that her Gabapentin, all get put into a small little amount of yogurt. The mix is, because the Potassium is very liquid, the mix is then thickened up with a little bit of Thick and Easy, and I spoon-feed this. (P2B)

One participant described how her daughter recognises yoghurt usually means

medications and can often refuse the spoon before eventually taking it.

I mix Sophie's Zonergan with a spoon of yoghurt – 1st having opened the capsules and emptied the powder out. I then draw up the Trileptal in 2 syringes. There was lots of shouting no, no, no, turning her head away from the spoon. Then she started screaming. After a minute she takes the spoon with the yoghurt. Often she will hold it in her mouth for a few minutes. Once she has swallowed this, there is no problem. (P11D)

Altering the form of drug to be given is also a common occurrence with many medications not produced in the form that is most suited to the individual child and therefore requiring some adaptation before administration to include reconstituting, splitting, crushing, capsule opening;

The capsules - we can't grind. He won't take a tablet whole. If we try and grind them down once they hit the mouth he can taste them, so he spits them out. So we found that capsules, if you open them up and mix them in with a yoghurt or a smoothie, they go down pretty quick and he doesn't realise he's taking those. (P5A)

Some medications cannot be altered and therefore present problems when being administered but if not administered have potentially life threatening consequences especially if it was an AED for seizure activity.

He seems to gag on it (Buccal Midazolam)...when you're syringing it in, it goes quicker than you want it to go and it kind it shoots off. You're trying to control it then and then you're massaging it in. If you taste it, it's vile. It could take your breath away, and I find, especially when he's in a seizure, he's not going to be well enough to control and it kind of goes with his breath I find. (P4A)

In some instances, the child drools constantly and therefore, to ensure the medication is swallowed, participants spoon back in drool or any residue that is passed out when giving the medicines. This repetitive process is also to ensure that the child has actually swallowed and not retained the medication mix within the oral cavity due to poor swallowing technique. Participants cited checking the bibs that the children wore to ensure no medications had been lost.

Morning time, all her tablets are crushed. They're all tablet form because she's not good with liquids. ...we have to try and mix it up, disguise it in food. It's generally a yoghurt and we feed it to her and generally end up spooning spit

back into her mouth to make sure it's gone in. (P3A)

While all children have specific daily medications, these were all subject to change. The inclusion of additional medications for acute illness such as antibiotics or other PRN medications was problematic especially when giving the daily medications was already a challenge;

...she was on an antibiotic, so it was actually quite difficult to administer. This particular one was four times a day, 5 ml, and for a child obviously with swallowing issues, on top of all the normal medications and her food, that was very challenging. (P15A)

Furthermore, while all participants had worked out the best way of 'giving medicines' to their child, there were times when this did not always go to plan. The status of the child was an indicator if medicines would be taken and if the child was tired or off-form, this presented more difficulties in giving the medications.

If I leave him too late going to bed his muscle tone drops and when he gets tired I can't get the medication into him then. (P10B)

Other difficulties experienced by participants include the struggle in sourcing specific medications their child is prescribed from the pharmacy or on occasion running out of the medication;

Chloral Hydrate is an unlicensed drug, so that's difficult. You have to make sure it's ordered and every once in a while, the supply is short in the UK and they're like, "Oh, we don't have any left." So once I did ring another parent and get some off them because you'd know in a group of friends who is on Chloral Hydrate. (P6A)

I don't know whether it was a Sunday or a Bank Holiday, and I realised that I'd no Clonazepam. I was panicking, didn't know what to do...my own pharmacy doesn't open on the Sunday or the Bank Holiday...And when I went out to the (shopping centre) on the day, the pharmacist, he used to work in the chemist down the road here so he knew me and he gave me a bottle of Clonazepam. (P1B)

All participants acknowledged their personal feelings of dread at giving medicines to their child especially where medications had a bad taste or where injections caused visible upset for their child and in turn the participant.

..you hate having to do it, the Sabril was the first medication she took for seizures, so it was right when she was really small. So that was very difficult, particularly when she was so little and you're giving her something that clearly she despises the taste of. (P15A)

At a point in each interview, participants referred to the potential side effects of medications their child was prescribed but also acknowledged that usually the benefits outweighed the risks for their child. Central to the concerns was the inability of the child to tell their mother if they had side effects and the pressure on the mother to be aware of such effects while not confusing them with being part of the condition and not a side effect of the drug.

I've totally resigned to it because I know he needs it. I've learned that if he doesn't get the Epilim, it's so much harder on himself really. But I suppose my biggest worry always is dry mouth, thirst. Because he's not able to tell us, (P10A)

It's very hard, the side effects, (child) can't tell us. We're guessing for him. I mean some can give you headaches. You've to look out, you know we wouldn't know whether he has a headache. He can't tell us. Nausea, he's never ever vomited. So if he was to go onto a new medicine and he vomited, I would say "right, that's the new meds." (P1B)

An alternative route for the delivery of medications was acknowledged by seven participants with a PEG insertion seen as a positive step despite reservations at moving away from oral administration. Resisting the idea of a PEG insertion was deliberated on by participants but in the end "we surrendered". (P3A)

One participant indicated the challenge of oral administration was getting so difficult that a PEG insertion was seen as a better alternative.

I really don't want a peg, but given what's been happening I'm beginning to see it as a better alternative... (P2B)

Similarly, as there was no guarantee their child was getting all of the medications due to excess drooling, a decision to look at alternatives was made by another participant also;

She's losing some of the medication. She's not getting the exact amount in, so that's definitely a concern for us and that's probably one of the reasons why we're looking at her getting a PEG at the end of next month. So at least we can be

sure that she's getting exactly the right quantity in and she hasn't lost any of the medication. (P15A)

The maintenance of oral feeding while adopting a PEG for medication administration and fluid intake was important and was discussed at length by two participants;

I suppose it's not something you take lightly, or it's not something you want to do, but after thinking about it, for quite a while, and trying to think of what's best for (child) as well. Certainly, it has huge advantages, principally in terms of the medication. You know exactly what she's taking. And secondly, in terms of taking in fluids as well, because she's not able to manage liquids at this point unless they're mixed in with food or that kind thing, so we can be sure that she's got plenty of liquids and plenty of fluids...and hopefully she will still be able to maintain an oral feed as well, which she loves to eat. (P15A)

It was important for participants to acknowledge that having a PEG impacted positively on their child's daily quality of life and meant their child was not woken early in the morning to receive medications. One participant whose child had a PEG inserted between our first and second interview described the positive change in their daily lives as a result of a PEG insertion.

it's a huge change. I mean, crushing tablets in the morning, putting them into sloppy food, trying to spoon them into her and then spooning back in spit; it was disastrous. The stress level of it. The kids were stressed. Everybody was stressed. Whereas now I know she's getting her medicines. She doesn't even see them going in. I stand behind her. I don't know does she get a sensation when they go in? But I know she's getting the correct medication now and it seems to be working for her. She's definitely brighter. She's been in good form. (P3B)

5.6.4 Summary of 'Lived Body'

This existential dimension corresponds with the participants' bodily experience of 'giving medicines'. The initial theme of 'just knowing' refers to participants' experience of knowing what was happening with their child whether this was by observing the child or attending to instinct that others may not experience. Learning about 'giving medicines' was the second emergent theme and pertained to not only learning about the medicine itself and side effects but also to how participants learned to give the medicine and learn relevant techniques and routes of administration. Frustration was evident in this theme as the majority of participants had never been given any relevant education or taught the 'how to' components involved in 'giving medicines'. The final theme to emerge

explored the challenges in 'giving medicines' to be considered on a daily basis from disguise and masking to altering textures. Additional or new medications yielded problems in administration and even when participants had worked out the best methods of giving medicines, the status of the child often determined whether these worked. Oral administration is not without its difficulties and PEG is often seen as the best alternative route of administration ideally where oral feeding can be maintained as well. Additionally, while participants experienced negative feelings at giving their child medications and worried about side effects, they felt the benefits outweighed the risks of not giving medicines. While all participants had significant storage space designated to medicines, some acknowledged running out of medications and having to deal with the resultant consequences.

5.7 Lived Time – The impact of 'giving medicines' on time

The existential dimension of 'lived time' provided an understanding of mothers' daily lives in terms of their experience of 'giving medicines' to their child with severe and profound intellectual disabilities. All participants were conscious of time and the demands placed upon their day with many clock watching throughout the day and some being all consumed by time (see Figure 6).

Figure 6: Lived Time



The concept of time was apparent in many of the conversations with all participants mentioning their need to live moment by moment and be ‘always on call’. Those represented in the excerpt presented in 5.3.1 (Anna and Tom) had their typical daily routine depicted below in Figure 7. Tom is prescribed 17 medications, requiring 13 daily medications and 4 PRN medications depending on his health status resulting in a total of 33 drug administrations per day. This sample figure is reflective of other participants’ daily medication giving pattern also and provides context to this existential dimension.

Figure 7: A depiction of the medication giving in a typical daily routine for Anna and Tom

(Yellow signifies those medications given in the night-time while green signifies the medications given during daytime)



The following 5 themes emerged from 'lived time'; always on call, adapting my life, time consuming, preparation of medications and being organised.

5.7.1 'Always on call'

All participants emphasised the pattern of their daily lives meant they were always in a state of 'on call' and carried their mobile phones if away from their child in case they were needed. Whether it was a weekend or holiday time, all participants had to get up and administer medications as *"they were going by the clock"* (P10D) and rarely experienced a lie-in. Due to the nature of some conditions namely epilepsy, any deviation in the time when medications should be given, could have led to an increase in seizure activity something emphasised by the 11 participants who had children with this diagnosis.

I think sometimes you'd love to just get into bed, especially when you're tired that you just want to sleep and wake up naturally. But you have to actually go by the clock. Oh God, some morning I would just love to be able to sleep. (P10B)

This participant described how she planned her life around knowing she needed to be home if on a night out and up early in the morning to give medications and so restrained herself when out;

if you were out you'd literally - you can't just let yourself go and have a good night till three or four o'clock in the morning because you have to keep an eye on the time and you have to think, Well... up in the morning. (P10B)

Furthermore, participants acknowledged the constant pace of their caring role and how they were always on alert due to the complexity of care their child required and the necessity of medication giving;

It's tiring. It's wearing because you constantly have to be on alert. (P15B)

One participant admitted that respite offered a break from the monotony of medication giving each morning and gave her a break from being constantly on call;

it's great having a break from the 7 am routine because everything is by the clock, even with the other children. So when Eoin is in respite we'd tend to go off for the day and do something totally random with the other kids, which is good. (P6B)

However, she also recognised that you couldn't just go off with your friends as you "you never really turn off" (P6B). The lack of escape from caring as there was no one else to take over was something one participant summed up as;

I couldn't just walk out that door now and not come back till tonight because it's impossible. You know Aaron ... he needs his meds. (P1A)

5.7.2 Adapting 'my' life

In keeping with the theme of being 'always on call', participants acknowledged they adapt what they do on a daily basis to suit their child and the routine of giving medicines. One participant described 'giving medicines' as part of her routine and something they needed to do;

it's probably one of those things that you're doing and you just take it for granted. It's one of those sort of hidden kind of things that just becomes part of your routine, the bottom line is we do whatever we need to do, and that's just part and parcel of what we need to do at the moment. (P15A)

Nine participants indicated they plan their lives with a lot of thought and very little spontaneity exists due to the full time nature of their role. One participant talked about going home to visit her parents with her child and family and after having a lovely day catching up, it being undone by the necessity to 'get in' (P10A) medications into her child who was tired and due to decreased muscle tone found it difficult to swallow. Moreover, this participant recognised she does not go out at night until she has her child in bed and medications given so as to alleviate her anxiety and reassure herself that he is okay. Another participant admitted that as the child needed liquidised foods for giving medicines it determined their lifestyle as they could not eat out because of this. Due to the complexity of some medication giving, choices about where participants could go with their child were limited and compromise was required;

Life is just compromised from day one, and it's just either (husband) is here or I'm here. Or if we have to go somewhere we'll work it round it that we'll give the meds, or we'll do it after or before. Or we'll say, "Well, if we've to go here, we'll go here and we'll give them." But really, giving the meds anywhere else but here or in your mother's house, or in a house... You know, you couldn't do it in a shopping centre. It's just not happening. There's too many variables with this dissolving and putting it in cups and drawing it up, and you need a counter space,

a surface. And she needs to be comfortable as well. (14A)

One participant gave the example of being tied to the house a lot and not going out in the evening or night time but returning home before 5pm as their child required privacy when medication giving due to the nature of the route of administration.

when we're out anywhere we have to be back in the house at five o'clock, otherwise he gets really upset, and it's not something you can do in public, a Glycerine suppository. So that's another frustration, especially if you've other children, because if we're out anywhere we have to back at five o'clock. So that ties you to the house a lot, more than you'd like. (P6B)

5.7.3 Time consuming

This theme refers to the amount of time that it takes participants to manage the task of 'giving medicines' and how time and the clock can impact on their daily life. All participants mentioned time for one reason or another with one participant suggesting 'giving medicines' was akin to another job you just had to do.

you just kind of keep on top of it all the time. It's nearly every night that it's part of the jobs. (P10A)

One participant described how time consuming it can be giving the medicines to her son, ensuring he gets them and no matter what hurry you were in, you just had to allow enough time for this. This was further compounded if additional medicines were prescribed such as an antibiotic.

it is so time-consuming getting them into him and just allowing time. There isn't a thing you can do. It's just he's so slow to eat and he's so slow to swallow that it's not like just, "Here's your tablets, take your tablets", that's it. He can't just swallow them. You just have to allow the time for it ... So you could be talking about the antibiotics, you're talking at least probably twenty minutes before we'd get it into him. And that's going good. We dread to hear he's on the antibiotics. (P10A)

This participant also reflected on time in her diary entries noting;

must be aware of times, if John gets too tired, his muscle tone reduces and unable to swallow meds. (P10A)

Similarly, another participant indicated how it was not as simple as giving the medicines on a spoon and her child swallowing;

it would be an effort to get him to swallow one spoonful, and then I'd have to put an empty spoon in his mouth so he'd give a double swallow to make sure that it was gone down; so that was very time consuming. (P1B)

Participants talked of family and friends not understanding the time constraints placed on their daily lives due to 'giving medicines' with one participant expressing her irritation clearly;

people don't realise the amount of time it takes. Even my own family now. Some of them wouldn't have a clue. They're nearly all teachers. They're brilliant but they wouldn't have a clue what it's like, of what it's actually like to take twenty or twenty-five minutes at a time. (P10A)

This was reinforced further by another participant who voiced her frustration, particularly in the morning time;

I get Aaron up in the mornings, first thing I do, straight away, is his meds, start to feed, and then I'm on to the nebulisers. So he's on his nebulisers and I'm flying. Like there's three nebulisers he has to get in the morning. So it does take a while...Hard. I'm finding it, especially on a school morning, trying to get the meds into him before he goes to school. I'm just finding it very time-consuming. Because I'm under pressure in the mornings, and I'm just finding it harder in the mornings...and double checking and making sure that everything is right. (P1A)

Time was also mentioned by participants especially relating to those using respite and how time taken to prepare the medicines and associated equipment took quite a while.

the management of those medicines is really time-consuming, getting it sorted. (P2A)

All participants acknowledged that time was spent ensuring you had enough stock of medicines and if not you were on the phone ordering either the prescription from the GP or the drugs from the pharmacist and you were completing an informal inventory of your supplies.

you have to constantly watch that you're not running out of something, and I suppose that you need to go up to the pharmacy to get a new one or order in a

new one of something. So it's another thing to keep on top of along with everything else. (P15A)

If not on the phone to the pharmacists, participants indicated they were making trips to the pharmacy, often on a daily basis for one thing or another;

It's busy, and between getting them and just keeping stock of the medicines, stocking up the cupboard and going to the chemist on a daily basis ...some hours can be very busy ... every day I'm onto the chemist (P8A)

Participants especially those who had to administer multiple medications on any given day, cited the reality that everything else got left undone. "You're against the clock the whole time" (P3A) is how one participant described her day with trying to get medicines into her child being very time consuming especially when there were other children in the mix.

we crush all her tablets and we're trying to get the others ready at the same time and try and eat a bit yourself, so it can be hectic. We did consider splitting Marie's meds up four times a day, so that we had smaller amounts to give her. But it's not practical. It's not practical to sit with Marie four times a day for meds. Then you've to get them into her and then obviously try and get her ready and get dressed and ready for school. (P3A)

This participant also conversed about a deterioration in her daughter's health meant more medicines and resulted in more time being consumed by medicines management;

There's a lot more syringes, a lot more flushes. It's more visits to the pharmacy. We're trying to figure out her prescriptions so that I'm only in the pharmacy once a month. The MST granules - at the moment the way her prescriptions are, I get them every two weeks. But if we could just fix them all together, it would make life a hell of a lot easier. (P3C)

The same participant reflected on Christmas time and how her husband was at home more and to give her a break undertook the medicines management making her appreciate how long the process actually takes;

looking back over Christmas, my husband was here. He was doing a lot of Marie's meds, and he'd be out here for twenty minutes, and I'd be saying, "What are you doing?" And he'd say, "I'm doing her meds." I'd say, "You couldn't be still doing the meds." I suppose I don't realise how many there is to syringe, and pull back. It

was only while he was doing them over Christmas I realised that there's a lot involved in it. (P3C)

Similarly, one participant expressed how she was so used to 'giving medicines', this research study placed the spotlight on it and she really began to reflect on it;

we do 30 medicines a day, 30 in 24 hours...this was just so consuming, and concentrating on every little dose, and making sure, and measuring, with the sterile technique that we have to do. Not to mention thinking to make sure that we had enough, or to order them. (P8A)

The time required for preparing and giving medicines was a real concern especially for those participants who had several medicines to administer and had other children to consider in their lives also;

for 24 hours, there's a medicine for every hour, and I'd say I probably spend about two hours a day getting medicines done up...Because for each medicine you give him, there's a pre and post flush, so it's a syringe for the medicine. It might sound silly, but come five o'clock, Tom is due medicines and he's due a feed, and from before five, quarter to five, getting this stuff ready, between that, his nebs, and then the other little lad to mind as well, like I wouldn't see it going from five till nearly half seven. (P8A)

Many of the participants highlighted their frustration not only in terms of giving the medicines and the challenges in time that can yield, but all of the other associated requirements such as paperwork, retrieving prescriptions from a doctor, then taking them to the pharmacist and collecting the medicines.

You're a full-time secretary as well as everything else, trying to keep paperwork up to date. (P4A)

5.7.4 Preparing Medications

All participants discussed the preparation of medicines and what this meant for their daily lives. Four of the participants expressed how this research study made them think about the preparation process and made them realise what it requires of them and how time consuming it can be. Not only was being prepared essential but being precise was as important for participants. With other children in the house, school runs and in some cases work commitments, being prepared was a top priority and a time saving strategy also. In the preparation process, nine participants acknowledged "drawing them all up at

night” (P7B) while others did not do this but prepared the daily medications in the morning. One participant described her level of organisation the night before and it is notable how complex this becomes when a PEG is being used as the route of administration also;

...the ones that I can get ready, I do. Drawing up the meds and leaving the ones that are needing to be dissolved in their little cup, and the ones that need to be crushed - crushing them and getting the right volume of fluid for them. I draw all that up and all the flushes up. I draw about 40 syringes up the night before I have everything literally ready to go because the morning is very busy and he gets a bus to school and I've to get twelve meds into him before that... if I had to draw them all up that would be a pain. I love having them ready. (P7B)

Another participant articulated that preparation was influenced by the medicines prescribed and required preparation just before administration, therefore meaning you could not be organised in advance;

When we're preparing her food, have the kettle boiled... with the Sabril in order to get it down to the least amount we use boiling water and basically add the powder to it in the least amount. We have it worked out down to the least amount to give to her. So obviously that has to be freshly done that morning. Then the others, it's just a question of drawing them up in the appropriate amount. So at the moment we have six syringes that have to be given in the morning, and it's one less in the evening. (15A)

Some participants described the technical elements of preparing medicines and this resulted in a more difficult administration process;

Anakinra was a bit of a pain because you had to take it out of one syringe and decant it into another one. This one is probably actually easier (referring to Humira), but it's just more fiddly because it's in a vial, and so you've to take it up and then you attach your syringe. (P7C)

All participants identified their own way of ‘giving medicines’ and how their technique worked for them. This was interesting as it was evident no two participants had the same way of administering but clearly adapted to their child’s individual needs.

I crush the Vitamin D tablet, the Kepra tablet. I've already put the 30ml of peppermint water and yoghurt, honey and her 5ml of Potassium Citrate into the bowl. I thicken them up and then I don't add the Vitamin D and the Kepra until just before I feed her. And I don't know why I do that. I just have this idea that I

don't want the Kepra interacting with other stuff for the 20 minutes it takes me to get her up. So I have it mostly ready and thickened - but only thickened slightly - otherwise, by the time I have her up it will be rock solid. (P2A)

As medicine giving requires a degree of accuracy to avoid any risks to the child, participants discussed the precision adopted in preparing the medicines for administration. Participants adopted procedures for ensuring safety, an important element especially when tablets or liquids looked similar in shape, size or colour.

I take all of the bottles out of the medicine cupboard and line them up, but when I've drawn the first one I close the bottle, put it back in the box and put it in the cupboard, so that there's no risk that I'll get confused about what I did or didn't already draw into syringes. (P2C)

A level of precision was also required in terms of measuring the various medicines especially if they required reconstitution, crushing or dispersal and the child was not on a full dose which meant participants were measuring portions of medicines and discarding the remainder. Additionally, flushes for gastrostomy tubes had to be considered also.

I have to put 40 ml of water into the cup, and I draw out 20 ml. That's one flush. The other 20 ml then I would put in the Zoton, which disperses normally itself, and the Topomax, I will have to crush that. So I crush it and then I add it to the water with the Zoton. Then I will draw up the 6 ml of Kepra and the 5 ml of the Omega 3...she'll either get the sachet of Movicol or the sachet of Osteofos. The powder is put in a glass and I usually have four vials that I will mix that with and then I'll have to draw up four syringes. I'll draw it up into syringes and that will be her flush as well. (P14A)

This level of precision was also used in terms of ensuring safety was a top priority with one participant acknowledging she cuts the tablet packs into groups of 3 so she knows she only needs to take out one piece of the packet per administration and in turn she felt this was safer than having all of the pack out on display. Precision was also made easier when participants adopted strategies such as using a specific size syringe for drawing up medicines or for administration, for example, 5ml syringe for 5ml medication. The need for precision was also a concern as some participants acknowledged levels of accuracy could be questionable when drawing up some medicines.

I was pouring the Epilim into a little cup and then I was flushing back because I was using a 20 ml syringe, and then the 20 ml syringe doesn't fit into the bottle. But now I'm using the 10 ml, so I just go into the bottle and I pull it out. 10 ml is easier...measuring out the Frisium, the Epilim, sometimes it's probably 7.4, sometimes it's probably 7.6, and it's a case of just go with it. (P3B)

Another participant voiced her desire to be prepared especially the night before as she found she was tired in the mornings and she had to stay up late at night anyway to switch off her daughter's feed, so this was time she used to prepare for the following day.

I do that last thing at night, usually while I'm pining away the last few minutes before I can get into bed...so I go out and get all the bottles and I'll get all the syringes that I need... I'll leave them all on the end of the worktop there, and I'll have them all ready to go, so I'm not walking in and out, because in the morning, a little bit sleepy and you might go and get something and then, Oh, I've forgotten that. (P14A)

One participant specified that many of the medicines her child was prescribed were only available in tablet form and required crushing and then dissolving further in liquid in order to administer more easily but this took more time in preparation.

you have to crush the tablets that you have and place them into the different containers of liquid, mix them, make sure they're dissolved well, set them up, have your sterilised water ready... I do find it difficult with the film-coated tablets. It takes a bit of elbow grease now to get them broken down... you have to crush and there's bits...just keep grinding and grinding and pushing. It does take a bit of force. You have to really clean it out well, not to leave anything behind, trying to get the last little bit... (P4A)

Similarly, another participant described her specific method of administering one particular medicine her son was prescribed;

I put the two tablets into a syringe and then I pull up ten ml of water... that's my way of doing it ... You just need to give the syringe a good shake when the tablets are in it and that dissolves the Ospolot. (P1A)

Being precise was also described by one participant relating to preparing an injection for her child. She also recognised her commitment to ensuring there was no scope for error by using the correct size syringe for the dose that was required;

I transfer his Anakinra to a syringe. I transfer from, it's 100 mg in 0.67 ml...it's a bit tricky, and you've to transfer that into an insulated syringe. He gets 0.47 ml at the moment and I give that in a 0.5 syringe...I really am a stickler... I try to use the correct size syringe, so like, he's on 0.8 of Sildenafil, so I use a 1ml syringe. He's on 2ml of Motilium, so I use a 2.5ml syringe. It just leaves less room for mistakes. (P7A)

Precision was also adopted by participants in terms of timing and how it was important that their child be positioned correctly to support the ingestion of medicines. One participant detailed how her child could not tolerate medications while in bed and had to be placed in his chair for all administrations.

I have to get him into his wheelchair sitting upright, before I can give the Kepra, because it's a syrup so it's more difficult to digest for Eoin...so he'd have to have that with about 20 or 30 ml of water. So he wouldn't tolerate it lying in bed, so I wait till he's in his wheelchair and give him that one. (P6A)

While all participants acknowledged the time required for preparation and administration of medicines one participant summed it up with her explanation of a typical day;

I guess, preparing every medicine, it's not just a second job; you've to get out everything sterile; you've to crush it. But with each medicine, while you mix with water, you've also got to have a flush afterwards. So for every medicine, you're talking three syringes, so multiply that by 30. And that's only a standard day, never mind if an antibiotic is thrown into the equation, which he'll get four times a day. So, for 24 hours, there's a medicine for every hour... (P8B)

5.7.5 Being organised

This theme refers to the level of organisation required in daily life relating to 'giving medicines' and encompasses concerns about ensuring medications are administered at appropriate times without delays to being organised in terms of travelling and ensuring medications are packed. Firstly, organisation is required to ensure medications are administered on time especially in the case of AEDs.

we have to be so organised. Because he's on the anti-convulsant medication, it's just imperative we get the medication into him. We can't go anywhere without being so organised with taking everything. I'm from the country, and if we go home I have to always make sure I have it all with me. (P10A)

On a daily basis all participants indicated the level of organisation required especially in the morning time but also throughout the day.

Jake is on 17 meds daily and he's on them numerous times a day. So in the morning he's on 12 medications and a Flixotide inhaler as well, or a nebuliser if he's unwell. So, mornings, you want to be organised. So I draw up all my meds the night before. He goes to school at quarter to nine in the morning, so I need him to have his meds before he's going on the bus. Then I have his meds drawn up for when he comes home from school. Then at nine o'clock he gets 8 meds. Then at ten o'clock he goes onto his water - you really have to stick to your regime. You just have to be ultra organised. It's a nightmare. (P7A)

This participant admitted that with the requirement to be so organised in terms of medications that sometimes she felt it was the only thing she could keep on top of. In addition to being organised in terms of giving the medications, participants also relayed the importance of ensuring your organisation included having the medications ordered.

you've got to be prepared to order meds regularly because you can literally run out of something in the middle of the night and need it. You have to always have your back-up supply and PRN stuff. It's all a balancing act, so really organisation is the key. (P7B)

Interestingly, one participant described her checking process as akin to preparing a shopping list;

You know how you go to the fridge to check what you need before you go to Dunnes (large supermarket)? Well, I go to the medicine cabinet and check what I need if I'm going out. It's that simple, but it's that ingrained in me, that if I'm going to the chemist, "Oh, I'll just check and see what we need. (P14A)

Participants also indicated that ensuring you kept copies of prescriptions was important especially when several people were involved in the process and to ensure the child got the correct drug and dose.

you really have to micro-manage and make sure that if the hospital is faxing the GP, they post the original to me so that I can make sure that what I'm getting from the GP is what the hospital prescribed. (P2C)

5.7.6 Summary of 'Lived Time'

The existential dimension of 'lived time' referred to the objective and subjective

experience of time. Participants conversed about their requirement to be ‘always on call’ in the first theme. Participants rarely experienced a weekend or holiday lie-in as they always had to be up to ‘give medicines’ and as a result planned their lives around this daily event. The second theme directly linked to this was the need for participants to adapt ‘my’ life. Participants experienced little or no spontaneity in their lives as they were stifled by the routine of ‘giving medicines’ and their caregiving role. How time consuming the task of ‘giving medicines’ is was apparent in the third theme with all participants talking of how time spent ‘giving medicines’ and the clock impacted their daily lives. Additionally, participants discussed at length, in the fourth theme, the preparation of medications and what this meant for their lives. Preparation was advocated as essential but so too was precision and accuracy. This was further supported in the final theme in this existential: being organised. The necessity to be organised was highlighted as important in ensuring children got their medications on time to being organised in terms of travelling and ensuring medications were packed.

5.8 Lived space – Physical and emotional space

‘Lived space’ was the fourth existential dimension to be considered (see Figure 8).

Figure 8: Lived Space



From Van Manen’s perspective this dimension of ‘lived space’ is concerned with the mother’s life and the space her life occupies. In this instance, mothers referred to space in terms of physical and emotional space. In all interviews this was participants’ first experience of having a child with disabilities and one that required adaptation in their lives and a raft of new skills. Daily life is all encompassing and for some the task of ‘giving medicines’ becomes the main force in their life dominating all actions with their child on

a daily basis. They inhabit a new personal space as they adapt to the demands of their child with little space left for themselves. All of the participants demonstrated resilience as a key skill in their lives and were resigned to the fact that they had no way of knowing how long their child might live into the future as many of the children had complex health challenges. This overarching theme gives an understanding of how mothers negotiate their days and provides insight into their 'emotional' space considering their feelings and their 'physical' space considering their environment and travelling. The two themes to emerge in relation to lived space were; emotional space - feelings experienced by mothers and physical space.

5.8.1 Emotional Space - Feelings experienced by Mothers

As all of the children were prescribed multiple medications, participants experienced and talked about many negative feelings associated with 'giving medicines' to their child. Three participants highlighted feelings of frustration within several areas of daily life such as pharmacists not having medications ready for collection, to never being able to switch off from their caring role. One participant indicated her frustration at knowing that by giving a medicine to her child it also had the potential to give side effects.

Knowing that you've to give him these drugs that will make him so sick, it is frustrating alright. (P6B)

Six participants conceded feeling guilty about one thing or another, whether it was guilt at giving medicines and contributing to the associated side effects to experiencing guilt that they can eat and drink normally, unlike their child. One participant described her feelings of guilt at sitting to have a cup of tea when she felt she should be doing something for her child;

If you sit down and have a cup of tea you feel guilty. You're constantly on about medicines. If you didn't make the phone call, 'Oh, that was for him; I should have done that. (P8B)

Feelings of guilt were also coupled with as one participant described the "harrowing" (P14A) experience of realising that their child had such complex daily needs.

I found it very harrowing taking her home with the pump and feeding her that

way. That was our 9/11. We were in the back of ambulance coming home with Emma with a pump in that September. She was born in the May. That's where I was when the twin towers came down and I couldn't have cared less about the twin towers. I was having my own 9/11 in the back of an ambulance. I remember thinking... you know, the nurse goes through the pump and I was thinking, "I could kill her. If I give her too much; if I don't give her enough." That was harrowing. (P14A)

In addition to feelings of guilt, one participant described being overwhelmed by what she does;

It's overwhelming really, because you know you've got to mind your child, do all the nursing and then along with giving him the medicines and making sure you're giving them at the right time. (P8A)

A sense of sadness was acknowledged by four participants particularly in terms of giving so many medications to their child and feeling helpless about that while one participant when interviewed on Pancake Tuesday acknowledged how sad it made her feel that her child who was PEG fed and a non-oral feeder could not enjoy pancakes with his siblings. Another participant became upset and cried when she became overwhelmed by her feelings;

I'm giving this child so many pharmaceutical drugs, I know it's nothing in comparison with some kids but I'm putting all these things into her body and I've no idea how she feels ... because she can't articulate it. (P2B)

Another participant appeared sad as she relayed her feelings;

some days now you just feel, "Oh, what did I do to deserve this? And what did she do to deserve this?" It does get you down, absolutely. You look at other people and you say, "Oh, I'd love that" or "Why can't we do that?" Or, going on a holiday - that's hard. You feel like you're missing out there. Or even things like Sunday lunch, you know? Going out. You can't do that. She won't sit. She won't sit for any length of time like that...everything is compromised. Everything is harder, but you learn to accept. You accept it and this is your life... You deal with today, and if today is not a good day you say, "Well, tomorrow will be better. There's always tomorrow." (P14A)

One participant admitted feeling "nervous" (P1B) when giving medications in case she had not double checked everything or made a mistake. The stress felt by three

participants was evident in their body language during interviews as well as being voiced. This stress usually emanated from trying to get their child to take the medicines they required and sometimes could not get them in coupled with trying to get out of the house with all of the relevant medicines and associated equipment.

there's times - I mean when everything kind of came to a head in February and I went to my consultant in (hospital) on a routine check and he ended up sitting with me for an hour and I couldn't stop crying. But the stress of it was unreal and I was saying to my husband, "I think I'm having a nervous breakdown." I was having palpitations, just anxiety. The dread of it, of putting these meds into her. (P3A)

Coupled with these feelings are the worries participants faced about their child experiencing effects and side effects from medications to worry about leaving their child in someone else's hands (i.e. respite). Other worries related to medications no longer working and if there was any other medication left to try and linked to fears around the future for their child. One participant acknowledged that when a deterioration is noted in her child's wellbeing she would often ask her husband;

Do you think is she dying? (P3A)

Nine participants expressed feelings of resignation towards the medications to be given and the challenges that ensued while also conveying the message that this caring role incorporating medication giving was something they accepted.

