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“Making the most of their body and their life”:

Parents’ experiences of health care

for their children with cerebral palsy

Thesis submitted by

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In June 2014

for the degree of Masters of Physiotherapy (Research)

in the School of Public Health, Tropical Medicine

and Rehabilitation Sciences

James Cook University

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- Emily Hayles was the chief investigator. She was responsible for developing the study design, searching and screening the literature for inclusion, analysis of the literature and manuscript preparation.
- Sally Ruston was involved in developing the conceptual design of the narrative review.
- Anne Jones, Desley Harvey and David Plummer contributed to the study design and review of the draft manuscript.

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Declaration on ethics

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research, 2007. The proposed research study received human research ethics approval from the Townsville Hospital & Health Service Human Research Ethics Committee (Reference Number: HREC/12/QTHS/44), the Mackay Hospital & Health Service Research Governance Committee (Reference Number: SSA/12/QMH/15), and the James Cook University Human Research Ethics Committee (Approval Number H4754).

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Abstract

Background:

Children with cerebral palsy often have numerous health care needs and require complex multidisciplinary health care. Holistic family centred care that is inclusive of the viewpoints of parents and children is regarded as best practice for health care service delivery for children with cerebral palsy and their families. However, dissatisfaction with care is an ongoing issue for parents of children with cerebral palsy, despite theoretical changes to health care service delivery practices toward a more family centred approach. In addition, current guidelines and standards of care for this population have been developed by health professionals without, or with little, involvement of parents. Parents' perceptions of their child's health care needs may differ from that of health professionals. If the existing guidelines and standards do not reflect the needs of the child and the family due to the lack of parental input, this may be part of the reason why parents of children with cerebral palsy continue to be dissatisfied with their child's care. No previous researchers have investigated how parents of children with cerebral palsy experience health care for their child.

Aim:

The aim of this study is to explore parents' experiences of health care for their children with cerebral palsy living in a regional area of Queensland, Australia. From this exploration, the aim of this study is to develop a conceptual model that explains parents' experiences and can be used to inform future clinical health care service delivery practices and guidelines and standards of care for children with cerebral palsy and their families.

Methods:

This study is a qualitative exploratory study using grounded theory methodology, and is underpinned by a relativist approach and social constructivist viewpoint. The study design was selected based on the purposes and clinical context of the study, as well as my positioning as a health professional with a background in physiotherapy who has provided health care to children with cerebral palsy and their families. Participants were parents of children with cerebral palsy living in a regional area of Queensland, Australia, and were recruited using convenience and theoretical sampling. Data collection and analysis was conducted concurrently following the grounded theory method of constant comparative analysis. Two focus groups and eight in-depth interviews were conducted with eleven parents over a ten month period. Data was analysed using systematic grounded theory methods including coding, memoing, sorting and diagramming. A conceptual model was developed to explain parents' experiences. The final conceptual model was compared and contrasted with relevant literature, enabling identification of how the study findings contributed to current understandings of health care service delivery for children with cerebral palsy and their families.

Results:

Parents living in a regional Queensland area experience health care for their children with cerebral palsy as an constant but evolving process of "making the most of their body and their life". The core category of "making the most of their body and their life" is how parents' experience the overall purpose for health care in the life of their child and family. Key categories of the conceptual model that represent important aspects of care for parents of children with cerebral palsy include learning as you go, navigating the systems, meeting needs through partnership, being empowered or disempowered, and finding a balance. These categories resonate with and support key principals of current approaches to health care service delivery for this population including family centred care, the concept of a partnership between parents and their children's health care providers, and empowerment. However, the findings of the study also identify new understandings of parents' experiences of health care for their children with cerebral palsy. These understandings include the temporal nature of the needs of the child and family evolving over time, the concept of being empowered or disempowered through the interactive processes of health care, the importance of having a community or network of supports to receiving information and guidance, and the importance of the attitudes and values of health care workers and services to parents' experiences of their child's health care.

Conclusion:

Health care workers and services should take into consideration parents' experiences of health care for their children with cerebral palsy and the impact it has on them, their child and their families. Modifications to health care service delivery practices to better reflect parents' experiences of health care and important aspects of care, as well as the development of new models of care that incorporate the conceptual model developed from this study, could potentially assist in improving parental satisfaction with care for their children with cerebral palsy. Further research exploring children's experiences of health care, as well as comparison of experiences in different geographical areas, with different models of service delivery, and with health professionals and policy makers, is required to develop a broader theory around health care service delivery for children with cerebral palsy and their families.

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Abbreviations used in the thesis

CFCS	Communication Function Classification System
CP	Cerebral Palsy
GMFCS	Gross Motor Function Classification System
ICF	International Classification of Functioning, Disability and Health
MACS	Manual Ability Classification System for Children with Cerebral Palsy aged 4-18 years

Chapter 1 Introducing the thesis

1.1 Research background

Cerebral palsy (CP) is a complex neurodevelopmental disorder and is the most common cause of physical disability for children in Australia, affecting two in every 1000 children (Australian Cerebral Palsy Register, 2009; Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007). Although cerebral palsy is primarily a disorder of movement and posture, children with this diagnosis can also present with a variety of associated conditions that also affect their functional abilities and impact on their participation in life activities (Rosenbaum et al., 2007). As a result, children with cerebral palsy often require complex and co-ordinated multidisciplinary health care (Rosenbaum, 2003). The aim of health care services for this population is to achieve the best possible health, functional, participatory and quality of life outcomes for the child and family according to their specific needs (Rosenbaum, 2003).

My reason for completing this thesis evolved from my experiences as a health practitioner working as part of a health care team that aimed to develop a new health care service for children with cerebral palsy and their families in a regional Queensland area. As a physiotherapist who works with children and their families, I have become familiar with and subsequently support the principals of family centred care, an approach to health care service delivery which is based on the understanding of the important role that parents and families hold in the health care of their children with disabilities and chronic health conditions (King, Teplicky, King, & Rosenbaum, 2004; Law et al., 2003b). Recommendations according to the family centred approach include involving families in their child's health care, which includes making decisions about their child's health care needs and participating in the development and evaluation of services for their child (Law et al., 2003b). However, my experiences of working with this population also supports studies that have concluded that parents of children with cerebral palsy continue to be dissatisfied with their child's health care, despite the theoretical changes of health care workers aiming to deliver services that are more family centred (Darrah, Magill-Evans, & Adkins, 2002; Irochu-Omare, 2004; McKay & Hensey, 1990; Reid, Carlin, & Reddihough, 2011). Delivering health care to children with cerebral palsy can be challenging due to the wide variety of health issues, the subsequent number of health care services and individual health care workers involved in the care of each child, and the variety of interventions available for this population (Goldstein, 2004; Jones, Morgan, & Shelton, 2007; Murphy & Such-Neibar, 2003).When planning for our new health care service, I turned to the available guidelines and standards of care to seek guidance in how to best provide health care services to children with cerebral palsy in our region. These guidelines and standards of care include specific medical and health considerations for children with cerebral palsy at different ages or by body systems and have been developed to try and help health care workers and services to provide the comprehensive and co-ordinated care this population requires (Bakheit et al., 2001; Berker & Yalçin, 2010; Koops, Burdo-Hartman, & Dodge, 2008; Nickel & Desch, 2000; Ohio Department of Health, 1995; Seattle Children's Hospital, 2011; Wilson & Cooley, 2000). However, these guidelines and standards lack information as to how health care services should be delivered. Previous researchers have demonstrated that parental dissatisfaction with care is associated with the way in which services are delivered, rather than what types of services they receive (Carter, Cummings, & Cooper, 2007; Darrah et al., 2002; Milner, Bungay, Jellinek, & Hall, 1996; Reid et al., 2011). In addition, the guidelines and standards have been developed by medical and health care professionals, with limited or no consultation or contribution from parents of children with cerebral palsy. This contradicts the principle of family centred care that recommends that families should be involved in the development of health care services for their children. Parents' perceptions of their child's health care needs may differ from those of health professionals (Landsman, 2006). If the existing guidelines and standards for care do not reflect the needs of the child and the family due to the lack of parental input, this may be part of the reason why parents of children with cerebral palsy continue to be dissatisfied with their child's health care. Further searching of the literature identified that although previous researchers have investigated parents' satisfaction with care or experiences of raising a child with cerebral palsy (Darrah et al., 2002; Irochu-Omare, 2004; McKay & Hensey, 1990; Reid et al., 2011), no research has explored parents' experiences of health care for their child, including what aspects of care they think are important and how they want health care services to be delivered. The aim of this thesis is to address this gap in the literature.

1.2 Aims of the thesis

My aim for the study conducted for this thesis is to explore parents' experiences of health care for their child with cerebral palsy in a regional area of Queensland. My research questions are:

- How do parents living in a regional area of Queensland experience of health care for their children with cerebral palsy?
- What do parents think are important aspects of their child's health care?
- How do parents want their child's health care needs to be met?

From this exploration, I aim to develop an explanatory conceptual model of parents' experiences of health care for their children with cerebral palsy that may be used to inform future health care service delivery practices and guidelines and standards of care for this population. By doing so, this could potentially contribute to improved health care service delivery for families of children with cerebral palsy, and subsequently, to improved parental satisfaction with care in the regional area.

The scope of the study is limited to exploration and discovery of parents' experiences of health care for their children with cerebral palsy living in a regional area of Queensland. Additional research is required, as outlined at the end of this thesis, to further develop a broad understanding and theory regarding health care service delivery practices for this population.

1.3 Positioning the researcher

I am an experienced physiotherapist who has worked at a hospital in a regional health service area in the area of paediatrics since 2007. As a result, I bring unique professional and personal knowledge, experiences and insights to this study that need to be acknowledged and understood (Charmaz, 2006).

Physiotherapists are health care professionals who provide assessment, treatment and management for movement disorders that cause or occur as a result of injury, disease or disability (Australian Physiotherapy Association, 2014). Within the area of paediatrics, physiotherapists can work with families from birth through to adolescence and young adulthood. For clients with chronic health conditions such as cerebral palsy, physiotherapists aim to work collaboratively with children and their families throughout childhood to help to address their individual needs, particularly in relation to their mobility, functional ability, participation and quality of life (Burns & MacDonald, 1996). In addition, physiotherapists working in paediatrics adopt a forward thinking approach to the treatment of children with disabilities and chronic health care conditions (Burns & MacDonald, 1996; Campbell, Vander Linden, & Palisano, 2006). For example, physiotherapists may work with a child and their family to help the child to gain independence in moving about on the floor, but may also help the child to strengthen their legs and provide special orthotics for the purpose of helping the child to stand and possibly walk later in childhood. Using this approach, a physiotherapist collaborates with the child and the family to work towards both their short and long term goals, and to maximise outcomes for the child's and family's future functioning (Campbell et al., 2006).

Physiotherapists are central health care professionals involved in the care of children with cerebral palsy and their families (O'Shea, 2008; Papavasiliou, 2009). Physiotherapists are frequently involved in the management of the child's movement disorder through the provision of therapy programs and equipment to facilitate functional mobility, independence and participation (Lipson Aisen et al., 2011; Papavasiliou, 2009). Due to the hands on nature of their therapeutic interventions, physiotherapists can spend a lot of time working with children with cerebral palsy alongside their family members. My experience of this intense and prolonged engagement with clients is that it often allows me, as a physiotherapist, to develop a close relationship with families, and to subsequently develop an in-depth understanding of some of the challenges faced by the families of children with cerebral palsy. Physiotherapists providing services to children with cerebral palsy and their families often work as part of a larger multidisciplinary team, which may include occupational therapists, speech and language pathologists, paediatricians, social workers, teachers, and other medical, allied health and nursing staff (Msall & Park, 2008).

My professional experiences as a physiotherapist have consisted of providing inpatient and outpatient services to children with a wide variety of conditions. The paediatric physiotherapy caseload at the hospital consists of acute, sub-acute and chronic conditions; however, the majority of patients tend to have chronic health conditions or disabilities such as cystic fibrosis, cerebral palsy, or other developmental delays and disabilities. My responsibilities as a physiotherapist have also included participation in the development and evaluation of new models of health care for children and their families, advocating for individual patients and their families to access the most appropriate care according to their individual priorities, and supporting, mentoring and training rural therapists, private therapists, and junior physiotherapists. In addition, I have undertaken professional training in trans-disciplinary and family partnerships care approaches. Trans-disciplinary health care involves individual therapists working with children and their families across traditional disciplinary or professional boundaries (Rosen et al., 1998). This approach is useful when working with children with complex health care needs as less individual professionals are involved in the child's care, which is potentially less confusing for parents and families (Warner, 2001). In addition, a trans-disciplinary approach can also potentially facilitate a more holistic approach to care because one therapist can address needs across a number of different disciplines (Cartmill, Soklaridis, & David Cassidy, 2011; Rosen et al., 1998). A trans-disciplinary approach does, however, require therapists to be reflective of the care they provide and to acknowledge when the child's or family's needs are beyond their individual skill set (Cartmill et al., 2011). The family partnership approach is similarly useful when working with children with complex and chronic health conditions such as cerebral palsy. The family partnership approach is a model for helping parents, which is combined with specific self-reflection activities and training in advanced communication skills (Davis, Day, & Bidmead, 2002). Training in the family partnership approach aims to provide health professionals with the skills to develop supportive and respectful relationships with parents and to enable parents find ways to adapt to and manage problems on their own in the long term (Davis et al., 2002). My training in these two approaches have shaped my professional philosophy and approach to health care service delivery for children with complex and chronic health conditions such as cerebral palsy

As a result of my experiences and training as a physiotherapist, I have developed specific knowledge and viewpoints related to the theoretical positioning of this research. I consider that children with cerebral palsy and their families each have different needs to be met, and have different expectations of how health care services may assist in meeting these needs. I reason that these variations are related, at least in part, to the child's level of disability and the parents' and child's perception of what is important to them. I also consider that parents' and children's perceptions and expectations of health care services are influenced by their life experiences, their current life context, their previous experiences and interactions with health care services, as well as their experiences and interactions with other people who have accessed health care. Subsequently, I consider that all these factors contribute to how parents experience health care for their child, how they perceive what aspects of health care are important, and their expectations of what health care services for their child should ideally be like. My viewpoints are in line with the principals of the family centred care and family partnership approaches to health care service delivery. Parents know their child and their child's needs best, and health professionals cannot assume to know what the needs of different children and their families will be (Davis et al., 2002; Law et al., 2003b). The role of health care professionals and health care services is to help children and their parents to identify and address their individual needs, using a flexible and collaborative partnership approach (Davis et al., 2002; Rosenbaum, King, Law, King, & Evans, 1998).

1.4 Research design

I was guided by my research questions and the clinical context of the study to select a qualitative research design for the study, which includes a relativist approach (ontology), social constructivist viewpoint (epistemology) and grounded theory methodology. A relativist approach considers that individuals have different understandings of reality as a result of their different experiences and interpretations of these experiences (Annells, 1996; Corbin & Strauss, 2008; Guba & Lincoln, 1994). Relativism reflects my experience and viewpoint that children with cerebral palsy and their families have different needs to be met, and that parents of children with cerebral palsy have different expectations of how health care services may assist in meeting these needs. A social constructivist viewpoint considers that an individuals' understanding of their world and their reality is constructed through social interactions and social experiences (Charmaz, 2006; Creswell, 2007; Liamputtong, 2009). This viewpoint is consistent with my understanding that the process of giving or receiving health care is a sociological experience in which multiple social processes and interactions occur, and these processes and interactions contribute to how parents experience health care for their child with cerebral palsy. Researchers utilising a social constructivist viewpoint also consider that they are active participants in the research process and that the research results are constructed from the perceptions of the participants as well as the researcher's interactions with the participants and the research context itself (Birks & Mills, 2011; Charmaz, 2006; Guba & Lincoln, 1994). As a physiotherapist who has worked with children with cerebral palsy and their families, I am ideally positioned to identify meaning in the data, a hallmark of social constructivist viewpoint (Birks & Mills, 2011; Charmaz, 2006). Finally, grounded theory is a qualitative research methodology of systematic methods that is used to generate new understanding and develop theoretical models to explain how social phenomenon are experienced (Birks & Mills, 2011; Creswell, 2007; Liamputtong, 2009). I chose grounded theory for this study as it suited the aim to explore parents' experiences of health care, my viewpoint that the process of health care is a social experience involving multiple interactions, and the need for a study outcome in the form of a conceptual model that can be practically implemented into health care practices to potentially improve quality of care for this population (Birks & Mills, 2011).

1.5 Thesis structure

This is a thesis by publication, with some chapters or parts of chapters consisting of manuscripts submitted for publication in peer reviewed journals. These manuscripts have been edited where indicated for inclusion in the thesis, to remove redundancy and improve readability of the thesis as a whole. The thesis comprises of three sections, and is made up of eight chapters:

In Section One, which comprises of Chapters Two and Three, I present the relevant background information for understanding the clinical context for this study. In Chapter Two, I outline the nature of cerebral palsy as a health condition, the impact cerebral palsy has on children using the World Health Organization's International Classification of Functioning, Disability and Health framework (ICF), and the types of health care interventions available. In Chapter Three, I describe the methods and findings of a narrative review exploring the literature related to health care service delivery practices and guidelines and standards of care for children with cerebral palsy and their families. The findings of this narrative review allowed identification of gaps in the literature regarding parents' experiences of health care for their children with cerebral palsy, which formed the purpose of the study.

In Section Two, I present the study design and methods. In Chapter Four, I provide an in-depth discussion of the research questions and clinical context to justify my selection of a relativist research viewpoint (ontology), social constructivist approach (epistemology), and grounded theory methodology for the study exploring parents' experiences of health care for their children with cerebral palsy living in a regional area of Queensland. In Chapter Five, I follow with a detailed account of the research processes and methods including data collection using focus groups and individual in-depth interviews and data analysis using coding, memoing, sorting, diagramming, and comparisons with the literature.

Finally, in Section Three, which comprises Chapter Six, Chapter Seven and Chapter Eight, I present the study findings, discussions and conclusions. In Chapter Six, I detail the findings of the study, a conceptual model which explains parents' experiences of health care for their children with cerebral palsy in a regional Queensland area. In Chapter Seven, I discuss the findings and conceptual model in relation to relevant literature. Finally, in Chapter Eight, I conclude the thesis with a summary of the thesis and the main study findings, a discussion of the clinical implications, and an outline of the study limitations and recommendations for future research.

1.6 Style

The use of a social constructivist approach to grounded theory methodology requires that my presence as a researcher in the study be made transparent (Birks & Mills, 2011). Accordingly, I have used the first person voice in certain chapters of this thesis to indicate my presence in the study. These chapters include: Chapter 1: *Introducing the Thesis*, Chapter 4: *Justification of Research Approach, Viewpoint and Methodology*, Chapter 5: *Research Process and Methods*. I use third person voice in the remaining chapters - Chapter 2: *Background – Understanding Cerebral Palsy*, Chapter 3: *Background – Understanding the Gaps in the Literature: Delivering Health Care Services to Children with Cerebral Palsy and their Families*, Chapter 6: *Findings of the Grounded Theory Study - Parents' experiences of health care for their children with cerebral palsy in regional Queensland*, Chapter 7: *Discussion*, and Chapter 8: *Summary and Conclusions* - to remain consistent with the style used in scientific literature.

An important aspect of grounded theory methodology is that the voices of the participants are maintained throughout the research (Birks & Mills, 2011; Charmaz, 2006). Accordingly, within this thesis, I have incorporated participants' words into the presentation of the findings and conceptual model in Chapter 6. Excerpts of participants' interview transcripts are identified by appearing in quotation marks or by indented excerpts for longer citations. To enable readers to follow participant's stories, all quotes are tagged with the participant's number in brackets following each quote e.g. (Participant 5). In order to maintain participant confidentiality, the names of the participants, their children, other people, and place and service names have been removed and replaced by generic descriptions in brackets. For example, each child's name has been replaced by '(child)', other people's names have been replaced by a descriptor such as '(paediatrician)' or '(nurse)', and place and service names have been replaced by, for example '(metropolitan area)' or '(community service)'.