Everything is harder, but you learn to accept. You accept it and this is your life and then when it's your time to have a break, then you make the most of that and you do the best. (P14A)

What do you do? I mean, you have to cope. You can't sit down and cry. Like, he needs minding and you just get on with it, and he's so good in himself. He's such a good little person, that you just do it. Look, you're a mother. You do it for your child. (P8B)

The loneliness and feeling of isolation experienced by participants was evident throughout interviews with some openly feeling more isolated than others. This feeling of isolation occurred more in those ten participants who did not work outside the home and nine of these conceded they had poor support structures outside of their husbands.

All of these acknowledged they would like to have more people to visit and bounce ideas off or take some responsibility off them. One participant described how she would love to have someone help her out;

there's lot of times where you're taking matters into your own hands and you would love somebody a little bit more of a link like that. That when you're in it, you feel there's times where you're a bit isolated. If only you had somebody who could just help you out. (P8B)

This feeling of isolation was further underlined when one participant described how social media impacted on her life in a positive manner and was deemed as a social outlet.

I love social media because I wouldn't be able to get in touch with a lot of people that I've met through Down Syndrome, so I... because I wouldn't get out that much, so that's probably my social life. (P5B)

The feeling of fear was extraordinary and indicated by all participants in some form. Fear of changing medications was one element of fear with one participant describing her fears for her son;

...with the new drug, Humira, there's risks associated with it, like everything, but TB is one of the risks, and then skin cancer is a big risk. The other risk is lymphoma, and Jake is kind of already at risk of that because he has Down Syndrome and he's 20% more likely to have leukaemia. (P7A)

Fear of changing medication was also referred to in terms of children coming off particular medications that they had been on for a number of years.

Lamictal had been one of her drugs. She only came off it a few months ago and it's almost like saying goodbye to a friend. I'd been giving her Lamictal dispersible tablets twice a day for so many years and they had worked so well. It was like losing a friend you didn't want in the first place, but that you came to trust somehow. (P2A)

This participant also stressed how she had to come to terms with her daughter being prescribed morphine.

it felt a bit weird bringing Morphine into the house, because psychologically I associate Morphine with post-op severe pain. Or, I associate Morphine, thinking

of friends and everything, with palliative pain relief. (P2A)

Fear of morphine was commonplace as other participants had similar concerns for their children;

I was very anxious about giving it to her because it's morphine. It's only a very small amount but I was afraid I'd overdose her. (P3B)

My biggest worry is that he'd become reliant on it and he'll start waking for it. So I have a three night rule, where I'll give it to him three nights but then on the fourth night he's not getting it. So I'll try everything else first. (P6A)

An additional fear for participants was around the future and what the future would look like for their child. This was particularly difficult for those who had poor support structures in place and feared for their child if they were not around.

If I was very sick I don't know what we'd do, or if he was very sick... It would be extremely difficult. (P11B)

Transition from child to adult services was another fear voiced by participants especially as long lasting relationships had been built up between themselves, service providers and children's hospitals. One particular participant whose daughter was 17 was very fearful for the future.

Ava is going to be eighteen in a few months and we're leaving them all (refers to staff). I just have huge trust in them. I'm very aware of the fact that we've got relationships that have built up over years and years. Therefore, we can have discussions; we have ways of communicating that will not be available to me as a stranger in the world of adult hospitals. I haven't yet really contemplated what management of Ava, pharmaceutically, is going to be like post next summer. (P2C)

5.8.2 Physical Space

In terms of physical space, in the case of the nine participants interviewed in the home, all had adapted their living environment to cope with the demands of having a child with severe and profound intellectual disabilities. In Appendix 20 (setting the scene), it was evident that Anna's house was adapted around her son Tom. This type of adaption encompassed those participants who had deliberately extended their houses to have more space for wheelchair and specialised equipment. Others had merely rearranged

their living environment to facilitate the needs of their child. With regard to travelling and how 'giving medicines' impacts on travelling from a variety of perspectives was considered by participants. The requirement to bring medicines when going out of the house or avoid travel due to the complexity of the medication giving process was commonplace. Additionally, issues like packing the medications and ensuring they were not forgotten was important. Ten participants talked about travelling at length. One participant acknowledged how she never forgets her sons' medication;

I'm from the country, and if we go home I have to always make sure I have it all with me...After many years, we never forget John's medication when we go travelling. But in his bag, even the Thick 'n' Easy, if you don't have it with you it can have such consequences. Because if you're out and about and you haven't got it, you can't get a drink into him because it's thickened fluid. So he could aspirate...But we've just learned that everything is in the bag. It's attached to his wheelchair...(P10D)

Similarly, another participant admitted she carries a changing bag with her when they are out and this contains relevant medicines and related equipment.

...in her change bag I would always have a number of suppositories... in case we need them...it depends on if you're away for a few days or if you're just out for a few hours in the middle of the day. If it was out for a few hours in the middle of the day, then I would bring the bottle of Clonazepam and a syringe with me, and then just draw it up with her lunch... if you're away for a few days then that's a different ball game. ...the lunch box comes with us, with all the bits and pieces and obviously a big block of syringes as well. (P15A)

Another participant conversed about visiting her mother at weekends and what that meant in terms of travel for her;

even going to Granny's for Sunday dinner, you have to bring everything with you. His bag on the back of his wheelchair always has his rescue meds in it. But I have to plan exactly what to bring...bring the medicine with me and I always have to bring painkillers. (P6A)

In particular the need to travel everywhere with an AED was highlighted by two participants.

I just have it in his bag. Every place he goes it's kind of part of it, like nearly putting your shoes on. The Buccal goes every place with him. (P10A)

Additionally, most trips out of the house require planning and organising but in case that is not always possible having a plan in place is necessary.

I've actually a bag there... We call it our emergency bag. If we had to go anywhere in a hurry there's syringes to sterile wipes to gloves and then the medicines can't really sit in it, so it's always just the last minute. Even if we go to go out for trip even if it's short-lived, we'd always think ahead for medicines because we've got caught out a few times and then we're stuck. (P8A)

Furthermore, depending on the prescribed medication the child takes, going out and about may require additional burdensome measures such as bringing cool bags or packing ice. One participant indicated her need to bring ice for one her son's medications in order to keep it at the required temperature and also how they often planned flights to the UK around when medication would be required to be administered.

you have to be organised because the Enbrel that he takes has to be kept in a fridge. It's only supposed to be left out for two hours at the most. That's just to bring it up to room temperature. So, if we're going somewhere we bring ice packs with us. One time, we were only going to England for a couple of days, but we booked it around him having his Enbrel injections so we didn't have to bring them with us. (P5A)

One participant admitted going anywhere with her son was very different to packing for her other children;

There's so much more than just an ordinary kid - the two older ones when they were small, and you look back, you know when you go on holidays and you've to pack this and you've to pack that. But it's so completely different. You can't afford to forget things. (P10A)

Another participant discussed a forthcoming weekend away where she and the family were travelling to the West of Ireland (a 4 hour trip away) and the resultant packing process that would be required.

We're actually going away to (location) for the weekend and going away is an absolute nightmare. All his drugs, and you want to bring enough of everything in case you need a bit more. Really, going on holidays is a bit of a nightmare. You've to bring syringes and water... Then you've to bring all the other stuff in case; all the PRN stuff. So there's things like Dioralyte and Ventolin, and then you might

need to bring your nebuliser with you because you might need to give a neb. (P7C)

Travelling abroad was an issue for only some of the participants as many out ruled travelling because of the complexity of care needs. However, one participant indicated her concerns and worries when travelling and how her hand luggage consisted of medicines;

We've been abroad a couple of times, and I suppose my concern is that if I dropped the bottle of Trileptal and it broke. Usually I will have a copy of the prescription with me, but you're in a foreign country and you're hoping that they'll recognise. You have to bring the medicines onto the plane with you, because obviously if your bag went astray. (P11A)

All ten participants who indicated travelling as a concern, acknowledged that they were the person with sole responsibility for ensuring they had everything medicine related packed.

I have a little cool bag that I generally put the medicines into, with syringes and spoons and yoghurts and whatever. It's just then I have to try and think, "Have I actually put that bag in the car? It is always me that has to remember to bring the medicines. (P11A)

If out and about a child requires medication, it was highlighted by one participant in particular that you would “work it round that so you'll have it done, or that you'll be somewhere that you can do it comfortably”. (P14A)

5.8.3 Summary of ‘Lived Space’

This existential dimension of ‘lived space’ is concerned with the mother’s life and the space her life occupies. In the first theme, emotional space was recognised with a mix of feelings experienced by all participants and were consistently negative in nature. Feelings of frustration and guilt were experienced on a regular basis. Worry and stress was also felt by participants regarding their child and the fact that they give them so many prescribed medicines. As well as feeling somewhat overwhelmed at times, there was a sadness experienced and a profound sense of loneliness and isolation especially by participants who a poor support structures. In the second theme concerning physical

space, participants identified key points in terms of adapting their environment to cope with the demands of their child. This warranted adapting the home environment but also concerned going out and about with their child and the requirement to travel with medications and associated equipment as necessary.

5.9 Lived things – Material things that influence mothers' experiences of 'giving medicines'

The final existential dimension to be considered was that of 'lived things' and refers to materiality and how certain material things in life can influence mothers' experiences of 'giving medicines' to their child. The material things mothers spoke about resulted in three themes (see Figure 9) and included; cost of medicines, keeping a record and documentation and associated equipment.

Figure 9: Lived Things



5.9.1 Cost of medicines

The cost of medicines was a concern for five participants although all of the children had long term illness (LTI) cards and therefore participants were not incurring charges for certain medications. However, one participant displayed her annoyance as she was incurring costs that should have been covered by this card.

*he's on his medical card and we use our long-term illness card as well. But no one told us you could use them together because you weren't allowed, and now you are. So for a long time I was paying €2.50 for things that I shouldn't have been.
(P7C)*

Another participant talked about her child being prescribed an unusual medication

requiring quite high doses on a daily basis and the formulation being changed on recommendation by the pharmacist from a liquid to a capsule most likely because of costs being incurred by the HSE.

it was also money driven, because the liquid is €16 for 100ml bottle and if she goes onto 40, four times a day, so you're talking 160ml a day at €16 for 100ml, and they're not on the medical card because it's a non-standard item. Even though it's not my money, I am utterly opposed to anyone being asked to spend €800 a month on a massively overpriced product. Because 20 capsules cost something like €7.95. I think the pharmacist might have been thinking about the difficulty the pharmacy might have in getting this funded. (P2A)

One participant discussed her surprise when she realised the cost of her daughter's medications and the relief of having a long term illness card;

The initial medications were really expensive. I remember sending my Dad down to pick up a few - and thinking, "Ok, it will be thirty or forty, maybe fifty quid." He came back and it was 120 or 130. So luckily, or thankfully, we managed to get the long term illness book. (P15A)

Another participant described how the recession and cutbacks had affected the supply of equipment made available to them and the consequences of that;

I used to get a box of syringes on Robbie's LTI book, but the cutbacks took them away. Robbie will take the medicine through the syringe. Now, he takes it through a spoon, but I did find that I had to buy them because the HSE cut back on them. Just for - they don't wash very well. You put them in the dishwasher; all the numbers come off them and you're kind of guessing. So we just have to buy stuff like that. (P5A)

The prescribing of unlicensed medications for children, while necessary if other alternatives were not available, was also highlighted and one participant acknowledged when sourced it was expensive to pay for.

his iron, the Fer-In-Sol, is there. It's an unlicensed drug...it's only a tiny 20 ml bottle, but it's €33... (P6B)

5.9.2 Keeping Records and Documentation

This refers to keeping a record of what medicines are given and sometimes what happens on a daily basis in order to make it easier when attending appointments instead

of recalling information. While for some participants records were not a priority, a large part of the 'giving medicines' process was linked to keeping records and documenting. Three participants admitted that their knowledge of drugs was not something they had or felt the need to document but more or less kept in their head.

I think I have it so much in my head now I know everything he needs. I don't actually need to. (P10A)

Maintaining a record of medications and other related information was important for participants with no two keeping the same standard records. Keeping either a diary or lists was identified by 12 participants.

I have a diary. I have my list of meds and my regime for the day pasted on the back of his medicine cupboard. (P7B)

Conversely, one participant admitted she does not currently use a schedule but had done in the past but was keeping a daily diary of events so she had a record for hospital visits;

she was on something like eleven drugs and between them, maybe some were once a day, some were twice, some were three times, I think I was giving her something like twenty-three doses of medicine per 24 hours. That was the only time that I actually wrote out a schedule and put it on the back of the cupboard door. I'm keeping a diary because between (doctor) and (another doctor) and people wondering what's happening, and me trying to follow what she is and isn't doing. (P2A)

Likewise, another participant described herself as a secretary and how she keeps notes constantly;

You're a full-time secretary as well as everything else, trying to keep paperwork up to date. I have notes that would fill the room here. (P4A)

While another participant admitted she was so busy with her child she felt she needed a secretary to deal with the paperwork;

With Tom there can be a lot of paperwork and there's a lot of notes and visits to the hospital, so sometimes I feel like I need a secretary as well to keep up with all this. (P8A)

What is recorded on these schedules was important with one participant explaining the content of what she would document, not for herself but for others if they were administering the medications;

I have, when Mammy isn't here, a go-to list of what she's on presently... and how to give it, and where it is, and the doses and everything. I have that written down now for when I'm not here. (P14A)

Eight participants acknowledged that keeping documentation was a fundamental part of their role in 'giving medicines'. One participant talked of there being no particular document that anyone gives you and therefore she devised her own.

I have a template on my computer and I just adjust the template...which included all of the categories of information... But I'm just typing them in and it's easier. It includes a list of all of her medicines, how many mls or how many tablets of what strength, what the expiry date of every tablet and every liquid is. (P2A)

Another participant who adopted a similar approach and had devised her own document, found it needed amending frequently due to changes in medications but was a useful aid in ensuring others knew what medications were being given.

Sometimes I have to adjust it so much that I need to do a new one because it's so messy. So I'm changing that a lot, but I find that if I type those things out it's just so much easier for everyone to read and you can't make mistakes. And I try to bring one to hospital with me to A & E and stuff. (P7B)

Keeping records of paperwork associated with 'giving medicines' was something highlighted by all of the participants. One participant described how she keeps prescriptions, letters and appointments all in folders and because of this she knows what medications her child has been on and what has changed.

we keep all the prescriptions, so we have a couple of folders with all of Niamh's letters and appointments, and then from a medication point of view, all her prescriptions are kept together. So I suppose there's a record in that sense from the first through to now. (15A)

With no specific documentation for those giving medicines at home to this group of children, one participant described her struggle at devising documentation that worked

for her and those caring for her son.

from being in (hospital) and seeing what they did - initially they actually gave us some copies of their daily sheets...Then the agency used to have a report that you'd fill in on his nightly care. You'd tick the medicines but it was nearly seven pages long. So by chance we came across this monthly chart, so you've got all the medicines for the month in one chart, and we just initial as we'd give it. (P8A)

The importance of such documentation for medication recording was highlighted by this participant and she acknowledged that each person who administers medications would sign it and if it was unsigned, there was a system in place that the individual on duty would be called to clarify if they had administered the medications. As this child required a minimum of 33 drug administrations in a day record keeping was essential to ensure his wellbeing.

5.9.3 Associated Equipment

Mothers acknowledged the process of 'giving medicines' requires a lot of additional equipment, whether this is a tablet crusher, pill breaker, syringes for measuring and administration or feeding equipment for a PEG that is also required for administration of medicines. With some children prescribed 17 medications, storage of medications at home requires a specific storage area with each participant describing or showing me the designated cupboards, some of which were locked to prevent the child's siblings accessing them. In some instances, large volumes of kitchen space was taken over by medications and the associated equipment. Fridge space for medications was also a requirement for many of the children with some of the children having their own specific medication fridge.

They're in a medicine cabinet out here in the utility room, and they're stored there. There's one press (cupboard) that's full of feed, one press (cupboard) that's full of water, one press (cupboard) that's full of boxes with syringes in them, and then there's another press (cupboard) and it's full of giving sets. So the utility room is given over to storing everything. The meds then, are in a medicine cabinet. (P14A)

Sourcing the equipment can often be a basis for stress with no clear guidance given as to who supplies certain equipment or if it should it be the pharmacist, HSE or public health

nurse. One participant mentioned how blood monitoring strips one month might be issued by the hospital and other times it was the pharmacist while more times you had to contact the manufacturer directly to get the supply you required. Another participant indicated her satisfaction at the public health nurse and the local equipment office but her frustration at only being given a limited amount of pH strips, something used multiple times in any given day.

I go through the public health nurse. That's the system...she writes it up and it goes to the equipment people ...they will hand me three months' supply of 5ml syringes and 10ml syringes and 50 or 60ml syringes and loads of giving sets and enough NG tubes to keep her going for a year, and one - one little tube of 100 pH strips (P2C)

Similarly, another participant expressed her annoyance at only being given one needle for administration of a weekly injection;

I love having an extra one (needle) in case you dropped it. They only give you, literally a month's supply. So I always said to them, "Will you give it to me the week before?" So I always have one extra. (P7B)

5.9.4 Summary of 'Lived Things'

The contribution of 'things' to the phenomenon under investigation was evident in all interviews with participants. The first theme to emerge in this dimension was the issue of cost of medicines. While all children had long term illness cards participants had an acute awareness of the cost their child placed on the State. Keeping records and the issue of documentation was the second theme to emerge with participants keeping records of what medicines are given as well as other information that might assist them at hospital appointments. Participants acknowledged there was no standard documentation they used to record information and therefore many made up their own recording documents. In the final theme, participants acknowledge that equipment is necessary for the administration of medicines but sourcing this equipment could be made easier with clear guidance as to who provides what and the volume of equipment to be issued. Furthermore, storage of such equipment requires designated cupboard or fridge space in the home with some participants having large volumes of space taken over by medicine related equipment.

5.10 Conclusion

This chapter was concerned with the findings emerging from this research study which was aimed at exploring mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities. Van Manen's (1990) existentials provided the overarching dimensions for this study with a total of 20 individual essential themes identified and aligned to one of the five existentials. An array of activities were depicted throughout all of the themes in terms of 'giving medicines' which was in line with objective two of the study *To identify the range of activities mothers of children with severe and profound intellectual disabilities "giving medicines" undertake*. In congruence with objective three, *To identify any issues experienced by mothers of children with complex needs "giving medicines"*, issues were identified that were of significance to the participants, again evident in all of the existentials. Conclusively, in order to meet the fourth and final objective *To analyse the meaning of mothers living with 'giving medicines' to children with severe and profound intellectual disabilities* as a basis for understanding and interpretation by others, an analysis and interpretation of the meaning of participants' experience was undertaken and represented through the formation of themes and underpinned by each existential dimension, depicted accordingly within each theme and with relevant verbatim material from participants in support of each theme. The following chapter, Chapter Six is concerned with the critical discussion and final interpretation of these findings. The findings interlaced with pertinent literature will result in a deeper understanding of the phenomenon.

Chapter Six Discussion

6.1 Introduction

Chapter Five presented the findings of this study under key headings. These findings embodied the exploration of mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities enabling the study objectives to be met. Prior to discussing these findings it is important to bear in mind the objectives of this study:

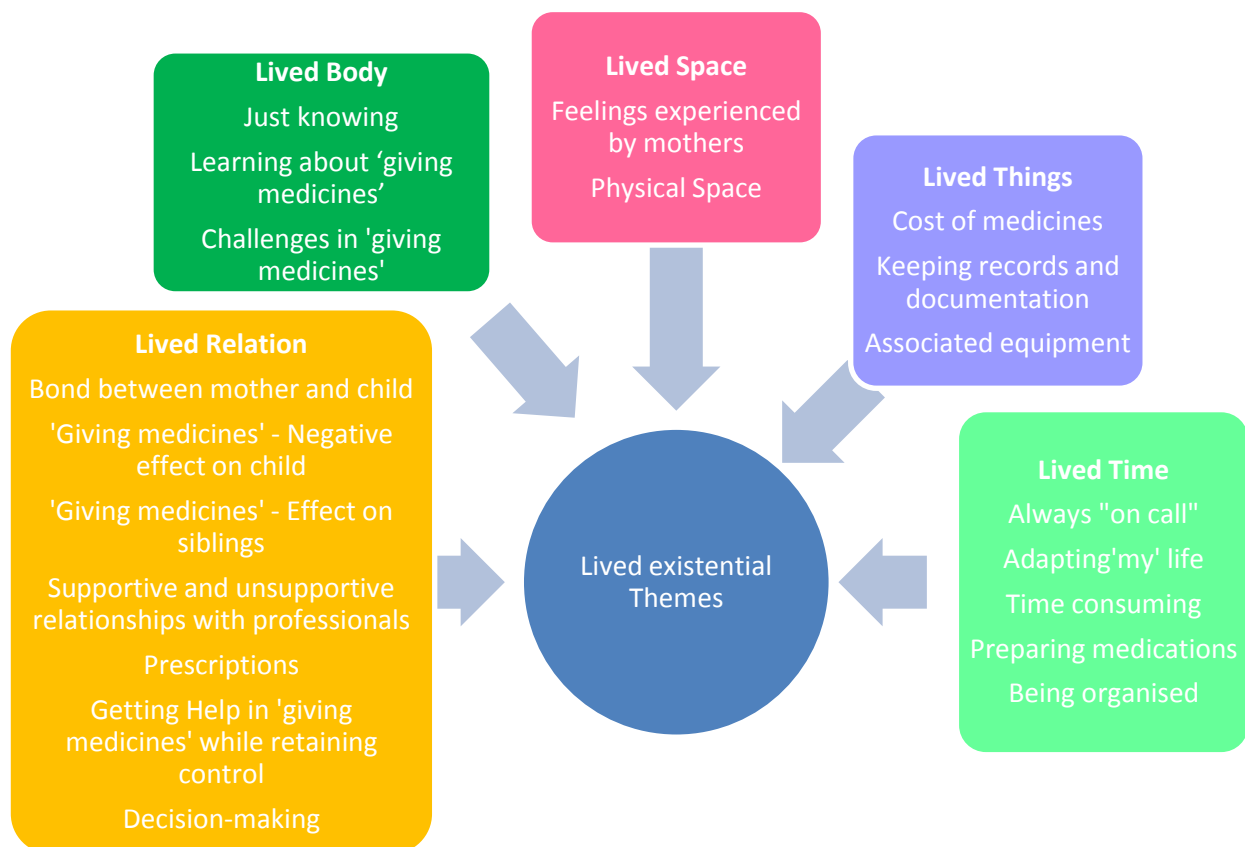
- To explore the experiences of mothers of children with severe and profound intellectual disabilities 'giving medicines';
- To identify the range of activities mothers of children with severe and profound intellectual disabilities 'giving medicines' undertake;
- To develop an understanding of how mothers learn about 'giving medicines';
- To identify any issues experienced by mothers of children with severe and profound intellectual disabilities 'giving medicines';
- To explicate the meaning of mothers living with 'giving medicines' to children with severe and profound intellectual disabilities as a basis for understanding and interpretation by others.

A hermeneutic phenomenological method was used identifying 20 essential themes presented within the existential dimensions. In this chapter, significant findings already highlighted in Chapter Five will be discussed and compared and contrasted with pre-existing relevant literature some of which was reviewed in Chapter Two relating to the various themes. Van Manen (1990) considers balancing the research context by considering parts and whole while delineating the finer details but then balancing these with the 'whole' picture. Bearing this in mind, each theme is a fragment of the overall picture and it did not appear useful to examine each essential theme individually, similar to examining pieces of a puzzle that actually make up a full jigsaw. It is imperative that a

balance is achieved between immersion in the smaller details with the bigger (whole) picture.

Therefore, this chapter will focus on the issues of importance and interest that arise from the findings in an integrated manner within the five existential dimensions already identified within Chapter Five. In examining the findings of this study, it is evident that insights have been illustrated that ‘make visible the invisible’ issue of ‘giving medicines’ to children with severe and profound intellectual disabilities and what the experience is like for mothers on a daily basis. The overall final interpretation is offered also while Figure 10 reminds us of the existentials and major themes identified.

Figure 10: Lived existential dimensions with themes identified



6.2 Lived Relation – The importance of relationships for mothers who ‘give medicines’

This overarching existential theme of ‘lived relation’ is about the importance of relationships for mothers who ‘give medicines’ to their child with severe and profound

intellectual disabilities. Relationships with others were of great significance and when supportive in nature, had the ability to improve mothers' experiences whether they were personal relationships with children, husband, family members or professional relationships with health or other professionals.

Foremost, participants' ability to contextualise each of their experiences in direct relation to their child and the clear bond that exists was evident. While the importance of the parent-child relationship is emphasised in research and policy such as the UN Convention on the Rights of the Child (1996), the National Children's Strategy (Department of Children and Youth Affairs (DCYA) 2000) and the Government Strategy for Babies, Young Children and their Families (Government of Ireland 2018), it is not clear how mothers actually experience the relationship. Bowlby (1958) suggests attachment is a deep and enduring emotional bond that connects one person to another but does not have to be reciprocal. In this study, it was difficult for many children to communicate or demonstrate reciprocity through a deep bond. Yet, mothers depicted an overwhelming desire and responsibility to care for their child and ensure a good quality of life.

'Normal Mothering', the bond between mother and child and the impact this has is well documented within the literature (Young 2013, Milne *et al.* 2018). However, the bond between mother and a child with intellectual disabilities is less considered and almost absent unless considering negative aspects, burden of care (Leiter *et al.* 2004, Condliffe 2006, Elias & Murphy 2012, Nicholl & Begley 2012, Sheehan & Guerin 2018) or those with a clearly visible disability (Home 2008). Howe (2006) suggests that the bond or attachment is complex in children with disabilities and impacted upon by the interactions with their mother. Motherhood can be defined as the potential relationship of any woman to her children or, raising a child (Oxford University Press 2018). Mothers are considered to bring distinctive approaches and qualities to their role and tend to be measured in society in terms of whether they are a good mother or not.

Arguably, there is a clear difference between 'normal mothering' and mothering a child with severe and profound intellectual disabilities. It was apparent that these mothers are very much mothers of 'difference' with imposed daily demands and expectations in terms of 'giving medicines' and clear and distinctive approaches to how they managed in daily life. These mothers are not only mothers in a mothering role but actually experience a multi-dimensional role of both mother and nurse. Kirk *et al.* (2005) discussed the parenting versus nursing role and suggested that parents felt their primary role was parenting and secondary a nursing role. Similar to those findings, mothers in this study were assuming their nursing role as 'just part of their life' and therefore, saw it as a core element of parenting their child with severe and profound intellectual disabilities. However, this often leaves the mother in a solitary and isolating place both physically and emotionally. While generally, parenting roles are never easy and require periods of adjustment and learning of key parenting skills, parents of children with severe and profound intellectual disabilities develop knowledge and skills far beyond that of 'normal mothering' requiring lifelong responsibility representing enormous burden for the family (Coad *et al.* 2014). This was evident in this study with mothers indicating how they delivered care in terms of 'giving medicines' and illuminated their skills in the area. Furthermore, according to Kirk (2001) the majority of parents, who are required to undertake clinical tasks and onerous care-giving, do so out of parental responsibility and desire to have their child cared for in the home environment, also similar to the desire of mothers in this study.

Green (2007) determined that mothers noted the physical burden of caring, feeling 'tired' and stressed. Yet, it was also confirmed by Green (2007) that mothers loved and valued their children and actually experienced significant benefit in the experience of raising them. More recently, Carter & Bray (2017) acknowledge the depth of enormous pressure felt by mothers of children with complex needs. These pressures require mothers to be highly skilled, competent providers of clinical skills, such as 'giving medicines' and undertaking ongoing assessments of their child's status all the while, making complex decisions. For mothers of 'difference', such as the mothers in this study with children with severe and profound intellectual disabilities, levels of expectation

tend to be greater because of their constant involvement with professionals and the perceived needs of their child (Khanlou *et al.* 2017). It is evident that being a mother is intertwined with the beliefs, perceptions and ideas mothers have about their family and children (Bower & Hayes 1998). It is generally acknowledged that the birth of a child with disabilities presents significant challenges (Harnett 2007, Harris 2010).

It was clear that mothers made daily sacrifices to ensure they were the one that cared for their child displaying stoicism in their role. Many did not reflect on the job they were doing or see any difference to other mothers in undertaking their own mothering role. Some did acknowledge however, their observation of their child in terms of noting the effect 'giving medicines' might have. With the exception of one mother, all of the participants had other children and acknowledged their boundless love for all of their children, despite one possibly demanding more time and care than the others. Yet, there is limited understanding within the literature, of this bond between mother and their child with severe and profound intellectual disabilities and if any fundamental differences exist. Bower & Hayes (1998) established that the experiences of mothering children with disabilities are characterised by similarities rather than differences and if differences are experienced they tend to be disability specific and relate to what mothers have to deal with. Contrary to Bower & Hayes (1998) suggestion that the experiences of mothering children with disabilities are characterised by similarities rather than differences, this study unmistakably identifies these mothers as different, possibly due to the extent of disability. As mothers of children with severe and profound intellectual disabilities all with varying complexity of care needs, care needs were high in all of these children requiring far more input than that expected with 'normal mothering'.

All of the participants voiced concerns and worries about the negative effect of 'giving medicines' on their child who could not express how they feel. Literature in this area is scant, although Francis *et al.* (2002) found the roles of carers stretched to identifying potential and actual side effects of medicines. However, contrary to those findings, many of the participants within this study indicated they were not told and had little

knowledge of side effects and how their child might react to a medicine causing them great concern.

Another personal relationship of significance for mothers was the impact of 'giving medicines' on a daily basis on their child's siblings and how it affected their lives as well as that of their child with severe and profound intellectual disabilities. Increasing recognition of the effect of disability on siblings is evident in the literature. It has been suggested that having a brother or sister with a chronic illness may have adverse effects on their siblings (Hewitt-Taylor 2005a) especially in terms of parents spending more time with the ill child than with their children who do not have a chronic illness. It is evident that children with daily care regimes such as medication management are more strongly associated with negative effects on siblings than those who do not have such requirements (Sharpe & Rossiter 2002). Concerns about adverse effects on siblings is known to add to parental stress (Taylor *et al.* 2001). However, it is also noted that the effect on siblings is often determined by how they perceive their parent to be coping and how the family manages to function (Taylor *et al.* 2001, Moyson & Roeyers 2012). Whiting (2014b) acknowledges findings from his study where parents identified themselves as being 'disabled families' because of the general disruption having a child with disabilities has on their family life.

Mulroy *et al.* (2008) report on the impact of having a sibling with either Down Syndrome or Rett Syndrome. What was notable was the suggestion that there were more disadvantages if it was a smaller family. Larger families and those who were socio-economically advantaged tended to describe more positives about the experience with negatives focusing on time constraints, restrictions, relationships, socialising and the burden of helping. Interestingly, burden of helping was also a concern for parents who worried about the stress this may have on their children. More recently, sibling quality of life was explored by Luijkx *et al.* (2016) who interviewed siblings of children with profound and multiple intellectual disabilities and reported both positively and negatively with an opportunity for shared activities being important. However, equally important was the freedom for siblings to have moments of private time. It is evident

that there is an overall impact on siblings but Emerson *et al.* (2006) suggests that it is less about having a brother or sister with an intellectual disability and more so shaped by overall family functioning, a view also supported by Dyke *et al.* (2009).

Outside of the family unit, other relationships emerged as a necessary and supportive part of day-to-day life with mothers of children with severe and profound intellectual disabilities interacting with many health professionals such as; the GP, pharmacist, hospital, school and respite staff. Children with severe and profound intellectual disabilities often require more contact with a GP due to the nature of their medical conditions (Nakken & Vlaskamp 2007, McConkey *et al.* 2007, HSE 2009, Simkiss 2011, Nicholl *et al.* 2013, Eddy 2013, Gates & Mafuba 2014). Therefore, the GP plays an important role in terms of answering parental queries on illness, securing prescriptions, writing letters, rewriting 'Kardex' or seeking advice. An approachable and accessible GP is preferable and someone who can interact in a meaningful way with the child. One study recognised that GPs felt inadequately trained to deal with individuals with intellectual disability and their associated health needs (Phillips *et al.* 2004). Complex medical problems were cited as an issue they felt unprepared for and therefore, acknowledged they would like further education and training in this area. A UK study (Contact a Family 2011) raised concerns, highlighting that GPs rarely get involved in the care of children with disabilities and lack understanding about them and the supports required or available, with 76% of mothers in the study admitting they did not visit their GP about their child's disability or condition. Furthermore, for those who did visit the GP the quality of care was found to be inconsistent.

While the delivery of high quality child health care remains a core component of GP training, research has also identified that GPs lack paediatric experience and training (Royal College of General Practitioners (RCGP) 2010). Developing and maintaining competence in the care of children and in this instance children with severe and profound intellectual disabilities requires high standards of clinical training, regular clinical exposure, continuing education, and audit of performance (Mathers & Harnden 2011). The Irish College of General Practitioners (ICGP) rolled out an updated curriculum

for GP training in 2018 (ICGP 2018) which includes both elements of child health and care of people with intellectual disability. However, it is unclear if this addresses in any great detail the intricacies of 'giving medicines' to this cohort of children.

While GPs cannot be experts in every field of care, children with severe and profound intellectual disabilities demand more input and mothers caring for these children require support. Contact a Family (2013) developed a GP practice guide aimed at providing key information GPs might find relevant for children with disabilities. This offers some fundamental information from identification of challenges to the more commonly presenting health issues they may need to be able to consider and advise on. However, this guide fails to identify the issues around 'giving medicines' as identified by the mothers within this study and the importance of accurate prescriptions. GPs are in a unique position whereby they can ascertain through interactions what supports a carer may need (Reeve & Baker 2005). More recently, the HSE have published guidance on 'Making Every Contact Count' (2017a). Acknowledging that 80% of GP consultations are about chronic health issues, by making every contact count between the GP and user, chronic illnesses can be managed more fully, possibly preventing the necessity for future hospitalisations. In launching this framework, the HSE have developed an e-learning training programme for health professionals and its aim is to provide effective tools and knowledge to undertake brief interventions with patients and users that will result in positive outcomes for all. However, this guidance does not delineate between patient groups or the issue of 'giving medicines' and the concept remains invisible within the advisory materials.

The issue of house calls by GPs was raised within this study with a perceived unwillingness on the part of GPs to engage in this service despite the complexities of mothers attending the GP clinic with a child with severe and profound intellectual disabilities and associated medical needs. Historically, house calls made up 40% of all patient-doctor encounters in the 1940's (Soh & Low 2018) while today the proportion of GP consultations that are house calls has dwindled to less than 1% (Kao *et al.* 2009). While reasons for the fall are attributed to more access to transportation, time

constraints and economic considerations, the benefits for children in this study would seem overwhelming with difficulty in transportation, equipment and risk of infection, real concerns for mothers. Additionally, while online consultations are developing in GP practice, this emergence has not been examined in detail, as an alternative to face to face consultations (Marshall *et al.* 2018).

Furthermore, although avoided unless there was no alternative, attending the hospital emergency department when the child was unwell was also cause for anxiety for participants in this study, with long wait times and high risk of infection causing most concern. Similar to the literature (Braddock *et al.* 2015), the requirement for hospital care was high for these children with some attending hospital frequently for ongoing medical conditions such as respiratory infections or prolonged seizure activity. Predictable patterns of admission via emergency departments are cited in studies concerning this group of children (Mahon & Kibirige 2004, Braddock *et al.* 2015) with inequalities existing in frequency of admissions of people with intellectual disabilities versus the general population (Dunn *et al.* 2018). However, in this study, while acute management of prolonged seizure activity was best managed in the emergency department, many participants advocated avoiding the emergency department and fast tracking to the children's unit for conditions such as respiratory infections where the child was well known and had a long history of care. Recently, based on the Care Quality Commissions views of best practice, Glasper (2017) has propounded that when admitted to hospital, children with special needs should have access to intellectual disability nurse provision; a clearly visible flagging system for identifying them; the use of hospital passports; and defined communication strategies.

Conversely, it could be argued that admission to hospital or attendance at emergency departments should be avoided where possible (Narramore 2008, Whiting 2014a, 2014b) and that well developed integrated care pathways would largely result in a reduction in hospital visits. Alternatively, if hospital needs to be accessed, open access to an acute children's ward would be preferable especially outside of normal working hours (Whiting 2014a, 2014b). The UK Council on Children with Disabilities (2005)

published guidance on care coordination for children with special health care needs in an attempt to facilitate the process of linking these children and their families with appropriate services and resources which in turn would see the requirement for attendance at hospital reduced. A more detailed guideline has been developed since then and gives 17 clear steps involved in the discharge planning process with a clear emphasis on individual assessment of need (Carlin 2010). More recently, a European wide study (Models of Child Health Appraised, MOCHA) undertaken by Brenner *et al.* (2018b, 2018c) indicated that less than half of the 30 European countries surveyed have policies and procedures in place to support care coordination for children with complex care needs with integration of care at various stages of development, depending on the clinical situation. Moreover, it was evident that the primary care physician had little involvement in planning for the discharge of these children from hospital settings. The MOCHA project has established core principles and standards for effective personalised care of children with complex care needs, the first of its kind that offer a means to benchmark existing services and may influence policy in relation to future service delivery across Europe.

Although care coordination can be complex and challenging, it is essential for efficient management of the issues surrounding caring for children with severe and profound intellectual disabilities and may reduce necessity for attendance at hospital. What is evident is the increasing acuity of child illness in those with complex needs and the evolving role of the parent as care provider especially within the home (Ward *et al.* 2014, Currie & Szabo 2019). A range of key skills are required when caring for a child with severe and profound intellectual disabilities and often parents feel their input is undervalued when compared to the input of a healthcare provider. Integrated care pathways are deemed essential for ensuring children and families are at the centre of planning for their care at home and that individual needs are responded to (Together for Short Lives 2013). While guidelines and policies offer a map, integrated care pathways are distinct in advising on who should be doing what and how it should be undertaken (Davis 2005). No 'one size fits all' approach to care should be adopted and evaluation of current models and care delivery systems should be undertaken (Pordes *et al.* 2018)

especially with regard to hospital attendance.

Similar to the GP, the pharmacist was regarded as a key person with a role of responsibility in the 'giving medicines' process and someone who could positively influence the impact of 'giving medicines' on participants' daily lives. The value pharmacists can bring to care of individuals with intellectual disabilities is underestimated and not well recognised (Flood & Henman 2010a, 2010b, O' Dwyer *et al.* 2015). Gray *et al.* (2017b) report on the important role of the pharmacist in the care of young people with chronic illness and how they can respond to the needs of these individuals in building trusting relationships, resourcing credible information and providing specialist expertise. Furthermore, McMillan *et al.* (2018) propound that pharmacy staff are well placed to support carers in respect of medication management but found in their study, that pharmacists insight into the impact of caring was not fully appreciated and through education, an increased awareness was evident. Pharmaceutical care is seen as a collaborative process and with a variety of healthcare needs, children with severe and profound intellectual disabilities require due consideration of their pharmaceutical needs. Pharmacist expertise is important where multiple drug interactions are possible or providing dose formulations for those who experience dysphagia, a difficulty identified by participants within this study. Information given by pharmacists encompasses possible side effects and measures to recognise and manage those (Barbui *et al.* 2009). The importance of continuity of relations with the pharmacist was evident in this study and is further supported in the literature (Flood & Henman 2011, Flood 2017, McMillan *et al.* 2018).

Similar to this study, it is apparent in the literature that problems exist when 'giving medicines' to children especially where there are frequent dosage changes, difficulties with formulation, administration difficulties and limited information on off-licence medications (Costello *et al.* 2004). In overcoming these challenges, few studies have explored the role of the community pharmacist in supporting parents of children with severe and profound intellectual disabilities who tend to have numerous interactions on a monthly basis. Flood & Henman (2011) propound that pharmacists can work to

improve the effectiveness of medication usage with those with intellectual disabilities. This would in turn lead to an increase in benefit for individuals and an overall risk reduction. Furthermore, McMillan *et al.* (2018) found that engaging with carers in conversation while in the pharmacy allowed for better understanding of their needs and may be a small step resulting in big gains for both carers and individuals. Additionally, Flanagan *et al.* (2010) discuss the advent of pharmacists making home visits especially as part of a transition from hospital to home where participants were prescribed six or more medications. These home visits were aimed at enhancing medication management and considered such issues as medication teaching, enhancing compliance, consideration of drug interactions and referral to other health professionals. Although this type of provision is a relatively new concept, Flanagan *et al.* (2010) illuminated the resultant positives from these home visits. While this system does not exist currently in Ireland, home visits are considered as a potential role in the future for pharmacists (Pharmaceutical Society of Ireland 2016).

Education and training for pharmacists is important as children with severe and profound intellectual disabilities require specialised input when taking numerous medications. Yet, at times participant dissatisfaction with pharmacy care was evident in this study. Being able to identify, prioritise and target interventions and support is crucial according to Flood & Henman (2011) and Flood (2017). The NHS have developed a learning package for pharmacists to address the delivery of high quality individualised pharmaceutical care to people with intellectual disabilities, their families and carers (NHS 2014). The package aims to allow pharmacists develop their knowledge and skills in the delivery of services and addresses topics from importance of consent to the differing complex health needs and risk of polypharmacy. This type of training is important as mothers in this study identified the pharmacist as an educator and someone who could provide individualised information on medicines. However, it is notable that this training does not consider such nuances identified within this study such as sourcing and changing formulations, using off-licence medications or difficulties in medicines administration to this cohort of children.

In addition to the relationship with GPs and the pharmacist, the relationship with school was deemed valuable by participants within this study, as the benefits of going to school for the child far outweighed the perceived need for organisation in terms of 'giving medicines' linked to attending school. Schooling is a basic entitlement regardless of the ability of a child and provisions should be suitably adapted to the child's requirements (DCYA 2014). This stance on entitlement has seen not only mainstream school developments but also enhanced special classes and special schools. Educational settings are challenged to adapt to meeting the medical as well as the educational needs of children with special health care needs. The use of medicines in school environments has been recognised as contentious especially when it is teachers that are required to administer medications (Bannon & Ross 1998, Costello *et al.* 2004). The importance of school nurses is widely evident (Moore *et al.* 2003, NCSE 2018) with the role encompassing management of health related equipment such as PEGs or tracheostomies and routine and unplanned administration of medications (Moore *et al.* 2003). Aruda *et al.* (2011) identified the concerns of parents regarding communication between them and the school provider. Availability of school nurses was identified as key to front line management of the child's medical needs. Both intellectual disability and paediatric trained nurses appear to be best positioned to meet the specialist health needs of children with intellectual disabilities (McCarron *et al.* 2018, NCSE 2018) especially within the school environment.

In this study, all children were attending a special school and any child requiring medicines during the school day, required a nurse to be present in order to administer these medicines with the likelihood of administration being high due to the nature of their complex health conditions. While provision of a school nurse in special schools providing education to children with severe and profound intellectual disabilities exists and is funded by the HSE, this provision can be somewhat unsystematic (NCSE 2018). In Ireland, there is no scheme or policy for provision of school nurses and therefore, funding can be minimal for such a role. This haphazardness was evident in this study, as there was not always a nurse on duty and on those specific days, mothers were asked to keep their child at home with little or no notice given. The NCSE report (2018) warns

that a lack of appropriate nursing support in schools might be a barrier to a child attending and recommends structures should include an application process for nursing support within school, whereby a child is not accommodated unless such supports are in place.

Given the high demands of caring for a child with severe and profound intellectual disabilities, respite is also of particular importance for mothers in this study, easing the burden of care for those who availed of it. Research has highlighted how parents feel imprisoned in their own homes as a result of the complex mechanism of travelling outside the home with their child and associated equipment (Kirk 1998, Brinchmann 1999, Neufeld *et al.* 2001, Nicholl 2013). Respite care can relieve parents from this for periods of time and enable parents to have a good night's sleep. However, many studies have found that securing respite care can be difficult and when received, it is on a limited basis (Diehl *et al.* 1991). Due to the increase in home-based care for these children, the issue of respite support is high on international and national agendas (Merriman & Canavan 2007, DOHC 2010). In Ireland, while the Disability Act (GOI 2005, Department of Social and Family Affairs (DSFA) 2005) does not address respite care as a specific issue, it does indicate the need for each individual with intellectual disability to have an independent assessment of need which is likely to propose respite care provision as one of the required supports. While some parents may be reluctant to use respite care, they do find it beneficial (Eaton 2008) with formal in-home care the preferred form of respite for carers in many studies (Hartrey & Wells 2003, Redmond & Richardson 2003, MacDonald & Callery 2004). Where possible parents suggest respite should be flexible and accessible locally (Ling 2012).

However, while mothers in this study valued respite and the 'lifeline' it offered, it did not come without challenges such as preparing a multitude of medication related equipment and organising medication 'Kardex'. In spite of this, much of the literature confirms the positive elements of respite (Terres 1999, Neufeld *et al.* 2001, Hartrey & Wells 2003, MacDonald & Callery 2008, Power 2008, Irish Hospice Foundation 2011, 2013, Mannan *et al.* 2011). This is evident in Ireland also but due to resource shortages,

the inability of parents to access respite in a consistent manner is widely cited (Ling 2012, Irish Hospice Foundation 2011, 2013). Contrary to the findings of this study, there is little evidence in the literature of the detail required on admission to respite or indeed the challenges cited by mothers in terms of 'giving medicines'.

Redmond & Richardson (2003) acknowledge the difficulties that arise from the experience of using respite and the associated preparation for travelling with a large volume of paraphernalia. They concluded that because of the difficulties experienced in preparation and travelling for respite, in-home respite was the preference of mothers. Nicholl (2013) supported this finding concluding that travelling for respite almost required two sets of equipment. It must be acknowledged that respite services are somewhat constrained in terms of requirements and need to act within their local policy guidelines on documentation and are influenced also by national guidelines published by NMBI (2007) and HIQA (2015). While the accuracy of a medication 'Kardex' is imperative, if respite could find the resources to support administration of medication such as supplying syringes this would mean less preparation for parents. This recognition by respite providers would see the responsibility or supply of equipment shift from the mother to the service. That said, Nicholl (2013) suggests that health providers such as respite, lack understanding and awareness of the intricacies of preparing for admission and need to recognise this additional burden on parents of children with severe and profound intellectual disabilities.

In interactions with the professionals identified by mothers in this study, the issue of repeated storytelling was a concern with repeated explanations often required. Information transfer between caregivers, service users and health professionals is one of the major safety issues in practice (Griffiths *et al.* 2014, Braaf *et al.* 2015, WHO 2017). A mechanism for ensuring consistent passage of information is the use of a hospital passport (including patient passports, healthcare passports and hand-held records), a document which contains key information regarding an individual's health, communication and support needs (Northway *et al.* 2017). This document then accompanies the individual on all appointments or hospital admissions and provides

valuable information while enhancing safety and also reducing the need for repeated storytelling. Michaels (2008) recognises hospital passports as a best practice initiative while Blair (2011) and Northway *et al.* (2017) note they have been adopted widely across the UK improving hospital care especially for individuals with intellectual disabilities. Bell (2012) identified 79 different versions were in use in the UK in 2012 with numbers expected to have risen since then. The UK Council for Disabled Children propounds the use of such passports such as that developed by the University Hospital Bristol (2011) while the National Autistic Society have tailored one specifically for those individuals with autism (2017).

Allsopp (2006) suggests the use of a passport document centred on communication as crucial for improving experiences for children with complex needs and Lee *et al.* (2016) highlight their use for hospitalised children. Through using this type of passport, specific needs can be prioritised although it must be acknowledged lines of responsibility for keeping it up to date especially in terms of medications is important and needs to be clarified. This is also linked to future planning and care preferences for children from diagnosis through to end of life care. As part of a large study, Noyes *et al.* (2013) developed a set of resources known as 'my choices' booklets in collaboration with parents, children, professionals and not for profit organisations. These were in turn evaluated by parents, children and professionals through interviews, questionnaires and a web-based consultation process. While some families adopted these plans others were more hesitant and identified challenges in their plans not being upheld.

However, as a result of Noyes *et al.* (2013) study, the 'my choices' booklets have been endorsed for use by the organisation 'Together for Short Lives' and promotes the use of such passport style documentation in interactions with health professionals. Yet, difficulties arise when hospital passports are inconsistent and no standardised version is adopted. Considerable variation exists between passports and many are self-designed by carers and users, not following a specific format (Northway *et al.* 2017). According to Northway *et al.* (2017) greater standardisation of passports but allowing for individualised information is necessary to ensure professionals can gather all necessary

information in one document. In Ireland, while some individual services have developed their own passports for use such as “My Personal Health Passport” (Mercy University Hospital 2016) and “Our Story (A helping guide)” (Laura Lynn 2012) no standardised hospital passport exists in the health service for children with severe and profound intellectual disabilities.

A component of repeated storytelling for participants in this study centred on up to date medication lists for the hospital, school, respite and pharmacy. It is suggested that maintenance of current medication lists for caregivers is essential and these lists should have clear dosage regimes (Elias *et al.* 2012). This in turn can facilitate timely refills, reduce the risk of medication errors and allow health care professionals to regularly monitor for any potential drug interactions. Medication passports tend to be patient-designed and patient held records adopted with the aim of individuals not having to recall medication lists. While hospital passports are becoming more common these medication passports are not widely cited in the literature or adopted in practice. Jubrai & Blair (2015) describe the use of ‘My Medication Passport’ (MMP) in a child with multiple disabilities who accessed healthcare professional appointments on a regular basis. The completed MMP was beneficial and provided a single medication record that belonged to the family and gave a simple overview of all medication, including changes for clinicians to see at a glance.

Gaining access to professionals and being listened to in interactions with these professionals was essential to participants and helped with continuity of care. It is evident that the relationship between parents and clinicians is critical to the care of children with life-limiting illness (Bluebond-Langner *et al.* 2017). Largely built on face to face consultations it is important that the relationship is maintained especially when progression of an illness or deterioration of the child is evident (Bluebond-Langner *et al.* 2017). In this study, seeking support from the hospital and various medical teams about medications and making medication related decisions was often difficult. Phua *et al.* (2005) previously recognised dissatisfaction of parents with hospital based care while Pordes *et al.* (2018) described different models of care and how they were hindered due

to poor communication mechanisms. While community care is propounded to be best for children with complex needs (Olsen & Maslin-Prothero 2001, Wang & Barnard 2004, Carnevale *et al.* 2008, Lindahl & Lindblad 2011, Mendes 2013) such as those identified within this study, a community based model of care requires remote access by mothers to health professionals who can respond to queries promptly.

Relationships again came to the fore when mothers highlighted the issue of ‘getting help’ and support in ‘giving medicines’. It is acknowledged in the literature that the effect of caring for a child with severe and profound intellectual disabilities is onerous with parents accepting vast responsibilities and co-ordinating care in the midst of normal family life (Wilson *et al.* 1998). Family functioning is disturbed by many factors such as the constant burden of caring, disruptions at home with medical equipment and visits by healthcare professionals (Glendinning & Kirk 2000) with adjustments required in order to accommodate the child’s needs (O’ Brien 2001). Despite the challenges experienced by participants in this study, sacrifices were made on a daily basis similar to those cited by Kars *et al.* (2008). Additionally, Woodgate *et al.* (2015) reported that parents were emotionally committed to their children and because of that they were cautious about entrusting care of their child to others who might not deliver care to their standard. This was in harmony with participants in this study who felt when others, even family, including their husband, were given responsibility, they needed to retain control to ensure no mistakes were made and therefore, issued clear instructions.

After returning home from a long stay in hospital where care needs had usually increased further, getting help or support was a real concern. Carter (2005) examined the use of a community home nursing service by parents of children with complex needs and notably established that nurses providing this service have “got to be as good as mum and dad” (p.49). Toly *et al.* (2012) who explored family functioning established that those parents who saw their children’s care burden increase also experienced an increase in depressive symptoms and benefited when respite was made available. In this study respite, while not accessible often enough, was seen as a positive source of getting help with many participants planning family time around their child being admitted for a

short respite break. This allowed the parents and other siblings to have some quality time together, a well-documented benefit of respite care (Terres 1999, Neufeld *et al.* 2001, Hartrey & Wells 2003, MacDonald & Callery 2008, Power 2008, Irish Hospice Foundation 2011, 2013). However, less evident in the literature is the need by mothers to retain control over how care is delivered.

While multiple agencies may be involved in the care of children with severe and profound intellectual disabilities, developing a positive supportive relationship with a voluntary organisation was promoted by participants as vital. The role voluntary organisations play in supporting and helping parents of children with severe and profound intellectual disabilities is not a new concept (Cornish *et al.* 1996, Doyle 2008a, 2008b, 2008c, 2010, Nicholl *et al.* 2009, Carter *et al.* 2015). Normand & Revill (2010) have evidenced that homecare delivery is more cost effective than hospital delivery but more significantly, that the wellbeing of families and their children was greatly enriched with home care delivery, without the health or wellbeing of the child being compromised.

The significance of the specialist Jack and Jill Children's Foundation nursing team working in Ireland with the child and family was explored recently and found to provide a positive cornerstone to delivery of high quality care in the home for this cohort of children (Coventry University 2017). Similarly, WellChild introduced a network of community nursing posts across the UK, aimed at improving provision of community nursing care for children with complex needs. It centres on coordination and planning for discharge of children with complex needs from hospital and supporting the child and family in the home (Johnson & Coad 2008, Carter *et al.* 2010, Coad *et al.* 2015). Comparable to the service delivered by Jack and Jill Children's Foundation, this service has been positively evaluated (Whiting 2017). A service not available in the Irish system for supporting families of children with severe and profound intellectual disabilities is that which Carter *et al.* (2015) refer to in the UK regarding use of family support workers. Such a service sees these workers provide supports that other services do not supply and are often not associated with direct clinical caregiving but offer pragmatic,

practical help and emotional, psychological and social support to the families.

As it is evident that parents of children with intellectual disabilities are “hungry for information” (Mackintosh *et al.* 2005, p.41) it is important to identify how parents access this in a supportive manner whether formal or informal and what relationships form this support mechanism. Further sources of support highlighted other than those identified earlier such as the GP or pharmacist were informal parent related supports such as chatting to other parents, contacting family members or using social media through a specific Facebook page entitled “extra special mummies”. Often these informal supports or contacts yielded an answer to a query much faster than attempting to access a formal support such as the hospital or a liaison nurse. Social media sites, in particular Facebook, offer immediacy and a high level of support to parents of children with special health care needs irrespective of distance from one another (Dehoff *et al.* 2016). Often this support is coming from others who are having similar experiences and can offer positive resource sharing mechanisms. When used by parents, Facebook support has been shown to increase parents feeling of connection and reduce feelings of isolation (Dehoff *et al.* 2016).

It can be argued that parents’ ability to cope is positively influenced by accessing support from other parents (Bray *et al.* 2017). Parent to parent peer support has been in existence since the early 1920’s and is deemed to be of value especially with parents of children with disability (Bray *et al.* 2017). It is recognised that web-based resources provide parents with a parent-to-parent support platform that allows them to share their experiences and information with other parents (Nicholl *et al.* 2017). Parent support groups have also been found to be useful and can provide reassurance to parents especially when they feel isolated and alone and that no one else has experienced what they are going through (Emond & Eaton 2004). Shilling *et al.* (2013) report on the benefits of peer parenting support schemes on parents, with practical supports and problem solving, key aspects. Kerr & McIntosh (2000) describe a formal parent to parent peer support whereas in this study the parent to parent support was informal, unstructured and formed part of daily life.

Formal or professional supports were also identified as essential for participants in terms of 'giving medicines'. Baretto *et al.* (2017) agrees that parents of children with intellectual disabilities require both informal and formal supports and not just at time of diagnosis. Formal supports are suggested to improve quality of life for both the child and the family (Kilic *et al.* 2013) and are essential especially for those individuals who do not access technology or have reduced literacy skills (Laragy *et al.* 2016). Recently, Currie & Szabo (2019) identified the need for a navigator or case manager to co-ordinate services for families caring for children with rare diseases. Similarly, in this study participants identified a liaison nurse as being essential in providing formal support. The care coordinator role, otherwise recognised in the literature as nurse liaison, case manager or keyworker, was examined by Hillis *et al.* (2016). It was found that this role was inconsistent and varied from country to country as well as region to region. While it was evident families placed great emphasis on the role and its importance in supporting them as carers, the broad range of skills possessed by these coordinators was difficult to pin down. The nature of interaction between care coordinators and families varied also and there was inequity evident.

Despite demonstrating that a care coordinator role is pivotal, the inconsistency discussed was also evident within this study where participants acknowledged the importance of being able to contact the liaison nurse but sometimes finding it difficult to get a response to a phone call not so much due to geographical location but more to do with how busy the liaison nurse was. Jansen *et al.* (2017) examined parents' experiences of collaborating with professionals in support of their child with profound and multiple intellectual disabilities. It was evident that contact with a key support person was crucial with the number of contacts ranging from 1.9 to 16.7 in any given month. A third of these contacts related to issues concerning health and therefore possibly medication related concerns. Similar to this study, Jansen *et al.* (2017) concluded that communication especially by telephone was a common and quick mechanism for supporting parents but not always readily accessible.

In providing support, care coordinator roles are often undertaken by nurses. Clinical nurse specialists (CNS) play a unique part in contributing to high quality care in a variety of health care settings (Begley *et al.* 2010, Mayo *et al.* 2017). While advanced nursing practice (ANP) is not a new concept internationally, these nursing posts tend to be developed as a direct response to population health need and organisational requirements and are relatively new since 2001 in Ireland (DOH 2017). The effectiveness of such roles has already been evaluated in several specialities including paediatrics (Niemes *et al.* 1992) and special needs (Looman *et al.* 2013) with the positive impact of the role evident (DOH 2017). One element of the role of CNS and ANP surrounds education of service users and caregivers. While there are estimated to be 130 CNS posts in intellectual disability services in Ireland, there is currently only one ANP (McCarron *et al.* 2018). Some of these CNS posts are in the area of neurodevelopmental disability and are held within the three national children's hospitals with few outside of the greater Dublin region. As a key health professional collaborator, both Gerrish *et al.* (2007) and the DOH (2017) established that these roles lead to enhanced wellness and greater levels of self-efficacy and support for individuals. Furthermore, McCarron *et al.* (2018) describe a core component of the CNS role as education and training, suggesting these nurses are well positioned to support mothers of children with severe and profound intellectual disabilities handling medication related queries. Additionally, it is suggested the best positioning for these CNS and ANP posts are between generic health facilities and the community (McCarron *et al.* 2018) which in turn would support home care.

What is evident in this dimension of 'lived relation' is the multiple interactions and relationships that can positively affect mothers and support them in their role of 'giving medicines' to their child. Foremost of significance is the bond between mother and child demonstrated in this study. Additionally, the concern mother's display for their child's siblings is also significant. Furthermore, this discussion exhibits the key roles that other professionals undertake such as GPs, pharmacists, hospitals, care coordinators, schools, respite care and voluntary services. In all of these interactions, the issue of repeated storytelling came to the fore and the importance of being listened to in all interactions.

The particular negative feelings experienced by mothers in this study were impacted upon by communicating with people, whether it was informally with their husband or other parent or formally with a health professional. This communication had the ability to alleviate some stress, increase learning and provide increased coping strategies to mothers. While supportive relationships have been discussed, healthcare literature highlights that effective and efficient communication is crucial and important for continuity of care and patient or carer satisfaction (Vermeir *et al.* 2015). Furthermore, a consistent relationship with health professionals, especially GPs, pharmacists or care coordinators is viewed as key to a high quality accessible support system whereby queries can be addressed and learning can take place (Contact a Family 2013). Also evident in this dialogue, is that non-professionals such as other parents also have the capacity to provide informal and formal means of support for mothers. An examination of the literature relating to all of these quality relationships has been undertaken in an attempt to explore how these can be enhanced and maintained.

6.3 Lived Body – Knowing, learning about and the challenges of ‘giving medicines’

The second existential dimension deliberated on was ‘lived body’. ‘Lived body’ is about how the mother’s body was present in conversations relating to ‘giving medicines’. The impact of ‘giving medicines’ was clearly inferred through discussion with the participants and related to both the bodily experience for the child and that of the mother. It was evident that everything the mother undertook and experienced in daily life was impacted upon both physically and through her understanding or cognition. Therefore, this dimension of ‘lived body’ is concerned with mothers knowing, learning about and the challenges of ‘giving medicines’.

Participants experience of ‘just knowing’ or using instincts was evident. Using instincts is not a new concept for mothers as ‘mothering’, discussed earlier, requires use of instinct on a daily basis (Young 2013, Milne *et al.* 2018). However, ‘just knowing’ in this study refers to more complex scenarios related to ‘giving medicines’. Notably, Carter *et al.* (2017) describe a study in which mothers develop a sense of knowing and acquiring skills in pain management in children with cognitive impairment. Similar to this study, Carter

et al. (2017) acknowledge mothers learned through a system of trial and error, learning to get on with it and in particular, learning to endure and to get things right often without any clear guidance or support. Earlier, Carter & Bray (2016) indicated that on top of 'ordinary' parenting, many parents are undertaking clinical assessments each time they look at their child while also undertaking skilled care. In the UK, the #notanurse_but parent driven campaign (WellChild 2019) aims to shine a light on the reality of life behind closed doors for families of children with complex needs at home. Notably, the element of caring, 'giving medicines' that is depicted by mothers in this study, is reflected somewhat in the stories that are told by parents in the #notanurse_but campaign aimed at highlighting to key decision makers, the gaps in support that exist and require filling.

Learning about 'giving medicines' was an important part of daily life for participants. However, there was variance in how this was achieved with learning stemming from the less traditional source of health professional to reading a medicine package information leaflet or gathering information from internet or other web based platforms. It has been established that medication management necessitates a high level of cognitive processing on the part of the carer (Smith *et al.* 2003). Medication management skills required by carers have been identified as the ability to acquire, store, track and discard medications as well as the ability to recognise and respond to medication effects (Lau *et al.* 2009). Additionally, skills should also encompass polypharmacy concerns (Travis *et al.* 2000, 2003) and importantly, training on medication related topics (Erickson *et al.* 2016). Yet, while 'giving medicines' is a core intervention of care with children with severe and profound intellectual disabilities (Dunworth-Fitzgerald & Sweeney 2013) and is often complex due to the sheer volume and routes of administration, participants in this study did not feel that education about 'giving medicines' was a priority and often found themselves alone and using their 'common sense' when it came to 'giving medicines'. What was evident was the ability of the prescriber to name the medicine and explain its purpose and function to participants. Beyond that, participants accessed their informal supports such as Facebook for advice or trawled the internet to gather more information. Interestingly, the literature identifies a plethora of medication information

sources such as package leaflets, pharmacists, doctors and the internet (Hodgetts *et al.* 2015, Hameen-Anttila *et al.* 2018). However, these were not all used by participants within this study.