1.7 Research contribution

This study is the first identified study to explore parents' experiences of health care for their children with cerebral palsy. The findings provide empirical evidence to support key principals relating to current approaches to health care service delivery, which include family centred care, the concept of a partnership relationship between parents and their children's health care providers, and empowerment approaches (Cooley, 2004; King et al., 2004; Law et al., 2003b; Rosenbaum et al., 1998; Zimmerman & Warschausky, 1998). These principals and approaches have been developed based on reasoned theoretical assumptions, and the previous research relating to these approaches have used these theoretical assumptions as pre-determined frameworks to evaluate parents experiences of health care (Darrah, Wiart, Magill-Evans, Ray, & Andersen, 2010; dos Santos, Pavão, de Campos, & Rocha, 2012; Law et al., 2011; Msall & Park, 2008; Saleh et al., 2008; Trabacca et al., 2012). However, due to the inductive methodology used to conduct this study, the findings provide new empirical evidence to support these approaches. The findings of this study also support current understanding of issues related to health care service delivery for children with cerebral palsy and their families such as lack of information and guidance and the importance of consistency of care and developing partnerships with parents and families (Bellin, Osteen, Heffernan, Levy, & Snyder-Vogel, 2011; Cooley, 2004; Jeglinsky, Autti-Rämö, & Brogren Carlberg, 2011; Nuutila & Salanterä, 2006). However, the findings of this study also contribute to new understanding of how parents' experience health care for their child with cerebral palsy, which include the temporal nature of needs evolving over time, the concept of being empowered or disempowered through the interactive processes of health care, and the importance of having a community or network of supports and the attitudes and values of health care professionals and services.

The topic of this study is cross-disciplinary in nature, rather than being specific to any one discipline or health care service type. As a result, the findings are relevant to the various clinical practices of health professionals and health services providing care to children with cerebral palsy and their families. The findings of this study and the explanatory model may be used to inform future health care practices and guidelines and standards of care for this population, and potentially contribute to improved satisfaction with care for parents of children with cerebral palsy. The contribution to health care service delivery practices developed from this study may be considered to be timely given the introduction of new disability funding models in Australia that provide individualised funding packages and increased consumer choice in care (Department of Families, 2013; DisabilityCare Australia, 2013).

1.8 Chapter summary

Health care service delivery for children with cerebral palsy and their families is a complex process, and requires collaboration with parents and families to ensure the child's and families' individual needs are met (King et al., 2004; Rosenbaum, 2003). Understanding parents' experiences of health care for their children with cerebral palsy is important to ensure that the care and services provided meet parents' expectations and achieve satisfaction with care. My clinical experience supports the findings of studies that have concluded that parents of children with cerebral palsy continue to be dissatisfied with their child's health care (Darrah et al., 2002; Irochu-Omare, 2004; McKay & Hensey, 1990; Reid et al., 2011). Current guidelines and standards of care have been developed by health professionals without involvement of parents (Bakheit et al., 2001; Berker & Yalçin, 2010; Koops et al., 2008; Nickel & Desch, 2000; Ohio Department of Health, 1995; Seattle Children's Hospital, 2011; Wilson & Cooley, 2000). Parents' perceptions of their child's health care needs may differ from that of health professionals. No previous research has explored parents' experiences of health care for their child with cerebral palsy. Thus, the aim of this study is to address this gap in knowledge with a population of parents of children with cerebral palsy living in a regional area of Queensland, and to provide new understanding that may contribute to improved health care service delivery practices and satisfaction for care for this population.

Chapter 2 Background - Understanding cerebral palsy

2.1 Introduction

Cerebral palsy is a complex and variable condition, and its effect on children and families varies widely. This chapter provides an overview of the clinical picture of cerebral palsy, the impact it has on the child and the types of health care interventions available for children with cerebral palsy.

2.2 Understanding cerebral palsy

A recent definition of cerebral palsy states:

> Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems. (Rosenbaum et al., 2007, p. 9).

As indicated by this definition, the presentation of cerebral palsy can vary significantly in different children, depending on the part of the brain affected and the extent and timing of the injury (Paneth, 2008; Rosenbaum et al., 2007). In addition, the presentation of cerebral palsy can change over time as the child grows and develops (Rosenbaum et al., 2007).

A diagnosis of cerebral palsy is descriptive, and is based on clinical observation and examination (Murphy & Such-Neibar, 2003; O'Shea, 2008; Paneth, 2008). Diagnosis of cerebral palsy typically occurs following identification of a delay or inability to achieve motor milestones, or due to qualitative differences in movement patterns such as decreased repertoire of movements or asymmetry of movements (Bax, Tydeman, & Flodmark, 2006; Koman, Smith, & Shilt, 2004; Rosenbaum, 2003). The diagnosis of cerebral palsy requires a complete history, physical examination and any necessary investigations to determine the presence, location and extent of the brain injury or to identify or exclude potential causes of the injury (Bax et al., 2006; Koman et al., 2004; Paneth, 2008). The potential causes of cerebral palsy vary greatly. It has been postulated that the development of cerebral palsy may be multifactorial, and in 50% of cases the underlying cause of the child's cerebral palsy cannot always be clearly identified (Koman et al., 2004; Murphy & Such-Neibar, 2003). However, incidence of cerebral palsy has been associated with a number of antenatal, perinatal and postnatal factors. Antenatal factors that cause or increase the risk of cerebral palsy include congenital brain malformations, antenatal vascular events, maternal infection, and antepartum haemorrhage (Cans, De-la-Cruz, & Mermet, 2008; Koman et al., 2004; Murphy & Such-Neibar, 2003; Reddihough & Collins, 2003). Perinatal factors include premature delivery, very low birth weight, multiple births, chorioamnionitis, prolonged second stage of labour, and foetal anoxic events or birth asphyxia (Blair & Watson, 2006; Koman et al., 2004; Reddihough & Collins, 2003). Postnatal factors include untreated hyperbilirubinaemia, brain injuries due to force, asphyxia or infective processes, or cerebral vascular events due to congenital cardiac malformation (Blair & Watson, 2006; Kuban & Leviton, 1994; Reddihough & Collins, 2003). However, despite understanding of these risk factors, a diagnosis of cerebral palsy only confirms the presence of the condition and in some cases the aetiology, but has limited capacity to determine prognosis or potential outcomes (Rosenbaum et al., 2007).

2.3 Impact of cerebral palsy using the International Classification of Functioning, Disability and Health (ICF)

Since 2001, the International Classification of Functioning, Disability and Health (ICF) has been used as a standardised framework for describing and measuring health and disability in terms of its impact on human functioning (World Health Organization, 2007). The ICF framework considers an individual's functioning from multiple perspectives including body structures and functions, activities, participation, and environmental and personal factors. Body structures and functions reflect the medical or biological aspects of health; impairments are problems with body structures and functions. Activities include the tasks or actions an individual might do; activity limitations are difficulties the individual has with performing these activities or tasks. Participation is an individual's involvement in life situations and represents a social perspective of functioning; participation restrictions are limitations an individual experiences in life situations. Environmental factors and personal factors are recognised as contextual components that impact on an individual's functioning. The multidimensional interactions that occur between components of the ICF framework all impact on an individual's functioning, as presented in Figure 2.1 (World Health Organization, 2007).

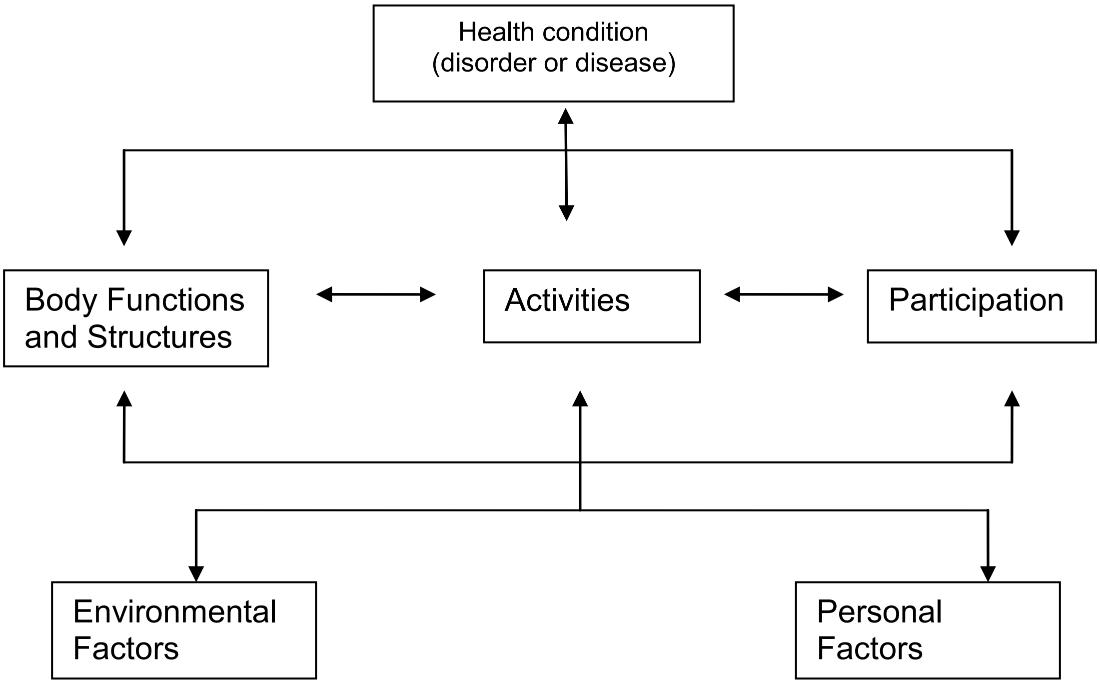


Figure 2.1 Framework demonstrating the multidimensional interactions between components of the ICF (World Health Organization, 2007).

The ICF is a holistic framework from which to consider the impact of cerebral palsy as a condition on children's functioning, which is explained in detail below.

2.3.1 Impact of cerebral palsy on body structures and functions

The primary impairment to body structures and functions in cerebral palsy occurs within the neurological system. An injury or insult to the developing brain causes an upper motor neuron lesion which subsequently causes spasticity, loss of sensation and loss of selective and co-ordinated motor control (Levitt, 2013). These primary neuro-motor impairments cause the characteristic motor types of spasticity, dyskinesia and ataxia that are observed in children with cerebral palsy (Levitt, 2013). The presentation of each of these motor types in children with cerebral palsy can vary greatly in severity, both between different motor types but also within each motor type. Many children with cerebral palsy may also present with mixed motor types, or primary and secondary motor types (Liptak & Accardo, 2004; Paneth, 2008; Rosenbaum et al., 2007). The description of the motor types and their prevalence in the Australian population are outlined in Table 2.1

Table 2.1

Types of motor disorders in cerebral palsy, and their prevalence in Australian children.

Motor type	Characteristics	Prevalence in Australian children*
Spasticity	Increased resistance to externally imposed movements, which increases as speed of movement increases and varies with direction of joint movement (Sanger, Delgado, Gaebler-Spira, Hallett, & Mink, 2003)	~85%
Dyskinesia **(Dystonia & Choreoathetosis)**	Sustained or intermittent involuntary muscle contractions; causes irregular movements and postures (Sanger et al., 2003)	1.5 – 3%
Ataxia	Loss or orderly muscle co-ordination causing abnormal accuracy, force and rhythm of movement (Cans, 2000)	2.8 – 4%

* (Howard et al., 2005; Rice, Russo, Halbert, Van Essen, & Haan, 2009)

The neuro-motor impairments of cerebral palsy can be further described according to the distribution of these impairments in the body. The most recent proposal for classification of motor impairment distribution is by presence of impairments on one (unilateral) or both sides of the body (bilateral) (Rosenbaum et al., 2007), combined with a count of the number of limbs involved (Love, 2007). Unilateral distribution of neuro-motor impairments includes the previously used classifications of hemiplegia (affecting both upper and lower limbs on one side of the body) and monoplegia (affecting only one limb). In Australia, 35-38% of children with cerebral palsy have unilateral distribution of neuro- motor impairments (Australian Cerebral Palsy Register, 2009; Howard et al., 2005; Rice et al., 2009). Bilateral distribution of neuro-motor impairments includes the previous classifications of diplegia (lower limbs more affected than the upper limbs) and quadriplegia (all four limbs affected, although the severity of impairment may vary between limbs). Typically, children who have dyskinetic or ataxic motor types have bilateral involvement affecting all four limbs. Bilateral distribution occurs in approximately 60-65% of all children with cerebral palsy (Australian Cerebral Palsy Register, 2009; Howard et al., 2005; Rice et al., 2009).

Along with primary neuro-motor impairments, children with cerebral palsy also present with a large and variable number of associated conditions or secondary impairments. Associated conditions occur as an accompaniment to the primary brain injury or malformation. Associated conditions that commonly present in children with cerebral palsy include epilepsy (~30% of children with cerebral palsy), severe intellectual impairment (~30%), and visual impairment (~10-40%) (Cans et al., 2008; Jones et al., 2007). Secondary impairments occur as a complication of the primary neuro-motor impairments, and can include:

- Musculoskeletal impairments such as loss of muscle strength, loss of muscle length or contracture, and joint deformities such as scoliosis and subluxation, particularly of the hips (Jones et al., 2007; Koman et al., 2004; Murphy & Such-Neibar, 2003; Quinby & Abraham, 2005);
- Oro-motor and swallowing difficulties and their subsequent impact on the child's nutrition and growth (Jones et al., 2007; Murphy & Such-Neibar, 2003; Pruitt & Tsai, 2009; Singhi, 2004);
- Gastrointestinal problems such as gastrointestinal reflux, constipation and motility issues (Jones et al., 2007; Pruitt & Tsai, 2009; Singhi, 2004);
- Cardiorespiratory conditions such as pneumonias due to aspiration or acquired infections, and cardiorespiratory compromise due to severe scoliosis or airway obstruction (Jones et al., 2007; Pruitt & Tsai, 2009);
- Genitourinary dysfunction including incontinence of the bladder and/ or bowel (Murphy & Such-Neibar, 2003; Pruitt & Tsai, 2009);
- Cognitive impairments (Liptak & Accardo, 2004; Pruitt & Tsai, 2009), and;
- Psychological impairments (Parkes & McCusker, 2008; Straub & Obrzut, 2009).

For some children with cerebral palsy, the associated conditions and secondary impairments can be more burdensome to their health and well-being than the primary neuro-motor impairments (Dickinson et al., 2007; Shelly et al., 2008; Shevell, 2010). The definition of cerebral palsy cited at the beginning of this chapter acknowledges the importance of associated conditions and secondary impairments to the overall health, well-being and functioning of the child with cerebral palsy (Rosenbaum et al., 2007).

2.3.2 Impact of cerebral palsy on activities

Performance of functional activities in daily life can vary significantly between different children with cerebral palsy. This is due to the variability of the presence and severity of impairments and the influence of environmental and personal factors such as accessibility to equipment and services and child motivation (Chiarello et al., 2012). As a result of the variability in functional abilities across the population of children with cerebral palsy, a number of classification systems have been developed to define the variety of abilities across gross motor, fine motor and communication activities. These classification systems are described below in order to illustrate the potential variation in requirements for health care and the subsequent variations of experiences of children with cerebral palsy and their families, an important understanding for the clinical context of this study.

The most widely used functional classification system for cerebral palsy is the Gross Motor Function Classification System (GMFCS) (Palisano, Rosenbaum, Bartlett, & Livingston, 2007). The GMFCS comprises five levels (I-V) of gross motor function that correlate to five distinct pathways or predicted trajectories of gross motor function across childhood and adolescence. The expected gross motor abilities of children with cerebral palsy are described for each level at different ages from infancy to 18 years of age (0-2 years; 2-4 years; 4-6 years; 6-12 years; 12-18 years). The focus of the classification levels is on the child's ability to perform the gross motor skills of sitting and walking, in their own environments, and considers the amount of support they require for these tasks. For example, in Table 2.2, the different levels of gross motor functional ability for each level of the GMFCS for a child aged 6-12 years old are outlined. The distribution of gross motor skills according to the five levels of the GMFCS across the population of children with cerebral palsy in Victoria and South Australia is also illustrated in Table 2.2 (Howard et al., 2005; Rice et al., 2009).

Table 2.2

Variability of gross motor function according to the Gross Motor Function Classification System (GMFCS) across two populations of children with cerebral palsy in Australia (Howard et al., 2005; Palisano et al., 2007; Rice et al., 2009).

GMFCS level	**Description of gross motor functional ability (aged 6-12 years)**	**Distribution in Victorian CP population (%)** (Howard et al., 2005)	**Distribution in South Australian CP population (%)** (Rice et al., 2009)
I	Walks unaided without any limitations in all environments, but has some difficulty with high level gross motor tasks such as running and jumping.	35%	50.6%
II	Walks unaided, but experiences limitations walking on uneven surfaces, in crowds or in confined spaces. At best may have only minimal ability to run or jump.	16%	18.2%
III	Walks with assistive mobility devices on level surfaces, but requires the use of a wheelchair for long distances or outdoors on uneven surfaces	14%	9.3%
IV	May walk short distances only with assistive devices and assistance or supervision. May achieve self-mobility using a power-wheelchair. Requires a wheelchair for all outdoor and community mobility.	16%	9.7%
V	Self-mobility is severely limited, even with the use of assistive technology. Have significant difficulty maintaining upright postures against gravity.	18%	12.1%

Children with cerebral palsy may also experience difficulties in fine motor or manual hand function if the distribution of their neuro-motor impairments affects their upper limbs.

The variability in fine motor function for children with cerebral palsy is illustrated by the Manual Ability Classification System for Children with Cerebral Palsy 4-18 years (MACS) (see Table 2.3) (Eliasson et al., 2006). Similar to the format of the GMFCS, the MACS uses five levels to classify a child's ability to handle objects in daily activities, and aims to describe the child's usual performance of manual tasks in the home, school and community environments.

Table 2.3

Variability of manual ability or fine motor function for children with cerebral palsy according to the Manual Ability Classification System (MACS).(Eliasson et al., 2006)

MACS level	Description of child's ability to handle objects in daily activities
I	Handles objects easily and successfully.
II	Handles most objects but with somewhat reduced quality and/or speed of achievement.
III	Handles objects with difficulty; needs help to prepare and/or modify activities.
IV	Handles a limited selection of easily managed objects in adapted situations.
V	Does not handle objects and has severely limited ability to perform even simple actions.

The combination of a child's gross and fine motor functional abilities contributes to their overall ability to achieve independence in self-care activities such as bathing, dressing, grooming, eating and toileting (Ketelaar, Gorter, Westers, Hanna, & Verhoef, 2014; Öhrvall, Eliasson, Löwing, Ödman, & Krumlinde-Sundholm, 2010; Phipps & Roberts, 2012; Wong et al., 2004). One study has demonstrated that more than half of all children with cerebral palsy achieve independence in self-care tasks either alone or with only supervision from their caregivers (Wong et al., 2004). Many children from GMFCS Levels I and II achieve independence in self-care activities, although this is achieved at a later age than typically developing children (Öhrvall et al., 2010). However, children with higher GMFCS and MACS levels are less likely to achieve independence in self-care activities (Ketelaar et al., 2014; Klingels et al., 2012; Öhrvall et al., 2010; Phipps & Roberts, 2012). A child's lack of independence in self-care activities results in an increased need for caregiver assistance for activities in everyday life (Phipps & Roberts, 2012).

Finally, children with cerebral palsy may also have difficulties in the activities of feeding and communication, which can occur as a result of sensory, cognitive and/ or motor impairments. Approximately 20% of all children with cerebral palsy have difficulties with feeding, such as difficulties swallowing, chewing and excessive drooling, which is associated with the child's gross motor function and degree of intellectual impairment (Parkes, Hill, Platt, & Donnelly, 2010). Speech, language and communication limitations are also present in 45-63% of children and adolescents with cerebral palsy (Australian Cerebral Palsy Register, 2009; Cans, 2000; Cockerill et al., 2014). Communication ability is associated with cognitive level, gross motor function, manual ability, and current epilepsy (Cockerill et al., 2014; Himmelmann, Lindh, & Cooley Hidecker, 2013; Parkes et al., 2010). In addition, children with bilateral spastic or dyskinetic motor types of cerebral palsy are more likely to have communication difficulties (Himmelmann et al., 2013). Similar to the GMFCS and the MACS, the Communication Function Classification System (CFCS) illustrates and classifies the variations in communication abilities in everyday life for children with cerebral palsy (Hidecker et al., 2011) (see Table 2.4).

Table 2.4

Variability of communication function for children with cerebral palsy according to the Communication Function Classification System (CFCS) (Hidecker et al., 2011).