Gates (2006), Brack *et al.* (2013) and Ramos *et al.* (2015) advises that it is important that caregivers know how to administer medication and this should form an integral component of planning for discharge. However, as many participants cited changes in medicines when at outpatient appointments, it is evident planning needs to consider not just discharge but also any interactions such as appointments. Interestingly, Gibson *et al.* (2017) acknowledged that medication teaching in the hospital environment can be challenging and may not always represent what it will be like in the home environment to give medicines. In some instances participants watched how the nurse administered medications and learned through unplanned informal observation. However, none of the participants within this study were shown how to administer through the more complex mechanisms of rectal or buccal routes.

Yet, it is clear within the NMBI guidelines (2007) on medication management for nurses that standards of service user education exist. These standards are clear in delineating what is expected such as; education be provided in relation to the use of medicinal products in an accessible and understandable format. However, participants in this study did not receive this type of education. If a PEG was inserted, and this was used for medication administration or an injection was required, a more formal education session was usually undertaken by a nurse but education was not revisited if medicines changed or administration became more complex. Nonetheless, it is suggested caregivers need to be taught and should demonstrate competency in clinical tasks such as care of feeding tubes, often used for medication administration and other medication management (Case 2000, Read 2001, Brett 2002, Condliffe 2006, Elias & Murphy 2012). It is also suggested that a systematic approach to care coordination should encompass medication training and education (Boosfeld & O' Toole 2000) with Nieboer *et al.* (2011) arguing that education should be delivered by professionals rather than through generic

sources such as the internet. Some developments in discharge planning and care coordination have seen frameworks and guidance developed that includes the importance of education and training (Noyes & Lewis 2005a, 2005b, 2007, Council on Children with Disabilities 2005, Carlin 2010).

Parents of children with intellectual disabilities or complex needs increasingly use the internet as an information resource especially for gathering information on medical conditions (Zaidman-Zait & Jamieson 2007, Nicholl *et al.* 2017). This source of information is beneficial as it allows worldwide access to information (Konrad 2007, Nicholl *et al.* 2014), often comes in large volumes from multiple sources and is accessible as required on mobile devices (Nicholl *et al.* 2017), which is particularly important for participants in this study who cannot freely leave the home. However, often internet material is unbalanced, unmonitored and unreliable with resultant information questionable (Nieuwboer *et al.* 2013, Tracey *et al.* 2018). Furthermore, it is usually presented in written text making accessibility difficult for some individuals and information can be complex (Sanders *et al.* 2009).

Thus, parents need to establish the reliability of the information they are acquiring from internet or social media resources. Brunetti & Hermes-DeSantis (2010) suggest the number of people accessing the internet for medication related information is on the rise and advises that health professionals should be competent in directing caregivers to reputable online resources reminding caregivers they need to evaluate the web source they are accessing. Furthermore, it is apparent that caregivers should be encouraged to discuss the materials they source with health professionals and they should enhance rather than replace the health professional interaction (Hameen-Anttila *et al.* 2018).

In Ireland, if accessing online information regarding medications, the Health Products Regulatory Authority is a recognised resource housing a comprehensive database of up

to date medicine listings and related information. Additionally, supported by WellChild, the UK website, Medicines for Children (2018) provides practical and reliable advice and guidance about giving medicines to children. It appears to use a variety of educational resources and not just text, but also educational videos on medication administration techniques. In addition, it provides leaflets for download on over 100 medicines. Furthermore, Medicines for Children (2018) are working to develop technology in the form of a mobile App that will provide assistance to parents and carers managing complex medicines regimes at home. While medicine information leaflets are geared towards caregivers and service users and are often supplied by pharmacists dispensing medications, Crawford (2012) suggests these are not always read and printed materials can sometimes be complex (Lau *et al.* 2009). Therefore, this UK website is a welcome initiative in supporting parents to learn about 'giving medicines'.

'Lived body' was further reflected upon when participants highlighted the challenges of physically administering medicines to their child and indicated it was influenced by whether the child fed orally or through the use of a PEG, adopted by seven of the children. Use of a PEG in this cohort of children is not unusual as gastrointestinal dysfunction among individuals with intellectual disabilities can result in dysphagia making eating, drinking and swallowing difficult (Kelly *et al.* 2009). Many children who have PEG insertions for feeding also have their medications administered via this route (Glasper *et al.* 2010, Dunworth-Fitzgerald & Sweeney 2013). Glasper *et al.* (2010) and Macqueen *et al.* (2012) supports the use of gastrostomy tubes for administering medicines in these circumstances, bypassing the need for administering by mouth. The advantage of this route of administration is that it provides an alternative to the oral route for children unable to swallow, such as some of those children within this study. Similar to the literature, participants acknowledged their desire to maintain oral feeding despite the necessity for a gastrostomy tube. This is not surprising as it is evident that eating, drinking and swallowing are essential activities of daily living and are a core component of social interaction (Griffiths *et al.* 2018). Furthermore, the decision to insert a PEG tube is not without concern with many parents reluctant to agree an insertion unless alternatives have been explored (Brotherton *et al.* 2007a, 2007b). As

gastrointestinal dysfunction resulted in dysphagia for many of the children, this determined their capacity to eat and drink and the resultant route of administration and the modifications required, an issue also identified in the literature (Calis *et al.* 2008, Kelly *et al.* 2009, Pawlyn & Carnaby 2009).

Alternative approaches to administering medications are cited in the literature such as crushing, dispersal and disguise (Wright & Kelly 2012). Within this study, if medicines were available in liquid form they were used but equally the method of crushing tablets was widely used. Richey *et al.* (2012) suggests that when medicines are not available in suitable formulation, there is no other choice but to crush and disguise as required. However, it can be argued that manipulating the medicine could affect the dose and stability and also pose potential risks (Crawford 2012, Donnell & Nunn 2011) especially when tablets are fractionalised for a dose (Verrue *et al.* 2011, Elliott *et al.* 2014). A lack of authorised, available, age-appropriate formulations makes it difficult to administer medicines especially to this cohort of children. Manipulations within this study and similar to Venables *et al.* (2015) included cutting transdermal patches, splitting/crushing tablets, dissolving tablets in water, fractionalising doses and cutting suppositories. In recent years, the issue of manipulating medicines for children has been to the forefront of discussions in the UK with the MODRIC research study investigating the issue (Richey *et al.* 2011, 2013, Alder Hey Children's NHS Trust 2013). Interestingly and similar to this study, many of the manipulations took place with children requiring highly specialist care and those with complex health needs. This resulted in development of a guideline aimed at using the available evidence on manipulation of medicines to achieve a proportional dose and also developing interventions that may avoid the need to manipulate medicines (Richey *et al.* 2011, 2013, Alder Hey Children's NHS Trust 2013). While having no equivalent guideline in Ireland this UK guidance is freely available and may go some way to supporting and guiding those who are required to manipulate medicines if there is no other alternative.

Ensuring their child had received their medicines was important but often challenging especially in instances where medicines must be given to prevent seizure activity. For

instance, if this meant their child required medicines that were not licensed for administration through a PEG, they would still receive them this way as it was agreed with their medical team that this was the only alternative. This is also cited as a common occurrence in the literature when it is the only option available (Wright & Tomlin 2011). Therefore, the risk/benefit ratio for the child must be pondered and alternative options for delivery of medicines deliberated upon (Kelly & Wright 2009). Within this study it was evident that despite having a plan for administering medicines and having decided what foodstuff it may go in, the status of the child determined how difficult it was to administer. Safe administration of medicines is clearly influenced by tiredness and state of wakefulness of the individual. Therefore, many participants were conscious they could still administer medicines through a PEG irrespective of whether the child was asleep or awake and found this beneficial, something further supported within the literature (Wright 2011). The importance of guidelines for the administration of medicines through a gastrostomy is highlighted further in the literature (Wright 2002, 2011, Bennett *et al.* 2013). In one study, it was noted that while good practices were observed, many poor practices in medication administration existed in a residential setting where many residents had a gastrostomy tube in situ (Joos *et al.* 2015, 2016). Moreover, the safe administration of medication via enteral tubes is not widely discussed and in reality practices may differ somewhat. Policies tend to be local specific and individualised to different hospitals with little evidence of plans for safe administration in the home setting or what training parents receive when being taught how to administer medicines via this route.

As well as manipulating the medication form, manipulating the medication for ingestion was also considered in this study and where the child took oral medications, disguise was widely used so that the child would take the medicines. For ease of administration when medicines are not available in liquid preparations, disguising by adding to food can occur (Richey *et al.* 2012). This is not unusual with children with or without intellectual disabilities (Halder *et al.* 2012, Bergene *et al.* 2017) and while it may well be argued that administering medicines in a covert manner is unethical (Griffith 2016a, 2016b) and should not be condoned (Treloar *et al.* 2000), it is often the only way essential medicines

can be administered. While some organisations have little or no formal policy, some guidelines exist on covert administration in the disability (HIQA 2015, NICE 2015) and mental health sector (Mental Welfare Commission 2017). Though it is recommended that medicines should be made in a palatable form for children (Nunn 2003) this is not always the case and many medicines have an unpalatable taste and texture making it particularly difficult for those with severe and profound intellectual disabilities to ingest (Venables *et al.* 2015).

The decision to disguise medicines is normally a difficult one and usually requires food or drink for the administration process (Crawford 2012). Participants within this study described using yoghurt, smoothies, thick and easy and fruit juices to mix medicines in, often 'spoiling' the food. When a tablet is crushed the resultant powder is often unpalatable and therefore strong flavoured foods such as jam are often used to disguise (Haw & Stubbs 2010a, 2010b). However, this can be problematic as many medicines interact with certain foods and therefore food-drug interactions are now more widely cited in the literature (Haw & Stubbs 2010a, 2010b, Bushra *et al.* 2011, Caylor 2015). Other products used for mixing medicines are prescribed nutritional foods such as fortipuddings and forticremes (Haw & Stubbs 2010a). Mixing medicines with foodstuff especially fruit or orange juice can be a particular problem especially when the pH of medicines are possibly altered (Bushra *et al.* 2011). This was a particular concern in a study undertaken by Venables *et al.* (2015) and was specifically highlighted by pharmacists. However, in the absence of any available advice, many participants within this study merely found a food that their child could ingest with medicines and stuck to this irrespective of possible alteration of drug effectiveness. This was further exacerbated when a child required additional medicines such as antibiotics for acute infections.

Another difficulty highlighted within this study was the issue of hypersalivation and the effect this had on the ingestion of medicines such as buccal Midazolam. Use of sublingual administration is widely accepted and quick acting especially for seizure activity (Brack *et al.* 2013). In those with hypersalivation it is now common to see

transdermal administration of medication to combat the problem and make administration easier for drugs such as buccal Midazolam. However, many of the medications for administration in this way contain a starting dose too high for use in children (Macqueen *et al.* 2012). Therefore, this results in cutting of patches to fractionalise the dose which can lead to inaccuracies in drug administration (Lee & Phillips 2002, Mato *et al.* 2010, Fairhurst & Cockerill 2011).

Similar to other studies (Ranelli & Aversa 1994, Ranelli & Hansen 1994), maintaining a continuous supply of medicines was highlighted as a challenge within this study, requiring participants to be prepared. Likewise, the need for organised and routine approaches to managing medication was also highlighted by Goldstein & Rivers (1996). Comparably, Kuo *et al.* (2011) highlight the importance of securing prescription medicines in a timely manner, such as anti-epileptic for seizure management. Supply of medicines was a particular concern in this study for mothers of children on specialist medicines with a short shelf life and similar to other studies (Smith *et al.* 2003) they found they were monitoring the need for supplies all of the time.

This dimension of 'lived body' has discussed the issue of mothers' instinct in 'just knowing' what to do, while also acknowledging the need for mothers to develop their knowledge and learn about 'giving medicines'. It is apparent from the literature that while informal mechanisms such as the internet or social media are often accessed as a learning tool, professional support and education is the recommended educational tool. Additionally, the physical challenges of 'giving medicines' were explored with relevant literature pondered pertaining to alternative approaches to administration, manipulating medicines and disguise.

6.4 Lived Time – The impact of 'giving medicines' on time

The existential dimension of 'lived time' is about providing an understanding of mothers' daily lives in terms of their experience of 'giving medicines' to their child with severe and profound intellectual disabilities. All participants mentioned the concept of time and the impact of 'giving medicines' was apparent, mothers being 'always on call' and the

constant full time pace of their caring role evident. This is to be expected, largely due to the nature of disability and the associated medical conditions requiring medication management (Green 2007, Nakken & Vlaskamp 2007). Often these conditions are complex and require a demanding schedule of care (Nakken & Vlaskamp 2007, Davies & Carter 2013, Davis *et al.* 2014). Nurturing a child with severe and profound intellectual disabilities develops into a lifelong responsibility placing enormous burden on families (Coad *et al.* 2014).

The difficulty highlighted by participants in this study surrounds the delivery of relentless complex care within the home setting, something that according to Leiter *et al.* (2004) may historically have been delivered in the healthcare setting where at least staff got a break. The intensity and unpredictability of participants caring responsibility as well as lack of escape from their role was evident and is also supported within the literature (Heaton *et al.* 2005, Bourke-Taylor *et al.* 2010, Swallow *et al.* 2011). Similar to the findings of this study, the high time demands on parents was explored by McCann *et al.* (2012) who identified that parents of children with complex needs carry significant caregiving burden often increasing as the child gets older. Furthermore, it was established that the concept of 'vigilance' was a large component of caregiving for these parents. This vigilance was also illuminated by participants in this study indicating that even if it was a bank holiday or a weekend, they still had to get up and 'give medicines', especially AED's, despite their desire to have a lie in.

In addition, the time it took to 'give medicines' to children was sometimes considerable within this study. This task is multi-faceted and encompasses many elements (Dunworth-Fitzgerald & Sweeney 2013) with the child's capacity to take medicines at the forefront of the preparation process. Comparable to the study by McCann *et al.* (2012), 'giving medicines' was particularly time consuming and complex if the child was on multiple medications, required coaxing to take medicines or required small amounts to allow ease of swallowing. The effort endured in 'giving medicines' to children with severe and profound intellectual disabilities is not considered in the literature. However, caregiver burden experienced with this cohort is contemplated and the unpredictability

of physical tasks, which may include 'giving medicines' are alluded to (Heaton *et al.* 2005, Nicholl & Begley 2012, McCann *et al.* 2015). This unpredictability was something participants in this study experienced and noticed especially when other demands were placed on them.

Furthermore, it became more time consuming when a PEG was being used as this required a more complex medicalised procedure or when a child's condition deteriorated and determined the need for yet more medications. When a PEG is used for 'giving medicines' this requires alteration to drug formulation and not all medicines are available in liquid form, the recommended formulation for administration using a PEG (Wright 2011). Therefore, alternative approaches to manage tablets are required to ensure the correct consistency to minimise blockage while also maintaining accuracy and precision (Wright & Kelly 2012). Additionally, consideration of the time required for maintaining a continuous supply of medicines, having up to date prescriptions and paperwork and linking with the GP and pharmacist to ensure there are no delays in securing the medicines, is not pondered in the literature.

Participants acknowledged they adapted their daily life to suit their child with severe and profound intellectual disabilities and the routine of 'giving medicines', with few spontaneous activities or social outings planned. Heaton *et al.* (2005) recognise this need to adapt and it is also supported by Crowe & Michael (2011) with an acknowledgement that typical days do not really exist for mothers of children with severe and profound intellectual disabilities. Finding the time to do anything other than care is difficult and stressful with the literature identifying specific difficulties for mothers in terms of employment, leisure activities or social interaction (Brandon 2007, Carnevale *et al.* 2008). While some participants in this study worked outside the home, this required immense planning and organisation for their child with severe and profound intellectual disabilities. Diehl *et al.* (1991) suggest that one parent usually ends up taking on the full time caring role. Evidence also indicates that the daily burden of routine and continual responsibilities can result in physical and emotional over burden for carers (Thomlinson 2002) with having enough time at the core of their experience.

In discussing the dimension of 'lived time' it is clear that mothers' experience of 'giving medicines' is very much relentless, requiring continuous input especially when there is a demanding schedule of challenging and complex medicine administrations. While caregiver burden is addressed in the literature, the intricacies of 'giving medicines' is less so. These mothers' lives lack spontaneity and for the most part daily life is adapted to the needs of their child with the experience of 'giving medicines' causing increased burden.

6.5 Lived Space – Physical and emotional space

'Lived space' was the fourth existential dimension to be considered. From van Manen's (1990) perspective this dimension of 'lived space' is concerned with the mother's life and the space her life occupies. In this instance, 'lived space' was about mothers' reference to physical space in terms of the environment and travelling outside of the home and the emotional space in their lives. Emotional space was explored through participants highlighting their feelings throughout data collection. Raising a child with severe and profound intellectual disabilities is often associated with negative feelings and the role can be relentless and intense (Bourke-Taylor *et al.* 2010). The reality for many parents is that they experience a combination of joy and sorrow with the presence of a child with intellectual disability (Kearney & Griffin 2001, Little & Clark 2006, Trute *et al.* 2007). The feelings of being overwhelmed by the extent of caring and the endless responsibility can be incredibly stressful (Carnevale *et al.* 2008). Moreover, enormous psychological challenges are highlighted in the literature with regard to caring for a child with intellectual disabilities with anxiety to the forefront of parental experiences (Cramm & Nieboer 2011, Norlin & Broberg 2013). Notably, higher levels of anxiety are experienced by parents of children with severe disabilities living at home (Emond & Eaton 2004, Heaton *et al.* 2006, Radriguez & King 2009) with many parents also registering higher depression scores (Olsson & Hwang 2001, Bemister *et al.* 2014). Anxiety and worry is often associated with financial concerns as one parent usually leaves employment (Diehl *et al.* 1991). Furthermore, while participants were resigned to their caring role, feeling lonely and isolated was commonplace in this study. Green

(2003) indicates that sometimes this is associated with the stigma of having a child that is 'different' and emotional reactions identified in this study such as sadness, worry, feelings of stress and isolation are also evident in the literature (Oti-Baodi 2017). Similar to Kars *et al.* (2008), it is evident that participants in this study sacrificed emotional wellbeing for the sake of their child.

However, what is notable is parents' ability to manage all of these negative feelings if coping strategies are in place such as informal family, friends and social support (Paster *et al.* 2009, Oti-Baodi 2017). Understanding the role of coping strategies and what people do to overcome negative feelings can enhance development of appropriate interventions and in turn result in enhanced family functioning (Oti-Baodi 2017). Additionally, mothers of children with severe and profound intellectual disabilities have suggested that more support at home and home-based respite services would be of benefit in reducing stress (Redmond & Richardson 2003, Whiting 2014). Furthermore, a co-ordinator of care would also alleviate some anxieties and stress according to Gravdal-Kvarme *et al.* (2016).

Feelings of fear were commonplace in this study linked to the challenges of 'giving medicines' already discussed in section 6.4 but also giving opioid medications or fear about the future and transition to adult services. A number of fears and anxieties have led to misconceptions about the use of opioids, particularly morphine. Much of the concerns are as a result of stigma attached to the historical use of morphine (Ballantyne 2007, Crouch & Chapelhow 2008). Fears surround the notion that opioid dependence results from its use and that it can cause respiratory depression and is associated with end of life care (Sykes 2007). However, prescribers of opioids use titrated doses and begin with the smallest possible effective dose in the range. Pain management in children with intellectual disabilities is challenging with difficulties reported in pain assessment, a high incidence of co-morbidities and the use of multiple medications (Valkenburg *et al.* 2015, Carter *et al.* 2017). Nevertheless, the requirement for pain management in children is high (Verghese & Hannallah 2010) and often opioids provide a solution to this, especially with children with chronic pain and intellectual disabilities.

It is widely used in symptom management for children requiring palliative care (Jassal 2014). Therefore, Crouch & Chapelhow (2008) suggest strategies need to be employed to reassure caregivers and reduce concerns.

Another fear highlighted by participants related to transition of children from child to adult services even if this was not happening for some time. This is not an unusual fear or anxiety as this move brings with it change, such as personnel and potential lack of knowledge (Wells & Manning 2017). A greater understanding of the transition process is important for both parents and professionals with the shortcomings of transition service development high on healthcare improvement agendas (Wells & Manning 2017). Together for Short Lives have developed a generic framework to be adapted for planning multi-agency services for young people with life-limiting illness as they move to adult services (Chambers 2015). Similarly, both the RCN (2013b) and NICE guidelines (2016) have been advanced with the aim of improving the planning and transition of health and social care for children moving across from child to adult services. Implementation of such guidelines is aimed at improving the experience for both children and their families.

Consideration of 'physical space' was pondered also. The suggested optimum environment for the child with severe and profound intellectual disabilities to live is in the home (Doyle & Buckley 2012). With improved developments in complex delivery of care within the home environment, more children are receiving this care while residing at home. In this study all of the children had high support requirements with many of the children demanding multiple pieces of equipment, some of which related to 'giving medicines'. However, it is evident that home care provision is 'beset with problems' (Hewitt-Taylor 2005a) including housing problems and suitability of the home environment (Noyes 2002). Part of service delivery for children with complex needs surrounds developing a service for home that is planned, proactive and specifies the extent of changes and requirements to the home environment (DOH 2008). Furthermore, such considerations need to include; adaptations or adaptive equipment required to facilitate daily life (DOH 2008).

Providing care when travelling is challenging for mothers of children with severe and profound intellectual disabilities who are 'giving medicines'. Nicholl (2013) suggests that all journeys outside the house require careful planning and preparation for children with complex needs. As the child's needs become more complex the requirement for more equipment becomes apparent making transport much more than just placing the child in the car. Similar to this study, Nicholl (2013) addresses the meticulous time consuming planning undertaken by mothers and the uncontrolled circumstances that might arise when travelling. This was particularly difficult for participants if driving a few hours to the respite service. Supporting this finding, Nicholl (2013) also highlighted this issue and reported that mothers felt time pressure to have reached their destination in order for them to administer care such as 'giving medications'. While the "Changing Places" campaign (Changing Places Ireland 2018) is a welcome addition in developing changing facilities in public places nationwide for those with disabilities, there is no similar campaign for suitable facilities for administering personal care such as 'giving medicines'.

The lack of understanding by health providers was something mothers in this study mentioned especially in terms of waiting times within the GP clinic or at the hospital. Nicholl (2013) reported the lack of appreciation by service providers of the challenges in travelling with a child with severe and profound intellectual disabilities and the inability of some children to wait. This was also evident in a study reported by Clark & McArthur (2008). Nonetheless, Hewitt-Taylor (2012) posits that as numbers of children with complex needs increase in the community so too does the need for travel. Therefore, an awareness of the difficulties of travelling with a child with severe and profound intellectual disabilities and how these may be overcome needs to be acknowledged by service providers.

Within this dimension considering 'lived space' it is apparent that mothers experience of 'giving medicines' to their child with severe and profound intellectual disabilities yields many emotions on a day to day basis. Evident on scrutinising the literature is the need for supportive coping mechanisms as outlined earlier in section 6.2. Additionally,

mothers were very clear that home is their preferred place of care for their child but also requires supports in order to alleviate some of the intense pressure they experienced. The physical challenge of travelling out of the home was also apparent and the literature has offered some advice on how best to address this issue and how to overcome the challenges.

6.6 Lived things – Material things that influence mothers' experiences of 'giving medicines'

The final existential dimension to be considered was that of 'lived things'. This refers to materiality and is about how certain material things in life can influence mothers' experiences of 'giving medicines' to their child. The material things mothers spoke about included documentation, associated equipment and cost of medicines. While medication administration records are an integral part of nursing practice in the hospital or community setting and are influenced by national guidelines such as NMBI (2007) and HIQA (2015), no such record is required in the home environment when care is delivered by a caregiver. Nonetheless, a nurse providing care in the home must keep a record but again this is not standardised and depends on the service they are employed by, such as the HSE, voluntary organisation or nursing agency. However, informal records kept by participants in this study, in many ways mirrored the information that might be held in a medication passport document such as that cited by Jubrai & Blair (2015). Interestingly, those participants that kept records had never been advised to do so but found it useful when communicating with health professionals at meetings but also for in home respite care when handing over to a nurse. A formal record such as a medication passport has the advantage of belonging to the caregiver and being a single medication record that provides a straightforward summary of all medication and can be presented at any health professional meeting or interaction as necessary (Elias *et al.* 2012, Jubrai & Blair 2015).

Discussing use of documentation and developing a medication record or passport may be an element of discharge planning (Samwell 2012) and should form part of multi-agency integrated and coordinated support (Tait *et al.* 2002). The purpose of such

records should be discussed with the caregiver and responsibility for maintaining it agreed (Stephens 2005). As well as providing education and training relating to 'giving medicines', the importance of keeping a record and supporting documentation should be explicit (Glasper *et al.* 2010). However, on examining a range of relevant care pathways (Department of Health, Social Services & Public Safety 2009, HSE 2015a, 2015b) explicit detail on 'giving medicines' is not evident and suggests there is a gap within current care coordination.

Cost of medicines and associated equipment was another component of 'lived things' in this study with 'giving medicines' requiring an amount of medication related equipment. While cost of medicines was a concern, all children with severe and profound intellectual disabilities receive long term illness cards, supplied by the HSE (2017b), meaning that the majority of medicines were covered and paid for by this card. Equipment adopted in 'giving medicines' may range from the less complex tablet crusher to the more complex syringe and PEG related equipment. The literature suggests that the proportion of children requiring technology or equipment for health needs is on the increase (Wang & Barnard 2004, Feudtner *et al.* 2005, Nicholl *et al.* 2013) and the number of medicines prescribed determines the volume of equipment required. Comparable to the findings of this study, equipment related concerns with children with severe and profound intellectual disabilities are common (Diehl *et al.* 1991, Moore *et al.* 2010, Nicholl *et al.* 2013, Bourke-Taylor *et al.* 2013). Like this study, Kirk (2008) established that the profile of children within the UK requiring ongoing medical technological support was indeed high with 60% of children using a gastrostomy feeding tube although she did not delineate if these were used for medication administration also. More recently, Nicholl *et al.* (2013) found over two thirds of participants in their study used medication equipment such as syringes or tablet crushers and similar to this study, required medication storage cupboards and designated fridge storage and preparation space.

Participants in this study not only had to have the medical equipment associated with 'giving medicines' but also had to have a steady supply of suitable foodstuffs for

administration also, an issue not addressed in the literature. Hewitt-Taylor (2005a, 2005c) admits that sourcing and securing equipment can be an additional stress for parents with supplies occasionally unreliable and difficult to acquire. This is not unusual with the DOH (2004) and Venables *et al.* (2015) identifying this as a problem and indicating that suppliers do not know the individual nuances of the situation and are not always willing to provide essential pieces of equipment, often causing an over or under supply of materials such as syringes. The issue of cutbacks and associated budgetary initiatives has also impacted on the supply of goods in the health service resulting in a hesitancy to supply and fund some equipment (Burke 2010). While the number of children with severe and profound intellectual disabilities may seem small, the numbers are increasing. And with a desire for these children to remain in the home and avoid hospital based care (Doyle & Buckley 2012), the technological supports need to be in place to support this. This is just one element of home care provision but this provision is renowned for its challenges especially in getting resources in place in the home (Noyes 2002, Kirk & Glendinning 2004, Hewitt-Taylor 2005a) and becomes further problematic when multiple agencies are required to work together (Tait *et al.* 2002, Abbott *et al.* 2005a, 2005b).

In summary, drawing on relevant literature, this dimension of 'lived things' discusses the material things that influence mothers' experiences of 'giving medicines'. The importance of having some form of medication record or document has been discussed. Additionally, the issue of cost and sourcing of medicines and equipment has been considered with challenges highlighted.

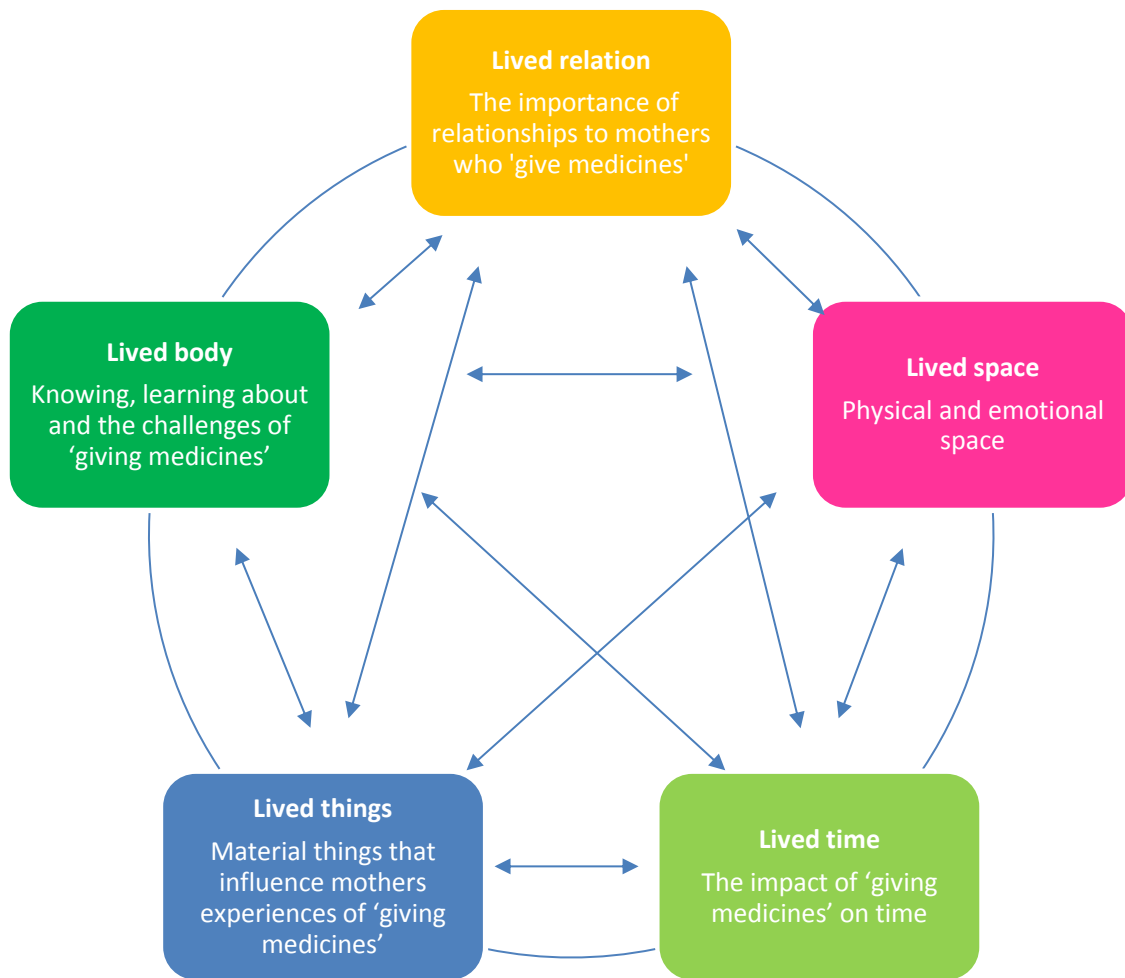
6.7 Overall final interpretation

As propounded in Chapter Three, a research study grounded in hermeneutic phenomenology involves developing an understanding through attributing meaning to a phenomenon. Pre-understandings have been acknowledged and using pertinent participant quotes, findings were explicated through presentation of essential themes within the five existential dimensions in Chapter Five. These were further examined incorporating relevant literature in this chapter and together the essential themes and

overall interpretation form the whole meaning resulting in the overall understanding that mothers' lived experience of 'giving medicines' to their child with severe and profound intellectual disabilities is a relentless and challenging, yet invisible element of their caring role.

According to van Manen (2014) each existential dimension; 'lived relation', 'lived body', 'lived space', 'lived time' and 'lived thing', pervades the lifeworld of human beings. What became obvious in the data analysis and presentation of findings was that while essential themes were delineated and applied within specific lifeworld existentials, significant overlap exists between each existential dimension where 'giving medicines' impacts all of the lifeworlds propounded by van Manen (2014). No symmetry was evident in this overlap and interrelation was not necessarily equal between each existential dimension (see Figure 11).