CFCS level	Description of child's ability to communicate effectively with a partner in everyday life
I	Sends and receives with familiar and unfamiliar partners effectively and efficiently
II	Sends and receives with familiar and unfamiliar partners but may need extra time
III	Sends and receives with familiar partners effectively, but not with unfamiliar partners
IV	Inconsistently sends and/ or receives, even with familiar partners
V	Seldom effectively sends and receives, even with familiar partners

2.3.3 Impact of cerebral palsy on participation

Children with cerebral palsy participate at various levels in a diverse range of life situations (Imms, Reilly, Carlin, & Dodd, 2008), which can include school or education activities, family, peer-group and community activities, and personal recreation and leisure activities. However, children with cerebral palsy tend to experience greater restrictions in participation than their peers without disabilities (Imms et al., 2008; Michelsen et al., 2009). Children with cerebral palsy predominantly participate in informal and less active physical activities than other children without disability (Imms et al., 2008; Shikako-Thomas et al., 2013). In addition, children with cerebral palsy more frequently participate in activities with family members or on their own, and activities in their own home or in a relative's house rather than in the community, compared to children without disabilities (Imms et al., 2008).

The severity of a child's activity limitations impacts on their level of participation; however, the relationship between activity limitations and participation restrictions is not yet clearly understood. Studies have demonstrated that children with higher gross motor function (GMFCS levels I and II) demonstrate higher levels of intensity and less restrictions to participation when compared with children with lower gross motor function (GMFCS Levels III-V) (Beckung & Hargberg, 2002; Chiarello et al., 2012; Imms et al., 2008; Michelsen et al., 2009). In contrast, another study demonstrated that a child's manual or fine motor ability had more impact on participation levels than their gross motor ability (Imms, Reilly, Carlin, & Dodd, 2009). Nevertheless, children with severe activity limitations do experience high levels of participation (Imms et al., 2008).

2.4 Health care for children with cerebral palsy

The aim of health care interventions for children with cerebral palsy is to help the child to achieve the best possible health, functional, participatory and quality of life outcomes according to their specific needs (Rosenbaum, 2003). Medical care for children with cerebral palsy includes monitoring aspects of the child's health and disability, as well as interventions and medications to help manage the various impairments or issues experienced by children with cerebral palsy, such as spasticity, epilepsy, pain, sleep disturbances, behavioural difficulties, malnutrition and wound care (Koman et al., 2004; Murphy & Such-Neibar, 2003; Papavasiliou, 2009; Pruitt & Tsai, 2009; Quinby & Abraham, 2005; Singhi, 2004). Surgical care often consists of orthopaedic interventions to prevent or correct musculoskeletal impairment or secondary conditions, and sometimes includes neurological interventions to manage spasticity or epilepsy, or gastro-intestinal surgery to supplement or replace oral feeding methods or to prevent gastro-oesophageal reflux and aspiration (Koman et al., 2004; Murphy & Such-Neibar, 2003; Quinby & Abraham, 2005). Therapy interventions for children with cerebral palsy can consist of therapy from different health care disciplines, such as physiotherapy, occupational therapy and speech and language therapy, or specific therapy approaches such as Bobath or neuro-developmental therapy or Vojta therapy (Koman et al., 2004; Murphy & Such-Neibar, 2003; O'Shea, 2008; Papavasiliou, 2009; Singhi, 2004). In addition, children with cerebral palsy may also require health care services to help access supportive equipment such as orthotics and braces, mobility aides, and/ or daily living aides which can address impairments, or enhance activity and or participation (Papavasiliou, 2009; Singhi, 2004). However, despite the wide range of health care interventions available and used in the clinical care of children with cerebral palsy, not all of these interventions are supported by strong scientific evidence (Liptak & Accardo, 2004; Murphy & Such-Neibar, 2003; Novak et al., 2013; O'Shea, 2008; Papavasiliou, 2009). As a result, decisions about which health care intervention should be used in the care of an individual child, at times, rely on the parent's or clinician's preferences (Landsman, 2006).

Due to the variations in impairments, activity limitations and participation restrictions experienced by different children with cerebral palsy, the type and focus of health care that each child receives can vary significantly. The delivery of health care services to this population, therefore, requires careful consideration of the individual needs and perspectives of each child and their family when evaluating and making decisions about important aspects of care (Landsman, 2006). Over the past two decades, health care service delivery practices for children with or at high risk of cerebral palsy have changed from a child-focused, professionally driven approach towards a family focused, collaborative approach (Dirks & Hadders-Algra, 2011). However, despite these changes, dissatisfaction with care is an ongoing problem for parents of children with cerebral palsy (Darrah et al., 2002; Irochu-Omare, 2004; McKay & Hensey, 1990; Reid et al., 2011). Parental dissatisfaction with care has been shown to be associated with organisational and interactive aspects of health care service delivery, rather than specific types of services or interventions (Darrah et al., 2002; McKay & Hensey, 1990). Therefore, it is important for clinicians to understand which approaches to health care service delivery for this population are supported in the literature and how these should be applied in clinical practice. This will be explored in Chapter Three.

2.5 Chapter summary

Cerebral palsy is a complex neurodevelopmental condition that causes impairments of movement and posture, and is the leading cause of physical disability in Australian Children. The impact of cerebral palsy on children and their families can vary significantly due to the variability of presentation, which includes primary and secondary impairments, activity limitations and participation restrictions. The types and focus of health care services for children with cerebral palsy vary according to the needs of the child and family. Health care services for children with cerebral palsy aim to achieve the best possible health, functional, participatory and quality of life outcomes. Dissatisfaction with care is an ongoing problem for parents of children with cerebral palsy, and has been shown to be associated with aspects of health care service delivery, rather than type of intervention. Approaches to health care service delivery and how these should be applied in clinical practice are explored in the next chapter.

Chapter 3 Background – Understanding the gaps in the literature: Delivering health care services to children with cerebral palsy and their families

3.1 Introduction

This chapter consists of a narrative review of literature related to health care service delivery for children with cerebral palsy and their families. The aim of this narrative review is to: (1) identify and review the evidence for current approaches to health care service delivery for children with cerebral palsy and their families, and; (2) identify current guidelines and standards of care for children with cerebral palsy that may be used in clinical practice, and evaluate these in terms of the current approaches to health care service delivery. The findings of this review provide the theoretical context and justification for the study into parents' experiences of health care for their children with cerebral palsy conducted for this thesis.

This chapter is adapted, with minor alterations to ensure consistency and to remove redundancy, from:

Hayles, E., Jones, A., Harvey, D., Plummer, D., & Ruston, S. (2014). *Delivering health care services to children with cerebral palsy and their families: A narrative review*. Health and Social Care in the Community. (In press)

3.2 Methods

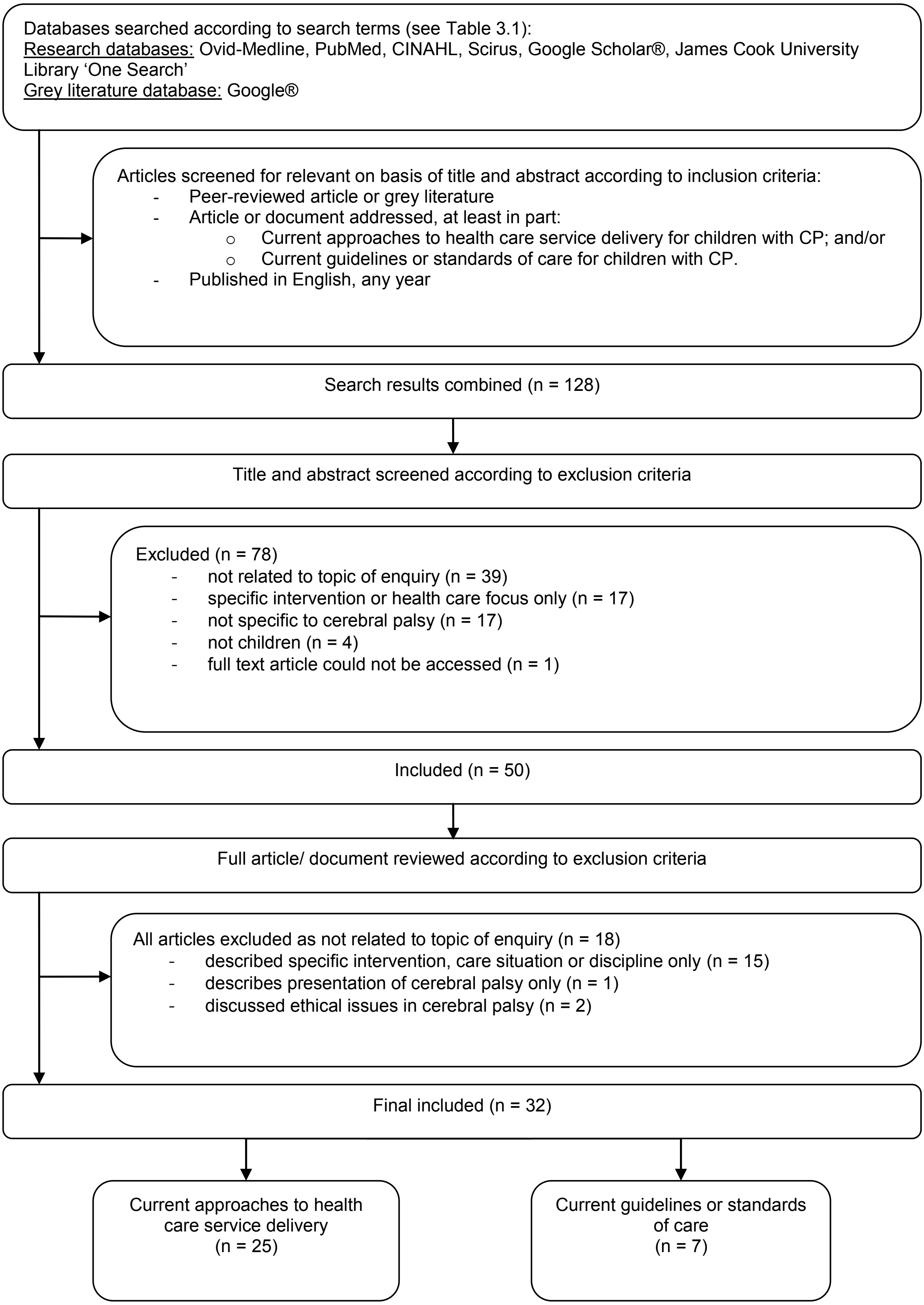
The aim of this review was to synthesise the thematic information and associated evidence relating to current approaches to health care service delivery for children with cerebral palsy and their families. Narrative style reviews are conducted to provide a broad overview and summary of the literature relating to a specific topic (Green, Johnson & Adams, 2001) and therefore suited the purposes of this review. Figure 3.1 illustrates the literature search process followed for this narrative review. Author one conducted all searching, screening, assessment for eligibility and document analysis. Databases including Ovid-Medline, PubMed, CINAHL, Scirus, Google Scholar®, and James Cook University Library 'One Search' were searched between December 2011 and February 2012, and updated in September 2013, to identify literature related to approaches to health care service delivery for children with cerebral palsy. The Google® search engine was also used to identify guidelines or standards of care for children with cerebral palsy available as grey literature. The PICO search strategy, which is used to search and identify literature focused on the key aspects of the topic of interest (Population; Phenomenon or intervention of interest; Comparison; and, Outcomes of interest)

(Pope, Mays & Popay, 2007), was used to develop literature search terms. Search terms included ‘paediatric’, ‘pediatric’, ‘child’, ‘children’, ‘cerebral palsy’, ‘intervention’, ‘care’, ‘health care’, ‘services’, ‘health services’, ‘recommendation’, ‘standard’, ‘guideline’, ‘practice guideline’(see Table 3.1). No year limits were applied to searches. Author one developed broad inclusion criteria, and screened the search results by title and abstract for relevance. Articles and documents were included for further review if they were a published peer-reviewed scientific article or a guideline or standard of care document published as grey literature, and the article or document addressed, at least in part, current approaches to health care service delivery for children with cerebral palsy and/ or were a current guideline or standard of care for children with cerebral palsy (see Figure 3.1).

Table 3.1

Search terms for narrative review using PICO criteria

Population	Phenomenon of interest	Comparison	Outcomes of interest
Children age 0-16 with cerebral palsy	Different philosophies & approaches to health care service delivery	Comparison of philosophies & approaches to health care service delivery	Parental views & experiences Professional perspectives Impacts on patient outcomes
a) ‘paediatric’ ‘pediatric’ ‘child’ ‘children’ (combined as ‘or’) AND b) ‘cerebral palsy’	AND ‘intervention’ ‘care’ ‘health care’ ‘services’ ‘health services’ ‘recommendation’ ‘standard’ ‘guideline’ ‘practice guideline’ (combined as ‘or’)	N/A	N/A



Databases searched according to search terms (see Table 3.1):
Research databases: Ovid-Medline, PubMed, CINAHL, Scirus, Google Scholar®, James Cook University Library 'One Search'
Grey literature database: Google®

Articles screened for relevant on basis of title and abstract according to inclusion criteria:

- Peer-reviewed article or grey literature
- Article or document addressed, at least in part:
  - Current approaches to health care service delivery for children with CP; and/or
  - Current guidelines or standards of care for children with CP.
- Published in English, any year

Search results combined (n = 128)

Title and abstract screened according to exclusion criteria

Excluded (n = 78)

- not related to topic of enquiry (n = 39)
- specific intervention or health care focus only (n = 17)
- not specific to cerebral palsy (n = 17)
- not children (n = 4)
- full text article could not be accessed (n = 1)

Included (n = 50)

Full article/ document reviewed according to exclusion criteria

All articles excluded as not related to topic of enquiry (n = 18)

- described specific intervention, care situation or discipline only (n = 15)
- describes presentation of cerebral palsy only (n = 1)
- discussed ethical issues in cerebral palsy (n = 2)

Final included (n = 32)

Current approaches to health care service delivery (n = 25)

Current guidelines or standards of care (n = 7)

Figure 3.1 Literature search process for narrative review that aimed to identify and review evidence for health care service delivery practices for children with cerebral palsy and their families.

One hundred and twenty-eight articles or documents were identified through initial searching, and their abstracts were read and assessed according to exclusion criteria (as listed in Figure 3.1). Literature reporting only on the care of adults or young people aged 16 or older were excluded from this review as adult services often use different approaches to health care service delivery. Literature describing health care approaches or practices for children with developmental disability or chronic health conditions but not specific to cerebral palsy (defined by less than 50% of the study population having cerebral palsy) were also excluded. For the guidelines and standards of care, only those that were specific to children with cerebral palsy were included for analysis.

Fifty documents were identified through abstract scanning, and underwent a full text review. During this full text review, 18 documents were excluded as they were not related to the topic of enquiry, which was not previously apparent during abstract scanning. The final 32 included articles or documents were read in detail and reviewed in two stages. Firstly, the content of each article relating to approaches to health care service delivery was thematically reviewed in terms of the main focus of the article and the results or arguments made, as well as critiqued in terms appropriateness of the methodology and methods used. The content of the included articles were then compared and contrasted. Recurrent themes, concepts, and relationships between individual articles were identified and collated to critically summarise the evidence for approaches to health care service delivery for children with cerebral palsy. Secondly, the identified guidelines and standards of care for children with cerebral palsy were reviewed and analysed. The purpose, structure, content and methodology for development of each guideline were reviewed. The content was then examined and compared in terms of the incorporation of the identified approaches to health care service delivery.

3.3 Results

Appendix 2 provides a summary of included articles and documents. Of the 32 articles and documents, 25 related to approaches to health care service delivery and seven were guidelines or standards of care. Eleven articles related to community based services, whereas only four articles related to care based at a hospital, with only one specifically related to inpatient care. Only five of the 32 documents could not be identified as peer-reviewed; these documents were guidelines of care for children with cerebral palsy (Berker & Yalçin, 2010; Koops et al., 2008; Ohio Department of Health, 1995; Seattle Children's Hospital, 2011; Wilson & Cooley, 2000).

The findings of this narrative review are presented according to the two aims, in sections below: (1) current approaches to health care service delivery; and (2) guidelines or standards of care for children with cerebral palsy.

3.3.1 Approaches to health care service delivery

Current approaches to health care service delivery for children with cerebral palsy identified in this review are: family centred care, the World Health Organization's International Classification of Functioning, Disability and Health (ICF), and collaborative community-based primary care.

3.3.1.1 Family centred care

Family centred care is a well-established approach to health care service delivery for children with cerebral palsy and their families (King et al., 2004). Numerous terms are used to describe family centred care within the literature, including family centred care, family centred service and family centred practice. This review will use the term family centred care.

3.3.1.1.1 Philosophical principals. Family centred care focuses on family strengths and promotes mutual respect and information sharing between families and health care providers (King et al., 2004). Family centred care recognises and respects that parents know their child and their child's needs best, and parents hold primary responsibility for identification and prioritisation of their child's health care needs (King et al., 2004). Health care providers work in a collaborative partnership with families, involve the family in the development and evaluation of services for their child, and provide flexible services to meet the specific needs of each family (King et al., 2004). By delivering services in this way, family centred care aims to enable and empower parents in the health care management of their child (King et al., 2004). Over the past two decades, principals of family centred care have been incorporated into therapy programs for children with or at high risk of cerebral palsy (Dirks & Hadders-Algra, 2011).

3.3.1.1.2 Outcomes related to this approach. Delivery of care that is family centred has been associated with positive outcomes for children with cerebral palsy and their parents and families in both hospital (Jeglinsky et al., 2011) and community based care settings (Morgan & Tan, 2010). For children, family centred care has been associated with improved health and development and better psychosocial adjustment and functioning (King et al., 2004). For parents, family centred care has been associated with improved emotional and psychological well-being and improved sense of personal confidence and competence (King, King, Rosenbaum, & Goffin, 1999; King et al., 2004). Parents who perceive that services are more family centred are more likely to have higher satisfaction with services (King et al., 2004; Ziviani, Darlington, Feeney, & Head, 2011).

3.3.1.1.3 Evidence of application in clinical practice. Although the principals and benefits of family centred care are well described, the literature reviewed also demonstrates that clinical practice does not always reflect these principals. Provision of information and education was rated poorly by parents of children with cerebral palsy when evaluating health services that aim to provide family centred care (Jeglinsky et al., 2011). Providing information to parents can increase their hope and assist them to set realistic goals and expectations for their child with cerebral palsy (Lindstrand, Brodin, & Lind, 2002). Lack of information or knowledge causes parents to feel unprepared, vulnerable and stressed (Iversen, Graue, & Clare, 2009).

Collaborative partnerships and shared decision making are also demonstrated to be lacking in health care service delivery for children with cerebral palsy. Variations between parents' and therapists' perceptions of the focus of therapy suggest that communication between therapists and parents may be inadequate (LaForme Fiss, McCoy, Chiarello, & Move & PLAY Study Team, 2012). Practitioners, parents and children have reported that they consider their role in making decisions about care as minimal, and that the other members of the partnership have greater responsibility for this task (Young, Klaber Moffett, Jackson, & McNulty, 2006). Children, in particular, have variable involvement in making decisions about their own health care and are often unequal participants in the doctor-parent-child relationship (Garth, Murphy, & Reddihough, 2009). In addition, program guidelines that reflect the principals of family centred care are lacking. Only 26 of 59 children's rehabilitation programs in Alberta, Canada had mission statements that reflect the principals of family centred care and only 11 had parent representation on their advisory boards (Darrah et al., 2010). In a similar evaluation of five rehabilitation programs in the Netherlands, no practical guidelines or protocols were available to assist rehabilitation professionals to implement family centred care (Nijhuis et al., 2007).

3.3.1.1.4 Evaluation of research methodologies. Both qualitative and quantitative methods were used in the literature to investigate family centred care. Quantitative data collection methods used included questionnaires (Karande, Patil, & Kulkarni, 2008; King et al., 1999; LaForme Fiss et al., 2012; Ziviani et al., 2011) and two variations of the tool the Measure of Process of Care (MPOC); one for parents and families (MPOC-20) and one for service providers (MPOC-SP) (Darrah et al., 2010; Jeglinsky et al., 2011; King et al., 1999; Ziviani et al., 2011). The MPOC is an evaluation tool designed to measure the extent to which a service or health professional demonstrates behaviours that are family centred (Jeglinsky et al., 2011). Questionnaires and the MPOC allow quantification and comparison of parent and service provider's perceptions of family centred care. However, these tools use pre-determined criteria based on the theoretical principals of family centred care to evaluate this approach to care, and therefore provide limited opportunity for exploration of relationships between different aspects of care and how that impacts parents' experiences. One study identified in this review explored the relationships between different aspects of family centred care and the well-being of parents of children with cerebral palsy (King et al., 1999). However, this study used pre-determined parameters so other issues not considered by the researchers could not be explored. In comparison, qualitative studies identified in this review provided more opportunity for exploration of perceptions of family centred care using focus groups or individual interviews with children, parents or service providers. Although the perceptions of family centred care in clinical practice were frequently investigated in the literature identified, no studies investigated how the principals of family centred care should be implemented into clinical practice. This lack of research into best practice implementation of family centred care makes it difficult for health care providers to know which behaviours or strategies ensure that the care delivered is perceived as family centred.