Figure 11: Interrelation between existential dimensions

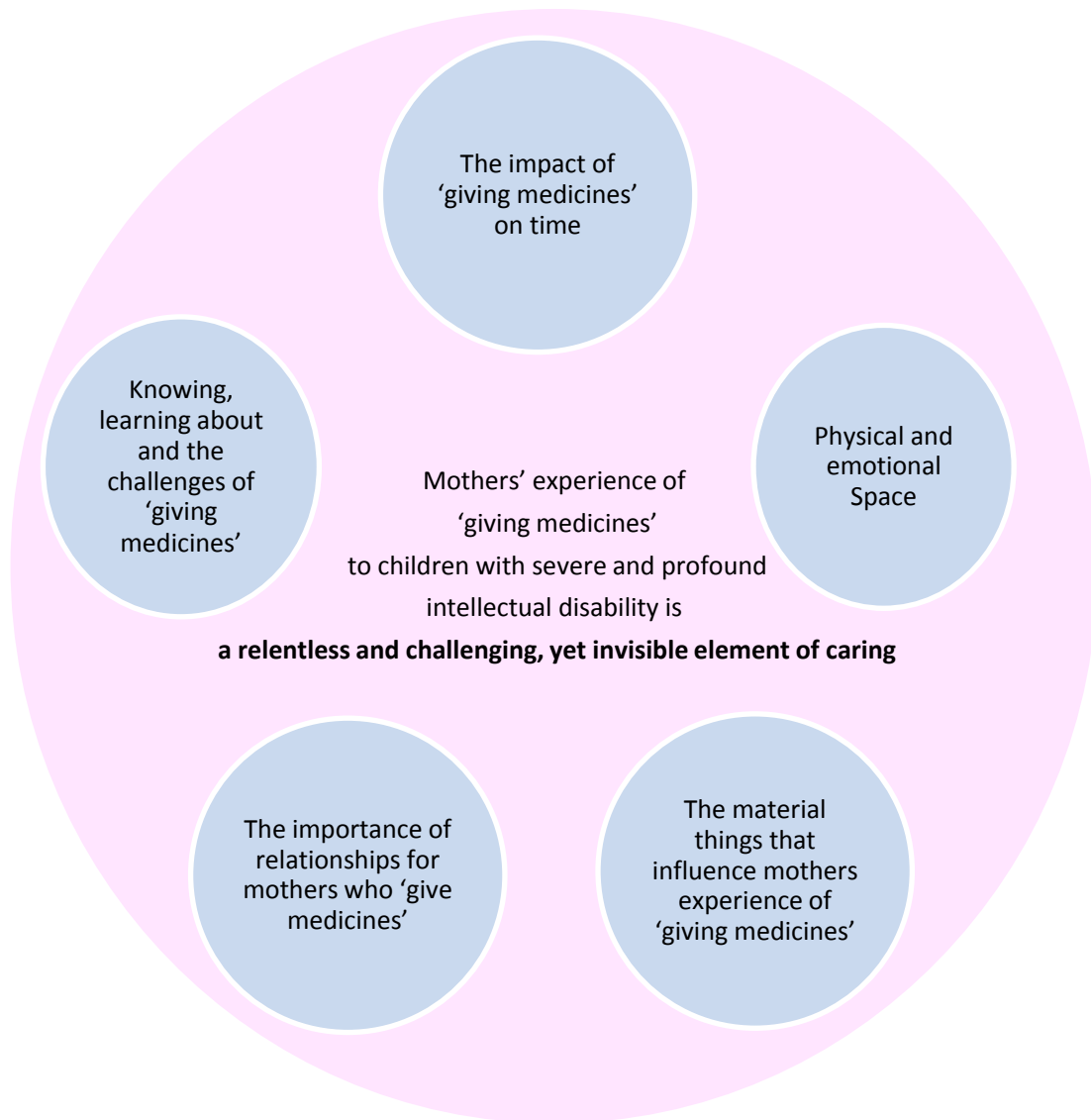


Van Manen (1990) proposes taking a step back and balancing the immersion in the parts with the bigger picture. This *balancing the research context by considering parts and whole* became clearer as the writing of this thesis continued. The existential dimensions were examined in a unified manner to further understand the phenomenon at hand. All existential dimensions together can demonstrate a fusion of the hermeneutic circle, a key component of phenomenology of practice (van Manen 1990, 2014). While each existential dimension can be differentiated they cannot be separated or viewed overall in isolation as the hermeneutic circle envisions a 'whole' arising from the detailed experience of everyday existence. Together the five existential dimensions form an intricate unity which is called the lifeworld and an examination of the lifeworld in its entirety is necessary.

This overall interpretation highlights the unique and overlapping aspects emphasised within the findings and earlier discussion. Acknowledging that understanding can never be truly complete in the hermeneutic phenomenological tradition, this new understanding has been developed through participant description and the resultant construction of meaning. The overall perspective on how themes identified in the study corresponded with the five dimensions of existence was evident. The existential of 'lived relation' encompassed seven themes, 'lived body' three themes, 'lived time' five themes, 'lived space' two themes and 'lived things' three themes. According to Laverly (2003) the interpretive process is fully realised through the hermeneutic circle which moves from the parts of experience to the whole of experience and back and forth again to increase the depth of engagement and understanding of texts. This demonstration of movement between the parts and the whole is an important element of interpretation (van Manen 1997, Cohen *et al.* 2000). In keeping with the concept of the 'hermeneutic circle', significant reading was assumed, text examined and presented in the findings chapter and discussion and interpretation undertaken within this chapter. Furthermore, in acknowledging the 'whole' it is important to recognise mothers don't compartmentalise their role into various lifeworlds but see their lives as a 'whole'.

As previously indicated in Figure 11, an interrelation exists between existential dimensions and essential themes. In a further development of this figure, Figure 12 displays the mother at the centre of the phenomenon depicting how each dimension relates to her experience and has the capacity to enhance or further exacerbate her experience.

Figure 12: Mothers' experience of 'giving medicines' to their child with severe and profound intellectual disability is **a relentless and challenging, yet invisible element of caring**



Viewing the phenomena through the 'whole' lens, in understanding this relentless and challenging, yet invisible element of mothers' caring role, it was apparent that mothers' experience of 'giving medicines' was a large part of their daily existence. The interrelation between essential themes and dimensions is evidently bound overall by the relationship between mother and child. This bond was explored earlier and it was posited that mothers in this study are 'mothers of difference'. In further understanding mothers' experience of 'giving medicines' to their child with severe and profound intellectual disabilities, it was evident from the outset in conversations, that this

element of their caring role was an invisible one, not often considered by others. Furthermore, until invited to participate in this study, many of the mothers had not considered or reflected upon this particular task or element of caring. It was not because 'giving medicines' was not a huge element of caring but because often it was viewed as 'just part of life' and was lost among all of the other elements of caring that are undertaken in daily life.

Additionally, mothers were able to verbalise the range of activities they take responsibility for with regard to 'giving medicines', a core objective of this study. Such activities included description of the experience of physically administering medicines and the associated challenges encountered on a daily basis. This was further delineated to who impacted the task positively, how this was impacted upon by both physical and emotional space, time and the material things that were necessary in order to undertake 'giving medicines'. What is clear overall, is that these activities or element of care described by mothers have heretofore remained largely invisible in the literature. 'Giving medicines' is much more than a clinical task with physical challenges requiring manipulation and alternative approaches to administration but also entails levels of skill, learning, preparation and organisation. Moreover, as the interviews and diaries attest, mothers often compromise and sacrifice their own wellbeing for that of their child in order to 'give medicines'.

The world of mothers 'giving medicines' to their child with severe and profound intellectual disabilities is explicated here as relentless, challenging, demanding, requiring observational skills and constant vigilance. However, this study places emphasis on the element of 'giving medicines' as one among many caregiving tasks that these mothers undertake. The nature of 'giving medicines' is that it is often unpredictable as well as demanding onerous preparation and planning and overcoming the challenges of physically giving the medicines. What was apparent was that all activities were inseparable from time with 'giving medicines' an all-consuming relentless task. Mothers in this study exhibited a fierce desire to protect and care for their child and as a result they became attuned to the needs of their child, often using their instinct and

observational skills in developing a sense of 'just knowing' what was required of them. In 'just knowing' what to do in terms of 'giving medicines', there was strong thread of experiential learning with mothers very much learning on the job and developing their learning through trial and error. Arguably, this is the way all mothers tend to learn their parenting skills. However, the intricacies of learning to 'give medicines' often requires clinical competency far beyond that of 'normal parenting'.

As outlined in Chapter Two, the literature in the field heretofore has largely been associated with burden of care. Despite literature not examining this issue on the experience of 'giving medicines' in any great detail previously, some commonality exists between caregiver burden literature and the findings of this study. Although much of the work explored in those studies have been undertaken with children with complex needs, most of their findings support the interpretation in this study that mothers' who 'give medicines' to children with severe and profound intellectual disabilities undertake a relentless and challenging, yet invisible element of caring in their role. That said, none of the previous literature fully represents the lifeworld of those mothers who undertake 'giving medicines' in daily life. The interviews represented a shift in focus, especially whereby some mothers had not contemplated the issue of 'giving medicines' until this study.

This exposition of the meaning of the phenomenon is essential in developing insight into the world of mothers 'giving medicines' to their child with severe and profound intellectual disabilities. Integrating the discussion and interpretation of the five existential dimensions contributes to the scientific discourse on the phenomenon of mothers' lived experience of 'giving medicines' to their child with severe and profound intellectual disabilities. This understanding of a unified *being in the world* or *dasein* is an important facet of hermeneutic phenomenology. The meaning of mothers' lived experience as it is revealed here helps us to know more about what this experience is like. Furthermore, bringing out the meaning in this unified manner highlights that the phenomenon is a common experience for these mothers, albeit particular nuances for each individual exists. It is also noteworthy that all of the mothers in this study were

striving for a meaningful life even if life was very much adapted to the needs of their child with severe and profound intellectual disabilities.

6.8 Conclusion

Being mindful of the overall aim and objectives of this study, the findings have been synthesised and literature consulted, culminating in development of the discussion. In identifying the range of activities mothers' of children with severe and profound intellectual disabilities 'giving medicines' undertake, it was enlightening to identify the minutiae of 'giving medicines' and realise it is much more than just the physical act of administration, transcending every component of daily life with many difficulties apparent. It was also clear that learning about 'giving medicines' was often a solo journey. While individually, all mothers' stories were unique, commonalities existed between participants as presented within the identified essential themes and discussed further with the literature. The enormity of their role was highlighted and it was obvious that mothers' ability to cope was influenced by their support strategies in place and their own ability to avail of activities outside of their caring role.

In conclusion, it was attempted to establish if the objectives described in Chapter One were achieved through analysis of the findings and consequently it is purported that very useful information has been gathered and interlaced with pertinent literature which presents a basis for understanding and interpretation by others. Not only does this study highlight the various components of 'giving medicines' to children with severe and profound intellectual disabilities, but it also signifies the importance of acknowledging mothers' lived experiences. Through explicating the meaning of mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities, many aspects of 'giving medicines' have been explored and presented here as a basis for understanding and interpretation by others, a core objective of this study. Taken together in the discussion, interpretation of the essential themes and existential dimensions led to the development of key recommendations presented in Chapter Seven, aimed at addressing the understanding of the relentless and challenging, yet invisible element of caring undertaken by mothers, who 'give medicines' to their child

with severe and profound intellectual disabilities. The following and final chapter of this thesis discusses the implications and recommendations for practice, service provision, research, research methodology and education arising from this study.

Chapter 7 – Conclusion, Implications and Recommendations

7.1 Introduction

Chapter Six provided a discussion of the key findings presented previously in Chapter Five. This discussion was supported with relevant literature some of which was presented within Chapter Two, the literature review. This final chapter considers the implications of the findings of this study in relation to research, research methodology, education, policy and practice. It sets out possible recommendations and suggestions for policy-makers, practitioners and mothers. It also outlines the strengths and limitations of the study before summarising the plan for dissemination.

With a clear gap existing around the experience of ‘giving medicines’ to children with severe and profound intellectual disabilities and detail of the specific lived experience for mothers, the motivation for undertaking this study was evident. Its aim was to explore mothers’ lived experience of ‘giving medicines’ to children with severe and profound intellectual disabilities. This goal was achieved by concentrating on key essential themes of which there were 20 identified and further delineated within the existential dimensions of ‘lived relation’, ‘lived body’, ‘lived space’, ‘lived time’ and ‘lived things’. Further discussion of these and an overall interpretation was provided in Chapter Six. The implications and recommendations outlined in this chapter arise from the findings and discussion provided in earlier chapters.

7.2 Implications and Recommendations of the Study

According to Parahoo (2014) all research has implications of some kind whether positive or negative. Furthermore, research implications suggest how the findings may be important for research, education, policy and practice. The significance and uniqueness of this study must be considered. This is the first study of its kind in Ireland that has included mothers’ lived experience of ‘giving medicines’ to children with severe and profound intellectual disabilities and therefore, will increase awareness of the phenomenon. A lack of routine dialogue between professionals and parents about what

it is like to 'give medicines' to their child means that this study is fundamental in opening an important conversation.

Recommendations on the other hand are specific and indicate actions that should be taken from the evidence provided in the study (Polit & Beck 2017). The conclusions drawn from the research findings have implications for research, research methodology, education, policy and practice. These implications are now presented in respect of each area with associated recommendations arising from the findings also emphasised.

7.2.1 Implications and Recommendations for Research

One of the functions of a qualitative study is to generate questions for further research (Parahoo 2014) and this has been achieved in determining the essence of the phenomenon with several areas in need of further exploration. This study gave voice to mothers of children with severe and profound intellectual disabilities on a subject not considered previously and generated possibilities for future research in many areas, which would suit a variety of methodologies. It provides a baseline for further work which may explore the contribution of this study to the care of children with severe and profound intellectual disabilities and the support needs of parents of these children.

The most obvious research possibility is that the present population needs to be further studied because the needs of this group are not being met by current research. In doing this, the current study could be expanded to establish if the findings are reflected within the wider population of children with severe and profound intellectual disabilities. As little research has been conducted on this topic and in particular minimal experiential perspectives explored, further existential research may be of benefit. As much of the research undertaken shows the all-encompassing burden of care on mothers of children with severe and profound intellectual disabilities, additional research would delve deeper into the intricacies of care with 'giving medicines' just one of the elements of care undertaken by mothers in daily care. As an emergent field of research, the focus on children with severe and profound intellectual disabilities needs to include such issues as the impact of 'giving medicines' on the children themselves. Additionally, it would be

interesting to undertake a comparative study using two different geographical areas as the national children's hospitals providing the bulk of child services nationally are based within one geographical area.

7.2.1.1 Recommendations for Research

The following recommendations are suggested as a result of this study:

- Further study of the phenomenon of lived experience when 'giving medicines' to children with severe and profound intellectual disabilities in a wider population to include children with severe and profound intellectual disabilities, husbands/partners, siblings, other family members and health professionals.
- Undertake a comparative study of the phenomenon using two different geographical locations.
- Further study exploring the level of support individual families require in 'giving medicines' and develop an integrated care pathway.
- Further examination of the bond between mother and child with a severe and profound intellectual disability to determine the existence of similarities and differences and the possible need for 'mothers of difference' to have access to more supports.
- Explore further the emotions experienced by mothers of children with severe and profound intellectual disabilities in daily life.
- Research into medication management in schools with the aim of development of a national schoolwide policy.
- Development of participatory and alternative research approaches such as observational or ethnographic studies to involve children with severe and profound intellectual disabilities in research studies.
- Families encouraged to actively participate in research studies with findings disseminated and feedback given on action that may be taken.

7.2.2 Implications and Recommendations for Research Methodology

Adopting an appropriate research methodology is a requirement for any research study (Polit & Beck 2017). In this study, the hermeneutic phenomenological methodology was

useful in capturing the essences of the phenomenon of mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities. Establishing an understanding of the philosophical underpinnings of this study was important in the research process. However, reading van Manens' work was at times difficult punctuated by moments of clarity but what soon became apparent was the need for exploring the nature of hermeneutics more fully and historically. Therefore, the earlier works of Heidegger, Gadamer and Merleau-Ponty were considered and were valuable in expanding and enhancing my understanding of what I found a complex language from the outset. I found this methodology to be intensive, rigorous and energy consuming constantly revisiting my philosophical understanding. I also chose to review the transcribed data using a software package NVIVO. Despite van Manen (1990, p.78) warning against "the mechanical application of frequency counts or coding of selected terms of transcripts and text", I found the use of this package beneficial and while being mindful of van Manen's stance on such packages I was at all times, more aware of the risk of over coding. Immersion in the data and being mindful of the philosophical underpinnings was essential throughout. Furthermore, I believe I have demonstrated that using a software package refutes the notion that they should not be adopted within hermeneutic phenomenological research and if anything can be adopted for ease of management once the researcher is aware of the potential pitfall of over coding. In writing this thesis, I found myself developing not only a new understanding of the essence of mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities but also a new, more enhanced understanding of my chosen research methodology. In adopting van Manen's (1990) methodological outline for doing hermeneutic phenomenology, I explored an existential perspective, an approach not widely used with this population.

7.2.2.1 Recommendations for Research Methodology

The following recommendation is suggested as a result of this study:

- Hermeneutic phenomenology adopting van Manen's methodological outline for doing hermeneutic phenomenology should be adopted more widely and time allowed for capturing the essence of experience using this research methodology.

7.2.3 Implications and Recommendations for Practice

This study is significant in that it provides much needed data and a deeper awareness of the intricacies of ‘giving medicines’ to children with severe and profound intellectual disabilities and provides meaning of mothers’ lived experience. Furthermore, it is suggested that there are implications for various other cohorts of children; those with complex health care needs and those with chronic illness and continuing medication requirements. Illuminating this phenomenon has highlighted that there seems to be no standard system of practice in Ireland for supporting mothers of children with severe and profound intellectual disabilities. Furthermore, depending on geographical location, additional disparities can be seen. Mothers within this study admitted not often being asked about their experiences and therefore placed value on participating in this study, providing a rare opportunity to discuss their daily lives. It was evident that mothers had experienced difficulties in ‘giving medicines’ from many different perspectives and had they been advised or educated these may have been prevented or alleviated. In turn this often meant difficulty impacted on the child with severe and profound intellectual disabilities. Therefore, offering insights such as those elucidated in this study, may ultimately impact practice and quality of life for these individual children. Furthermore, the findings make the phenomenon more understandable to the wider audience.

7.2.3.1 Recommendations for Practice

The following recommendations are suggested as a result of this study:

For parents

- Development of one single medication administration record – ideally this should form part of the medication passport where a record of daily administration is recorded.

Health Professionals

- Recognition of the family’s central role in caring for a child with severe and profound intellectual disabilities.
- Appreciate the challenges in travelling with a child with severe and profound intellectual disabilities. Only essential trips to appointments should be warranted

and efforts made by a care coordinator to ensure appointments are clustered with the multi-disciplinary team to avoid multiple trips.

- Quality and quantity of information for family's needs to have more emphasis on 'giving medicines'.
- Knowledge in order to enable referral to appropriate reputable parent support groups whether face to face or available through other media platforms.

Service Providers (Voluntary and Statutory)

- Acknowledgement of the role voluntary organisations play in supporting families and children with severe and profound intellectual disabilities in the home environment.
- Stable voluntary and statutory supports be offered.
- Develop a network (information database) of children and families giving them skills to support each other.
- Availability of in-home respite as a positive coping strategy.
- Access to a care coordinator.
- Standardised but yet individualised information leaflets and support documentation be developed in partnership with mothers. It should also include resources available such as a phone service that is accessible (this may be a care coordinator or a designated helpline).

7.2.4 Implications and Recommendations for Education

This study indicated the importance of quality education for parents and health professionals. An important focus in nurse education is preparing parents for the discharge home of their child and while this is a key component of current education programmes there is a need to address the complexity of the situation when there are continuing medication needs. Therefore, in light of this study such detail needs to be embedded in undergraduate and post graduate nursing programmes in both the field of intellectual disabilities, children's and community or public health nursing, if not already being addressed. Similarly, since CNS and ANPs are becoming increasingly central to effective management of chronic conditions, post graduate Diploma and Masters

Courses should incorporate the needs of families in 'giving medicines' when considering the overall management of the child with severe and profound intellectual disabilities. Furthermore, education for other health professionals is required and specific indicative content defined as a result of this study.

7.2.4.1 Recommendations for Education

The following recommendations are suggested as a result of this study:

Education for Mothers (Parents)

Formal education and training for mothers (parents) developed and implemented by professionals to encompass all elements related to 'giving medicines' in order to empower mothers (parents) to be confident and competent in 'giving medicines' to include:

- The importance of observations and development of observational skills.
- Demonstration of clinical competencies. For example, can the mother administer medicines accurately and reliably from basic oral administration to 'giving medicines' via enteral tube, 'giving medicines' intravenously or manipulating medicines.
- Advice that mothers can request key information such as the prescriber ordering the most simplified version of the medicine or specifying the manipulations that may be required (should be consultation between the prescriber, pharmacist and mother).
- Advice that mothers can request that the medication administration is timed in a way that suits the child and family routine.
- Advice on how to get a new prescription or a prescription refill.
- Information on side effects of medicines using simple language such as common, uncommon, very uncommon.
- Information on medicine interactions.
- Information on use of opioids (allay fears and misconceptions).
- Guidance on the manipulation of and covert administration of medicines and appropriate interventions in the home setting. This is important in

guiding and supporting mothers who are required to manipulate medicines when there is no alternative.

- Advice on how to maintain a supply of medicines and medicine related equipment to avoid running out of anything.
- Information on appropriate storage of medicines. For example, correct temperature, fridge storage as required.
- Advice on the importance of maintaining a medication list (this may be a medication passport).
- Information on who mothers can seek professional advice from, relating to 'giving medicines'.
-

Education for all Health Professionals (to include nurses)

- In service educational programmes be developed for all members of the multidisciplinary team working with children with severe and profound intellectual disabilities requiring medicines. This should include contemporary management issues and realistic scenarios. For example, how to use off label medicines when there is no alternative and those not licenced for use in PEG tubes.
- Development/redevelopment of education programmes and learning packages at level 8 and 9 of the National Qualifications Authority of Ireland (NQAI) that encompass key competencies, so nurses have the requisite knowledge and skills for autonomous posts such as care coordinators, CNS and ANP in children's intellectual disability care.
- Development/redevelopment of undergraduate and post graduate Irish nursing and other curricula that considers embedding material on continuing medication needs especially in the field of intellectual disabilities, children's and community or public health nursing, pharmacy and medicine.

Education for GPs

- Develop a learning package for training and education on the needs of children with severe and profound intellectual disabilities and the intricacies of 'giving medicines' to this cohort, in particular the individual nuances that may present

with each child and the implications of prescribing additional medicines. For example, an antibiotic.

- Recognition by GPs of the need to be accessible either by phone, within the clinic or consideration of house calls. House call exposure in clinical practice and medical training can increase confidence of primary care practitioners to incorporate house calls into their practice. This needs to be considered and embedded within undergraduate and postgraduate medical training programmes.
- Inclusion of detail on the intricacies of 'giving medicines' to this cohort of children within the Irish College of General Practitioners (ICGP) updated curriculum for GP training in 2018 (ICGP 2018).
- Encouraged to promote continuity of relations between GPs and individuals.
- Clearly and accurately write prescriptions and complete 'Kardex' for both respite and school facilities with clear instructions for administering medicines.
- Development and implementation of guidance on manipulation of and covert administration of medicines and appropriate interventions in the community setting.
- Encouraged to increase awareness of changes made to medicines at hospital appointments and implications of such changes for their role in prescribing any further additional medicines.

Pharmacists

- Develop a learning package for training and education on the needs of children with severe and profound intellectual disabilities and increased awareness of the individual nuances that may present with each child.
- Encouraged to promote continuity of relations between pharmacists and individuals. For example, same pharmacist manages prescriptions for the child if possible.
- Develop a pilot scheme for community pharmacy home visits which will enhance medication management. This may include teaching parents about compliance, medicine interactions, manipulation and administration of medicines.

- Develop a system of referral to other professionals regarding the needs of the child relating to ‘giving medicines’. For example, GP, dietician, physiotherapist, occupational therapist.
- Development and implementation of guidance on manipulation and covert administration of medicines and appropriate interventions in the community setting.

7.2.5 Implications and Recommendations for Service Provision and Policy

This study findings highlight mothers’ lived experience of ‘giving medicines’ to a child with severe and profound intellectual disabilities and identifies many issues that have implications that may be addressed by service providers. It has generated important knowledge on an area not previously considered. Therefore, there are many recommendations for improvements in service provision that will serve to enhance the lives of children with severe and profound intellectual disabilities and their mothers.

7.2.5.1 Recommendations for Service Provision and Policy

The following recommendations are suggested as a result of this study:

Strategic and Policy Level

- Map service provision to identify gaps with this cohort of children. This mapping exercise would in turn stimulate development of services, enabling sharing of good practice especially within the context of ‘giving medicines’.
- Working group be established with the aim of focusing on how to meet the needs of children with severe and profound intellectual disabilities in service development and integration across sectors.
- Authors of national policy documents need to consider in detail the challenges experienced by mothers caring for their child with severe and profound intellectual disabilities in ‘giving medicines’.
- Emphasis to improve collaboration and joined up communication across sectors especially with regard to ‘giving medicines’.

- Coordination and a clear funding stream be made available for appropriate home adaptations or purchase of adaptive equipment required to facilitate daily life in terms of 'giving medicines'. This needs to take cognisance of storage and preparation facilities required for medicines and medicine related equipment.
- Guidance on who the suppliers of care and medicine related equipment are. Development of a centralised system where parents can access the supplies from one location. For example, pharmacist or PHN.
- Develop and grow accessible family support through 'giving medicines' helpline, digital services and reputable resources.
- Develop and implement a clear flagging system on admission to hospital that initiates an individualised management process with clearly defined communication strategies and adoption of individualised communication passports, hospital passports and avoidance of emergency departments if appropriate. A flagging system would also enhance knowledge of 'giving medicines' process for individual children.
- Development and implementation of medication passport (if not already included within hospital passport) as standard practice. This should include a full up-to-date medication list that maintains accuracy and is acceptable to all personnel using it. A universal document could be piloted across all agencies. Additionally, this could be advanced through development and use of an innovative mobile App accessible by relevant professionals such as GP, hospital staff, pharmacist and parents. Furthermore, development of electronic prescribing using this type of mobile App would remove the necessity for multiple iterations of prescriptions and 'Kardex' and transporting these from hospital to GP, to pharmacist, to respite, to school.
- Information technology supports and funding to develop information sharing. For example, development of electronic prescribing using a mobile App accessible by relevant professionals.
- Development of family support worker roles that offer practical help to families.
- Families should be supported through a model of care that provides navigation and coordination. Mechanisms for liaising and coordinating care with community

based services such as GP, pharmacist, public health nurse and practice nurse so as to ensure seamless transition and home management. For example, access to a hospital liaison nurse (may also be the care coordinator), CNS or ANP who has a registration qualification in intellectual disabilities.

- Development and implementation of an integrated care pathway that spans the acute and primary care sector and considers the intricacies of 'giving medicines'. This pathway needs to consider all of the associated issues in 'giving medicines'. Relevant parties need to be involved at an early stage. This pathway should have a wide range and extent including a needs assessment while in hospital and preparing and planning for discharge but also an in-home needs assessment that is continuous and considers ongoing changes in the needs of the child. It also needs to consider other care environments such as school and respite.

Hospital

- Letters that are communicated to GPs with medication details are copied to parents, as often these are faxed to GP clinics and are mislaid causing a time delay for receipt of prescriptions.

Schools

- Every child has the right to access education. Funding should be provided so that a school nurse can be employed in all special schools (preferably with a training qualification in intellectual disabilities and/or children's nursing) to allow children with severe and profound intellectual disabilities attend on a daily basis without concerns about who will 'give medicines'.

Respite

- More access to respite available locally on a regular basis to alleviate the relentless element of care that is 'giving medicines'. This in turn allows parents to care at home for longer.
- An offering of flexibility in the type of respite care available. For example, both in and out of home.

- Respite supply medication related equipment (especially generic equipment such as syringes) where possible in order to reduce the burden of preparation for mothers.

7.3 Limitations of the Study

While the findings of this study are rich and provide valuable insight into mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities, it is worth noting that there are limitations akin to any study (Parahoo 2014, Polit & Beck 2017). Acknowledgment of strengths and limitations help to formulate realistic recommendations for implementation and to ensure development and improvement of subsequent research. It is important to recognise limitations, as these are a means of ensuring development and improvements in subsequent work. This study was no exception with the following highlighted as possible limitations:

- A purposive sample is more likely to have an opinion on the topic under investigation. Those choosing to participate may have done so, as they had experienced particular difficulties in 'giving medicines' to their child with severe and profound intellectual disabilities. Similarly, those who are highly stressed and in arduous caring roles may have decided not to partake due to time constraints and therefore, their views may be underrepresented.
- The participant experiences are captured at a moment in time and therefore, subsequent experiences might influence their future understanding and resultant reflections upon the phenomenon. Therefore, this interpretation represents mothers' experiences at a particular point in their lives. Nevertheless, participants were mothers of a broad age range of children and therefore had a wide variety of experiences.
- This study involved the co-construction of an interpretation. It included participant accounts, my pre-understandings, my interactions with participants, the method of data analysis interlaced with the available literature resulting in a new understanding. However, a different researcher may have their own pre-understandings that would influence the research process and possibly result in a

different interpretation of the experience. Nevertheless, this interpretation is important in enhancing the understanding on the topic.

- Recruitment was slow initially and interestingly one organisation did not permit an invitation to participate to be sent to possible participants who met the criteria, who had taken part in a different study (unrelated) in the previous five years. However, when recruitment took place via the website detailed in Chapter Four, some of these potential participants were recruited and did not feel the organisation had justification to omit them from potential participation.

7.4 Unique Strengths of this Study

Parahoo (2014) advises that admitting the strengths of a research study is important. In this instance, the strengths of this study far outweigh the possible limitations. Strengths of this study are indicated as follows:

- First study of its kind to be undertaken in Ireland.
- First-hand understanding of mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities.
- Findings may be transferable to similar populations especially those with continuing medication needs.
- The age range of participants children was varied from 2 to 17 years which allowed for different perspectives based on the child's age, with some mothers having far more experience of 'giving medicines' than others.
- For mothers of children with severe and profound intellectual disabilities it is an important step in recognising their role in 'giving medicines' and facilitating the goals of care.
- It provides evidence of the issues that are incurred by mothers but also illuminates the challenges in taking medications for children with severe and profound intellectual disabilities.

- Professionals are afforded an opportunity to understand how mothers attend to the task of 'giving medicines' and consider it in discharge planning and provision of supports within the community.
- Service providers may recognise mothers' expertise and provide individually tailored supports that consider individual needs and adaptation of practice for the home setting.
- In elucidating the meaning of mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities underpinned by van Manens' (1990) work, it enhances understanding and knowledge of hermeneutic phenomenology.
- This study provides a baseline for further research studies in this area.
- This study has aided the formulation of many realistic recommendations for implementation, which may enhance the future development of care for children with severe and profound intellectual disabilities.

7.5 Dissemination

It can be argued that dissemination of research findings is in fact an 'art' (Saks & Allsop 2013). As well as adding to the body of knowledge on the subject area, research studies that are written up, disseminated and published bring a number of benefits. Aside from the prestige of publishing, displaying a track record in writing and demonstrating the utility of their research is important. Who will benefit from the findings should be considered in the dissemination plan. To this end, it was important for me to ensure that my target audience was not only professionals but also my population of participants. It can be argued that the research process is not complete until the findings have been disseminated and published. Dissemination is important to me as the identified gap will remain if I do not make the findings available to a wider audience. The results of this study will be made available to add to the existing knowledge base, to encourage development of guidelines and procedures and to inform future policy development either service specific or nationally. It is the responsibility of the researcher to promote

the application of their research findings to nursing practice and I intend to do this as outlined earlier in section 7.2.3, implications and recommendations for practice.

I also believe that dissemination of the findings is an ethical obligation to the participants who gave freely of their time to contribute to the study. Firstly, I have prepared and distributed an executive summary of the findings to each participant with those conclusions offering insight into the reality that is their world. It is planned to identify and present the findings to all organisations where the study is likely to be relevant especially those through which sampling took place. Peer reviewed conference presentations have already begun with findings first presented at the RCN Children's conference in 2017 (see Appendix 21 for full list of these). Few academic research studies discuss the existential perspective of mothers in this cohort of children and therefore I intend to address this through publishing a paper in this realm. I would also like to publish an academic book detailing aspects of this study but centred on supporting the child with severe and profound intellectual disabilities and their family.