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

The World Health Organization's International Classification of Functioning, Disability and Health (ICF) is the second approach to health care service delivery for children with cerebral palsy identified in the literature.

3.3.1.2.1 Philosophical principals. The ICF is a framework that considers the multidimensional interactions between an individual's health, functioning, participation and the social and environmental context of their life (World Health Organization, 2007).The ICF can be utilised to guide health care service delivery for children with cerebral palsy, supporting health professionals to provide services at any level of the ICF, all of which may be beneficial their patients or clients (dos Santos et al., 2012; Msall & Park, 2008). For example, services for a school-aged child with cerebral palsy who is having difficulty walking may be directed towards changing the impairment (e.g. muscle strength), the task or activity (e.g. using a walking aid), the child's participation (e.g. providing alternative inclusive activities for a physical education program), or the environment (e.g. organising suitable environmental access at school), depending on how that problem is impacting the child's life. Each of these interventions has merit and can positively influence the child's well-being and functional ability.

3.3.1.2.2 Outcomes related to this approach. Delivery of care following the ICF framework has demonstrated benefits for children with cerebral palsy and their families. Use of the ICF to guide clinical assessment and treatment of a 12 year old boy with cerebral palsy enabled his health care team to deliver interventions that were specific to the child's needs and resulted in meaningful improvements for the child and his family (Trabacca et al., 2012). Furthermore, one recent randomised controlled trial has demonstrated that therapy aimed at changing only the activity or environment was equally as effective as therapy that aimed to improve the child's impairments and performance of tasks (Law et al., 2011). Therapists have reported challenges when providing therapy in this way as it contrasts with the focus of their professional training (Darrah et al., 2011). However, this trial provides evidence to support the delivery of health care interventions for children with cerebral palsy and their families which are directed only at the activity and environment level of the ICF.

3.3.1.2.3 Evidence of application in clinical practice. Although the ICF has been promoted as an approach to health care service delivery for people with disabilities, it appears that clinicians still tend to adopt a biomedical approach, which focuses primarily on the physical processes of disease and disability without consideration of the social determinants of health (Yuill, Crinson & Duncan, 2010), when working with children with cerebral palsy and their families. A study reviewing occupational therapy and physiotherapy practices for young children with cerebral palsy in Canada demonstrated that the majority of interventions described by therapists were aimed at the impairment and activity, and few focused on aspects of participation such as play and socialisation (Saleh et al., 2008). In another similar study, goals identified by occupational therapists and physiotherapists for case scenarios of children with cerebral palsy focused primarily on improving the activity (61%) and the impairment (24%), which was in contrast to the children's parents, whose goals for their child were predominantly related to social participation (Darrah et al., 2010). In other studies, parents have rated activities and participation for their child as their highest need (Buran, Sawin, Grayson, & Criss, 2009; LaForme Fiss et al., 2012) and specifically commented on the importance of participation and the social environment (Reid et al., 2011).

3.3.1.2.4 Evaluation of research methodologies. Six of the ten articles relating to this approach used the ICF as a pre-determined framework to evaluate clinical practices (Darrah et al., 2010; dos Santos et al., 2012; Law et al., 2011; Msall & Park, 2008; Saleh et al., 2008; Trabacca et al., 2012). Only two articles did not have the ICF framework as part of the original research design (Buran et al., 2009; Reid et al., 2011). The limited research using inductive methods to support this approach to health care service delivery for children with cerebral palsy and their families could result in false assumptions about the applicability of this approach for this population. However, a number of included articles supported the use of the ICF as a framework for health care service delivery for children with cerebral palsy and their families (Buran et al., 2009; Darrah et al., 2010; LaForme Fiss et al., 2012; Trabacca et al., 2012), including one randomised controlled trial (Law et al., 2011).

Information regarding how the ICF should be implemented in clinical practice was lacking in the literature identified in this review. Although a number of articles evaluated clinicians' performance of health care tasks such as goal setting (Darrah et al., 2010; LaForme Fiss et al., 2012; Saleh et al., 2008), only one article described how the ICF could be implemented into clinical practice (Darrah et al., 2011). The lack of evidence about how to apply the ICF in clinical practice might be part of the reason why implementation into clinical practices remains poor.

3.3.1.3 Collaborative, community-based primary care.

Although only four articles were identified from the literature search, collaborative community-based primary care is the third approach to health care service delivery for children with cerebral palsy identified in this review (Cooley, 2004; Lipson Aisen et al., 2011; Liptak, Murphy, & Disabilities, 2011; Reid et al., 2011).

3.3.1.3.1Philosophical principals.

Collaborative, community-based primary care is also described in the literature as the 'medical home' and to some extent aligns with the principals of family centred care (Liptak et al., 2011). The community-based primary care approach advocates for all primary and preventative health care services for the child and their family to be delivered in the community by a general or specialist physician in collaboration with other health service providers (Cooley, 2004; Liptak et al., 2011). All services are co-ordinated and aim to meet the needs of the child and the family.

3.3.1.3.2 Outcomes related to this approach.

Parents of children with cerebral palsy have identified that collaborative care provided in the community contributes to more positive experiences with health care services and helps parents to cope (Reid et al., 2011).

3.3.1.3.3 Evaluation of research methodologies.

The lack of research investigating collaborative community-based primary care limits the strength of evidence for this approach to health care service delivery for children with cerebral palsy. Of the included articles relating to collaborative community-based primary care, only one was empirical research (Reid et al, 2011); the other three articles were clinical reports (Cooley, 2004; Liptak, Murphy & Council on Children with Disabilities, 2011; Lipson Aisen et al, 2011). Further research investigating the impact of collaborative community-based primary care on children with cerebral palsy and their families is required.

3.3.2 Guidelines or standards of care for children with cerebral palsy

Seven guidelines or standards of care for children with cerebral palsy and their families were identified from the literature search (Bakheit et al., 2001; Berker & Yalçin, 2010; Koops et al., 2008; Nickel & Desch, 2000; Ohio Department of Health, 1995; Seattle Children's Hospital, 2011; Wilson & Cooley, 2000). These consisted of three guidelines or standards developed by an individual hospital or state department of health in the USA (Koops et al., 2008; Ohio Department of Health, 1995; Seattle Children's Hospital, 2011), one guideline published by a humanitarian organisation (Berker & Yalçin 2010), two reference documents published within physician reference books (Nickel & Desch, 2000; Wilson & Cooley, 2000) and one peer-reviewed journal article (Bakheit et al., 2001). Each guideline or standard of care provides both general and specific information for the care of children with cerebral palsy, with the information organised by age group (Nickel & Desch, 2000; Seattle Children's Hospital, 2011; Wilson & Cooley, 2000), body system (Koops et al., 2008) or potential presenting problems (Bakheit et al., 2001; Berker & Yalçin, 2010; Ohio Department of Health, 1995).

3.3.2.1 Reflection of current approaches to health care service delivery

The content of the guidelines or standards of care identified in this review generally reflected a biomedical model with only limited incorporation of the current approaches to health care service delivery. The health care issues and interventions outlined in each of these documents primarily focuses on the child's physiological impairments and functional achievements, with less focus on participation needs. Three of the guidelines or standards of care do promote participation in life situations for adolescents and young adults, such as involvement in social, recreational and leisure activities (Nickel & Desch, 2000; Ohio Department of Health, 1995; Seattle Children's Hospital, 2011), but none consider this need for the younger child. Only two guidelines or standards of care recommended a community-based primary care approach (Ohio Department of Health, 1995; Seattle Children's Hospital, 2011). The needs of the family are considered in each of the guidelines or standards of care, but the extent to which the family is incorporated into the child's care varies greatly. Five of the guidelines or standards of care provided descriptions or checklists of the potential needs of the family (Berker & Yalçin, 2010; Nickel & Desch, 2000; Ohio Department of Health, 1995; Seattle Children's Hospital, 2011; Wilson & Cooley, 2000). However, only three made specific mention of family participation in decision making and development of treatment plans (Bakheit et al., 2001; Ohio Department of Health, 1995; Seattle Children's Hospital, 2011). As far as can be identified, only one guideline or standard of care included consultation with parents during its development (Seattle Children's Hospital, 2011). No other guideline or standard of care included parents or children in their development, which is in contrast to the principals of family centred care.

3.3.2.2 Evaluation of methodologies

The methodological processes followed for the development of the guidelines and standards of care were difficult to evaluate. Only one document described the process of developing standards of care by a multidisciplinary group of practitioners based on clinical experience and published scientific evidence (Bakheit et al., 2001). However, the extent and level of scientific evidence used to justify each of the recommendations was not provided in this published version of the document. Three of the seven guidelines and standards of care were identified as peer-reviewed, being published in reference books or a scientific journal (Bakheit et al., 2001; Nickel & Desch, 2000; Wilson & Cooley, 2000). However, few references, if any, are listed for each of the documents. Four of the guidelines and standards appear to have been developed or reviewed by panels of medical or multidisciplinary experts (Berker & Yalçin, 2010; Koops et al., 2008; Ohio Department of Health, 1995; Seattle Children's Hospital, 2011). However, the processes of development of these guidelines or standards of care are not clearly described. The lack of information regarding process of development and level of scientific evidence limits the clinicians' understanding of the relevance of each guideline or standard to their clinical practice.

3.4 Discussion

The current approaches to health care service delivery for children with cerebral palsy and their families identified in this narrative review are family centred care, care delivered according to the World Health Organization's International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2007), and collaborative community-based primary care. These approaches have demonstrated benefits for children with cerebral palsy, and their parents and families. However, when compared with the literature on current clinical practices and parents' experiences, this review demonstrates that care inconsistently reflects these approaches and inconsistently meets the needs of children with cerebral palsy and their families. Despite the emergence of these approaches as central tenets for health care of children with disabilities globally, their influence on changing clinical practices appear to be slower and improvements to health care service delivery practices for children with cerebral palsy and their families are still required. Areas for improvement include: provision of information to parents; working in a collaborative partnership; and providing health care services across all levels of the ICF, particularly for participation and the social environment. These issues with health care service delivery are the same issues that contribute to parents' dissatisfaction with their child's care as identified in previous research (Darrah et al., 2002; Irochu-Omare, 2004; McKay & Hensey, 1990; Reid et al., 2011).

One potential contributor to the gap between theory and practice is the limited research on how these approaches to health care service delivery should be applied in clinical practice. This lack of research may also explain why the guidelines and standards of care for children with cerebral palsy and their families identified in this review have limited incorporation of the approaches to health care service delivery and limited description of how services should be delivered. Other discipline specific treatment guidelines for children with cerebral palsy that did not fit the focus of this review also lack guidance on the approach to health care service delivery to be used in clinical practice (see e.g. Andrew, Parr, & Sullivan, 2012; Pennington, Goldbart, & Marshall, 2011). This would suggest that the theoretical approaches to health care service delivery are not filtering down into clinical practices for children with cerebral palsy and their families. Previous researchers have demonstrated that parents' dissatisfaction with health care services is associated with the way in which health care services are delivered, rather than what services are provided (Darrah et al., 2002; Irochu-Omare, 2004; McKay & Hensey, 1990; Reid et al., 2011). The lack of guidance about how services should be delivered is a notable omission within the available guidelines or standards of cares. In addition, almost all the guidelines and standards of care identified in this review appear to have been developed by health care professionals without consultation or collaboration with children with cerebral palsy and their parents, which is in contrast to the principals of family centred care. Parents' perceptions of their child's health care needs may differ from those of health professionals. Furthermore, children's perceptions of their own health care needs may also differ from that of their parents and of health professionals. Without input of children with cerebral palsy and their parents, the current guidelines or standards of care may not adequately reflect the actual needs of this population. If the existing guidelines or standards of care for children with cerebral palsy do not describe how to deliver health care services according to the current approaches and do not reflect the needs of the child and family due to the lack of child and parental input, then this may be part of the reason why parents of children with cerebral palsy continue to be dissatisfied with their child's health care.

3.4.1 Limitations of the narrative review

The limitations of this narrative review need to be taken into consideration when interpreting the findings. Firstly, the literature searching process, particularly with regards to the guidelines and standards of care, was not exhaustive. For example, leading researchers, practitioners, or health care organisations were not contacted for information available outside the search databases. In addition, this narrative review does not identify whether there is any additional literature or guidelines or standards of care available in languages other than English, causing a potential language bias. However, despite these limitations, the literature searching process for this narrative review enabled the collation of a comprehensive data set that reflects current understandings and was sufficient for the purposes of this review. Secondly, although the quality of the included evidence was reviewed, the quality of the evidence did not preclude inclusion for review and was not evaluated using objective criteria as would occur in a systematic review. This may impact on the robustness of the interpretation of the evidence presented. Finally, the assumption of what constitutes a 'family' is somewhat stereotypical within the context of this review which may limit the applicability of the findings across alternative family configurations.

3.4.2 Identifying the gaps in the literature

The understandings identified from this narrative review can be used to identify gaps in the literature relating to health care service delivery approaches and practices for children with cerebral palsy that require further research. Over half of the literature identified in this review regarding approaches to health care service delivery related to family centred care (15 articles), with less evidence being available on the ICF (10 articles) and collaborative community-based primary care (four articles). Further research is required to strengthen the evidence base for these two approaches for children with cerebral palsy and their families. Additionally, only one article specifically described approaches for acute inpatient health care situations (Iversen et al., 2009). Although services for children with cerebral palsy and their families are often based in the community, many children with cerebral palsy will require admission to hospital and inpatient care for issues such as respiratory infections, orthopaedic procedures or acute seizure management (Jones et al., 2007). These hospital admissions can be highly stressful for the children with cerebral palsy and their parents (Phua, Reid, Walstab, & Reddihough, 2005). Further research into approaches to care for acute health care situations is required. The findings of this narrative review have also identified a limited integration of current approaches to health care service delivery for children with cerebral palsy into clinical practices and guidelines and standards of care for this population. In addition, parents have had limited involvement in the development of the guidelines and standards of care for their children with cerebral palsy. Future research is required to explore parents' experiences of health care for their children with cerebral palsy in order to address this gap in knowledge.

3.5 Chapter summary

Approaches to health care service delivery for children with cerebral palsy and their families include family centred care, care delivered according to the International Classification of Functioning, Disability and Health, and collaborative, community-based primary care. However, health care services for this population are inconsistently delivered according to these approaches. Current guidelines and standards of care for children with cerebral palsy have limited incorporation of the current approaches to care, and have been developed without input of children and families to determine their health care needs. No previous research has explored parents' experiences of health care for their children with cerebral palsy. This is the gap in the literature that is explored and addressed in this thesis.

Chapter 4 Justification of research design using a relativist approach, social constructivist viewpoint and grounded theory methodology

4.1 Introduction

As outlined in the previous chapters, cerebral palsy is a complex condition and its impact on children and families can vary. As a result, parents' experiences of health care for their children with cerebral palsy can also vary. Understanding patient and carer experiences of health care are important for delivering improvements in quality and outcomes of health care services (see Abelson, Miller, & Giacomini, 2009; Chow, Mayer, Darzi, & Athanasiou, 2009; Prakash, 2010; Williams, 1998). Research investigating patients' experiences of health care often focuses on evaluation of important aspects of care as understood from the health professional viewpoint, such as access to services, health professional communication styles, unmet needs and satisfaction with care (Garwick, Kohrman, Wolman, & Blum, 1998; Liptak et al., 2006; McKay & Hensey, 1990; Phua et al., 2005). However, patients' and carers' understanding of important aspects of health care can differ from that of health professionals. The current approach to investigating the health care experiences from the health professional viewpoint limits the exploration of the viewpoint of patients and their families.

The purpose of this study was to explore parents' experiences of health care for their children with cerebral palsy, and to develop a conceptual model that explains variations in parents' experiences and can be incorporated into clinical practice. In this chapter, I detail the theoretical aspects of the research questions and clinical context to justify my study design, which used grounded theory methodology. The various approaches to grounded theory are discussed to provide explanation and justification for my use of a relativist approach and social constructivist viewpoint to grounded theory methodology.

This chapter has been adapted with alterations to ensure consistency and remove redundancy, from:

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4.2 Exploring the research questions and clinical context that guided the study design

Choosing a research approach, viewpoint and methodology that fits the background, clinical context and aims of a research study is an important process of research design that ensures methodological rigour (Maggs-Rapport, 2001). Methodological rigour is one method used to evaluate qualitative research, and relates to the credibility of a study which incorporates how well the chosen methodology fits the aims of the research, as well as how appropriate the methodology is applied given the research context and theoretical background (Liamputtong, 2009; Maggs-Rapport, 2001). My choice of research design for this study, including the theoretical approach, viewpoint and methodology, was guided by the key theoretical aspects of the study, which included:

- The complexity and variability of the experiences of health care for children with cerebral palsy and their families;
- My dual role as a clinician and researcher;
- The cross-disciplinary nature of the study aims;
- The lack of previous research available and the need to generate new information, and;
- The need for the study outcome of an explanatory model to be useful in clinical practice to affect quality improvement in health care for children with cerebral palsy and their families.

4.2.1 Complexity and variability of the experiences of health care for children with cerebral palsy and their families

The process of delivering health care to children with cerebral palsy and their families involves a complex and variable interactive process between the child, the parent, the family and the health care providers. Parents' experiences of health care for their children with cerebral palsy in my study will vary due to the variability of the nature and severity of the child's cerebral palsy, but also due to the variability in the type and amount of supports and services available in different parts of the regional area. The regional health service for the study encompasses both regional and rural geographical areas. Children with cerebral palsy and their parents living close to the regional town have access to local specialist paediatric services. In contrast, those who live in more rural areas of the region do not have access to local paediatric specialist services, and might have utilised videoconferencing or travelled long distances to attend specialist paediatric appointments. In addition, cerebral palsy is a lifelong condition and the focus of health care and the relative importance of different aspects of health care can change over time. The heterogeneity of needs and parents' subsequent experiences of health care, both between cases and within cases across childhood and across the regional area, indicated that the study design needed to be able to capture and explore these variations in parents' experiences.

4.2.2 My dual role as clinician and researcher

My previous experience as a physiotherapist and my continued involvement in the clinical care of children with cerebral palsy and their families required the selection of a study design that suited this dual role. My experience as a physiotherapist has contributed to me developing both personal and professional viewpoints about health care services for children with cerebral palsy and their families, as outlined in Chapter One. My viewpoints and familiarity with the area of enquiry were both a strength and a liability for the quality of the research conduct and study outcomes. While my professional experience provides me with unique access, insights and sensitivity to underlying issues for families of children with cerebral palsy, they also had the potential to unduly influence the interpretations I made during the course of data analysis. Of key importance to this study was the aim to capture parents' experiences of health care for their children with cerebral palsy, not health professional perspectives. Therefore, my choice of study design needed to manage my preconceptions about the study topic and enable me to take a fresh look at the issues from the vantage point of parents of children with cerebral palsy. By doing so, the credibility and trustworthiness of my study outcomes would be maintained.

4.2.3 Cross-disciplinary nature of the study aims

The aim to explore parents' experiences of health care for their children with cerebral palsy required a holistic, cross-disciplinary research approach, rather than following the approach of any specific health discipline or type of health care service. In addition, the choice of methodology and data collection methods needed to ensure the parents of children with cerebral palsy were able to openly discuss their experiences and their understandings of important aspects of health care from their viewpoint, without influence of any current approach to care or disciplinary principals of care. By adopting an open-ended approach to the exploration of parents' experiences, the study outcomes could therefore also be widely applicable across different disciplines, health care services, and service settings within the regional area.

4.2.4 Limited availability of previous research & need to generate new information and understanding

The topic of enquiry for my study had limited previous literature available to guide the study design. No previous research has explored parents' experiences of health care for their child with cerebral palsy. As a result, the choice of research design needed allow the generation of new information in order to address the gap in the literature. This purpose guided my selection of an inductive qualitative research methodology that could discover parents' experiences of the process of health care.

4.2.5 Outcomes of the study needed to have potential to affect quality improvement in health care

The purpose for my study developed from a clinical context that aimed to improve service delivery and care for children with cerebral palsy and their families. As a result, the outcomes derived from the study needed to be useful and applicable in this clinical context in order to inform improvements in health care service delivery practices. I had identified that the study outcome of an explanatory model was required to enable explanation of the variability of parents' experiences of health care. However, to ensure that this clinically useful study outcome was delivered, I needed to choose a research methodology that could facilitate the development of an explanatory model and, therefore, meet the purpose of affecting improvements in health care for this population (Becker, 1993).

4.3 Choosing a study design

My choice of research design, including the research methodology, and coinciding approach and viewpoint, were guided by the key theoretical aspects of the study described above.

4.3.1 Choosing grounded theory methodology

Grounded theory is a qualitative research methodology that has increasingly been used for research that investigates patients' experiences of health and health care (Artinian, 1998; Charmaz, 2006; Corbin & Strauss, 2007; Glaser & Strauss, 1967; McCann & Clark, 2003; Mullen, 2006). Grounded theory had three key methodological principals that suited the purposes and clinical context of my study investigating parents' experiences of health care for their children with cerebral palsy:

1. Grounded theory methodology is exploratory in nature, and facilitates discovery of new understandings of social phenomena and experiences (Birks & Mills, 2011; Charmaz, 2006; Corbin & Strauss, 2008; Cutcliffe, 2000; Glaser & Strauss, 1967);

2. Grounded theory aims to develop explanatory theories or models (Birks & Mills, 2011; Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967);

3. The outcomes of research using grounded theory methodology are 'grounded' in the data and attempt to reflect the participants' viewpoints as closely as possible (Birks &

Mills, 2011; Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967; Mills, Bonner & Francis, 2006).

The congruence of these key principals with the clinical context and purposes of my study exploring parents' experiences of health care for their children with cerebral palsy are explained in detail below.

4.3.1.1 Grounded theory methodology is exploratory in nature, and facilitates discovery of new information and understandings of social phenomena or experiences

Grounded theory methodology suits research that aims to develop new knowledge and understanding of poorly understood social phenomena (Cutcliffe, 2000). In the field of health care, grounded theory particularly suits research that aims to explore complex and socially interactive aspects of health care, such as patients' experiences of health and health care, how social and organisational processes contribute to patients' experiences, and how variations in patients' experiences occur (McCaffery, 2003). This principle of grounded theory methodology fits two important purposes of my study. First, I have identified a lack of research into parents' experiences of health care for their children with cerebral palsy which requires exploration and discovery of new information. Second, the process of health care for children with cerebral palsy and their families is a complex, multi-dimensional and changing interaction that occurs between the child, the parent, the health care professional, the health care service and the larger governing health care organisation. Consequently, grounded theory methodology fits the purpose of the study to explore parents' experiences of health care for their child, which encompasses a complex socially interactive phenomenon.

4.3.1.2 Grounded theory aims to develop explanatory theories or models

The aim of research using grounded theory methodology is to develop theories or models which explain how a social situation occurs in a variety of situations. The theories developed using grounded theory methodology can be considered either formal theories or substantive theories, depending on the scope and purposes of the study (Birks & Mills, 2011). Formal theories provide a conceptually abstract understanding of a generic phenomenon, such as the formation of identity, which can be applied across multiple contexts (Birks & Mills, 2011; Charmaz, 2006). In comparison, substantive theories, which can also be described as 'everyday' explanatory models, provide understanding of a specific experience in a specific area or context (Birks & Mills, 2011; Charmaz, 2006; Corbin & Strauss, 2008). The development of these substantive theories in the form of explanatory models is particularly useful for health care research that aims to deliver practical outcomes that can improve patients and carers experiences of health care (Becker, 1993). For this study, the development of an explanatory model provides predictive explanations for how parents' experience health care for their child, and their perceptions of important aspects of care. Grounded theory, therefore, is a methodology that can meet the purpose of the study of a practically useful study outcome that can potentially contribute to improved quality of and satisfaction with care for this population.

4.3.1.3 The outcomes of research using grounded theory methodology are 'grounded' in the data and attempt to reflect the participants' viewpoints as closely as possible

Capturing parents' viewpoints of their experiences of health care for their children with cerebral palsy is an essential aim of this study. Grounded theory methodology achieves grounding of the research outcomes in participants' 'raw' data through the key method of constant comparative analysis (Birks & Mills, 2011; Glaser & Strauss, 1967). Following the constant comparative method, data collection and analysis occur concurrently - new data is analysed, checked and compared with old data, as well as the codes, categories and theories that are developing through ongoing analysis (Birks & Mills, 2011; Glaser & Strauss, 1967). The process of constant comparative analysis facilitates a continuous cycle of adaptation and remodelling of the emerging theory or model according to the participants' 'raw' data, and therefore helps to ensure that the study outcomes closely reflect parents' viewpoints (Glaser & Strauss, 1967; Mills, Bonner, & Francis, 2006).

4.3.2 Choosing a relativist approach and social constructivist viewpoint to grounded theory

Although it was evident that grounded theory methodology suited the purposes of my research study, a number of different approaches to grounded theory exist (Hunter et al, 2011; Mills, Bonner & Francis, 2006), so it was important that I also identified an approach and viewpoint to grounded theory that was congruent with the context of my research study. The different approaches to grounded theory methodology reflect variations the underlying assumptions the researcher has about the nature of reality (ontology), what can be learnt about that reality through research (epistemology), and the nature of the relationship between the researcher and participants (Heath & Cowley, 2004; Hunter et al, 2011; Mills, Bonner & Francis, 2006). These assumptions, affect the way a grounded theory study is designed and conducted, and therefore needed to be considered when planning my research study. The three key approaches to grounded theory methodology to be considered were the classic or Glaserian approach (Glaser, 1978; Glaser, 2002), the divergent approach of Corbin & Strauss (Corbin & Strauss, 2008), and the social constructivist approach developed by Charmaz (2006).

Classic grounded theory originated with the work of Glaser and Strauss (1967), and has been promoted by Glaser, who remains the major proponent for this approach, as the theoretically pure form of grounded theory (1978, 2002). The theoretical assumptions of classic grounded theory can be considered to be underpinned by a positivist ontology (Birks & Mills, 2011; Bryant, 2003; Charmaz, 2006; Cooney, 2010), which considers that there is one truth or understanding that can be known about reality, and that reality exists separate to the people that experience that reality (Denzin & Lincoln, 2005). This understanding contrasted with my professional experiences and viewpoint that children with cerebral palsy and their families each have different needs to be met and therefore have different experiences of health care. In addition, when following the classic approach to grounded theory, the researcher, their experiences and understandings of the social phenomenon, as well as previous literature relating to the social phenomenon, exist separately from the data and should not influence the data analysis so as to avoid 'forcing the data' (Glaser, 1978). I considered that this assumption overlooked the unique insights that my clinical experiences as a physiotherapist could provide to the understanding of the emerging analysis. In addition, maintenance of this assumption would also be difficult to theoretically uphold given my dual role as both a clinician and researcher. As a result, the classic approach to grounded theory methodology was not congruent with the clinical context and purposes of my research.

In contrast with the ontology of classic grounded theory, the divergent approach of Corbin & Strauss (2008) and the social constructionist approach of Charmaz (2006) are underpinned by relativism. Relativism as an ontology considers that a single objective reality cannot be known, but that individuals have different views and perspectives of reality and truth which are created through their experiences and individual interpretations of these experiences (Annells, 1996; Corbin & Strauss, 2008; Guba & Lincoln, 1994). This understanding was congruent with my understanding of the variations of parents' needs and experiences of health care for their child with cerebral palsy. In addition, the aim of my study was to explore the parents' experiences, in all their variations. Consequently, a relativist approach suited the purposes and context of my study.

Complementary to a relativist approach was a constructivist viewpoint or epistemology. A constructivist viewpoint considers that each individual's understandings of their reality are constructed through social interactions and experiences (Charmaz, 2006; Creswell, 2009; Liamputtong, 2009). My clinical experiences had led me to consider that parents' experiences of health care for their child are shaped by their interactions with health care workers and services, which was congruent with the constructivist viewpoint. Both Corbin & Strauss (2008) and Charmaz's approaches to grounded theory methodology utilise a constructivist viewpoint, and so could be used in my research study. However, the two approaches differed significantly in the application of methods during data collection and analysis. Corbin & Strauss' divergent approach to grounded theory details specific strategies and techniques of deduction and verification to be applied during data analysis (Corbin & Strauss, 2008). While their approach provides clearer guidelines for the process of data analysis, this approach has been criticised as being too focused on the technical procedures of analysis, with Melia (1996) claiming that 'the technical tail is beginning to wag the theoretical dog' (p. 376). In addition, the strategies and techniques appeared complicated and were overwhelming as a novice researcher. In contrast, Charmaz's social constructivist approach to grounded theory (Charmaz, 2006) presented a more flexible process that focuses on gathering rich data and immersion in the data, and enables collaboration between the researcher and participants. This approach resonated with my purpose of focusing on understanding experiences of health care from the perspectives of the parents. In addition, when using Charmaz's social constructivist approach, researchers consider themselves as active participants in the research process and that new understandings and research outcomes are constructed from participants' perspectives as shared and interpreted with the researcher during the research process (Birks & Mills, 2011; Charmaz, 2006). This viewpoint suited my dual role as both a health professional and researcher.

4.4 Chapter summary

The design for my study exploring parents' experiences of health care for their children with cerebral palsy comprises a relativist approach, a social constructivist viewpoint, and grounded theory methodology. These aspects of the study design suit key theoretical aspects of the study purpose and clinical context which includes the complexity and variability of the experiences of health care for children with cerebral palsy and their families, my dual role as a clinician and researcher, the cross disciplinary nature of the study aims, the lack of previous research and the subsequent need to generate new information, and the need for a study outcome of an explanatory model that can be incorporated into clinical practice. My demonstration of the congruence of the purposes and clinical context with the study design enhances the methodological credibility of the study (Maggs-Rapport, 2001).

Chapter 5 Research methods and results

5.1 Introduction

In the previous chapter, I discussed how the clinical and theoretical context of the study guided my selection of grounded theory methodology using a relativist approach and a social constructivist viewpoint for the study design. This chapter adds to the previous chapter by outlining the research processes and methods for the grounded theory study that aimed to explore parents' experiences of health care for their children with cerebral palsy living in a regional Queensland area. The study setting and participants are described, as well as the processes of concurrent data collection and analysis using the constant comparative method (Birks & Mills, 2011). Data was collected using focus groups and interviews. Participants were recruited using convenience and theoretical sampling strategies. Data was analysed using the methods of coding and memoing. A conceptual model that explains parents' experiences of health care for their child with cerebral palsy was then constructed using the methods of sorting of codes, writing a storyline, and diagramming. Finally, the process for assessing the plausibility of the conceptual model and the quality and rigor of the study is discussed.

5.2 Study setting

This study was conducted in a regional area on the east coast of Australia. The regional area includes a regional city and surrounding rural towns and remote areas. Health services for this region include a regional referral hospital, eight rural hospitals or community health centres, and a limited number of other government and private community based health services. All paediatric specific services in the regional area are located in the regional city, with very limited access to paediatric specific services in the rural towns. Families living in rural towns or remote areas may have to travel up to four hours to access paediatric care in the regional town and hospital. In addition to the local services, various specialist doctors and their teams from tertiary hospitals and state-wide health care programs provide outreach services to patients from the regional hospital. The nearest specialist paediatric tertiary hospital is located approximately 1000 kilometres away. Children requiring specialist paediatric care or interventions are often required to travel this distance to access the specialist care they require.

5.3 Processes of data collection and analysis

In line with grounded theory methodology, data collection and analysis was conducted concurrently following the method of constant comparative analysis (Birks & Mills, 2011; Charmaz, 2006). Using the constant comparative analysis, new data is compared with old data and the developing analysis, providing a rigorous means of ensuring that the theory developed during analysis is grounded in the raw data (Birks & Mills, 2011; Liamputtong, 2009).

5.3.1 Data collection

Interviewing is a core method used to generate data in grounded theory research (Liamputtong, 2009; McCaffery, 2003). Interviews allow the researcher to elicit in-depth discussion and exploration of participants' experiences and perspectives (Birks & Mills, 2011; Hunt, Chan & Mehta, 2011; McCaffery, 2003), which was an important purpose for my study. Interviews can be conducted with an individual participant, or with a group of participants as a focus group which enables the researcher to utilise group interactions to stimulate conversation and examine variations in participants' experiences and perspectives in order to generate rich data (Birks & Mills, 2011; McCaffery, 2003). Over a ten month period, from September 2012 through to July 2013, I conducted two focus groups and eight individual in-depth interviews. A timeline of my data collection process is provided in Table 5.1. The focus groups were conducted early in the data collection process in order to generate rich information from which to commence data analysis. The focus groups were also conducted at two different sites, one in the regional town and the other at a rural hospital, to sample for variations in access to paediatric services and subsequent differences in parents' experiences. The individual in-depth interviews were conducted with eight participants, either in person at the regional hospital or by telephone.

Table 5.1

Timeline of data collection process

Date	Interview/ Focus Group	Number of Participants	Method
24.09.12	Focus Group (Regional city)	3	Face to face
26.09.12	Interview	1	Face to face
26.11.12	Interview	1	Telephone
01.02.13	Focus Group (Rural town)	2	Face to face
11.02.13	Interview	1	Telephone
15.04.13	Interview	1	Telephone
17.06.13	Interview	1	Face to face
24.06.13	Interview	1	Telephone
11.07.13	Interview	1	Face to face
11.07.13	Interview	1	Face to face
Total participants = 13			

5.3.1.1 Participants, recruitment and sampling

Participants for the study were parents of children with a diagnosis of cerebral palsy aged less than 17 years old and who resided in the regional area. Parents of children aged over 17 years were excluded from participation as this is the age that children in the regional area commence transition from paediatric to adult service providers, which have a different approach to health care service delivery. Descriptive information about the parent participants is provided in Table 5.2.

Parents were notified of the study through participant flyers (Appendix 3). Participant flyers were posted in relevant health care services, such as the hospital clinic and community service waiting rooms, distributed through administration staff or other health professionals who provide services to families of children with cerebral palsy, and included in regular mail correspondence to parents from health professionals such as with appointment letters. Parents made voluntary contact with me to express their interest in participating. At the time of initial contact with the potential participant, I explained the study in detail and provided the parents with a participant information sheet (Appendix 4). I kept a log of participant details, which included contact details, their preference for participation in a focus group or individual interview, and any preferred day or time for attending their focus group or interview. Parents gave written consent for participation at the time of their focus group or interview (Appendices 5 and 6). All parents who expressed interest in participating were recruited to the study.

Participants were recruited using non-probability sampling strategies to recruit, as best as possible, participants who could provide rich information for the study, from a variety of backgrounds and contexts and with a wide variety of experiences (Birks & Mills, 2011; Charmaz, 2006; Cutcliffe, 2000). Table 5.2 outlines the strategies followed for participant sampling. Initially, I recruited participants using convenience and purposive sampling (Liamputtong, 2009), which enabled me to collect rich information from which I could then commence the process of data analysis (Cutcliffe, 2000). Theoretical sampling is a key method in grounded theory methodology that allows the researcher to identify and pursue clues that arise during analysis (Birks & Mills, 2011; Charmaz, 2006; Liamputtong, 2009). Following this method, as the numbers of potential participants grew and once I had identified emerging concepts from my initial data collection and analysis, I used theoretical sampling for the final six participants based on variations in their backgrounds or experiences, to further explore and test the emerging concepts and my understandings of the developing analysis.

Table 5.2

Descriptive details of parents sampled for the study, and their child with CP

Participant number	**Mother/ Father**	**Residential location (regional/ rural)**	**Child with CP**		**Family structure**	**Sampling method**	**Purpose of sampling**
			GMFCS level (I-V) ***(Palisano et al, 2007)***	**Associated conditions/ impairments**			
1	Mother	Regional	IV	Epilepsy	Mother, father, 2 children	Convenience	Rich information/ Geographical variations in access to paediatric services
2	Father	Regional	-	-	As above	Convenience	Rich information/ Geographical variations in access to paediatric services
3	Mother	Regional	I	Nil	Mother, father, 3 children	Convenience	Rich information/ Geographical variations in access to paediatric services
4	Mother	Regional	III	Epilepsy; cognitive impairment	Mother, stepfather, 2 children	Purposive	Rich information
5	Mother	Rural	V	Epilepsy; cognitive impairment; visual impairment	Mother, father, 2 children	Purposive	Rich information
6	Mother	Rural	II	Nil	Mother, father, 5 children	Theoretical	Geographical variations in access to paediatric services
7	Mother	Rural	II	Epilepsy;	Mother, father	Theoretical	Geographical variations in

				cognitive impairment	2 children		access to paediatric services
8	Father	Regional	I	Hydrocephalus	Mother, father, 2 children	Theoretical	Has received consistent care
9	Mother	Regional	II	Nil	Mother, father, 2 children	Theoretical	Only child; shared care between tertiary outreach service and local service
10	Mother	Regional	IV	Epilepsy; cognitive impairment	Mother, father, 1 child	Theoretical	Older child
11	Mother	Rural	II	Nil	Mother, father, 2 children	Theoretical	Previous experiences from large metropolitan city
12	Mother	Regional	V	Epilepsy; cognitive impairment; visual impairment	Mother, father, 2 children	Theoretical	Younger child
13	Mother	Regional	V	Epilepsy; cognitive impairment; visual impairment	Mother, father, 1 child	Theoretical	Complex medical needs

5.3.1.2 Processes followed during focus group and interviews

Grounded theory interviews are loosely structured conversations with the aim of generating rich information for the developing theory (Birks & Mills, 2011). When using a constructivist approach, interview questions are generally broad and open-ended to elicit the participants' experiences and understandings (Charmaz, 2006). The researcher is an active participant in the generation of data and meaning (McCaffery, 2003). As the interview progresses, the researcher encourages and probes the participant to reflect on their experiences and meanings, and may pursue additional information relating to a particular topic or theme (Charmaz, 2006; McCaffery, 2003).

Charmaz (2006) suggests that "having an interview guide with well-planned open-ended questions and ready probes can increase your confidence and permit you to concentrate on what the person is saying" (p. 29). In preparation for commencement of data collection, I developed focus group and interview guides that contained open-ended questions to provide a loose framework for the interview, a checklist of topics to facilitate exploration of variations in parents' experiences, as well as probing questions to encourage further in-depth discussion and reflection (see Appendices 8 and 9). The focus group guide also contained introductory information regarding the conduct of the group that I read out and discussed with the participants at the commencement of the session.

My initial question for the focus groups was "What are the health care needs of children with cerebral palsy to live a good life?", and for the interviews was "What have been the health care needs of your child at different stages?" My subsequent questioning followed the lead of the participant/s, allowing the participant to raise issues of importance from their perspective. During each focus group and interview, I noted down key topics, concepts, experiences or phrases that were being discussed in a field journal. I referred back to this field journal and to the checklist of topics if a particular topic required additional clarification or exploration.

Following the constructivist approach to grounded theory methodology, as the process of data collection and analysis progressed, theoretical sampling was used to further explore concepts that emerge from the developing analysis (Charmaz, 2006). I used theoretical sampling to modify the interview questions to explore specific experiences and understandings that had emerged from my analysis of previous interviews. For example, I explored the process of finding information about the child's health care needs and where to get help with future participants by adding in the question: 'How have you come to know what your child's health care needs are?' Later, I explored the concepts of developing a sense of control in managing their child's care and of 'living a normal life' by asking the questions: 'I'm interested in what you feel your sense of control is in managing your child's health care and getting the care you need for your child. Can you explain to me what your experience is with this, and how a sense of control might develop?' and 'A concept has emerged from talking with other parents about trying to lead a "normal life". What does leading a "normal life" mean to you? How can this occur?'