7.6 My PhD journey

Reflexivity has already been addressed in Chapter Four where I described how I was reflexive in designing, conducting and analysing the research. I was also reflexive in the writing of the findings and the discussion. I have attempted to be transparent throughout the research process and in the way I describe the analytical process. During the process, I have grounded my discussion in the findings and the actual statements made by participants while also taking into account my own thoughts and feelings I had written in my journal. My findings following analysis exceeded my earlier expectations and demonstrated how mothers experience 'giving medicines' to their child with severe and profound intellectual disabilities across all dimensions of their lives.

I was struck at the outset when it came to recruitment of participants how open those participants were. Most participants would not have been able to leave their homes due to the nature of their caring role and in many cases I was welcomed into their homes meeting their child and siblings and often other family members. This was my first time

meeting with them and I was hearing details of their daily world for which I was grateful. I recall many times in the early stages of developing the overall aim, being questioned by both friends and colleagues about the topic area and handling views of pity for these mothers and children with such perceived complexity of need. Conversely, all of the mothers that participated in this study were without doubt fulfilling their responsibility in their caring role with very little support. Many of the mothers were resigned in their caring role, indicating this was 'just part of' being a mother. However, what struck me was how little education or preparation the mothers were afforded in terms of 'giving medicines' and evidently learned 'on the job'. Some of the participants maintained contact after interview and since then three of the children have died during the span of the research project.

Mothers interviewed for this study all mentioned they enjoyed talking about their experiences and how it made them reflect on what life is like. Additionally, some of the mothers due to their geographical location had never been invited to participate in a research study of this nature and were delighted to have an opportunity to speak. By providing this opportunity mothers could speak freely for the first time about their experiences of 'giving medicines'.

I also recall in the early days attending a workshop on van Manen's (1990) framework and being reminded that one must do phenomenology to grasp its significance. I now understand this in a more fulfilled manner and feel I have a better understanding of the complex language of hermeneutic phenomenology. My depth of engagement increased each day during the research process, further enhancing my PhD journey.

My journal entries commenced with the first page reflecting my thoughts on being unsure of what I should be writing as I barely had the bones of a research proposal. However, the 'pink' diary has travelled the length and breadth of the country with me on many journeys and has captured many thoughts and reflections on my experiences since starting this voyage. I must acknowledge that another researcher may well take the same participant stories and have a different interpretation, something that can be common in hermeneutic phenomenology. I found the journey insightful but at times I

experienced moments of doubt as to whether I possessed the ability to write a text that would be understood by those who would read it and do justice to the meaning of the experience. Nevertheless, this thesis has had several iterations with much writing and rewriting so I feel van Manen would be proud of the end product.

7.7 Summary of Chapters

This thesis is comprised of seven chapters that constitute an inquiry into mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities. A summary of each chapter is now portrayed.

7.7.1 Chapter One

Chapter One provided the introduction to the thesis, focusing on the background and rationale for the purpose of this study. Terminology was defined in the context of this study and the aims and objectives were clearly outlined. It was important to contextualise this study and set the scene. This research was underpinned by the desire to explore mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities. Currently, in Ireland no such study has investigated this area and it was clear it was an area worthy of consideration.

7.7.2 Chapter Two

Chapter Two sought to review literature pertaining to the research topic and a number of themes were identified. Each theme was discussed in detail and components connected to the study discussed. It also highlighted the lack of specific research on the topic at hand. Relevant conclusions were drawn from impartial examination of the studies, an important facet of developing the research study further.

7.7.3 Chapter Three

Chapter Three encompassed an exploration of the philosophical underpinnings of the study alongside methodological issues. Hermeneutic phenomenology formed the chosen philosophical underpinning and was deemed the most appropriate to explore mothers'

lived experience of 'giving medicines' to children with severe and profound intellectual disabilities. As van Manen (1990) was deemed to be the most appropriate framework to guide this study, description of his framework was offered. Van Manen's (1990) approach brought structure to the research process. Consequently, the six guidelines to approaching hermeneutic phenomenology that guided the research design and data analysis process were clarified with each activity delineated.

7.7.4 Chapter Four

Chapter Four outlined the methods employed and why they were appropriate in meeting the study aim and objectives. It discussed in detail the whole methodological process identifying population and sample adopted, alongside the recruitment procedure. It detailed at length, the data collection and analysis process involved. Ethical issues pertaining to the study were also considered and the integrity of the study was addressed.

7.7.5 Chapter Five

Chapter Five presented the key findings of the study following analysis, which were further supported by extracts from the participant interviewees' transcripts and diary entries. An outline of the findings is represented in a presentation of 20 essential themes guided by the five existential dimensions that form part of the lifeworld and overall existential perspective.

7.7.6 Chapter Six

Chapter Six discussed the findings in light of relevant and current literature some of which was reviewed earlier in Chapter Two relating to the various themes. An overall interpretation was offered with clear evidence of the impact of 'giving medicines' on the daily lives of mothers of children with severe and profound intellectual disabilities.

7.7.7 Chapter Seven

This final chapter has discussed the implications and recommendations of this study for research, research methodology, practice, education and service provision. Additionally,

the strengths and limitations of the study are outlined and dissemination considered. Finally, my PhD journey is reflected upon highlighting the personal experiences of the whole process over a five and a half year period.

7.8 Conclusion

This thesis comprised of seven chapters detailing the key elements of the study. The words of the 15 participants make it possible to interpret mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities. This was essential in order to grasp insight into what has largely remained elusive in published literature. The adoption of hermeneutic phenomenology and presentation through existential dimensions makes it possible to understand the phenomenon as a human experience shared by the participants involved in this study, albeit with various individual nuances. Specifically, this hermeneutic phenomenological study has enabled an exhaustive exploration and familiarity with the lifeworld of mothers of children with severe and profound intellectual disabilities. This new understanding offers meaning and includes an emergent focus on the challenges experienced by mothers in 'giving medicines'. It was concluded that mothers' experience of 'giving medicines' to children with severe and profound intellectual disabilities is a relentless and challenging, yet invisible element of care. This research addresses a gap in understanding of how mothers experience 'giving medicines' to their child with severe and profound intellectual disabilities and as such may be useful in facilitating the development of care especially at a time when the numbers of children with severe and profound intellectual disability are increasing.

My ultimate goal was to ensure I wrote a text (thesis) that participants would see as their own reality. I also wanted to leave other professionals with a richer, more thoughtful understanding of the phenomenon of mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities. Mainly, I wanted to give voice to all those mothers of children with severe and profound intellectual disabilities and in doing so make their lives more comprehensible.

In conclusion, this study involved a process of gathering data and discussing it with a view to making relevant recommendations. It is hoped that this piece of research is instrumental in highlighting the pertinent issues relating to the nature of mothers' lived experience of 'giving medicines' to children with severe and profound intellectual disabilities and provides a rich and deeper understanding. Ultimately, it is my intention that this study will assist in enhancing the support and care of mothers and children with severe and profound intellectual disabilities and provide a platform for further deliberation.

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Appendix 1

Search Terms

Concept 1: Intellectual Disability OR Learning Disability

Medline: (MH "Mentally Disabled Persons") OR (MH "Mentally Ill Persons") OR (MH "Intellectual Disability+") OR (MH "Learning Disorders+") OR (MH "Mental Retardation, X-Linked+") OR (MH "Developmental Disabilities")

CINAHL: (MH "Developmental Disabilities") OR (MH "Intellectual Disability") OR (MH "Mentally Disabled Persons") OR (MH "Mental Retardation, X-Linked+")

Embase: 'mentally disabled person'/exp OR 'mental deficiency'/exp

PsycINFO: (DE "Intellectual Development Disorder" OR DE "Developmental Disabilities" OR DE "Intellectual Development Disorder" OR DE "Learning Disorders")

Keywords: TI/AB "Intellectual* Disabil*" OR "mental* disab*" OR "learning disabil*" OR "mentally impaired" OR "Intellectual Development Disorder*" OR "Learning Disorder*" OR "Learning disabil*" OR "mental* handicap*" OR "mental* impair*" OR "intellectual* impair*" OR "developmental disabl*" OR "Complex needs" OR "special needs" OR "severe" OR "profound" OR "intellectual disab*" OR disab* OR "developmental delay" OR "developmental disab*" OR "learning disab**" OR "technology dependent" OR "technology-dependent" OR "technology dependence" OR "complex health* need*" OR "multiple need*" OR "childhood disability" OR "life limiting illness" OR "life-limiting illness" OR "disabled child*" OR "special healthcare needs" OR "complex condition*" OR "complex care need*" OR "complex and continuing health needs" OR "medical complexity" OR "complex chronic condition" OR "chronic illness*" OR "chronically ill*" OR "technical care giving" OR "disabilities" OR "technical caregiving" OR "life threaten*" OR "medically fragile" OR "severe neurological impairment" OR "mental defici*" OR "intellectual retard*" OR "mental retard*" OR "mentally retarded" OR "intellectually challenged" OR "intellectually deficient*" OR "intellectually handicapped" OR "intellectually retarded" OR "mental retard*" OR "mentally challenged" OR "mentally deficient"

EMBASE Keywords: Intellectual* Disabil* OR mental* disab* OR learning disabil* OR mentally impaired OR Intellectual Development Disorder* OR Learning Disorder* OR Learning disabil* OR mental* handicap* OR mental* impair* OR intellectual* impair* OR developmental disabl* OR Complex needs OR special needs OR severe OR profound OR intellectual disab* OR disab* OR developmental delay OR developmental disab* OR learning disab** OR technology dependent

OR technology-dependent OR technology dependence OR complex health* need* OR multiple need* OR childhood disability OR life limiting illness OR life-limiting illness OR disabled child* OR special healthcare needs OR complex condition* OR complex care need* OR complex and continuing health needs OR medical complexity OR complex chronic condition OR chronic illness* OR chronically ill* OR technical care giving OR disabilities OR technical caregiving OR life threaten* OR medically fragile OR severe neurological impairment OR mental defici* OR intellectual retard* OR mental retard* OR mentally retarded OR intellectually challenged OR intellectually deficient* OR intellectually handicapped OR intellectually retarded OR mental retard* OR mentally challenged OR mentally deficient

Concept 2: Giving Medicines/Medicating/Medicine administration/management

Medline: (MH "Polypharmacy") OR (MH "Drug Prescriptions+") OR (MH "Drug Administration Routes+") OR (MH "Medication Therapy Management") OR (MH "Prescriptions+")

CINAHL: (MH "Medication Management")

Embase: 'behind the counter drug'/exp OR 'medication therapy management'/exp OR 'drug administration'/de OR 'prescription'/exp OR 'polypharmacy'/exp

PsycINFO: (DE "Polypharmacy" OR DE "Drug Administration Methods" OR DE "Prescription Drugs" OR DE "Nonprescription Drugs")

Keywords: TI/AB (medicin* OR medication* OR drug* OR dosag* OR dose* OR prescript* OR pharmac*) N2 (administ* OR manag* OR deliver* OR giv* OR control* OR use* OR usage*) OR over the counter OR "pharmacy" OR "pharmacy services" OR polypharmacy OR poly-pharmacy OR palliativ*

Embase Keywords: (medicin* OR medication* OR drug* OR dosag* OR dose* OR prescript* OR pharmac*) NEAR/2 (administ* OR manag* OR deliver* OR giv* OR control* OR use* OR usage*) OR over the counter OR pharmacy OR pharmacy services OR polypharmacy OR poly-pharmacy OR palliativ*)

Concept 3: Mothers**Medline:** (MH "Single Parent") OR (MH "Parents") OR (MH "Mothers")**CINAHL:** (MH "Parents") OR (MH "Mothers") OR (MH "Mothers, Working") OR (MH "Adolescent Mothers") OR (MH "Parents of Disabled Children") OR (MH "Single Parent")**EMBASE:** 'mother'/de OR 'parent'/de OR 'single parent'/exp OR 'separated parent'/exp**PsycINFO:** DE "Mothers" OR DE "Parents" OR DE "Single Mothers"**Keywords:** TI/AB "mother*" OR "Mum*" OR "mom*" OR parent*

	CINAHL	Medline	PsycINFO	EMBASE	Web Of Science
Mothers	205,678	712,021	365,666)	834,049	1,421,091
Medicines Management	185,559	1,294,554	116,719	340,321	125,381
ID	286,230	1,287,423	303,979	334,964	1,333,028
Combined	884	4773	657	400	558
Peer Review ** not available	840	**	512	**	**
TOTAL Number of articles retrieved in the search	840	4773	512	400	578

- Total number of articles removed during deduplication through merging of individual Endnote Libraries to a combined Endnote Library = 1,130
- An additional 103 manual duplicates were identified through a manual screen of the articles.
- The total number of articles for review was 4,968.

Appendix 2

Routes of Medication Administration

Oral administration

According to Blair & Standing (2011) the oral route or by mouth is the most common form of drug administration in children and is favoured for several reasons; associated with less pain and anxiety and often cheaper than other preparations. Medicines supplied for this route come in various forms; liquids, suspensions, elixirs, syrups, tablets, capsules, granules and powders. Additionally, these oral medicines come in a number of different strengths and flavours. Tablets and capsules are easy to store and transport while also not containing sugar. Children under the age of 4 or those with poorer cognitive ability may have difficulty swallowing these and are therefore at risk of choking or aspiration. Tablets and capsules can be enteric coated and have a sustained release for better absorption, thereby meaning they are unsuitable for crushing or opening (Baber & Pritchard 2003). When tablet or capsule is the only oral form available, advice should be sought from the pharmacist or manufacturer as to whether it is safe to crush or open the capsule as this interference can make the medicine unlicensed for use (Wright 2002). It then may be mixed with a small amount (usually teaspoon) of sterile water or pleasant tasting liquid or food.

Medicines supplied as powder, granules or sprinkles should only be mixed with small quantities of food or drink to ensure the whole amount is taken. It is noted that some medicines are absorbed more completely without food. When a child learns to swallow tablets, can vary, and can take encouragement. Teaching children to swallow tablets can make the experience less unpleasant than when taking liquids. Minitablets, with a maximum 3mm diameter are now being developed for use as a potential new formulation with small children (Thomson *et al.* 2009). Liquid medicine preparations are more appropriate for younger children and infants as they are easier to swallow although can taste extremely unpleasant (Macqueen *et al.* 2012). The type of vesicle for administration usually depends on the child's developmental status with droppers or syringes often used to deliver these preparations to the child with severe and profound intellectual disabilities.

Administration via enteral tubes

Eating, drinking and swallowing are essential activities of daily living and are a core element of social interaction (Griffiths *et al.* 2018). The problem of poor oral feeding has been addressed with percutaneous endoscopic gastrostomy feeding (PEG) which while improving nutrition also improves quality of life (Dunworth Fitzgerald & Sweeney 2013, Catto-Smith & Jimenez 2006). Medicines are frequently administered via feeding tubes to children with severe and profound intellectual disabilities. This may be via nasogastric, orogastric, gastrostomy, naso jejunal and jejunostomy tubes and usually only administered this way if the child is unable to take oral medicines. The tube allows the medicine to be administered directly into either the stomach or jejunal area. The benefits of this route of administration are that it provides an alternative to the oral route for children unable to swallow and is also a slower absorption time than that for intravenous administration (Macqueen *et al.* 2012). With the range of enteral feeding tubes and medicines increasing in recent years, the gap between clinical practice and best practice must be addressed. Therefore, many guidelines have been published to advise on administration through this mechanism (Pickering 2003, Griffiths *et al.* 2018). While many medications are unlicensed for administration through enteral tubes because they have not been tested in this manner, using a gastrostomy for administration is often the only option available to the child (Wright & Tomlin 2011).

Joos *et al.* (2015) specifically chose residential care facilities for those with intellectual disabilities, to undertake an observational study on drug administration via enteral feeding tubes. Six Belgian facilities took part with administration to 48 residents. While good practices were observed there were many poor practices with mixing of multiple drugs, not diluting liquid formulations, not shaking suspensions or emulsions, not selecting the most appropriate medication form despite medication preparation guidelines being available. Education was seen as key to improving guideline adherence in this study.

In order to administer in this manner, the medicine must be in liquid form. Crushed or opened tablets can block the tube when they fragment. If unavoidable, it is recommended that crushing to a fine powder and dispersing with water may be better. Thick liquids have the potential to block fine bore tubes and may need further dilution. Medicines unsuitable for crushing include;

- Enteric coated tablets designed with a coating that resists gastric acid to protect the drug and reduce gastric side effects.
- Modified release, slow/sustained release, long acting and extended release tablets are designed to release the drug over a long period of time. Crushing these drugs will cause the entire drug to be released at once and will cause toxic side effects.
- Lipid based drugs such as phenytoin can adhere to the side of the tube and cause incomplete delivery of the dose (Bauer 1982).

Crushing or opening tablets and administering via feeding tubes usually falls outside the drug product licence and therefore the prescriber, pharmacist and person administering, must accept liability for side effects that result from this method of delivery. The majority of medicines given this way are not licensed for enteral administration (Wright 2000). Sterile water is also used for flushing enteral tubes after administration of medication. There is limited research available on the administration of medication via enteral tubes and therefore, in reality practices differ.

When giving medicines to the child with severe and profound intellectual disabilities, the risk/benefit ratio must be considered and alternative options for delivery of medicines contemplated (Kelly & Wright 2009). The last decade has seen the development of clear protocols to guide clinical decision making in this sphere (Bennett *et al.* 2013). Having an intact swallow is less the norm in this population and therefore, dependency for administration of medicines lies with the carer and in turn results in an increased workload (Wright & Kelly 2012). Often the transition from oral administration of medicines to enteral administration can be difficult for parents.

Subcutaneous Administration

The subcutaneous route involves injection into the tissue just below the skin. Absorption of medication via this route is slower than intramuscular and the rate of absorption varies depending on the site used. This route is avoided if possible in children as may cause unnecessary upset (Blair & Standing 2011) and is not a route widely used in those children with severe and profound intellectual disabilities.

Rectal administration

Suppositories and liquids can be administered via the rectal route. The route is particularly useful when other routes cannot be tolerated. However, the rectal route is invasive and is used mainly for administration of rectal diazepam for treatment of seizures in children with severe and profound intellectual disabilities (Blair & Standing 2011).

Buccal and sublingual administration

Buccal medications are absorbed rapidly in the bloodstream through the mucous membranes of the mouth (Blair & Standing 2011). A commonly used drug in children with severe and profound intellectual disabilities is buccal Midazolam as a rescue medicine for active seizures. The route is deemed more effective than other routes because it bypasses the digestive system so swallowing the medication should be prevented. However, this route of administration can be problematic for those diagnosed with hypersalivation. The onset of action is faster in sublingual administration than buccal but has a shorter duration of effect (Brack *et al.* 2013).

Transdermal administration

A number of drugs can be administered in this manner providing a systemic effect of a medication passing slowly from the patch through the skin and into the bloodstream (Macqueen *et al.* 2012). One main advantage of this route is it is painless. However, many of the medications for administration in this way contain a starting dose too high for use in children (Macqueen *et al.* 2012). Therefore, if used, patches are usually cut down in size to lower the dose administered. This is not without problems as cutting or partial administration can destroy the release of medication and also presents inaccuracies in dose administration (Lee & Phillips 2002). Scopoderm (hyoscine) patches are commonly used in those children with severe and profound intellectual disabilities experiencing hypersalivation (Mato *et al.* 2010).

Nebuliser administration

Nebulisers deliver medicines in the form of vapour that can be breathed in through a mask or mouthpiece and are commonly used in management of respiratory conditions. The nebuliser machine uses compressed gas or vibration to aerolise liquids administered through a mask or mouthpiece attached to a nebuliser pot (Macqueen *et al.* 2012). Deposition of the medicine in

the lungs is enhanced using this method of administration (O' Callaghan & Barry 2000). As respiratory problems are prevalent in those children with severe and profound intellectual disabilities (Seddon & Khan 2003), this route is used widely for administration of bronchodilators.

Appendix 3

Ethical approval from SNMREC, Trinity College and six sites

College Ethical Approval

19th September 2014

Re: Ethical Approval for study 'Mothers' experiences of "giving medicines" to children with complex needs'.

Dear Carmel,

I am pleased to inform you that your study has been granted ethical approval from the Chair of the School of Nursing and Midwifery Research Ethics Committee.

Please submit the missing front page and signatory page of the School's ethics form which will be attached with your application form for our records.

Yours sincerely,



Chair of SNMREC

Site 1 Ethical Approval

Ms Carmel Doyle
[REDACTED]
[REDACTED]
[REDACTED]
Dublin 4
[REDACTED]

13 November 2014

Dear Carmel,

Re: "Mothers experiences of "giving medicines" to children with complex needs" - APPLICATION
PROVISIONALLY APPROVED

Thank you for resubmitting your application form to the Research Ethics Committee in [REDACTED]. During the course of our second review, we found some matters which still require some clarification;

- With regard to A3 (c), please note that although the base for [REDACTED] is a national service and families have a wide geographical spread across the country which may impact on your second region.
- With regard to the reference made in K1 and K3C, please clarify which psychology "service" the participant will be asked to avail of. Private independently funded (by whom) [REDACTED]. The Research Ethics Committee at [REDACTED] do not wish to increase a potential burden on a new and developing psychology service.

I therefore write on behalf of the Chairman and Committee to inform you that you have the permission of the Research Ethics Committee to proceed with this research providing that you send clarification of the above mentioned points in writing to [REDACTED] within 15 working days from the date of this letter.

Your response will be acknowledged and a further letter sent out to confirm that you have met the requirements set out by the Committee. Having received this formal approval, depending on which departments will be involved in this study, you will then be required to obtain permission for staff to complete the questionnaire/participate in your interview from the relevant head(s) of department at LauraLynn.

Yours sincerely,
[REDACTED]
[REDACTED]

Site 2 Ethical Approval

8th May 2015

Carmel Doyle
Assistant Professor
School of Nursing & Midwifery
Trinity College
24 D'Olier Street
Dublin 2

RE :-
REQUEST FOR PERMISSION TO CARRY OUT RESEARCH
STUDY 'MOTHERS' EXPERIENCES OF "GIVING MEDICINES" TO CHILDREN
WITH COMPLEX NEEDS

Dear Carmel,

The Ethics Committee has considered your correspondence re request for research details and wish to confirm your application for same has been granted.

You should liaise with [REDACTED] Nurse for the Services [REDACTED] on all future matters pertaining to this research project.

[REDACTED] Contact Details are –
[REDACTED]

We wish you well in your research and look forward to your findings / recommendations.

Regards,
[REDACTED]
[REDACTED]

Site 3 Ethical Approval

Monday, 18th May 2015

**Ms Carmel Doyle
Assistant Professor
School of Nursing & Midwifery
Trinity College
24 D'Olier Street
Dublin 2**

RE: Ethics Application

Dear Carmel,

You may regard this note as a confirmation of [REDACTED] approval for the research proposal which you shared with us. The focus of your study is highly relevant in relation to everyday practice and we are very happy to facilitate the access which you require.

Yours faithfully,

[REDACTED]
[REDACTED]
CHIEF EXECUTIVE OFFICER

Site 4 Ethical Approval

Carmel Doyle

From: [REDACTED]
Sent: 30 September 2015 15:46
To: Carmel Doyle
Subject: RE: QUERY - RESEARCH STUDY

Hi Carmel,

Thanks for that information.

Here is the link for the website piece

[http://\[REDACTED\]trinity-college-school-nursing-midwifery-research-project](http://[REDACTED]trinity-college-school-nursing-midwifery-research-project)

I will also add to social media channels in the morning when we get more traffic.

Let me know if that is okay.

Kind Regards,

Site 5 Ethical Approval

Carmel Doyle

From: [REDACTED]
Sent: 15 October 2015 19:03
To: Carmel Doyle
Subject: Accessing families

Hi Carmel

We will allow you access families from [REDACTED] for your PHD. Sorry I am only getting back to you today.
Not sure what you need to do next but you can let me know.

I think you said it would be about four families. We feel its a valuable piece of research. Look forward to hearing from you.

Kind regards

[REDACTED]

Site 6 Ethical Approval

Carmel Doyle

From: [REDACTED]
Sent: 21 October 2015 14:02
To: Carmel Doyle
Subject: Re:ETHICS APPLICATION

Dear Carmel,

Re: Mothers' experiences of 'giving medicines' to children with complex needs

Thank you for the revised documentation which you submitted to the Research Ethics Committee. This has been reviewed and Full Ethical Approval has been granted from our committee to conduct your research study.

Kind Regards,

[REDACTED]

[REDACTED]
Research Ethics Committee



Appendix 4

Details of the six sites and participants recruited from each one

Site	Number of Information Packs distributed	Number of Participants Recruited
Site 1	16	2
Site 2	6	1
Site 3	12	5
Site 4	6	5
Site 5	6	1
Site 6	4	1

Appendix 5

Summary of participants and the data collection method

Participant Number	Number of Interviews	Diary Completed
1	2	No
2	3	No
3	3	No
4	1	Yes
5	2	No
6	2	Yes
7	3	Yes
8	2	No
9	1	No
10	2	Yes
11	2	Yes
12	1	No
13	1	No
14	1	Yes
15	2	Yes
Total Number	28	7

Appendix 6

A Sample of Interview (Subsequent) Questions arising from previous data or an attempt to elaborate further on key issues

Opening Question	<i>Tell me about your experience of giving medicines to your child with severe and profound intellectual disabilities</i>	All participants
A Sample of Subsequent Questions arising from previous data or an attempt to elaborate further on key issues	<i>And how did you learn to do that?</i> (This question was posed as the participant talked about her way of checking if her child had swallowed his medications)	(P 10B)
	<i>How do you know about all the side effects?</i>	(P 7B)
	<i>Tell me a bit more about how relentless that can be?</i> (This question was posed as the participant talked about the sheer volume of medication administrations and how time consuming and relentless that can be). <i>You mentioned about the interaction that you'd have with the GP and the pharmacist and (medical supply company) and the hospital. Can you tell me what that is like?</i> <i>When you started it (giving medicines), how did you learn?</i> <i>If you were to sum up in a few words what your experience of giving medicines is like on a daily basis, how would you say it?</i>	
	<i>Tell me how do you keep note of your regime?</i> (This question was posed as the participant talked about preparing 12 medications for administration in the morning).	
	<i>And what's that like?</i> (This question was posed as the participant talked about how difficult it is to get meds in). <i>Would you have had to educate anybody about how to use that?</i> (This question was posed as the participant talked about administering buccal medication in an emergency situation and she being the only one that could do it).	
	<i>You mentioned there that you've done up your own template for keeping a record of the medicines. Tell me</i>	(P 2B)

	<p><i>why did you do that?</i></p> <p><i>You mentioned there you've a good relationship with your GP, tell me a bit more on why this is important to you.</i></p> <p><i>If you wanted more information on a drug, where would you find that information?</i></p>	
	<p><i>You give some of her meds in the morning and then some of them in the evening. Maybe tell me a bit about what it's like in the mornings for you in terms of giving them.</i></p> <p><i>How does that make you feel, having to give her something that doesn't taste so pleasant?</i> (This question was posed as the participant talked about how awful one of the medications tasted and how her daughter struggled to take it).</p> <p><i>And is there anybody you'd ask for advice in terms of the meds and if so, who?</i></p> <p><i>Tell me a bit about what equipment have you for meds?</i></p> <p><i>What is the overall effect on your life in terms of the fact that X requires medicines three times a day?</i></p>	(P 15B)
	<p><i>How do you deal with any changes then in the dosages? Or does that make any big difference?</i></p> <p><i>Tell me about how you feel when making those decisions?</i> (This question was posed as the participant talked about having to decide whether to increase pain relief medication that may then result in overall drowsiness for their son).</p>	(P 12A)
	<p><i>Have you ever got any advice, professional advice on how to give? How did you learn to do this?</i> (This question was posed as the participant talked about the various medications her daughter is taking).</p> <p><i>How do you feel about putting in a peg just for meds?</i></p> <p><i>How do you feel making those decisions</i></p> <p><i>How do you manage that stress?</i> (This question was posed as the participant talked about the stress of giving medications to her daughter when it was so difficult and her other children found the process so upsetting).</p>	(P 3B)

Appendix 7

Prompts and probes used during the interview process as appropriate

- Tell me more...
- Can you expand on this...?
- Can you describe what happened when you...?
- With who?
- Like what?
- Like when?
- Would you care to add to this...?
- Would you care to expand on this?

Appendix 8

Diary

PRIVATE & CONFIDENTIAL

Research Study Title:

Mothers' experiences of 'giving medicines' to children with severe and profound intellectual disabilities

Participant Name:

Instructions:

How do I complete this diary?

Firstly, the amount of entries are not specified and how much or little you write is your decision. You may wish to write about an experience you have when 'giving medicines', which is of significance to you. Please comment on anything you think will help me understand what it is like to 'give medicines' to your child. Examples of things you may wish to write about could include; how you give the medicine, an experience you had relating to 'giving medicines' on a particular day, a change in medicine, a change in the dosage, going to the pharmacy, collecting prescriptions etc.

- Do not worry about what you write. As such you may write freely about your experience of 'giving medicines' and the above examples are just suggestions.
- Please ensure you date each entry as this will help when I am reading what you have written.
- If you mention names of persons or places these will be removed and no identifiers will remain.
- I will give you a stamped addressed envelope and you can return the diary to me before the second interview (after about 8 weeks).

Appendix 9

Review of Draft Diary for Carmel Doyle relating to PhD research study
entitled:

“Mothers experiences of ‘giving medicines’ to children with severe and profound intellectual disabilities”.

Is the diary easy to read and understand?

Are the instructions clear and easy to read?

Are the instructions too long/short?

Is there jargon? If so, can you point out where?

Have you identified any complex information that could be adapted to make it easier to read/understand?

Appendix 10

Review of information pack relating to PhD research study entitled:
“Mothers experiences of ‘giving medicines’ to children with severe and profound intellectual disabilities”.

Are the documents easy to read and understand?

Are the paragraphs clear and easy to read?

Is there jargon? If so, can you point out where?

Is there any section that is too long/too short?

Have you identified any complex information that could be adapted to make it easier to read/understand?

Appendix 11 - Participant Information Pack

Participant Letter of Invitation

School of Nursing & Midwifery

Trinity College

24 D'Olier Street

Dublin 2.

January 2015

Dear Madam,

My name is Carmel Doyle and I am a Registered Nurse in Intellectual Disability (RNID) and a Registered Children's Nurse (RCN). I am also an Assistant Professor at the School of Nursing & Midwifery, Trinity College, Dublin. I am currently undertaking a research study as part of a PhD, entitled "Mothers' experiences of 'giving medicines' to children with severe and profound intellectual disabilities".

I am contacting you as I am interested in talking to you about your experiences of 'giving medicines' to your child with severe and profound intellectual disabilities. There is little known about what it is like to give medicines to children with severe and profound intellectual disabilities and I am keen to know more about this so that I can identify issues that may help the practice of caring for children with severe and profound intellectual disabilities.

Enclosed is information about the study that I would like you to read. I would like your input by participating in up to 3 interviews and keeping a brief diary in between interviews over a six to nine month period.

If you need any further information or if anything in the documents is unclear, please contact me at the following number **(phone number)** or **(phone number)** or by email **(email address)** and I will be happy to talk to you and discuss the study further.

What you should do next:

1. Please read the information sheet that I have included.
2. Decide if you are interested in the study.
3. Fill in and return the expression of interest slip in the stamped addressed envelope provided.

Please feel free to contact me with any queries. I would be really grateful for your co-operation and look forward to further contact with you in relation to this research study.

Yours sincerely,

Ms. Carmel Doyle

Participant Information Sheet

You are invited to participate in a study which will explore **“Mothers’ experiences of “giving medicines” to children with severe and profound intellectual disabilities”**. Before you decide whether you wish to take part or not, I would appreciate you reading this information sheet.

Title of Study: Mothers experiences of “giving medicines” to children with severe and profound intellectual disabilities.

Who am I? My name is Carmel Doyle and I am a researcher, a Registered Nurse in Intellectual Disability and Registered Children’s Nurse. I work as an Assistant Professor at the School of Nursing & Midwifery, Trinity College, Dublin.

Introduction: I would like to invite you to consider taking part in my research study which is being undertaken as part of my PhD, which is about exploring your story of “giving medicines” to your child with severe and profound intellectual disabilities. I am an experienced researcher and a qualified nurse in both intellectual disabilities and children’s nursing. I have experience of working with families of and children with severe and profound intellectual disabilities. I believe the study is important and I am keen to know more about your experience of ‘giving medicines’ to your child. You may benefit from the opportunity to reflect on and discuss your experiences. The following information is designed to enable you to gain an understanding of the study before you formally agree to take part. Be sure to ask any questions you have about the study, your part in it and/or the information contained in this information sheet.