Audio recording of interviews is commonplace in qualitative research, particularly when the emphasis of the research is on capturing participants' own voices and language (Birks & Mills, 2011; McCaffery, 2003). Recording and transcription of interviews also provides a method for retaining an accurate record of the spoken word and access to verbatim quotations to illustrate meaning during analysis and presentation of the theory (Birks & Mills, 2011). Since the purpose of my study was to discover parents' experiences of health care from their own perspective, all focus groups and interviews were recorded on a digital audio recorder to allow for transcription and subsequent data analysis. The audio recordings of all focus groups and interviews were transcribed verbatim by an external provider (Transcript Divas, 2013). All transcripts were de-identified to protect the privacy of participants. Member checking of transcripts can allow the participants to check the accuracy of the narratives and to provide opportunity to volunteer additional information that might have been missed in the interview process (Carlson, 2010). I sent a copy of the relevant transcript to each participant and offered them the opportunity to review the content and to provide additional stories, comments, feedback or reflections; however, no participants replied or made contact with the author.

5.3.1.3 Ethical considerations

The nature of the topic of investigation and my role as both clinician and researcher raised a number of ethical issues that needed to be managed in this study. First, my clinical experiences of working with families of children with cerebral palsy in the regional area matched literature that concluded that services to these children and families was currently inadequate and unsatisfactory (Darrah, Magil-Evans & Adkins, 2002; Irochu-Omare, 2004; McKay & Hensey, 1990; Reid et al., 2011). As a result, I anticipated that exploration of parents' experiences of health care through the focus groups and in-depth interviews had the potential to elicit stories that were underpinned by strong thoughts and feelings. In addition, I had previously provided clinical care to the children of the parents who participated in this study as one member of a wider health care team and service. Therefore, the parents' experiences would inherently include those they had shared with me as a professional, as well as with other health professionals who were my colleagues. The constructivist approach to grounded theory positions the interview as a process of mutual exchange for the purpose of developing a shared understanding of the phenomenon of interest (Mills, Bonner & Francis, 2006). During the focus groups and interviews, I adopted a non-judgmental stance, answered questions asked by the participants honestly, and shared my developing understanding of parents' experiences as the data analysis progressed. If participants experienced emotional distress or discomfort during the interview or focus group, the opportunity for further support following participation was available, and participants could also choose to withdraw from the study at any time for any reason. However, this was not required or requested by any of the participants. Second, confidentiality of the parents' participation in the study was maintained by conducting interviews and focus groups at a venue that was separate from any clinical areas or via telephone. Stories and opinions provided by the participants that contained information potentially identifiable by others were modified or disguised, without altering the meaning of the situation described by the participants. This ensured the confidentiality of the participants, as well as that of the health professionals and services involved in the care of the child and family. Finally, my familiarity with the participants through my role as a clinician raised the possibility of parent perceptions of coercion to participate and of potential direct benefit from participation in the study in terms of improvements in quality of care for their child and family. For this reason, participant flyers were distributed through third parties and parents were required to make voluntary contact with me, rather than being followed up by me. In addition, the parents' expectations of outcomes of participation were managed by explicitly explaining on the participant information sheet and during the informed consent processes that their participation would not have any direct impact on the care their child and family received. Ethics approval for the study was received from the human research ethics committees of the regional health care service (HREC/12/QTHS/44; SSA/12/QMH/15) and the university supervising the study (H4754) (Appendix 7).

5.3.2 Data analysis

Grounded theory methodology has a specific set of processes and methods used to analyse data and subsequently generate theories (Birks & Mills, 2011; Charmaz, 2006; Corbin & Strauss, 2008; Creswell, 2007). In this study, these processes included coding the data and writing memos to identify and explore underlying concepts in the data (Birks & Mills, 2011; Charmaz, 2006; Creswell, 2007; Liamputtong, 2009). Following Charmaz's approach to grounded theory, the strategies of theoretical sorting of codes and memos, writing a storyline and diagramming were then used to organise my developing analysis and construct the overall theory (Birks & Mills, 2011; Charmaz, 2006). In this study, all data analysis was completed in written form in a fieldwork journal and on the computer using Microsoft Word (2010).

5.3.2.1 Coding and memoing

Coding is a process of identifying and interpreting a segment of data and applying a short name or phrase that summarises that segment of data (Birks & Mills, 2011; Charmaz, 2006; Liamputtong, 2009). Memos are informal analytic notes written throughout a grounded theory study to keep a record of the developing analysis (Birks & Mills, 2011; Charmaz, 2006; Corbin & Strauss, 2008). Memos can record comparisons and contrasts, relationships between information, new ideas, insights, identify gaps in the data or questions the researcher has of the data (Birks & Mills, 2011; Charmaz, 2006). The process of writing analytical notes facilitates the process of analysis from concrete data to abstract theories, as well as provides thorough documentation of the analytical and methodological steps taken during the research process, providing an audit trail of each decision made (Birks & Mills, 2011; Charmaz, 2006; Cooney, 2010).

My process of data analysis commenced immediately following completion of each focus group or interview. I reviewed my field notes and wrote a reflective memo describing my general thoughts about the interview and any important concepts or themes identified from the interview. An example of an initial reflective memo for the focus group held in the regional city is provided in Memo example 1. These reflective memos provided an opportunity for me to develop early familiarity with the participants' experiences and perceptions, and opportunity to make any necessary modifications to the interview process or questions in preparation for the next interview.

Memo example 1

Initial reflections following focus group one

29.04.2012

Conducted my first focus group today. Only had 3 participants, one couple of a 13 yo girl with CP requiring a wheelchair and one Mum of a seven year old boy with CP affecting only one leg. Two other participants who had intended on coming couldn't come along. This may have potential to impact how much discussion could be had as there was only two different contexts from which to draw information.

Focus group lasted 95 minutes, lots of discussion was had with the parents. The parents of the older girl seemed to have more to say and more experiences, but the other Mum did express her views openly and contributed to the discussion. I think towards the end of the discussion the Mum of the 7 yo may have felt that her issues were less significant than those of the other parents as she would still contribute to the discussion but was quick to pass the opportunity to talk onto the other parents.

An important aspect of health care that came up frequently during the discussion was consistency. Consistency was described in terms of who was providing health care (ie: the service as well as the individual therapists) and how the health care was delivered (ie: regularly scheduled care, preferably provided in the home (for the parents of the child with more disabilities) and over a prolonged episode of care or period of time). The parents felt that by having consistency of care, the benefits included the child being familiar with the therapist, the therapist better knowing the child and their abilities, the parents having a better rapport with the therapist which enabled them to work better with the therapist or team, provided them with regular information that is specific to their child's needs and provided direction for what care is needed.

Providing regular information to families was also an important aspect of care that was mentioned frequently. The parents reported that it was they often didn't know where to go to get the services they needed, and so would have to ring around to find out for themselves about where to receive services. There were comments about the parents feeling like they were the one's directing their own child's care, even if they didn't know what the child's need are or what they would be in the future. They didn't feel like they understood or were given information about what the future would be like for their children.

When asked about what a good life for their child would look like, the parent's description was that health services would work with the child and for the child to make the most of what they have available, to make the most of what is available to use with their body and their life.

In grounded theory research, immersion in the data during data analysis is a fundamental requirement to enable the researcher to gain insight and sensitivity to the meanings within the data (Birks & Mills, 2011; Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967). Once I had received the transcript for an interview, I read each transcript two or three times to become immersed in the interview data. I made note of specific remarks or concepts that seemed pertinent to me at the time. I wrote a reflective memo describing three to four initial ideas or concepts from the data (see Memo example 2). I used these concepts to commence coding of the transcript, or if they were not substantiated by the data, they were discarded.

Memo example 2

General reflections after reading of interview three

- This parent has had positive experiences, they are very happy with the health care they have been provided

  - Why? – receiving the right care at the right time; consistency of care/ continuity of care; being linked in with various services within a single network; regular checks and monitoring, keeping on top of things

- Minimal impact of child's condition and health care needs on life (except in infancy/ at birth or acute admission for shunt infection) – leading a 'normal' life

Coding in grounded theory allows the analysis to progress from concrete data to increasingly abstract concepts and categories that reflect the meaning in the data (Birks & Mills, 2011; Charmaz, 2006). Coding in Charmaz's constructivist grounded theory includes initial coding, focused coding and theoretical coding (Charmaz, 2006).

Initial coding should stick closely to the data (Charmaz, 2006). I coded each line or incident of the transcript, using a short descriptive phrase that described what was happening within the participants' narrative (see Coding example 1). I used two types of coding styles - process coding and in vivo coding (Charmaz, 2006; Saldaña, 2013). Process coding involved the use of gerunds, or action words ending in –ing (Charmaz, 2006; Saldaña, 2013), and enabled me to focus on the processes and actions occurring in the participants' narratives. Examples of process codes included 'receiving a diagnosis', 'maximising opportunity', and 'learning to push'. This style of coding was important to develop understanding of how parents come to understand important aspects of their child's health care. I also used in vivo codes (Charmaz, 2006) when specific words or phrases used by the participants captured parents' understandings and meanings closely. Examples of in vivo codes include "flying blind", "living with unknowns" and "making the most of their body and their life". I specifically chose to use the in vivo method of coding for two reasons. First, the purpose of the study was to develop an understanding of parents' experiences. The use of in vivo codes allowed me to more closely focus on the parents' perceptions and meanings, rather than my interpretations or understandings as a health professional. Second, the initial review of the literature (as outlined in Chapter 3) identified that communication and shared understanding between parents and health professionals was an ongoing issue that contributed to parental dissatisfaction with care. By closely considering the parents' language, and where appropriate, using their own language in the analysis and developing theory, I aimed to better reflect parents' understandings and therefore minimise this issue in the final explanatory model.

Following the process of constant comparative analysis, I continued collecting and analyzing data concurrently. This process of constantly collecting and comparing data with the developing analysis builds a conceptual abstract theory with rich descriptions that has explanatory power for the social process being investigated (Birks & Mills, 2011; Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967). I compared new data with old data, codes, and emerging themes and concepts. I re-read transcripts and, where necessary, re-coded sections of data, and wrote extensive memos documenting all conceptual advances and analytic decisions, as demonstrated in Memo example 3.

Memo example 3

Reflective memo during initial coding of interview two

13.04.2014

- This mother has described that her son is doing extremely well at the moment. She then goes on to talk about the issues they are still dealing with. So, even though there are some seemingly serious issues still continuing and the parents are dealing with these issues daily, this Mum is very happy with how well he has been. So, being well does not necessarily mean everything is perfect, but parents' perceptions that their child is doing well (?general health) is important for this Mum.

*** I think this idea links or is related to the idea that the parents take the added challenges of everyday life for granted. So, the parents perceive that the child is doing extremely well, and that things are good at the moment, because they take the other challenges in life for granted. Maybe this is related to the level of physical disability of each child? Parents of children with significant physical disabilities are more likely to take the added challenges in life for granted, because they deal with it daily, and that is just part of life for them. So their perception of what 'doing extremely well' could be very different to how another parent of a less disabled child perceives it. I need to explore this further with my future participants.

During this process of comparing and re-reading, I commenced the process of focused coding. Focused coding enables the researcher sift through, synthesize and explain larger amounts of data (Charmaz. 2006). In this study, focused coding involved selecting a code or developing a new code that described larger sections of data, incorporated a number of initial codes and described a whole incident or process as experienced by the parents. Examples of focused codes included 'navigating the systems', 'working together' and 'balancing needs'. I compared each focused code with the raw data, initial codes and the previous analysis. I also added sub-codes to some focused codes to add additional descriptive information about the situations in which these codes occurred. For example, for the focused code of 'being empowered', I also added sub-codes such as 'making a choice', 'being regarded', 'shared guidance' and 'having a voice'. An example of initial and focused coding of raw participant data is provided in Coding example 1. I wrote extensive memos describing these focused codes, how they related or varied between each other or between different participant experiences, and my developing understanding of the processes represented by the focused codes (see Memo example 4).

Coding example

Initial and focused coding of raw participant data

Interview or Focus Group Data	Initial Coding	Focused Coding
I: What do you think are the important aspects of your child's health care needs?		
P2: I would think consistency has been one thing that we, in the past, haven't found it easy to have a consistent approach, and it would be nice to be able to have that approach across the board. We found that … like, the system started from the zero to five year-old, six year-old mark, that we had consistent care, in that section. Then we went into a different system where we had at Queensland, because we started school and had that system looking after her, and that was difficult. Now we're in another system because we've swapped across to a private system, and now, once again, we're having difficulty knowing where we get the consistency of care from.	*valuing consistency* - *across systems* *changing systems* *having consistent care* *changing systems* *swapping systems* *navigating different systems*	***navigating the systems*** *(moving between systems; different ages/ developmental stages)*
P3:And I guess for me it's more regular, as well as consistent, as in that you know that it's going to be every ... definite periods of time, instead of just me ringing up going, oh, I think it could be now that I need to come in. Just a more of a definite plan.	*wanting regular contact* *initiating contact* *anticipating needs* *having a plan*	***anticipating needs*** *(regular/ consistency; having a plan)*
P11: And when we went back to the paediatrician he just basically said yeah, you were right, he has cerebral palsy, see you later. I think that parents need more information than that. I was lucky... I've got a little brother who's got Downs Syndrome so I knew what was available, but for a parent that's never dealt with anybody with disabilities I wouldn't have known that he needed physio, or that he needed early intervention, or any of those things because nobody told me. I think that it should start at that level – paediatricians, GPs should be given even just packages of information that describe what's available to kids that need help. That would have been helpful because there were still some things I didn't know, but we got straight into physio, and then we went to early intervention, so we had... and early intervention was a great programme, they gave us all the information we could possibly need, they got us in contact with an orthotist, got us specialised physio and OT, got us in touch with the clinic at (tertiary hospital) in (capital city) because we hadn't even been referred to a hospital, we hadn't been referred to anybody, we'd basically just been sent home	*confirming diagnosis* *lacking support* *needing more information* *having background knowledge* *receiving no guidance* *needing more information* *starting therapy early* *receiving the information needed* *putting us in contact* *getting the help we needed*	***navigating the systems*** *- needing information and guidance*

Memo example 4

Early reflective memo on 'navigating the systems'

29.04.13

NAVIGATING THE SYSTEMS has different aspects or elements that can enhance the process or make the process of NAVIGATING THE SYSTEMS harder or easier for parents.

These are the situations in which NAVIGATING THE SYSTEMS has occurred in this transcript:

- being referred between different services due to different speciality, but also being referred between services when moving town
- receiving different levels of services depending on which service you are accessing or where you are living
- navigating between private and public systems – one participant had originally gone private for all her daughter's health care needs, but an anaesthetist advised her to:
- "get into the public system, but you need to go into a private clinic, not into the 'normal' clinic, so make sure that you get into that consultation"
- "bouncing" – when you go into a clinic – and seeing all different Dr's and saying the same things over and over again. (IS THIS NAVIGATING THE SYSTEMS OR IS THIS SOMETHING ELSE???)
- seeing different services prior to diagnosis and then being discharged from that service into another one, but then the service approach was different – "once he was discharged from there, it was sort of like living in limbo. He was then sort of put under (service provider), to see them there, and we'd see them once in a blue moon"
- having different eligibility criteria across different services eg: "so, in the hospital, when you… I think they're a certain age when they say "No, we can't do it anymore". I think it's twelve months… when you're part of that… but they were good… but when you're discharged… yeah.
- two incidents of 'getting lost in the system' – one where the child wasn't referred to a service she should have been eligible for, and therefore missed out on early screening, and one where the child's birth history records where lost, so the Mum had to tell her child's history over and over again when preparing for the birth of her next child.
- facing a 'road block' – a situation where the family moved and services seemed to stop – 'then we moved and things sort of stopped…. Like (child) was… you know, she was diagnosed as mild spastic quadriplegia, but mild and she still couldn't talk, and she was walking around holding up walls, and where do we go? What do we do? Not knowing what she had, with what was happening in her brain, how it was formed, it's the not knowing, and who to talk to".
- being given advice about what kind of service to look for when moving to a new town, but that advice not be reasonable given the lack of services available in the town.
- 'fighting the system' and having to navigate amongst services to have some recommendations from a specialist implemented. This participant described the experience of being recommended a particular assistive device, but having to "fight a battle" with the school and the education system to have this recommendation honoured. During this process, the mother was belittled or what the mother was telling the school was disregarded, and she had to be the one doing all the explaining, negotiating and chasing up of support from the original prescribing Dr. This is an interesting experience that describes both NAVIGATING THE SYSTEMS and BEARING PRIMARY RESPONSIBILITY FOR CARE (see below, I am still yet to

explain this code)

There are examples of parents NAVIGATING THE SYSTEMS by themselves or of their own accord, and examples of parents NAVIGATING THE SYSTEMS with the help of others or even by others. One example is a local physio who co-ordinates care at a local level:

“Yeah, look… I think (physio)’s been very good. She rings you up and she chats to you… and those sorts of things she offered… when he had his Botox… when he has his aftercare stuff, and all that sort of stuff. She’s been really, really good. I think she’s actually the one that gets on top of all the visiting OT’s… and speechies if they come… to have contact with the parents.”

The sharing of information seems to help parents to navigate the systems. When asked about where they get their information from, the first answer the parents have given is ‘other parents’:

“Parents. Each other. I was the same. Like I said earlier, I didn’t know for years about services and what we could do. It’s only been another…running into somebody in the park even, or anywhere…shopping, swimming pool…who has said “Oh, did you know you can do this? Did you know this?” It’s never come from…I couldn’t even say it’s come…nobody’s told me from…like a paediatrican’s never told me what I could do. Some of the paperwork that’s involved is just horrendous. Sometimes you need one of them to help you to fill it out. So even if they say “You’ve got to do this.” You look at it and go

‘Having a plan’ – when discussing a team approach versus receiving services from individual therapists, this participant talked about:

“I think … it’s ok to have the individual, once you’ve got a plan. I think you need to have that overall team where they’re in control, to set that plan, and then you can go off and do what that plan says you should do.

Then it’s got to be revised, because as you know, when they grow…”

This, to me, indicates that having these processes in place helps the parents to NAVIGATE THE SYSTEMS.

Through the process of coding and memoing of each transcript, and comparing codes across transcripts, I identified certain focused codes that repeated throughout the data and appeared to represent significant meaning in the data. I re-read and explored examples of the focused code and the raw data represented by the focused code to become familiar with each significant focused code. I wrote a formal memo on each of these significant codes (see Memo example 5), using the following questions to develop an in-depth understanding of the process represented by the focused code and to identify gaps in understanding for exploration in future interviews and memos:

- How can I define this process?
- How does this process develop?
- How does the research participant act while in this process?
- What does the research participant profess to think and feel while in this process?
- What might the research participant’s behaviour indicate?

- When, why, and how does the process change?
- What are the consequences of the process?

(Charmaz, 2006, p. 51)

Memo example 5

Formal memo on 'navigating the systems'

05.05.13

NAVIGATING THE SYSTEMS

Sub-codes (descriptors) – moving between systems (according to different ages or developmental stages); knowing who to approach; moving between systems (private vs public school systems and hospital vs school systems); finding out who to receive services from; seeking services; moving between systems (private vs public); navigating within individual systems (eg: referral processes or other policies and procedures); knowing where to get services; processes within systems (eg: access and eligibility; referral and diagnosis processes); finding out which services are available; changing systems (according to age and developmental stage); eligibility for services; seeking help needed; finding the help you need; finding available services; choosing services; accessing different services concurrently; linking in with services; seeking support;

How can I define this code?

Navigating the systems is the process that parents go through to search for, find and receive the care they need from the available health services or health care systems throughout the child's life. In this definition, the health care services or health care systems that are available exist as individual entities, and have individual eligibility criteria and processes or procedures to access and receive care. Parents need to navigate through the maze of eligibility, accessibility, availability, policies and (usefulness/ service focus or purposes) to find the services that are required to meet the child's and family's needs throughout the child's life. Additionally, navigating the systems also occurs once the child and family are linked in and receiving services from an individual service. Each individual health care service or system has internal policies and procedures that need to be navigated by the parents once they have found that this is the service their child is eligible for or the service that will meet their needs at that particular time.

Navigating the systems is an evolving or repeating process, which changes in accordance with the changing needs of the child or family.

How does this process develop?

The process of navigating the systems can develop by:

– a need is identified, and so a process of seeking services is commenced to find a service that may be able to help address that need. Parents don't know who to approach to get the help they need.

"...because we found that because we don't know who to approach to get the care that we're requiring. It all comes from us and we don't know what exactly we need."

- the child may no longer be eligible or no longer require a particular service and so changes or transitions to another service. The eligibility for services tends to be defined by the child's age or developmental stage, or by the caseload that the service typically sees.

- the parent chooses to try and get services through the private health systems, but then get directed back to the public health system

"Initially I was thinking, yeah, I'd go the private route, but there's no private route, as such, in Mackay that I could find anyway. And everyone kept saying, you have to go back to the (Public hospital), that's your best option.”

“I did try once when we weren't happy with the AFO that we did try a private, but they said to us to stick with who you're with, with the (public service), we don't want to know in a (private service).”

- once the child and family are linked in with a service, the parents then need to navigate the processes within that system. These processes might be in terms of processes of diagnosis or referral processes.

“…the other thing that I had a bit of a thing with was when you had to go get your referral again from the paediatrician. I remember coming to one appointment, and he was like, well what are you here for? And I'm like, well, I've just got the letter to say I had to come here, I assume to go back to get ongoing physio, or something. But it was like, why are you here? And I'm like, I don't know why really, but just that communication was lost, I guess.”

“And I think we had one piece of equipment that arrived, and it had to leave our house by midday the following day. We had for less than 24 hours because it was due to go up to (another regional town), or somewhere else.”

“They have changed the way they go about things. The last process I had to go through. I guess if we've got a question we can always ring (community service), and they're supposed to direct us to some degree of where you go for those things, and that's there now, that once you get on their books … they went through a period of up and down, though, too where they changed their processes.”

“She was meeting her milestones up until she wasn't sitting, and she didn't start the crawling. She rolled though. So then he said, we'll leave it until 12 months and we'll send you to a paediatrician at 12 months. Because we were out at (rural town), the closest paediatrician was in (regional town). So he sent us down to (regional town), and then she basically diagnosed (child) very quickly.”

How does the research participant act while involved in this process?
Participants may take this process into their own hands and commence calling around to various different services to try and find the help they need.
Participants may commence contacting people who they think might help guide them through this process. This person might be another parent, or might be a health professional they know or a service they have used before. Alternatively, they might call around to different services who they think might help them.

“And yeah, we've had to come back to using therapists here at the (regional hospital) because … well, we don't have (education service) on-board any more, and the (education service) doesn't have … they have the positions, I think, for therapists, but they're just not filled.”

“And if that fails we'll ring another mum with a daughter with cerebral palsy.”

What does the research participant profess to think and feel while in this process?
Parents report find it difficult to find a consistent approach.
Participants report feeling stressed and annoyed when trying to find out information about the systems and services that are available.

When, why, and how does the process change?
There are different elements or aspects that can facilitate the process of navigating the systems, or alternatively, make the process harder for parents:

- Communication and information sharing. This aspect affects the process of navigating the systems in two ways: (a) Parents find it difficult to get information about the services available or services that they will eligible for or will benefit from. This means that when they identify a need, they don't know where to go to get the help that they need.

"I guess, overall, when you look at the health services from (child), from birth right through, we've always been able to access the service that we've needed, it's just a matter of knowing where to access what we need and who does it. And it's changed over time. And finding out that information is really the most difficult thing to do. Who is it at the time? Who is it at the time that you're going to see?"

"…you often find out bits and pieces from them on what you should … where you should be going to access this, or doing this, or what paperwork you need to fill in. It's not consistent as to … nobody hands you a little booklet and says, well look, these are things you've got to do."

- Having someone to help guide them through the systems assists children and parents to transition more smoothly between different systems. Parents think this has been done well when a therapist works across the two different services which the child is moving between.

- The variations in service eligibility or accessibility of the different children's services can make the process of navigating the system more difficult for parents. For example, a child with cerebral palsy who is receiving care from (community service) prior to starting school may receive regular therapy in the child's home from a team of therapists. Once this child moves to school age, (community service) cease (child is no longer eligible due to their age) and the child commences in the school system. The school system, in comparison to what was previously received by (community service), has very different eligibility criteria and very different accessibility to services. These variations in service provision make the process of 'navigating the systems' more difficult for parents.

What are the consequences of the process?
- Loss of consistency of care because the child is moving between different services.

P1: "We found that … like, the system started from the zero to five year-old, six year-old mark, that we had consistent care, in that section. Then we went into a different system… because we started school and had that system looking after her, and that was difficult. Now we're in another system because we've swapped across to a private system, and now, once again, we're having difficulty knowing where we get the consistency of care from."

P3:"So with the (community service), does that just stop after a certain age, or something?"

P1:"When they go to school, it sort of drops off, and you notice it goes more to the (education service)."

- Parents spend a lot of time and effort trying to get the help they need.

"I'll just get on there and make 50 million phone calls when I want to find out something."

"Well, (OT) knew what sort of phone calls I did for that one. Like, I'm getting this money, I don't care how I get, I'm getting it. Yes. As I said, I even went to the Local Member to try and find out information for that one. As I said, I usually end up finding out the information, but sometimes that's quite stressful. We've got to find the time track this all down. It's just so annoying."

- Parents rely on services they are already familiar with.

“We've always had to try and find out where do we receive these services from? Where should we be looking? And it's not there that we know where we should go. We're not sure. We usually always have to come back here to the (public hospital) and say, well look, is it you guy that should be servicing us, and how long does that happen for?”
The care provided becomes “piecey” – the delivery is organisation is more disjointed, and the combination of services may not meet their needs.

“What seems to have happened is, we got the best care, I think, when she was zero to six. Then the care in her biggest growth period has become not as consistent and regular, and so that's where we've been dumped in it to some degree. Now that we need more support with what equipment she needs, how her growth is going, how you can transfer her, and all that, it seems to have left us. And said, you know, that's where we've found it piecey. Where can we access this from, and we're always trying to pull things from different places.”
- The child or the parent might miss out on services that they are eligible for and entitled to. This then may impact on the quality of care they receive, and potentially on their satisfaction with care.

“Because a lot of parents are going alone because of, maybe, not knowing what is available in utilising the amount of therapy or services that we have in the area. And unfortunately, as they said with the personal funding, and what (participant 2) just asked about was that if some of them don't realise that these funds are out there, or that the assistance is there and they haven't applied for it…”

5.3.2.2 Ceasing data collection

In a grounded theory study, the decision to cease data collection is based on careful consideration of the richness of the data collected in relation to the theoretical purposes of the research and the ability to answer the research questions (Charmaz, 2006; Creswell, 2007). In grounded theory methodology, the concept of theoretical saturation is used to determine when to cease data collection (Birks & Mills, 2011; Charmaz, 2006). Theoretical saturation occurs when major thematic categories can be fully explained from the available data and when additional data collection will yield no new theoretical insights or understanding (Charmaz, 2006).

My decision to cease gathering additional data from participants occurred after ten months of data collection and analysis. I had gathered rich data that described a variety of parents' experiences. I had a list of 54 focused codes, all of which had corresponding memos explaining the processes they described, and exploring the connections and relationships between different codes. Although I had not yet fully constructed the conceptual model nor identified the core category, after conducting two focus groups and eight interviews, I felt that I had sufficient information for this to occur with continued analysis of the current data. In addition, during my initial reading of the transcripts of the final two interviews, I identified that no new information or concepts were raised in these interviews and the codes I had already developed could be used to explain the processes present in this new data. As a result, I made the decision to cease data collection in August 2013, one month following the completion of the final interview.

5.3.2.3 Constructing the conceptual model

The final stage of constructivist grounded theory analysis involves constructing the theory or conceptual model (Charmaz, 2006). In this study, the process of constructing the conceptual model required identification of key categories and the relationships between categories, and identification of a core category that explained the overall process of health care for children with cerebral palsy as experienced by their parents (Birks & Mills, 2011). Prior to this stage of the analysis, I had identified some key focused codes from the data that strongly reflected and potentially explained how the parents had come to experience their child's health care. These concepts included 'being empowered or disempowered' and 'maximising opportunities'. However, I was wary of selecting one of these codes as the core category without having developed an understanding of how the categories related to each other as an overall process (Boychuck Duchscher & Morgan, 2004; Glaser, 2004). My analysis required additional abstraction and integration, which can be achieved in grounded theory research through theoretical sorting, diagramming, and writing a storyline (Birks & Mills, 2011;

Charmaz, 2006). Theoretical sorting provides organization and logic to the developing conceptual model, and involves sorting through codes and memos to identify or refine theoretical links (Charmaz, 2006). Diagramming provides a means for developing a visual representation of the developing conceptual model, and enables exploration of relationships between concepts and categories (Birks & Mills, 2011; Charmaz, 2006). The writing of a story line assists the grounded theory researcher to conceptualise and explain their understanding of the overall theory or model (Birks & Mills, 2011). A storyline is also a means for understanding and presenting the conceptual model from the participants' point of view, and thereby ensuring the conceptualization of the model remains grounded in the data (Birks & Mills, 2011). By using these methods, I was able to identify the relationships between categories, identify a core category, and develop an overall understanding of (Birks & Mills, 2011).

I commenced constructing the conceptual model by sorting my focused codes into groups, which eventually became the categories. I wrote each of the 54 focused codes onto post-it notes, and put them all out on a table. Alongside the post-it notes, I also had all of my memos on each of these focused codes. I grouped together all the codes on post-it notes that I thought meant the same process or represented aspects of the same process, constantly referring back to the memos on these codes for clarification and exploration of my understanding. Through my initial sorting, I grouped the 54 codes into 15 groups of codes. I then reviewed these groups, and explored how they fit together. During this review of the groups, I moved some codes from one group to another if I thought the code fit better into another group. I also identified which groups of codes could be collapsed together to represent a single process. This left me with nine groups of codes. I reviewed these groups, and collapsed together the groups that I thought reflected the same overall processes. This process of sorting of focused codes, which is demonstrated in Memo example 6, resulted in six groups of codes, which I further explored by writing a memo describing what process each of the groups of codes represented. By identifying the process that each of these groups of codes represented, I was able to give them a name or title, and these six groups of codes became the categories – evolving needs; learning as you go; navigating the systems; meeting needs through partnership; being empowered/ disempowered; and, finding a balance - that were eventually integrated into the overall conceptual model.

Memo example 6

Sorting of focused codes into categories

18.07.13
Version 1

- Navigating the systems; having someone to contact; receiving information/guidance/direction; having a plan
- Anticipating needs; navigating our needs; evolving/changing needs; preparing for change/ dealing with changes
- Dealing with one issue after another; dealing with added challenges; living the benefits and disadvantages
- Considering the whole/bigger picture; impacting whole family; needing care for whole family unit
- Enabling abilities; maximising potential; making the most of their life and their body; taking a backwards step; leading a fulfilling life; receiving individualised care
- Maximising opportunity; being in the right place; missing out
- Being regarded/ disregarded; taking the time; feeling accommodated; overlooking needs; fighting the systems
- Having a voice; directing/leading care; making a choice/having a choice; taking a stand/standing up for yourself; knowing child well' being understood; ? making decisions
- Leading a "normal" life; wanting acceptance/ fit in with peers
- Learning as you go; learning to understand and accept needs; living with unknowns
- Chasing the care needed; bearing primary responsibility for care; doing it on your own; lacking support
- Finding a balance; making lives around child's needs; "surviving"
- Working together; shared guidance; sharing information
- Being empowered; developing trust and confidence
- Meeting all expectations; receiving reliable services; getting the help needed

Version 2

- Navigating the systems; having someone to contact; receiving information /direction; getting the help needed; receiving individualised care; chasing the care needed; bearing primary responsibility for care; doing it on your own; lacking support; sharing information
- Anticipating needs; navigating our needs; evolving/changing needs (dealing with one issue after another); preparing for change/ dealing with changes; learning as you go; learning to understand and accept needs; having a plan
- Dealing with added challenges/ living the benefits and disadvantages (same thing) – (includes meeting all expectations; receiving reliable services)
- Considering the whole/ bigger picture; impacting whole family; needing care for the whole family unit; finding a balance; making lives around child's needs; "surviving"
- Enabling abilities; maximising potential; making the most of their life and their body; taking a backwards step; leading a fulfilling life; maximising opportunity; being in the right place; missing out
- Being regarded/ disregarded; taking the time; feeling accommodated; overlooking needs; fighting the systems
- Having a voice; directing/leading care; making a choice/having a choice; taking a stand/standing up for yourself; knowing child well' being understood; ? making decisions; working together; shared guidance; receiving information/ guidance
- Leading a "normal" life; wanting acceptance/ fit in with peers
- Being empowered; developing trust and confidence

Version 3

- *Navigating the systems* - having someone to contact; receiving information /direction; chasing the care needed; bearing primary responsibility for care; doing it on your own; lacking support;
- *Evolving/changing needs* - (dealing with one issue after another); anticipating needs; navigating our needs preparing for change/ dealing with changes;
- *Finding a balance* - dealing with added challenges/ living the benefits and disadvantages (same thing) – (includes meeting all expectations; receiving reliable services); considering the whole/ bigger picture; impacting whole family; needing care for the whole family unit; making lives around child's needs; "surviving"
- *"making the most of their body and their life"* - enabling abilities; maximising potential; taking a backwards step; leading a fulfilling life; maximising opportunity; being in the right place; missing out; leading a "normal" life; wanting acceptance/ fit in with peers
- *Being empowered or disempowered* - developing trust and confidence; feeling accommodated; fighting the systems; having a voice; directing/leading care; making a choice/having a choice; taking a stand/standing up for yourself; being understood;
- *Meeting needs through partnership* - being regarded/ disregarded; taking the time; knowing child well; ? making decisions; working together; overlooking needs; receiving individualised care; getting the help needed;
- *Learning as you go* - learning to understand and accept needs; having a plan; sharing information; shared guidance; receiving information/ guidance/ direction

Codes that don't fit in (yet??) – 'having consistency' and 'living with unknowns'. I feel like 'having consistency' tends to overlook all of the groups of codes, or is a similar aspect of each group. 'Having consistency' is perceived as beneficial to all the groups of processes.

Once I had identified the six categories, I used additional memoing, writing of a story line and diagramming to construct the overall conceptual model. First, I wrote a formal memo on each of the six categories in order to further explore and understand the characteristics of each process they represented. The characteristics I explored included the conditions under which the process occurred, the enablers and barriers to the process, and the consequences of the process (Charmaz, 2006). An example of one of these memos is provided as Memo example 6. While writing these memos I theoretically sampled for each category from the existing data and memos in order to remain grounded in the data.

Memo example 7

Formal memo on category 'meeting needs through partnership'

What does this category mean or represent?

- It's about being respected and regarded as a partner in the healthcare relationship; it's about being regarded as a partner in care (although this does not occur in all cases, the level of input varies)
- It's about having an input into care; having a voice

Conditions:

- Being understood/ sharing understanding with health professional
- Occurs during interactions between parents and health care professionals
- Acknowledgement that both health care professionals and parent have a role to play in health care (mutual regard)
- Recognition of important role parent has in child's health care
- Requires open communication, collaboration and compromise
- Incorporates respect for the needs of the child, the well-being of the child, and respect for the parents' perception of those needs
- May vary depending on the child's level of disability
- Incorporates the needs of the child, family, as well as the needs of all children with cerebral palsy

Enablers:

- Being respected and regarded; being listened to
- Consistency of care (seeing the same person)
- Taking the time
- Feeling accommodated
- Receiving information and guidance (verbal and written)
- Having a rapport with therapists
- Being asked opinion

Barriers:

- Being disregarded by health care professional
- Needs being overlooked
- Lacking support
- Time limited consultations
- Organisation of health care services limit parents' input due to limited scope of care or limited availability of services eg: eligibility criteria, waiting lists, prioritisation of needs across the population of children with cerebral palsy

Consequences:

- Fighting the systems
- Needs not being met, therefore more difficult to 'find a balance'
- Taking a stand/ standing up for yourself
- Parental empowerment/ feeling of confidence in self, confidence in the care the child is receiving
- ? Navigating the systems
- "making the most of their body and their life"

Once I had developed an understanding of each category and the relationships between categories, I then wrote a story line to describe how each of these processes fit together to explain parents' experiences of health care for their child with cerebral palsy (see below). To write the story line, I wrote a narrative description of parents' experience of health care in a chronological format, starting from their first experience of health care for their child with cerebral palsy. The story line enabled me to conceptualize the overall process as a sociological experience from the parents' perspective (Birks & Mills, 2011), rather than as a health care process.

Memo example 8

Storyline

Prompt questions: How does the process start? How does the process occur? How do parents move through the process?

The process of health care starts when an event occurs, which can occur before birth, at birth or after birth, in which a concern around the child's development arises. As a result, the parent anticipates a need for health care input. They search out health care systems for identification of needs or help or a diagnosis, but after a diagnosis is confirmed, the go through a process of 'learning as you go' to learn about the child's health care needs. At the same time, they are also going through the process of 'navigating the systems' to fine the help that they need. This process is ongoing throughout the child's life as new issues arise or as the needs of the child and family change, or as the systems change.

Parents can get a bit stuck in navigating the systems, but eventually they get the help they need. This occurs only by 'meeting needs through partnership'. Depending on how parents experience 'meeting needs through partnership', they can either be empowered or disempowered by this process. At the same time, 'meeting needs through partnership' can help them to 'find a balance' (as long as the needs have been met).

Then as the child's needs change, the family's needs change, or the systems change (eg: eligibility criteria), then parents go through the process of 'navigating the systems' and 'learning as you go' again.

From the story line, I then commenced diagramming to explore how this process would look as a conceptual model. I used the story line to guide the order of the processes, and used my understanding of the relationships between the categories to link certain categories. After modifying the diagram a number of times, I was able to develop a diagram that captured parents' experiences of health care for their child with cerebral palsy (see below). Through diagramming and re-reviewing the memos and data, I also identified one category that was central to all of the other categories, and underpinned all of the processes represented by these categories – "making the most of their body and their life". This category, therefore, became the core category of the conceptual model.

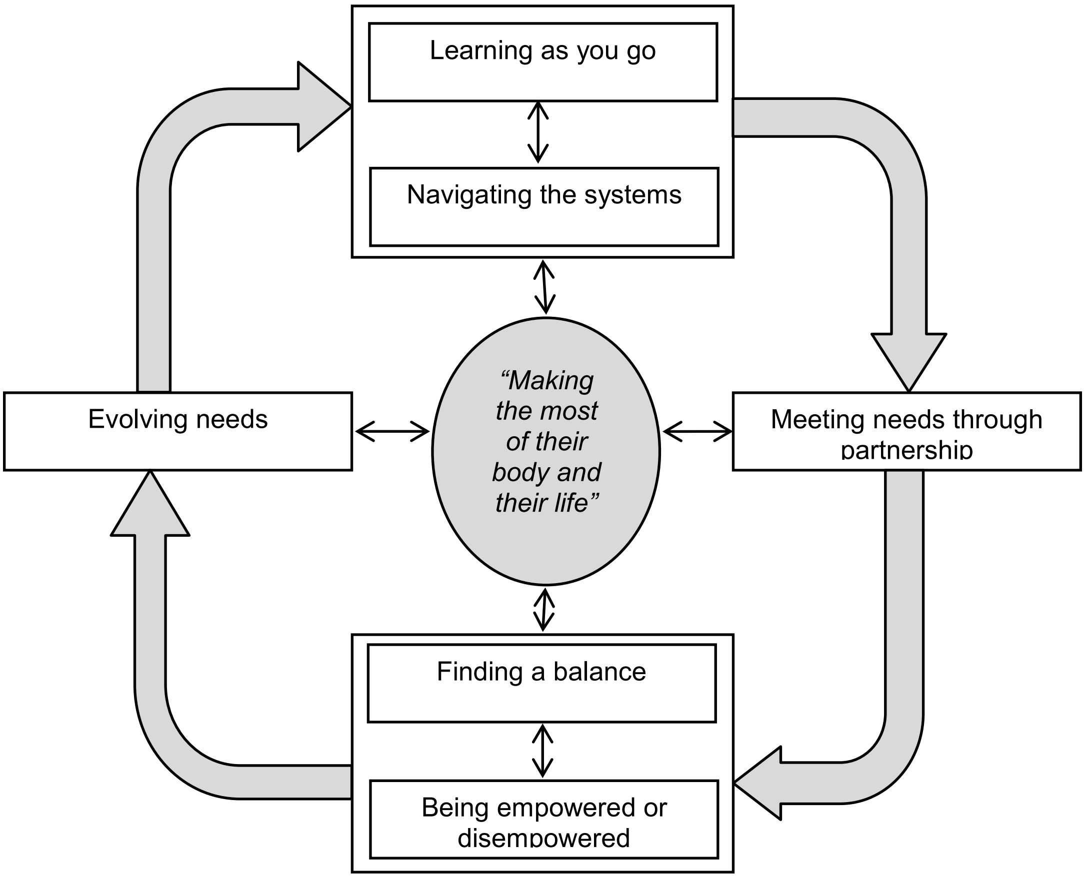

Figure 5.1 Final diagram that captured parents' experiences of health care for their child with cerebral palsy.