Purpose of the Study: The purpose of this research study is to explore mothers’ lived experience of “giving medicines” to children with severe and profound intellectual disabilities.

The specific objectives of this study are:

- To explore the experiences of mothers of children with severe and profound intellectual disabilities “giving medicines”.
- To identify the range of activities mothers of children with severe and profound intellectual disabilities “giving medicines” undertake.
- To develop an understanding of how mothers learn about “giving medicines”.
- To identify any issues experienced by mothers of children with severe and profound intellectual disabilities “giving medicines”.
- To analyse the meaning of mothers living with ‘giving medicines’ to children with severe and profound intellectual disabilities as a basis for understanding and interpretation by others.

Why have I been asked to take part in the study? As a mother of a child with severe and profound intellectual disabilities your experiences of giving medicines are relevant.

Who else is taking part? Other mothers from your service provider have been invited to participate in the same manner as you have been.

Procedures: In order to take part in the study you must be a mother of a child with severe and profound intellectual disabilities aged between 2-18 years of age who needs medications administered to them every day.

You can take part in the study in the following way:

- Meet with me to tell me your story of ‘giving medicines’ to your child with severe and profound intellectual disabilities **AND**

- Keep a written diary of your everyday life as it relates to 'giving medicines' to your child with severe and profound intellectual disabilities.

What will participation involve? This will mean meeting with me more than once (up to 3 times) over a six to nine month period. I will meet you at a time and a place that is best for you. Each meeting will last about 90 minutes (at most). I do not expect you to travel to meet me – I will come to you. We can meet in a public place or wherever you feel most comfortable.

I do not have any specific questions that I needed answered and I will not be using a questionnaire. I am interested in whatever you want to tell me about your life in terms of 'giving medicines' to your child with severe and profound intellectual disabilities. We will talk for as long as you want. If you change your mind at any time you can stop and you do not have to meet me again.

With your permission each interview will be audio tape recorded so that I do not have to take lengthy notes and I can concentrate on what you are telling me. When the interview is finished it will be transcribed (typed out) from the recorder. If you wish, these transcripts will be sent to you in the post so you can read them. If you mention the names of people or places in the interview these will be removed so that their identity will not be known.

I will supply you with a diary (only a few pages) and in between our meetings you might like to keep an account of the things that happen in your life on a day to day basis relating to 'giving medicines'. There are no specific amounts of diary entries needed, so you can write in it as often as you like, you can write whatever you wish and in whatever way you want. There is no penalty for having none/few. There are no rules except that you are willing to let me read it later. I will ask you to write in it for a period of six to nine months. I will transcribe the contents of the diary and if you wish, a copy of the diary entries will be sent to you in the post so you can read them.

Benefits: There are no direct benefits of you participating in the study although some people do find it beneficial to talk about their experiences. It is anticipated that indirectly, the findings of this study will give a better understanding of what it is like to give medicines every day to children with severe and profound intellectual disabilities. It will help identify implications for healthcare professionals and the practice of caring for children with severe and profound intellectual disabilities in relation to giving medicines and how best to support mothers.

Risks/Stopping the Study: There are no foreseeable risks to you associated with participating in this study. However, if you wish to stop any of our conversations because you are feeling discomfort you are free to do so at any time. I will stop the interview or alternatively take a break. The interview will only be recommenced if you indicate that you would like to continue. You are advised that if you tell me or write down any information that suggests unsafe practice or gives reasonable ground for concern, I will adhere fully to the Children First, National Guidance for the Protection and Welfare of Children (2011). I will advise you to contact a relevant person to seek advice/support (i.e. key worker, liaison nurse, GP, pharmacist or relevant other) or with your permission I will make contact with one of the above. If for any reason or your child's condition deteriorates during the study you may withdraw without any penalties.

Confidentiality: Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone. I will be the only person to have access to the tapes and diaries and your identity will remain anonymous throughout. The study data will use false names so they will not be linked to your name. Your identity will not be revealed whilst the study is being conducted or when the study is reported or published or if the data is used in future studies. All study data will be collected by me and will be stored in a secure place and not shared with any other person.

Compensation: This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

Voluntary participation/Do I have to take part? If you agree to participate in the study you will be asked to sign a consent form indicating that you are willing to take part. You are under no obligation to take part or not, the decision is entirely yours, and you may withdraw, without question, at any time.

What approval does the study have? This study has received ethical approval and permission to undertake the study has been obtained from the service provider (name inserted).

What do I do now? If you are interested in the research study, please complete the expression of interest slip below and return it in the stamped addressed envelope I have provided. If you do not wish to take part in the study you do not need to take any further action.

How long do I have to decide whether I want to partake or not? Don't feel you must rush your decision. However, if interested, it would be helpful if you could return the completed expression of interest slip in the stamped addressed envelope provided by (insert date).

What will happen the findings from this research study? I will analyse all of the findings from the interviews and diaries. If you wish, on completion of the study, an anonymised executive summary of the findings will be sent to you in the post. It is my intention to publish the findings in an appropriate journal and present them at a suitable conference. I can forward you a copy of publications if you wish. Please note that no publication or presentation will identify you, your child or your service provider.

Dissemination of the findings from this research study is expected to continue beyond the life of the study. Raw data will be destroyed. However, anonymised data from this research study will be retained for longer than the recommended accepted best practice 5 year period, so access to the data is available beyond the specified time and may be used in future related research studies.

Where can I get additional information? You can get more information or answers to your questions about the study, your participation in the study, and your rights, from me, Carmel Doyle who can be telephoned at (insert number). If I learn of important new information that might affect your wish to remain in the study, you will be informed at once.

Contact Details of Research Supervisor: You can contact the research supervisor I am undertaking this study with. Her name is **(supervisor name)** who can be telephoned at **(phone number)** or emailed at **(email address)**.

I realise that this may be a busy time for you and thank you for taking the time to read this information sheet. I will meet with you personally to discuss any aspects which require further explanation.

Yours sincerely,

Ms. Carmel Doyle

Expression of Interest Slip

What should I do now?

- If you do not wish to take part in the study, you do not need to take any further action.
- If you are interested in the study please complete the slip below.
- Return it in the Stamped Addressed Envelope provided.
- I will contact you by telephone and speak with you or arrange to meet with you to discuss the study and answer any questions.
- If, having had your questions answered, you wish to take part in the study; I will arrange a time and place to meet with you to get your consent.
- Even after signing the consent form you have the right to withdraw from the study, without question, at any time in the future.

Detach here

I would like some more information about the study

I am interested in taking part in the study

NAME: _____

CONTACT TELEPHONE NUMBER: _____

BEST TIME OF DAY TO TELEPHONE: _____

Informed Consent Form

Please indicate your informed consent to take part in this research study by completing this form. I ask that you read each statement and place an X in the appropriate box.

STATEMENTS	YES	NO
I have read, or had read to me, this consent form.		
I have had a chance to discuss and ask questions about this research study and all of my questions have been answered to my satisfaction.		
I understand what the research study is about.		
I understand that the interview will be audio tape recorded.		
I understand that if I keep a written account in the diary over the six to nine months and give this to the researcher I am willing to share this diary.		
I understand that if I disclose any information that suggests unsafe practice or gives reasonable ground for concern I will contact a relevant person to seek advice/support or with my permission the researcher will make contact with a relevant person.		
I know that, in order to minimise the chance of identifying interviewees, the researcher will not link comments to individual participants.		
I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.		
I have received a copy of this agreement.		
I understand I may withdraw without question from the study at any time, without having to explain my decision, or suffer any adverse effects.		
I wish to receive a copy of the diary entries I made over the six to nine month period.		
I wish to receive a copy of the transcripts from the interviews I took part in.		
I wish to receive a copy of the executive summary of the research study on completion of the study in 2019.		
I wish to receive a copy of publications relating to the study.		

PARTICIPANT'S NAME: _____

CONTACT DETAILS: _____

PARTICIPANT'S SIGNATURE: _____

DATE: _____

Statement of researcher's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

RESEARCHER'S SIGNATURE: _____

DATE: _____

Appendix 12

Thank You Letter

School of Nursing & Midwifery
Trinity College
24 D'Olier Street
Dublin 2.

September 2015

Dear (participant),

This is just a short note to say thank you for agreeing to participate in my research study as part of a PhD, entitled **“Mothers’ experiences of ‘giving medicines’ to children with severe and profound intellectual disabilities”**. Both interviews you participated in were excellent and yielded very important information. It was lovely to meet (child) and the rest of your family in the home also.

At this stage I continue to collect data with other mothers. It is my intention that the study will be completed late 2018. At that point and after completion, I will prepare a summary of the findings and send you a copy. Meanwhile, if there is anything you wish to discuss don't hesitate in contacting me at the following numbers **(phone number)** mobile **(phone number)** or by email **(email address)** and I will be happy to talk to you and discuss the study further.

Yours sincerely,

Ms. Carmel Doyle

Appendix 13

Sample Interview Transcript

<p>Transcript for Participant 3 – Olivia and Marie</p> <p>(please note pseudonyms have been adopted)</p>	Speaker
Thank you Olivia . You're happy to continue with an interview for the study?	Interviewer
Yes.	Respondent
Perfect, thank you. You already know the purpose of the interview is to talk about what it's like to give medicines to Marie on a daily basis. Would you like to tell me what daily life is like in terms of giving medicines?	Interviewer
<p>Well, I guess her meds - I give them to her twice a day, morning time and evening time. Morning time, all her tablets are crushed. They're all tablet form because she's not good with liquids. Her feeding isn't great at the moment either; so we have to try and mix it up, disguise it in food. It's generally a yoghurt at the moment and we feed it to her and generally end up spooning spit back into her mouth to make sure it's gone in. It can be very stressful obviously to try and get this into her. I feel we've probably spoiled a lot of her food from feeding her meds through her food, but it's the only way that we can get them in. And again, it's the same in the evening. We have to give her these meds, the same amount of meds again. We try it with yoghurt; we try it with lots of things, sweet things. We put sugar on stuff. It's difficult to get them in. And I suppose when Marie is sick, which is a lot, we have to wake her to feed her these meds through food. Sometimes she's not able for food but we have to try and get them into her. So it can be very stressful, very stressful. Then you're not sure if everything's gone in because she spits out a lot of stuff. She might gag and throw it out. So you're left wondering is it gone in? Do I give her more? You just don't know. I suppose Marie's feeding has been very bad in the last few months, although it's improved in the last couple of weeks and we can honestly say that there was times when we just didn't get the meds in. She just refused them. She sometimes lost them in her mouth, which I'm told some children are clever enough to do. Sometimes you think it's gone and all of a sudden it's back. I think she's having problems with her feeding at the moment. We were up in (hospital) last Thursday, or last Friday actually with a speech and language therapist and she feels that Marie is likely aspirating on her fluids and at risk of aspirating with some of her food. So they're going to look into that further. But she was saying, "You know sometimes when Marie swallows, we think she's swallowed; it's actually not. It's still sitting there on her voice box and then it comes back out."</p>	Respondent

Ok, and how do you observe that? Do you watch Marie for fifteen minutes after she gets her meds?	Interviewer
Well no, it's almost instant. You can tell if it's gone or not. You can, you can tell. And my husband would always say to me that for such a small little girl, she stores a lot in her mouth. It just all comes out and we're constantly spooning, literally drool and spit back into her mouth. My six-year old was here a few weeks ago and she was telling my husband, "Stop Daddy. Marie doesn't like it" because we were so stressed trying to get it into her. I suppose as the mother, I am the main giver of medication and I was doing it and about two or three months ago I just had to say, "I can't give it anymore", because I just couldn't get it into her. My husband took over. Now you can trick Marie from time to time. He seemed to be calmer and he was managing. I'd say about two weeks into it then he was stressed big time. He just couldn't get it into her. We kind of do it as a team now. It's an issue every day. First thing in the morning we have to have a slice of toast ready for her and then we're trying to hide these meds and sneak them in while she's not really paying attention. It's an issue. It's an issue first thing in the morning and it's a dread in the evening that we've to get these into her.	Respondent
So in the mornings then you obviously get up, you have other kids to get up as well. What's the process like? Do you crush the tablets first? Do you get the kids up? Or how does it play out?	Interviewer
Well, I suppose we'll all get up together and we're trying to feed them breakfast while we're melting the Losec and crush some of the tablets. Marie used to be great for feeding, i.e. Weetabix and porridge. We hid a lot through that. She doesn't eat them anymore. If we put Weetabix or porridge in her mouth she just gags. I don't know if we spoilt her food from the meds, but I suppose her doctors are saying it's probably more central - there's something going on there with her swallow. So we crush all her tablets and we're trying to get the others ready at the same time and try and eat a bit yourself, so it can be hectic. It can be hectic. We did consider splitting Marie's meds up four times a day, so that we had smaller amounts to give her. But it's not practical. It's not practical to sit with Marie four times a day for meds. It's just not practical. So it can be hectic. Then you've to get them into her and then obviously try and get her ready and get dressed and ready for school and you're against the clock the whole time.	Respondent
I can imagine. So in the mornings then you've to crush the tablets, so you had to buy a pestle and mortar?	Interviewer
Yeah.	Respondent
Ok, and is it you that would crush them?	Interviewer
Yeah, I'd crush the tablets, yeah.	Respondent
Ok. What kind of volumes do you mix those in with yoghurt?	Interviewer

<p>I'd keep a piece of the yoghurt to one side and I mix it up and actually, what I did the last few days - I was in (hospital) on Friday and I didn't have a proper bowl, so I actually poured some of the yoghurt into the tablet crusher, which I found was handy because it scooped up all of the meds. So the last few days we've put some food into the little tablet crusher and we're just conscious of this little container now, that once that's gone in, we're happy. So that's what we're doing at the moment and that might work for a few weeks.</p>	<p>Respondent</p>
<p>So it's really trial and error, what works for you in terms of giving the meds. Have you ever got any advice, professional advice on how to give? How did you learn to do this?</p>	<p>Interviewer</p>
<p>No, no. I mean I remember being prescribed meds. Marie can't take liquids. We've tried Epilim in liquid form. It's like a bloodbath. Marie drools a lot, so when the liquid goes in it seems to duplicate the meds. So you don't know what's going in. Marie's meds are in tablet form and some of them are quite small. For instance, the Frisium. She has to take one and a half Frisium twice a day. So even chopping that tablet - I remember saying to them up in (hospital), "I can't weigh it. It doesn't come up on the scales. What do I do?" And they said, "It's just to the best of your knowledge, to the nearest 5 grammes if you can." So even at that some days she probably gets more in the morning than she does in the evening. It's just trial and error. Some people have suggested to me, "Did you try the syringe down the back of the throat?" Yes, we have for different things. Marie just throws it all up. She has very bad gag reflex. So no, we've had no advice really. Marie goes into respite in (name of respite centre). Now they are super up there at putting in meds. They have complained about getting in her meds and to the point of I'm like, "Well, what do people do in these circumstances? What should we do with Marie?" And they have told me that children like Marie are peg fed their meds, which is what we're looking to do now.</p>	<p>Respondent</p>
<p>How do you feel about putting in a peg just for meds?</p>	<p>Interviewer</p>
<p>I suppose for a long time we were against it. It's just another thing to worry about. It's another thing Marie can't do. It's another obstacle for us. It's an extra thing to carry with us. But we've surrendered to that now because it has been very stressful and now that we've surrendered to the idea of it, we just want it. But we're having all these assessments now, feeding assessments, radioscopies. We've to meet the surgeon and then we've to get a date and there's talk about, "Look, if she is aspirating on fluids, we may need an NG tube next week" et cetera, et cetera. So I suppose once you do surrender to it, it takes time then. But apparently all our appointments have been quick, so hopefully we'll get something quickly. People have advised me that once this happens, we will sit back and say, "Why didn't we do this a year ago?" I'm hoping that's the case and every now and again I think, "Yeah, this is definitely the way to go." But I was only</p>	<p>Respondent</p>

<p>thinking of it this morning, I was like, "Oh gosh. It's hectic in the mornings trying to spoon something into her. What's it going to be like flushing through a tube and putting the stuff in and holding her down to do this with her?" I was in (hospital) Friday and they've told me I've to thicken up her milk now and stuff and they told me not to give her toast and not to give her bread because she's at risk. And at the moment, the slice of toast is the only thing that Marie enjoys. The last few days I had to give it to her because I couldn't take it away from her. Now I think she's more able for toast than the doctors seemed to think on Friday. I don't think she's that bad. But yeah, hopefully we'll all sit back and say, "Yeah, this is a good thing for Marie." I suppose we did do some respite with (name of respite provider) and we were taken to (location) with all (name of respite provider) children. Most of them, the majority of them, actually Marie was probably the only one that wasn't peg fed and we were asking - children of similar ages, "How are they? Are they very cross? Are they always sick?" "Oh god, no - very happy children and never sick." And we were thinking, "What are we doing wrong?" And the parents felt it was down to the peg, that they were getting all their nutrients, everything. They had a balanced diet. They got everything they needed. They were full. All of their meds were put in through the tube. They were nearly given stuff to help them sleep, to help them wake up. And we were thinking, "Gosh, maybe Marie does need it." So we're hoping it will help her be a happier child and take away that irritability. She gets a lot of irritability, cerebral irritability and the way her feeding has gone because of her meds, she's hungry. That's only adding -</p>	
<p>It adds to the whole frustration even for you and husband. In terms of her meds, obviously she's had a few changes and you talked there about maybe the Lyrica being increased and maybe to get her off Frisium is it?</p>	Interviewer
<p>Yes.</p>	Respondent
<p>So she's going to have changes in meds along the way, but so far, how have you managed changes in medication? Did somebody say to you, "This is how you manage it"?</p>	Interviewer
<p>Well with Marie, we'll say for instance Marie's Frisium. When Marie started off on Frisium, she was probably on 5mg a day. She's now on 30, which is her maximum for her size and weight. According to her neurologist, Marie is probably one of the few children that she has on that maximum dose that they would prefer to pull her back. So she started off on 5 and over the last year she's gone up to that full 30mg, but in that year we'll say, she's gone up and up and up. You could see there's a cycle of events that happens with Marie. She gets tired, then she gets irritable. Then you bring her to the GP. You rule out ears, throat etc., broken bones and you get a pat on the back saying, "No sorry. It's definitely her head." So we had this plan in place with hospital that if this irritability strikes up, that we can increase Marie's Frisium. Well we did have a plan, by 2.5</p>	Respondent

<p>or half - 2.5 Frisium. So we were doing that and then I would get in touch with hospital and advise them of this increase and they would say, "Ok. Keep her on that and if it happens again, you can go up again." There was times where they had a plan in place, "Well look, if it happens again and you don't see a big improvement, go up a quarter of a tablet twice a day." With the Frisium it's an immediate effect. You can see that Marie is responding to it, so therefore you're confirmed in your thinking that it is her head. So when she got to 25mg they didn't want her going any further. So the idea then was that Marie would, when she got this irritation starting, that we would go up a quarter of a tablet, 2.5mg for a week or ten days until the irritability stopped and then we would pull her back. And I was told that a lot of girls for instance around the time of the month that are on Frisium would have this increase for that period time and then would pull back. Now Marie is four and a half. So what was happening was we were going up on the two and a half and she would become normal again, happy and relaxed. Then we would pull her back by the two and a half and then two weeks later we were back to the same cycle. And that went on for months, up and down, up and down, up and down, until everything came to a head in maybe February of this year and she was put onto the full max for Frisium. We were also on Epilim and various other things. But first of all, we had this plan in place that we can give her extra but we're not medics and you're thinking, "Is she irritable? Is she getting a cold? Is she this?" and you nearly wait till the last and you bring her to the GP and they're like, "No. I think you should give it to her." Then you're hoping that that's what was wrong with her. So it's difficult. It is difficult.</p>	
<p>And how do you feel making those decisions, where you've to say, "Right you know what - I will go with the extra."?</p>	<p>Interviewer</p>
<p>I suppose I've got used to it now, but I'm not comfortable with it and I haven't been comfortable with it to the point where my husband would come home and he'd say, "You need to give her the extra" and I'd say, "God, no, I'm afraid. I'm afraid." And up until recently, I didn't know 'cause I would have spoken to the neurologist nurses who are fantastic and I would have asked them, "Why are we not allowed to give her the full max, the maximum of the Frisium?" I said to them, "Are you trying to save her kidneys or her liver? Or what is it? What's the point in worrying about her liver when she's up the walls and nothing else works? It doesn't matter. We need to help her." But I suppose what they told me only in the last few months - it's not her liver side effects, it's her breathing that sometimes the Frisium can relax your breathing and that was new to me. I only found that out in the last few months. Marie's on Frisium years now and I didn't realise that was the side effect that they were worried about, that it could suppress her breathing. So when she is put onto an increase like that - initially it used to be under persistence from my husband, "Look, I'll give it to her." Then we'd check her twenty times a night before</p>	<p>Respondent</p>

we go to bed. We're in and out checking her.	
Because you're worried?	Interviewer
Yeah. And actually we've also got Chloral Hydrate suppositories on the basis that if she's extremely irritable, we can give her one of these. Last November when we were with (name of respite provider) in (location), as it happens, Marie was like an anti-christ and we gave her one and it really didn't do a lot for her. So the next day when we came back from (location) we gave her another. Now she's on a small enough dosage. And within minutes of taking that second one, she went unconscious. She was exhausted anyway. I don't know how many times we checked her that night, that was a Sunday and the following morning I was in at my GP, panicked, telling her that she conked out. "Did I give her too much?" and she told me, "No, and if it happens again, do give it to her. She's better off to sleep through her irritability."	Respondent
Obviously, it relaxed her so much that she fell into a deep sleep?	Interviewer
Mm, mm.	Respondent
So making those decisions are hard, yeah?	Interviewer
Absolutely.	Respondent
Obviously, your husband, is he very supportive when it comes to decisions?	Interviewer
Oh yeah, yeah.	Respondent
And who else then would support you? You'd feel comfortable ringing the GP?	Interviewer
Yeah. My GP - I've two GPs in the practice and there's a rule now - there's a lot of doctors in that building, but one of the two will see her and it doesn't matter how busy they are, they'll fit her in. Now it doesn't mean you get seen any quicker or anything like that. So that helps. And then I have the nurses down in (nearest hospital). I mean they're quite good too. And again there's a plan in place that if Marie is unwell, that I can bring her down and bring her straight up to them. Avoid A&E. Now again, it doesn't mean we get seen any quicker, but they know her and it avoids being in contact with people that are sick and stuff.	Respondent
Yeah, she'd be more vulnerable. Ok, tell me, you touched there obviously on one of the side effects of Frisium and you've only just learnt of that as such. How do you learn about the medications? Does anybody give you tips on the side effects? On their good effects? Or how do you educate yourself?	Interviewer
I suppose the doctors will tell us what it's for initially. They don't really tell us about the side effects, but they'll tell us what it's going to treat and what hopefully it will do and how it stays in their system. Like, Frisium is instant. It goes in and out of your system. Epilim tends to stay in your system and stuff like that. I suppose we look it up a little bit online. That's where we get a lot of stuff from. Now, in saying that, I have a friend who is familiar with epilepsy medication and she told me once that Epilim makes your hair curly.	Respondent

<p>You lose some of your hair with the Epilim and it grows back curly. I was like, "Ok." I have friends that - this particular friend is very good at informing me on different things like that. But no, we'd look them up. Strangely enough, when Marie was diagnosed - she was about one and a half when she was diagnosed with her condition - there was fifteen children in the world with the same condition. None in Ireland. There's one been diagnosed in Ireland recently, one other. But just in the last few months I've joined this Facebook forum and there's sixty children now in the world with this condition. Now there's probably lots more but they were never diagnosed. It's all new testing and we've joined this particular forum. One mother Facebooked me and asked me what medication Marie was on and of course, I sent back the list of stuff. She came back to me and she said, "Oh, we had to take my child off Frisium because of x, y and z." I just thought, "Oh. That's the only thing that works for Marie." All these forums are great, but it just shows that every child, even though they have the same condition, they react differently to meds. I tend to just look them up myself and ignore all the curly hair and everything else (laughs).</p>	
<p>It might be just as well (laughs).</p>	<p>Interviewer</p>
<p>Yeah.</p>	<p>Respondent</p>
<p>Ok. Tell me in terms of daily life, you give the meds in the morning and the evening. Do you document? How do you know what you've crushed, what you haven't crushed? Do you have a system in place in the mornings and the evenings? Or is something you've just learnt to do?</p>	<p>Interviewer</p>
<p>Just learned, just learned. I mean I have my meds up in a press there and I actually cut the Epilim into threes, so that I just take out three tablets at any one time. No, you just know that you've given them to her and anyone that's here - like my parents sometimes come and they'll help give her meds and I'd have a little slip in the container as well that they would know. But nobody would ever give Marie meds unless they've spoken to me because I would be the main giver of them. If she's going somewhere, sometimes I actually put them in their foils in the tablet crusher and whoever is going to give them to her will see them there. A lady that does that for me from time to time, she will send back the crusher with the empty foils so that I know that she's had them and they haven't fell out somewhere because the empty foils are in there. So that's what we do with that.</p>	<p>Respondent</p>
<p>Ok. So when she's going off somewhere you have to be prepared and organised in terms of meds. Do you find that time-consuming?</p>	<p>Interviewer</p>
<p>Yeah. Just recently, I don't know how, she must have had a few increases in Epilim or we were running out of Epilim, and then just recently I've just gone to my chemist and I said to him, "Look, I've eighteen days left of x, y and z. Just give me eighteen days of Epilim to try and tally them altogether, because otherwise you're in and out of the chemist the</p>	<p>Respondent</p>

whole time. No, it is time-consuming and you have to find - check the dates. We have Stesolid for if she's in a seizure and we've had a couple of them sitting there for a year or so and they're now out of date. It's something that you don't generally look at and, while the chemist will say they're good for a while, (name of respite provider) won't take you in unless everything is in date, which is understandable. So you've to go again and get another prescription, which is time-consuming because I've to go in, well I've to ring or get the prescription and then go to the chemist.	
So that can be time-consuming?	Interviewer
Absolutely	Respondent
So you've to call the GP, order a prescription and then go to the pharmacy. Would you have a good relationship with the pharmacy?	Interviewer
Yes. And like you were saying about finding out about meds, he is very good. He would be very good at that. If I've any kind of questions or if I don't understand something that someone has said to me I'll say, "Did you ever hear of this?" He'll know exactly what I'm talking about and he'll tell me. So yeah, he has a general knowledge of stuff and he's very good at explaining things too.	Respondent
It's good to have that relationship, isn't it?	Interviewer
Yeah, yeah. And you know if I'm ever stuck for stuff, he's there too. Yeah, he's there.	Respondent
Ok. And tell me, aside from the medication itself, what other equipment? You mentioned you have a pestle and mortar, you have a cutter.	Interviewer
Which is a blade.	Respondent
A blade cutter, ok (laughs).	Interviewer
Because the tablets are too small	Respondent
Yeah. You have the tablet crusher?	Interviewer
Yeah.	Respondent
Ok. Anything else?	Interviewer
What else do we have? No, that's it really. That's it really. And again, any pain relief that Marie would need, it's all suppositories. The Paralinks, the Neurofen, the Volterol, all of those things go in in suppositories. And I often wonder why they don't have antibiotics and various other things in, yeah.	Respondent
And how do you find that, because that's a different method of giving medication? You're used to giving it orally.	Interviewer
Yeah, well for me with her, it's easier because she's not good with liquids. So it's much easier. At least you know it's gone in. Funny enough, sometimes when she's really constipated a Neurofen will actually get things started for her. Now, when she's in pain she might poo straight afterwards, so it's hard to tell whether it's gone in or not. But at the same time it's just easier to just put it up her bum. The Augmentin duo antibiotic,	Respondent

she's not too bad at taking that.	
That comes in liquid form?	Interviewer
Yeah, that's one thing now that we've kept in liquid form that she's not too bad at taking.	Respondent
Ok. You mentioned obviously she has siblings. So she's got her eldest brother would be ten?	Interviewer
Yeah.	Respondent
So would they ever get involved in the medication side of things?	Interviewer
No.	Respondent
Distraction? Anything like that?	Interviewer
Well they help distract. I'm constantly saying, "Quick! Sing a song. Sing a song to Marie." There's various songs Marie likes or they know what station to put on the TV. They know what station she doesn't like. Yeah, they're very good at distracting her. There's certain - we don't know how well Marie can hear. Certain sounds they make, make her laugh. And we could have meds in her mouth and we just need her just to laugh for a second for it to just go down and they try and help out that way. But they find it stressful now with the medication. Definitely. And particularly in the last few months it's been stressful for them.	Respondent
How do you manage that stress?	Interviewer
Oh I don't know. Sometimes when you're in the best of your health and everything else it's fine and when you're being rational it's fine. But there's times - I mean everything kind of came to a head in February and I went to my consultant in (nearest hospital) on a routine check and he ended up sitting with me for an hour and I couldn't stop crying. I was mortified, absolutely mortified. But the stress of it was unreal and I was saying to my husband, "I think I'm having a heart attack." I was having palpitations, just anxiety. The dread of it, of putting these meds into her. But no, at the moment we're all good again. I try to get out for walks and I go to gym classes and things like that.	Respondent
That's important. I suppose finally, is there anything else that you think maybe we haven't touched on in terms of the medicines that you think might be important?	Interviewer
No, I don't think so. I don't think so. Just that we find it very stressful, very stressful.	Respondent
Hopefully the future will bring - over the summer months things might improve.	Interviewer
Yeah, yeah. You know, we're travelling in August now too, and it's just like, "Will she be well?" Marie is sick every other week. Is she going to manage it?	Respondent
In terms of, you mentioned you're travelling, how are you going to manage the medications, having to pack them up, bring them on holidays?	Interviewer
Pack them all up and bring them, yeah.	Respondent
Ok. Are you going on a plane?	Interviewer
Yeah.	Respondent

Ok. So do you have to get a letter then saying what they have? That kind of thing?	Interviewer
Yeah. Most of Marie's are tablet form so they're not concerned with liquids. So it does make it a little bit easier that they're in tablet form. But we have to make sure that we have everything with us. Know where the local hospital is, know everything. I mean if it was last week, if we were going there on Saturday, she wouldn't have been able to fly because her ear had popped. We travelled last August and on the way over she spiked a seriously high temperature. It came out of nowhere. It was probably something brewing that just rose it's head on the flight. I remember thinking, "Gosh. How would we actually land this plane if we had to?" You know, just the realisation we have a sick child with us and like that we were giving her suppositories on the flight over. But she just got suddenly sick on the airplane and I don't know whether it was the travelling itself, or it was something brewing. She was sick for a few days.	Respondent
Would you go prepared, armed with antibiotics?	Interviewer
Yes. All dried so that we just mix them then ourselves. Yes, absolutely. We're like a pharmacy going away on holidays (laughs). But you have to. You have to.	Respondent
You need that break. It's good for the family unit.	Interviewer
Yeah.	Respondent
Ok Olivia, thank you very much. You're very good for participating.	Interviewer
You're welcome, thank you.	Respondent

Appendix 14

Diary Transcript Participant 4 –Jane and Barry

(Please note pseudonyms have been adopted)

DATE: 16/7/15 TIME: 10pm

Visit to chemist today (**name of chemist**) to collect food supplements, Nutrison and Fortisip. I ordered these items a few days before. Once again the order is not ready – incomplete. Problem – Fortisip ordered from wrong supplier. I will have to call again, next time I'm going! Also collected the balance of another med which chemist was short of on my last visit. This happens quite a lot.

DATE: 24/8/15 TIME: 5pm

The same situation again with meds and chemist. Back to chemist today to collect balance of some meds and collect food supplements which were not in stock when I called last week. This is an ongoing problem every time I go to collect scripts.

Also script for Desunin was printed wrong by the doctors. 200mg per day – should have been 400mg per day. So I will have to phone doctors and get the correct script (yet more extra trips to and from!!).

DATE: 6/9/15 TIME: Now 10pm

Giving film coated tablets – a problem. I was giving 2 tablets morning and night (Vimpat) by PEG, when **Barry** wasn't eating much. It was hard to crush. Then he improved in eating – so I changed to giving them in his food. Tonight he was off his food – head cold starting. Didn't want to swallow but tablet no 1 was in his mouth and going nowhere. He held on to it for a while and then I got him to swallow. Same with the second tablet, this time he spit it out, so got it back in again and down. I thought he was going to get sick. At this point the coating had melted away and he was getting the full taste of the tablet – not nice I guess.

Just note the difficulty with tablets with film coating – i.e. hard to crush, and when the coating melts in the mouth.

DATE: 9/11/15 TIME: 9.30pm

Difficulty when changing meds i.e. starting a new med and stopping another. Every week has to be planned out and written out week by week, increasing new med, decreasing old one. Then you are dealing with a new type of med i.e. in **Barry's** case a big, very big bottle of Phenobarbitol. And when the syringe no longer reaches down into the liquid – you have the task of pouring out this sticky med into container and then filling syringe. You should see the state of the bottle when it comes back from respite (it's like a sticky sweet). With weekly changes the Kardex has to be updated every time for respite.

Appendix 15

Van Manen and NVIVO - Stages and Process

Van Manen's six components of phenomenological research	Process in NVIVO
Turning to the nature of lived experience	In-depth interviews, transcribing, reading and re-reading transcripts & constructing a qualitative database (NVIVO).
Investigating experience as we live it	Create first order constructs from transcripts (what I call open coding). Initial themes identified. Selective reading approach (van Manen 1997) was adopted.
Reflecting on the essential themes which characterise the phenomenon	Managing constructs and creating second order constructs – by reorganising, renaming, merging, distilling, and clustering related constructs under broader categories of constructs (essential themes identified). Holistic reading approach (van Manen 1997) adopted.
Describing the phenomenon in the art of writing and re-writing	Writing summary statement to synthesise the stories embedded in the essential themes and to create thick descriptions of the phenomenon (Linked memos in NVIVO and own personal diary notes also). Writing of the findings.
Maintaining a strong and oriented relation to the phenomenon	Writing memos and revisiting aim and objectives while data collecting, analysing and writing.
Balancing the research context by considering the parts and the whole	Data reduction – synthesising the findings into a cohesive and coherent findings document where only the parts relevant to the broader research context are included. Creating a narrative that is true to the stories and experiences of study participants.

Appendix 16

Short paragraph to express a participant experience

This short paragraph is a summary based on the transcript already presented in Appendix 13.

Within this interview Olivia has indicated her experience of 'giving medicines' to her daughter with a profound intellectual disability. She outlines in great detail the intricacies of 'giving medicines' and the challenges she encounters in daily life with Marie. It is clear that Olivia has many worries and her concern about the effect of 'giving medicines' to her daughter is evident. So too, is her worry about the effect on Marie's siblings and the stress they may endure. Throughout the interview Olivia displays many emotions and feelings from love to frustration, stress, worry and resignation. Olivia also details the time pressure she experiences and her level of organisation, especially in the morning, indicating her husband, GP and pharmacist as people who are supportive. She regularly seeks advice on 'giving medicines' but does not always find this advice satisfactory. She admits using her own instincts and judgements constantly but isn't always content she has made the right decision. She acknowledges she has learned her way of doing things and what works for her and Marie.

Appendix 17

Informed Consent Form

Please indicate your informed consent to take part in this research study by completing this form. I ask that you read each statement and place an X in the appropriate box.

STATEMENTS	YES	NO
I have read, or had read to me, this consent form.		
I have had a chance to discuss and ask questions about this research study and all of my questions have been answered to my satisfaction.		
I understand what the research study is about.		
I understand that the interview will be audio tape recorded.		
I understand that if I keep a written account in the diary over the six to nine months and give this to the researcher I am willing to share this diary.		
I understand that if I disclose any information that suggests unsafe practice or gives reasonable ground for concern I will contact a relevant person to seek advice/support or with my permission the researcher will make contact with a relevant person.		
I know that, in order to minimise the chance of identifying interviewees, the researcher will not link comments to individual participants.		
I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.		
I have received a copy of this agreement.		
I understand I may withdraw without question from the study at any time, without having to explain my decision, or suffer any adverse effects.		
I wish to receive a copy of the diary entries I made over the six to nine month period.		
I wish to receive a copy of the transcripts from the interviews I took part in.		
I wish to receive a copy of the executive summary of the research study on completion of the study in 2018.		
I understand the researcher must let the resource & data officer, <i>(name of organisation)</i> , know that I have participated in this research study after data collection is finished (this is so that I am not over exposed to research studies).		

PARTICIPANT'S NAME: _____

CONTACT DETAILS: _____

PARTICIPANT'S SIGNATURE: _____

DATE: _____

Statement of researcher's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

RESEARCHER'S SIGNATURE: _____

DATE: _____

Appendix 18

Participant Profiles

Please see below a profile of each of the 15 participants who took part in this research study.

Participant 1– Catherine and Aaron

Catherine is mother to Aaron a 13 year old boy with a profound intellectual disability and diagnosis of global developmental delay. Aaron also has epilepsy, a long history of GORD and has had a PEG inserted. He has limited mobility and is fully incontinent also. Aaron requires 24 hour care, is no longer an oral feeder and is PEG fed, communicating through the odd vocalisation. Catherine works part time and Aaron requires 24 hour care on a continuous basis. She also has 2 younger children living at home. Her husband is unemployed but acknowledges his presence at home enables her to get out and work without worrying so much about who will mind Aaron. Otherwise, they have a limited support structure. Aaron attends a special school 5 days per week. He also receives respite care for 3 nights per month from one respite facility and 2 nights per month from another respite facility. Aaron is prescribed 9 medications, requiring 8 daily medications and 1 PRN medication depending on his health status. He has a total of 19 drug administrations per day (not including PRN medications) using a variety of routes of administration; PEG, buccal and nebulised. Many of these drugs are modified for administration requiring crushing, halving, mixing or further measurement. I had the pleasure of meeting Aaron, his siblings and his father. A clear bond was evident between all and while their living space was limited due to a small family home, Catherine was resigned to this being what they had.

Participant 2 –Gillian and Ava

Gillian is mother to Ava a 17 year old girl with a severe to profound intellectual disability and diagnosis of 1P36 Deletion syndrome. Ava also has epilepsy, moderate to severe hearing loss, cortical vortex impairment with associated vision loss, a long history of recurrent renal calculi and a history of a heart defect repair following birth and a Nissens fundoplication at 4 months old. She also has neuromuscular scoliosis and suffers with neuropathic pain. She takes semi soft diet and thickened fluids, requiring an NG tube insertion at intervals if not taking fluids well. She requires 24 hour care with no ability to walk and is non-verbal. Gillian works part time from home and cares for Ava on a continuous basis. She also has 1 older daughter living at home who

has a chronic debilitating illness. She has no additional support structure. Ava attends a special school 5 days per week (due to cease without other alternatives once she turns 18). She receives respite care for 3 nights per month (due to cease without other alternatives once she turns 18). Ava is prescribed 16 medications, requiring 11 daily medications and 5 PRN medications depending on his health status. She has a total of 24 drug administrations per day (not including PRN medications) using a variety of routes of administration; oral, buccal, rectal and nebulised. Many of these drugs are modified for administration requiring crushing, halving, mixing or further measurement. While I did not meet Ava, her mother showed me pictures of her and it was evident through her words how much a part of her life she is. Gillian also acknowledged her ongoing worries about what the future holds for Ava.

Participant 3 – Olivia and Marie

Olivia is mother to Marie a 4 year old girl with a profound intellectual disability and diagnosis of a neurological condition, Ponto Cerebellar Hypoplasia with cask. Marie has microcephaly and needs 24 hour care with no ability to walk or speak. She has epilepsy, is incontinent, and experiences constipation and chronic irritability. Her ability to swallow deteriorated rapidly between interviews and resulted in having a PEG insertion for feeding and giving medicines. Olivia is stay at home mother who cares for Marie on a continuous basis. She also has 3 older children living at home and her husband goes out to work Monday to Friday but as he is self-employed this often entails him working over weekends also. She has 'good' support from her family with her parents assisting when required. Marie attends a special school when stable. She receives respite care for 3 nights every 8 weeks. However, this facility is some distance from home and requires planning in terms of getting to and from. Marie is prescribed 11 medications, requiring 8 daily medications and 3 PRN medications depending on his health status. She has a total of 17 drug administrations per day (not including PRN medications) using a variety of routes of administration; oral, buccal and nebulised, pre PEG insertion when no further oral administrations were given. Many of these drugs are modified for administration requiring crushing, halving, mixing or further measurement. While I did not meet Marie, her mother showed me pictures of her and it was evident through her words how much a part of her life she was. Her condition further deteriorated since the final interview and she died peacefully at home surrounded by her family.

Participant 4 –Jane and Barry

Jane is mother to Barry a 14 year old boy with a profound intellectual disability and diagnosis of global developmental delay with lissencephaly and pachygyria. He is immobile, incontinent, has epilepsy and scoliosis. He has had a PEG insertion and a vagus nerve stimulator inserted for the treatment of epilepsy. Jane is a stay at home mother who cares for Barry on a continuous 24 hour basis and helps out on the family farm when she can. She also has 3 older children living at home and her husband is self-employed on his own dairy farm. Jane and her husband rely on each other for support and have no other family supports. Barry attends a special school 5 days per week and receives some in home supports for 1 hour three days per week. He also receives respite care in a respite facility 4 nights per month. However, this facility is some distance from home and requires planning in terms of getting to and from. Barry is prescribed 8 medications, requiring 7 daily medications and 1 PRN medication depending on his health status. He has a total of 9 drug administrations per day (not including PRN medications) using a variety of routes of administration; PEG and buccal. Many of these drugs are modified for administration requiring crushing, halving, mixing or further measurement. While I did not meet Barry, his mother showed me pictures of him and it was evident through our conversation how she very much planned her daily life around him.

Participant 5– June and Robbie

June is mother to Robbie a 13 year old boy with a severe intellectual disability and diagnosis of Down Syndrome and autism. He also has rheumatoid arthritis and is visually impaired. He frequently requires treatment for recurrent chest and ear infections. He self feeds orally with a mashed diet. While fully mobile with some words, he requires 24 hour supervision and assistance with activities of living. June is a stay at home mother who cares for Robbie on a continuous basis. She also has 1 younger daughter living at home and her husband goes out to work Monday to Friday. While they rely on each other for support, there are other family members they can ask for support from. Robbie attends a special school 5 days per week. He does not avail of respite at the family's request. Robbie is prescribed 9 medications, requiring 7 daily medications and 2 PRN medications depending on his health status. He has a total of 8 drug administrations per day (not including PRN medications) using a variety of routes of administration; oral and injection. Many of these drugs are modified for administration requiring crushing, halving, mixing or further measurement. I had the pleasure of meeting Robbie, his sister and his father. A clear bond was evident between all and he responded to me with vocalisations.

Participant 6– Grace and Eoin

Grace is mother to Eoin a 10 year old boy with a profound intellectual disability and diagnosis of Chromosome disorder 29 (24.2-31 deletion). Eoin has a myriad of complex health needs including epilepsy, scoliosis, a visual impairment, hypotonia, unilateral hearing impairment, a ventricular septal defect (repaired) and history of a fundoplication. He is a non-oral feeder and had a PEGJ inserted in 2012. He experiences chronic pain with very poor motility resulting in constipation and is incontinent. Additionally, he requires suctioning on an ongoing basis. He requires 24 hour care with no ability to walk. Grace is a stay at home mother who cares for Eoin on a continuous basis. She also has 3 other children (1 younger and 2 older) living at home and her husband goes out to work Monday to Friday. While they rely on each other for support, there are other family members they can ask for support if required. Eoin attends a special school 5 days per week. He receives respite care for 2 nights every month and also receives a home care family support package of 12 hours per week. Eoin is prescribed 11 medications, requiring 10 daily medications and 1 PRN medication depending on his health status. He has a total of 17 drug administrations per day (not including PRN medications) using a variety of routes of administration; PEGJ and rectal. Many of these drugs are modified for administration requiring crushing, halving, mixing or further measurement. I had the pleasure of meeting Eoin as well as his little brother. A clear bond was evident between all. Between the first and second interview Grace and the family moved out of the family home to temporary accommodation while renovations to improve living arrangements for Eoin were undertaken. This placed enormous stress on the family but Grace was confident it would be worth it when the living environment was adapted to suit Eoin's increasing needs.

Participant 7 –Liz and Jake

Liz is mother to Jake a 10 year old boy with a profound intellectual disability and diagnosis of Down Syndrome and chronic infantile neuro cutaneous articular syndrome (CINCA). Jake also has scoliosis, hip dysplasia and a repaired heart defect. He experiences chronic chest infections and is oxygen dependent. He requires 24 hour care with no ability to walk, although can mobilise by 'bum shuffling' and communicates through the use of LAMH (sign language used in intellectual disability practice). He is incontinent, experiences constipation and has some hearing and vision loss. As he has no suck and aspirates frequently he has had a PEG insertion and no longer feeds orally. Liz is a stay at home single mother who cares for Jake on a 24 hour continuous basis. She also has 1 older daughter living at home and relies largely on her own

family to help when needed. Jake attends a special school 5 days per week. He receives respite care for 2 nights every month and also receives HSE funded in home respite care 8 nights per month. Jake is prescribed 17 daily medications requiring a total of 30 drug administrations per day using a variety of routes of administration; injection, nebulised and via PEG. Many of these drugs are modified for administration requiring crushing, mixing or further measurement. While I did not meet Jake, his mother showed me pictures of him and it was evident through her words how much a part of her life he is. She acknowledges that having Jake has made her campaign nationally for better services and the rights of children with intellectual disabilities.

Participant 8 – Anna and Tom

Tom is a 5 year old boy who experienced anoxia at birth resulting in development of a profound intellectual disability with associated cerebral palsy, quadriplegia and epilepsy. He is oxygen dependent and contracts pneumonia regularly. He is also JeJ fed with no suck, swallow or gag reflex and requires suctioning frequently throughout the day. Tom is incontinent and immobile requiring 24 hour care for his daily activities of living. Anna is a stay at home mother who cares for Tom on a continuous basis. She also has a 2 year old boy and her husband goes out to work Monday to Friday. She has little or no support other than her husband. Tom attends a special school, but as he needs full nursing care and the school can only provide this 2 days per week he only attends for 2 mornings when stable. He receives respite care for 3 nights every 7 weeks and also requires a nurse at night time from 11pm-7am. Tom is prescribed 17 medications, requiring 13 daily medications and 4 PRN medications depending on his health status. He has a total of 33 drug administrations per day (not including PRN medications) using a variety of routes of administration; JeJ, rectal, buccal and nebulised. Many of these drugs are modified for administration requiring crushing, halving, mixing or further measurement. I had the pleasure of meeting Tom with his mother and witnessed a clear bond with him responding to her voice, often with a smile.

Participant 9 –Martha and Max

Martha is mother to Max a 16 year old boy with a severe intellectual disability and diagnosis of autism. Max also has Type 1 Diabetes and coeliac disease. He is continent but has frequent toileting accidents. While he has some words he can remain non-verbal at times. He requires 24 hour care for his daily activities of living and supervision. He enjoys his diet and self feeds orally. Martha works part time outside of the home while her husband works Monday to Friday. She also has one younger son living at home. Max attends a special school 5 days per week. He

receives 2 nights respite care in a respite facility every 6 weeks and also receives in home supports for 17 hours per week. They have very little by way of support structure other than themselves. Max is prescribed 6 medications, requiring 4 daily medications and 2 PRN medications depending on his health status. He has a total of 6 drug administrations per day (not including PRN medications) using a variety of routes of administration; oral and injection. Some of these drugs are modified for administration requiring further measurement. While I did not meet Max, his mother showed me pictures of him and it was evident through her words how much a part of her life he is and the challenges that she faces in daily care.

Participant 10 – Pam and John

Pam is mother to John, a 17 year old boy with a profound intellectual disability and diagnosis of deletion of the long arm of chromosome 5. John also has severe scoliosis, epilepsy and talipes equinovarus. He has had a colostomy due to polyposis coli malignant polyps and suffers with recurrent cellulitis of his legs. He is incontinent and immobile requiring 24 hour care for his daily activities of living and is non-verbal. He enjoys his diet and is orally fed with a soft texture diet and drinks from a spoon. Pam also works outside of the home as a nurse and juggles caring for John with work and home life. She also has 2 grown up children who live away from home. Her husband also works 5 days per week but undertakes a night shift pattern so he can be home in the mornings and afternoons to care for John. John attends a special school 5 days per week. The family have chosen not to seek respite care for John. Pam and her husband rely on each other for John's care and outside of this have no other family supports. John is prescribed 6 medications, requiring 4 daily medications and 2 PRN medications depending on his health status. He has a total of 7 drug administrations per day (not including PRN medications) using a variety of routes of administration; oral, buccal and nebulised. Many of these drugs are modified for administration requiring crushing, halving, mixing or further measurement. I had the pleasure of meeting John and his father. A clear bond was evident between all and he responded to her voice, often with a smile. John's condition deteriorated since the final interview and he died peacefully at home in his parents' arms.

Participant 11–Mags and Sophie

Mags is mother to Sophie a 9 year old girl with a severe intellectual disability who when born prematurely, sustained a brain haemorrhage resulting in complex difficulties. Sophie also has cerebral palsy, hydrocephalus, epilepsy, is immobile, is incontinent and vocalises with sounds and the odd word. She experiences constipation on an ongoing basis and is also experiencing

precocious puberty. She is orally fed with a mashed diet. Mags (herself a nurse) works outside the home 2 days per week and juggles care for Sophie on a continuous basis. Her husband is self-employed and goes out to work Monday to Friday. Sophie attends a special school 5 days per week. The family have chosen not to seek respite care for Sophie. Mags and her husband rely on each other for Sophie's care and outside of this have no other family supports and do not live near grandparents. Sophie is prescribed 5 medications, requiring 4 daily medications and 1 PRN medication depending on her health status. She has a total of 6 drug administrations per day (not including PRN medications) using a variety of routes of administration; oral and injection. Many of these drugs are modified for administration requiring crushing, halving, mixing or further measurement. While I did not meet Sophie, her mother showed me pictures of her and it was evident through her words how much a part of her life she is. Her reluctance to avail of respite care was something Mags discussed at length and her fear for the future as they had limited supports and as Sophie has no siblings.

Participant 12—Sadie and Todd

Sadie is mother to Todd an 11 year old boy with a profound intellectual disability and diagnosis of Lissencephaly. Todd also has epilepsy, is immobile, incontinent and vocalises without words. He is orally fed with a mashed diet. Sadie is a stay at home mother who cares for Todd on a 24 hour continuous basis. She also has 2 other children and her husband goes out to work Monday to Friday. Todd attends a special school 5 days per week. The family have chosen not to seek respite care for Todd but do avail of home share every Saturday 12-6pm which sees Todd go to another family for this period of time. Sadie and her husband rely on each other for Todd's care and outside of this have no other family supports. Todd is prescribed 6 medications, requiring 5 daily medications and 1 PRN medication depending on his health status. He has a total of 8 drug administrations per day (not including PRN medications) using a variety of routes of administration; oral and buccal. Many of these drugs are modified for administration requiring crushing, halving, mixing or further measurement. While I did not meet Todd, his mother showed me pictures of him and it was evident through her words how much a part of her life he is.

Participant 13—Helen and Shay

Helen is mother to Shay a 17 year old boy with a severe intellectual disability and diagnosis of Down Syndrome and autism. Shay is also incontinent, is non-verbal and experiences behavioural

challenges around hyperactivity and sensitivity. While Shay self feeds orally it is a mashed diet. Helen and her husband work outside the home 5 days per week. She also has 3 older children (2 live away from home) and has limited support structures otherwise. Shay attends a special school 5 days per week. He receives 14 nights respite care in a respite facility per month. Shay is prescribed 6 daily medications and has a total of 8 drug administrations per day using the oral route of administration. Some of these drugs are modified for administration requiring crushing, halving, mixing or further measurement. While I did not meet Shay, his mother showed me pictures of him and it was evident through her words how much a part of her life he is and the challenges that she faces in daily care. She also acknowledged how her health (in particular her mental health) had suffered as a result of being a carer and the sacrifices she has made in recent years. I was also shown damage to the house incurred as a result of behavioural outbursts displayed by Shay.

Participant 14 –Lynn and Emma

Lynn is mother to Emma a 14 year old girl with a profound intellectual disability and quadriplegic cerebral palsy. Emma is immobile, has epilepsy, gastro oesophageal reflux and experiences constipation. She also has psoriasis and is a non-oral feeder with a PEG inserted. She makes vocalisations but has no words. Lynn is a stay at home mother who cares for Emma on a 24 hour continuous basis. She also has one other daughter living at home and her husband goes out to work Monday to Friday. Lynn and her husband rely on each other for Emma's care and outside of this they have no other family supports. Emma attends a special school 5 days per week. She receives 7 nights respite care in a respite facility per month. Emma is prescribed 13 medications, requiring 10 daily medications and 3 PRN medications depending on her health status. She has a total of 14 drug administrations per day (not including PRN medications) using a variety of routes of administration; absorption and PEG. Many of these drugs are modified for administration requiring crushing, halving, mixing or further measurement. While I did not meet Emma, her mother showed me pictures of her and it was evident through her words how much a part of her life she is.

Participant 15–Siobhan and Niamh

Siobhan is mother to Niamh a 2 year old girl with a severe intellectual disability and diagnosis of Pyruvate Dehydrogenase Deficiency (PDH) a rare degenerative and progressive mitochondrial disorder. Niamh has epilepsy, limited mobility, both visual and hearing impairments, scoliosis, is

incontinent and suffers with constipation. She makes vocalisations but has no words and on my first meeting she was orally fed, by the time we met again she had a PEG inserted for administration of medicines and fluid top up while remaining to orally feed. Siobhan has taken a career break from her job due to Niamh's condition she felt she had no other option), and is now a stay at home mother who cares for Niamh on a 24 hour continuous basis. Her husband goes out to work Monday to Friday. Siobhan and her husband rely on each other for Niamh's care and outside of this have the support of Siobhan's elderly father who lives nearby. Niamh attends a support organisation 2 mornings per week and a different support organisation one morning per week. She receives 24 hours in home respite care per month and 15 nights respite care in a respite facility per year. Niamh is prescribed 7 medications, requiring 5 daily medications and 2 PRN medications depending on her health status. She has a total of 10 drug administrations per day (not including PRN medications) using a variety of routes of administration; oral, rectal, PEG and nebulised. Many of these drugs are modified for administration requiring crushing, halving, mixing or further measurement. I had the pleasure of meeting Niamh with her mother. A clear bond was evident between them and she responded to her voice, often with a smile. Siobhan discussed the possibility of a lot of changes in medications into the future as her daughters condition deteriorates. On a personal level she voiced her concerns regarding having more children in the future and her capacity to care for all considering Niamh's complex care needs.

Appendix 19

List of Medicines

Explanatory Notes:

- A generic drug is a medication created to be the same as an existing approved brand-name drug in dosage form, safety, strength, route of administration, quality, and performance characteristics. A generic medicine works in the same way and provides the same clinical benefit as its brand-name version.
- Any medication prescribed for a child is listed here whether over the counter or prescription only.
- If a drug has more than one function it is categorised here under the function for which it is prescribed for the child.
- If a mother identified the brand name only, the generic name has been identified and supplied here in the list.
- If a mother identified the generic name only, no brand name has been identified.

ANTIBIOTICS	
GENERIC NAME	BRAND OR TRADE NAME
Azithromycin	Zithromax Azithromax
Flucloxacillin	Floxapen
Fusidic acid and hydrocortisone	Fucidin H (topical antibiotic with corticosteroid)

ANTI-CHOLINERGIC	
GENERIC NAME	BRAND OR TRADE NAME
Glycopyronium bromide	Glycopyrolate
Procyclidine	Kemadrin

ANTI-CHOLINERGIC BRONCHODILATOR	
GENERIC NAME	BRAND OR TRADE NAME
Ipratropium bromide	Atrovent

ANTI- DEPRESSANTS	
GENERIC NAME	BRAND OR TRADE NAME
Escitalopram	Lexapro
Fluoxetine	Prozac
Amitriptyline	Elavil

ANTI-EMETIC	
GENERIC NAME	BRAND OR TRADE NAME
Domperidone	Motilium
Scopolamine	Scopoderm
Ondansetron	Zofran

ANTI-EPILEPTIC DRUGS	
GENERIC NAME	BRAND OR TRADE NAME
Phenytoin sodium	Epanutin Phenytoin
Sodium valproate	Epilim
Gabapentin	Neurontin
Lacosamide	Vimpat
Levetiracetum	Keppra
Lamotrigine	Lamictal
Pregabalin	Lyrica
Sultiame	Ospolot
Rufinamide	Inovelon
Vigabatrin	Sabril
Carbamazepine	Tegretol
Topiramate	Topamax
Oxcarbazepine	Trileptal
Ethosuximide	Zarontin
Zonisamide	Zonegran

ANTI-FIBRINOLYTIC HEMOSTATIC	
GENERIC NAME	BRAND OR TRADE NAME
Tranexamic acid	Cyklokapron

ANTI-HISTAMINE	
GENERIC NAME	BRAND OR TRADE NAME
Promethazine	Phenergan

ANTI-PSYCHOTIC	
GENERIC NAME	BRAND OR TRADE NAME
Risperidone	Risperdal

ANTI- SPASTIC (MUSCLE RELAXANT)	
GENERIC NAME	BRAND OR TRADE NAME
Baclofen	

BENZODIAZEPINES	
GENERIC NAME	BRAND OR TRADE NAME
Clonazepam	Clobazam Rivotril Frisium
Diazepam	Stesolid
Nitrazepam (Benzodiazepine hypnotic)	Mogadon

BIOLOGIC	
GENERIC NAME	BRAND OR TRADE NAME
Anakinra	Kineret
Adalimumab	Humira

CORTICOSTEROIDS	
GENERIC NAME	BRAND OR TRADE NAME
Fluticasone propionate	Flixotide
Prednisolone	Prednesol
Budesonide	Pulmicort

DISEASE-MODIFYING ANTI-RHEUMATIC DRUG (DMARD)	
GENERIC NAME	BRAND OR TRADE NAME
Methotrexate	

EYE OINTMENT	
GENERIC NAME	BRAND OR TRADE NAME
Dexamethasone/polymyxin B sulphate and neomycin sulphate	Maxitrol

GASTRO OESOPHAGEAL REFLUX	
GENERIC NAME	BRAND OR TRADE NAME
Ranitidine(Proton pump inhibitor)	Zantac
Lansoprazole (H2 receptor antagonist)	Zoton

DRUGS FOR DIABETES	
GENERIC NAME	BRAND OR TRADE NAME
Pancreatic hormone	Glucagon
Insulin detemir	Levimir
Insulin aspart	Novorapid

HORMONES	
GENERIC NAME	BRAND OR TRADE NAME
Triptorelin	Decapeptyl
Enbrel	Etanercept
Barium sulfate	Epistat

HYPNOTIC/SEDATIVE	
GENERIC NAME	BRAND OR TRADE NAME
Chloral Hydrate	
Melatonin (Psycholeptic)	Circadin

LAXATIVES	
GENERIC NAME	BRAND OR TRADE NAME
Glycerine suppository	Babylax suppository
Osmotic laxative	Movicol

LOOP DIURETIC	
GENERIC NAME	BRAND OR TRADE NAME
Frusemide	Lasix B name

NON OPIOID ANALGESIA	
GENERIC NAME	BRAND OR TRADE NAME
Paracetamol	Calpol Paralink

OPIOID ANALGESIA	
GENERIC NAME	BRAND OR TRADE NAME
Morphine sulphate	Oramorph
	MST

NON STEROIDAL ANTI- INFLAMMATORIES	
GENERIC NAME	BRAND OR TRADE NAME
Ibuprofen	Brufen Neurofen
Naproxen and esomeprazole magnesium	Vimovo
Diclofenac sodium	Difene

RESPIRATORY	
GENERIC NAME	BRAND OR TRADE NAME
Hypertonic Saline	
Mucoclear	Mucolytic
Salbutamol	Ventolin

POTASSIUM	
GENERIC NAME	BRAND OR TRADE NAME
K+ Potassium	
Potassium citrate	Urocit

PULMONARY ARTERIAL HYPERTENSION	
GENERIC NAME	BRAND OR TRADE NAME
Sildenafil	Viagra

SEDATIVE (Rescue medication for seizures)	
GENERIC NAME	BRAND OR TRADE NAME
Midazolam	

STEROIDS	
GENERIC NAME	BRAND OR TRADE NAME
Calcipotriol/betamethasone dipropionate	Dovobet
Spironolactone	

SUPPLEMENTS	
GENERIC NAME	BRAND OR TRADE NAME
Calcium supplement	Calcichew
Ferrous sulphate iron supplement	Fer in sol
Folic acid	Vitamin B supplement
High energy nutritional drink	Fresubin
Medium chain triglyceride	Liquigen
Calcium phosphate	Osteofos
Peppermint water	
Probiotic	
Vitamin B1	Thiamine
Vitamin D	

TOPICAL PREPARATIONS	
GENERIC NAME	BRAND OR TRADE NAME
Metanium cream	Barrier ointment for nappy rash
Tacromilus	Protopic cream

WOUND DRESSING	
Acticoat Flex 3 (antimicrobial wound dressing)	

Appendix 20

Reflection relating to Participant 8

Setting the scene

After a 45 minute drive from the city, I reached my destination and after enquiring with the postman about the address, I rang the doorbell of the small semi-detached bungalow noting the floral display in pots at the front door, to be greeted by a woman called Anna (mother of Tom). Immediately, I was brought through the small hall into a large room which looked like a bedroom, where Tom lay in his bed sleeping. I was reminded to sanitise my hands before going any further as he was susceptible to infection. The room had a large glass rear wall with sliding doors and an accessible ramp, so that Tom could see the garden even on wet days and other furniture included 2 armchairs, a large beanbag and a wall of built in presses, which Anna informed me housed some of Tom's equipment and medications. Other items visible were his ventilation equipment, suction machine and specialist chair. Another wall played host to a selection of family photographs and artwork completed by Tom while beneath this was a box of toys belonging to his 2 year old brother who liked to play at his brother's bedside. Anna indicated that not being able to afford a move to a bigger house, this house but essentially this room had been extended recently to make space for all of Tom's equipment and meant general living space was compromised and therefore it was important to have armchairs present in his room so the family spent time together. While making tea, Anna showed me around the house and it was clear that due to the size of Tom's wheelchair and the associated equipment required, that Tom and the family spent most of their time within his large bedroom. The only bathroom in the house had also been extended to house a wetroom style shower with a large shower trolley for Tom. On that occasion, I spent 3 and half hours at the house (not all of this time was interviewing) and witnessed the bond between mother and child with her gentle touches and his facial reaction to her voice. What was also striking was the loneliness and isolation that Anna felt in her world at home with her son and her easy acceptance of me, a stranger and her reluctance to see me leave after completion of the interview.

Appendix 21

Peer Reviewed Conference Presentations

Doyle C. & Nicholl H. (2015) Mothers' who 'give medicines' to children with complex needs - Considerations in Gaining Access. *7th International Cardiff Conference on Paediatric Palliative Care*, Cardiff University, Wales, 8th-10th July. Retrieve from <http://www.icpcn.org/cardiffppc2015/>

Doyle C. (2016) Recruiting mothers of children with complex needs - Overcoming the Challenges. *15th International Qualitative Methods Conference*, Glasgow, 3rd May. Retrieve from [Published abstract on <http://www.cvent.com/events/15th-qualitative-methods-conference>]

Doyle C. & Cronin P. (2017) Difficulties in 'giving medicines' to children with severe and profound intellectual disabilities - mothers' experiences. *RCPCH/RCN Conference*, Birmingham, 24-26th May.

Doyle C. & Cronin P. (2017) Difficulties in 'giving medicines' to children with severe and profound intellectual disabilities - mothers' experiences. *Archives of Disease in Childhood* **102** (Suppl 1), pA16.3 - A17.

Doyle C. (2018) Mothers' experiences of 'giving medicines' through alternative routes of administration to children with severe and profound intellectual disabilities. *Children's Nursing Research Symposia*, Trinity College, Dublin, 2nd May.

Doyle C. (2019) Supporting mothers of children with severe and profound intellectual disabilities to 'give medicines' – the role of the GP. *Trinity Health and Education International Research Conference*, Trinity College, Dublin, 6th March.

Doyle C. (2019) 'Giving Medicines' to children with severe and profound intellectual disabilities - mothers' experiences. *The World Congress of the International Association for the Scientific Study of Intellectual Developmental Disabilities*, Glasgow, Scotland, 6-9 August.