5.3.3 Testing the plausibility of the conceptual model

Plausibility is one characteristic of a credible grounded theory, and relates to the ability of the theory or model to explain all variations of the experience being studied (Charmaz, 2006; Glaser & Strauss, 1967). Although I was confident that the theory and conceptual model developed through the research process reflected the data and my clinical experiences of working with families with children with cerebral palsy, this was based on my own assumptions only. It was important to explore and assess the plausibility of the developed grounded theory and conceptual model, as this would determine its acceptance and usefulness in future clinical practice (Birks & Mills, 2011; Glaser & Strauss, 1967). I assessed the plausibility of the theory and model in three ways. First, I compared the model and theory to the experiences and perceptions of the parents who participated in the final two interviews. Although I had read these interviews thoroughly, was familiar with some of the concepts apparent in the parents' narratives, and had used some of the data in the analysis and development of the categories, I had not yet coded the data. Therefore, these two transcripts provided me with 'raw' un-coded data that I could use to check the fit of the model. I read through each of these transcripts and systematically considered whether the incidents in the data fit with the conceptual model. This process allowed me to confirm that the conceptual model explained these parents' experiences. The second method for checking the plausibility involved reviewing the literature to explore the applicability of the concepts within the model to current health care practices and other research exploring parents' experiences of health care and caring for children with cerebral palsy. I conducted a broad scan of the literature relating to health care service delivery for children with cerebral palsy and their families. The purpose of this second literature review was to identify any relevant literature that could be compared or contrasted with the findings of the study and the conceptual model. I conducted the search via James Cook University Library's One Search service, which conducts concurrent searches of multiple databases of electronic journals as well as the university's library catalogue, and used key words that resonated with the findings of the study and the conceptual model including 'partnership', 'empowerment', 'family centred care', 'consistency of care' and 'dealing with change'. No date limits were applied to the search process. I reviewed the search results, and only literature that related to health care for children with cerebral palsy, or for people with disabilities or chronic health conditions, were included for review. I read each of the relevant articles and compared and contrasted the understandings or results with the findings of my study. This process enabled me to determine the relevance and fit of the findings of my study in the broader context of the related literature. In addition, this process enabled me to identify how the findings of each of the categories and the overall conceptual model confirmed, refuted or extended current understandings of health care service delivery for this population. Finally, I presented the study findings and conceptual model at national and international conferences for the purposes of peer review. Feedback from the conference delegates at these presentations confirmed the relevance of the model to other current research into health care service delivery as well as the current clinical philosophies adopted by health professionals working with this population. I will also provide study feedback sessions and develop handouts in order to share the study findings with the parent participants.

5.4 Quality and rigor of the study

My commitment to credibility, trustworthiness and auditability, key standards of quality and rigor in qualitative research (Birks & Mills, 2011; Creswell, 2007) are demonstrated throughout the study process. The methodological credibility of the study was maintained through congruence of the research questions and clinical context with my chosen approach and research methodology. In addition, the theoretical credibility of the study was also maintained through obtaining thick descriptions from participants, theoretically sampling for a variety of parents' experiences, and using direct quotes from participants during data analysis and presentation of findings to preserve the parents' viewpoints (Birks & Mills, 2011; Chiovitti &

Piran, 2003; Cutcliffe, 2000). I frequently sought consultation and peer review from my study supervisors, who have extensive experience in the grounded theory methodology, to ensure that the methodological and analytical processes of the study were consistently sound. The trustworthiness of the study findings are supported by my prolonged immersion in the data, as well as my prolonged engagement with the participants, which provided me with unique insights and familiarity with the study setting and data (Charmaz, 2006). In addition, participants were sent the transcripts of their interviews and were offered opportunity to clarify or add further explanation to their data if they felt understanding was lacking. I also used an open process of reflexive thinking and critical reflection throughout data collection and analysis to ensure my analysis and interpretations remained focused on the study topic and participants viewpoints (Birks & Mills, 2011; Charmaz, 2006). Finally, the auditability of the study was maintained through a transparent audit trail of all the research processes (Creswell, 2007). I wrote extensive memos clearly describing the study setting and context, how the data was collected and analysed, and each methodological and interpretive decision made, including coding and sampling decisions, and details of how my understandings of the overall theory developed. By providing a full and accurate description of the study context, research design and processes, I aimed to allow for others to determine the usefulness of the study findings to other settings and contexts (Charmaz, 2006).

5.5 Chapter summary

This chapter details the research processes and methods followed for the grounded theory study exploring parents' experiences of health care for their children with cerebral palsy living in a regional Queensland area. Participants were parents of children with cerebral palsy, and were recruited using convenience and theoretical sampling. Data collection and analysis occurred concurrently and followed the process of constant comparative analysis. Data was collected using focus groups and individual in-depth interviews, and data was analysed using coding, memoing, sorting, identification of categories, and diagramming, which allowed the development of a conceptual model of parents' experiences of health care for their children with cerebral palsy. The plausibility of the conceptual model was explored by comparing the model to participants' raw data and to relevant literature, as well as peer review of the study findings and the conceptual model through presentations at national and international conferences. The findings of the study and the conceptual model will be presented in the next chapter.

Chapter 6 Findings of the grounded theory study: “Making the most of their body and their life”: Parents’ experiences of health care for their children with cerebral palsy in regional Queensland

6.1 Introduction

As outlined in previous chapters, current health care service delivery approaches for children with cerebral palsy recognize the importance of including parents in the health care of their child. Although much literature is dedicated to the evaluation of health interventions and service delivery practices for children with cerebral palsy, no previous researchers have inductively explored parents’ experiences of health care for their child. The aim of this study was to address this gap in knowledge.

In this chapter, the findings of the grounded theory study exploring parents’ experiences of health care for their children with cerebral palsy in regional Queensland are presented. Parents of children with cerebral palsy in this study experienced health care for their child as a cyclical process of “making the most of their body and their life”. Important aspects of care included evolving needs, learning as you go, navigating the systems, meeting needs through partnership, being empowered or disempowered, and finding a balance.

This chapter is adapted, with alterations to ensure consistency and reduce redundancy, from:

Hayles, E., Harvey, D., Plummer, D., & Jones, A. (2014). Parents’ experiences of health care for their child with cerebral palsy. *Qualitative Health Research*. (Manuscript submitted for publication).

6.2 Findings

Participants for the study were 13 parents of children with CP aged less than 17 years old and who resided in the regional area. The 13 participants consisted of 11 mothers and two fathers, which included one foster mother and one adoptive mother. Nine of the parents lived in the regional city. Four participants lived in a rural location, with three of those participants living more than 100 kilometres from the regional town. The participants’ children with CP ranged in age from 22 months to 16 years, their functional abilities were spread across the five levels of the Gross Motor Function Classification Scale (Palisano et al, 2007), and their associated impairments most frequently included visual impairments (3), cognitive impairment

(5) and epilepsy (7). Table 5.2 provides additional descriptive information about the participants and their children with cerebral palsy.

The analysis of the narratives of the participants in this study indicated that parents of children with cerebral palsy experienced health care for their child as a constantly evolving process of "making the most of their body and their life". Parents felt that they held primary responsibility for meeting the needs of their child, and this sense of responsibility impacted on parents' experiences of their child's health care. Parents' experiences of health care are depicted as a model using a flow diagram (Figure 6.1). Six categories or processes that parents identified as important aspects of health care for their children with cerebral palsy included – evolving needs, learning as you go, navigating the systems, meeting needs through partnership, being empowered/ disempowered, and finding a balance.

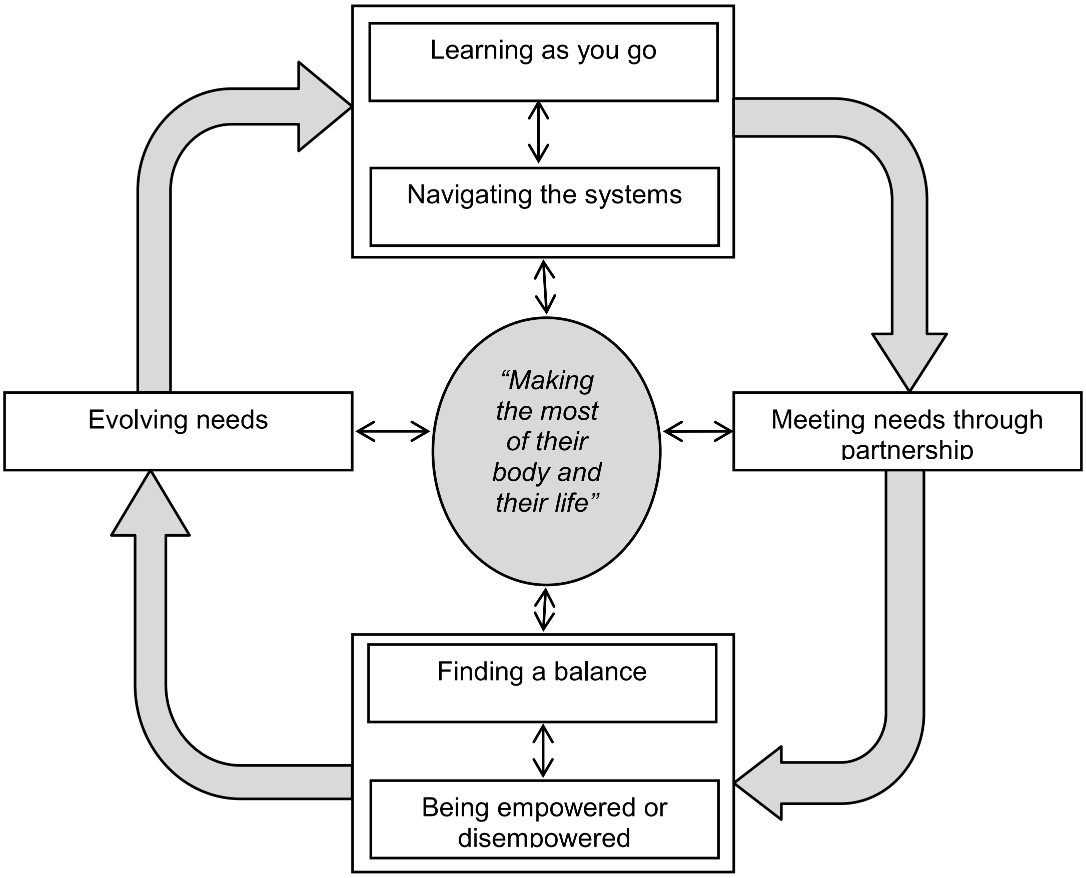

Figure 6.1 Parents' experiences of the process of health care for their children with cerebral palsy.

The cyclical model of health care is interactive in nature – parents' experiences of each process occurred as a result of the previous process, and in turn affected parents' experiences of the next process. For example, parents' experiences of meeting needs through partnership are affected by their experiences of learning as you go and navigating the systems. Subsequently, parents' experiences of meeting needs through partnership affected their experiences of being empowered or disempowered and finding a balance. The six key categories or processes are arranged around the core category – "making the most of their body and their life" - to reflect the understanding that parents' experiences of the core category have a two way interaction. Parents' experiences of each of the key categories is motivated by their perceptions of the core category; however, parents' experiences of each key category also impacts on their experiences of being able to make the most of their body and their life.

6.2.1 Evolving needs

Parents' described health care for their child with cerebral palsy as an ongoing cycle of dealing with one issue after another, with the needs of the child and family constantly changing or evolving:

> When (child) was small he used to get aspirated pneumonias … so we ended up having to get the (gastrostomy) button in… That stopped the aspirated pneumonias. After that we had problems getting the proper standing frame for him... Once we got it, his hips were already out, so we had to have the operation for his hips. Once he had his operation for his hips, the main thing was the gagging and choking, having to suction him. (Participant 4)

All parents in the study experienced this process regardless of their child's age or functional level. The needs of the child and their family changed as a result of increases in the child's functional abilities or size, increases in the child's independence and participation in health care decisions and processes, or in response to the changing demands in life such as school attendance and social acceptance: "…now we have a 13 year-old who just wants to be like other 13 year-old girls, and she doesn't want to wear AFO's… that's a decision she's going to make, and there's nothing much we can do about that" (Participant 2). In some cases, parents described how the needs of their child evolved as a result of issues not being adequately addressed or as a side effect of previous treatments or interventions. Parents frequently reflected on their experiences of changing or evolving health care needs:

> She was much more mobile as a smaller child. As an older child, now it's become more of... a focus on how we deal with her day-to-day living, as far as transferring her from bed to chair, chair to toilet. Just transferring her without injuring her or ourselves. (Participant 2)

Because of the constantly changing or evolving needs for their child with cerebral palsy and their family, parents considered health care to be a constant in the child's and family's life: "The physio and the occupational therapists will be forever in (child)'s life as far as needs go. And definitely some sort of health care."; "Because obviously cerebral palsy's not something that goes away…” (Participant 2). The evolving cycles of health care also had an apparent cumulative effect in terms of parents’ subsequent experiences of health care. Each time a new need emerged, the knowledge and experience that the parents’ had gained through the previous cycle of health care affected their experience of managing the new need, in either a positive or negative way, or with more empowerment and know-how, or less.

6.2.2 Learning as you go

Parents’ descriptions of the process of learning as you go reflected the evolving nature of health care for children with cerebral palsy and their families: “…each time something happened … we learnt by it. …No one told us what to expect, no one could tell us, you know, we just winged it each year, by the year” (Participant 10). Parents progressively developed knowledge and understanding of the needs of their child and family.

Parents in this study reflected that learning as you go comprised three aspects of learning. Initially, parents learnt about the child’s needs, both at the time of diagnosis, but also as each new need evolved: “We didn’t know for a couple of years, with what was going on with her…then we found a place where we had a lot of answers, and we were getting the help we wanted...” (Participant 7). Parents then learnt to accept their child’s situation and needs: “…the day they introduced the wheelchair into the whole scenario… that really floored me… And then a couple of months later, it was the best thing ever” (Participant 2). Subsequently, parents’ experienced learning as you go through developing the capacity to think ahead and anticipate for the future needs for their child and family.

> See, we're about to go through another change where (child)'s hormones are going to come on-board and she will … you know,… go through puberty. Well, that's another big deal for us to have to go through, and need direction and help with from our support services… (Participant 2)

Parents progressively developed knowledge and understanding of the needs of their child and family throughout childhood.

Parents in this study learnt and developed knowledge of their child’s needs in two ways: through experience and through receiving information and guidance. Most frequently, parents described learning about their child’s needs through experience and finding out information for themselves, as each need arises: “You find out when you're needing it, at that moment” (Participant 3). However, parents also reported that learning as you go through experience created uncertainty. One parent described this as “flying blind”: “You just have to make your own decisions and hope that you’re making the right decision… it’s like flying blind” (Participant 6). Parents’ preferred method for learning as you go was through receiving information and guidance in an anticipatory way: “We were put in the right direction, which was really good” (Participant 7). Although parents did report receiving some information and guidance from health care providers, this did not frequently occur nor to the extent that the parents believed they needed:

> …we need more information, it always comes down to the parents need more information. If there is something available that may be beneficial to our child, or it may not be, we still want to know what it is so we can make a decision. (Participant 11)

Parents in this study considered that the information they did receive from health professionals and health care providers was often received by chance, in an ad hoc way: “I didn’t know about the growth plate things until one of the physio’s mentioned it to me once” (Participant 11). Many parents described that most of their learning occurred through sharing information with other parents of children with cerebral palsy or similar disabilities. For example, parents described their experiences of receiving most of their information through other parents at a playgroup and in waiting rooms:

> We were, sort of, put in a room with all the kids…. And there'd be a group of parents sitting on the side helping, and we’d start talking, and introducing each other. And then you'd say, “Oh, did you hear about this?” Or, “Did you know that you could do that?” (Participant 1)

> And the thing is, us parents, we do, we sit in those waiting rooms together and we talk, and, you know, we’ll say “Oh my son’s had this done, and he’s had this done, and this was his diagnosis, and this is how I got that done”, and so we teach each other because nobody’s teaching us. (Participant 11)

Parents’ frequently reflected on the importance of having links with other parents, or a social network of parents and carers, as a powerful method for information sharing and problem solving.

Although parents continually learnt about their child’s needs over time, some parents also described the experience of ‘living with unknowns’: “I guess it's coming to terms… you'll never get the answers you're looking for. Why did (child) have cerebral palsy in the first place?” (Participant 1). However, parents also identified that knowing about possible outcomes or potential problems was more important than actual confirmation of these outcomes and provided parents with a degree of certainty: “As I said, in the hospital, once (child) was born, I didn’t have the same thing where I didn’t know. I knew it was a possibility right from the word ‘go’ with him” (Participant 6). Having unknowns in the early years of their child’s life made it more difficult for parents to learn about their child’s needs because they didn’t know what to expect. Although they eventually learnt about their child’s needs through experience, parents reported that having knowledge of potential problems and outcomes was important because this enabled them to anticipate the future for their child and family:

> …I can understand doctors and professionals really not giving their opinion, but they don’t give any opinion at all, and it would be nice to say “Well… the possibilities are that yes, (child)’s going to be in a wheelchair”. Like not saying “Yes, he will be”, but “The possibility is there.” (Participant 12)

6.2.3 Navigating the systems

Parents experienced the process of navigating the systems when searching for health care services or systems that could meet the needs of their child and family. Parents’ descriptions of health care services and organisations reflected their understanding of health care as a multitude of systems with different eligibility, accessibility, availability, policies, procedures and funding that needed to be navigated in order to find the help they required to meet the needs of their child and family.

> We found that… the system started from zero to five-year-old, six-year mark… Then we went into a different system… because we started school and had that system looking after her… Now we’re in another system because we’ve swapped to a private system… (Participant 2)

Parents navigated the systems throughout childhood and some parents anticipated the need to do this again as they prepared for the child’s transition to adult services and planned for their child’s future.

> Well I think my biggest fear is that it’s all going to stop soon, he’s going to hit an age where there’s going... we’re not going to have the access that we have now because he’s still classed as a child. I need to know now… as a parent, I need is to know what the continuing healthcare needs that are going to be available to him. (Participant 11)

Parents described that their experiences of navigating the systems varied depending on the type of need required, the complexity of the health care system or systems in which they were engaged, and their level of participation in the process. During their child’s infancy and early childhood, parents were more likely to navigate the systems for general needs, such as guidance about what their child might need and what services were available for their child.

Later on in childhood, as they developed knowledge of their child's needs, parents also navigated the systems for specific needs. In addition, parents navigated between different care systems, for example between the health system and the education system, or within a single care system, such as navigating between a general paediatrician and rehabilitation specialist who they access within the one health system: "The consultant, who's the specialist, … doesn't have the ability to oversee (child)'s care medically, so we have to go back to (the paediatrician)…" (Participant 13). Finally, parents were also either active or passive participants in the process of navigating the systems. Parents actively navigated the systems when they enquired about services to find which service they should access or which service could meet their needs. In contrast, parents passively navigated the systems when their child was discharged from a service, or referred or passed on to another service, which gave them a decreased sense of control over the situation: "It was all new to me… and once he was discharged from the clinics … it was sort of like living in limbo" (Participant 6); "… you bounce…you go to the clinic…and you're seeing all different doctors, you're saying the same things over and over again" (Participant 6).

Most parents' indicated that the process of navigating the systems was difficult, with multiple organisational, communication and access issues creating barriers to finding the help that they need: "We've always had to try and find out where do we receive these services from? Where should we be looking?" (Participant 2). Parents reported that challenges to navigating the systems included a lack of information, variability in eligibility, accessibility and availability of different services and across different geographical areas within the regional area, and gaps between services.

> So, yeah, it's, you know, school doesn't do home, and community won't do this, and this won't do this, and so the kids all fall through the...there's no one that does everything and just says "I will come out to the home, I'll do this, I'll do that, and I'll do that". There's no one here that does that. (Participant 10)

Parents consistently described a need for, yet lack of, information and guidance about services and supports regardless of the age or developmental level of the child. Parents frequently described the experience of 'doing it on your own' and 'lacking support' or 'chasing the care needed' when reflecting on their experiences of navigating the systems: "It's hard, because you've got to find out all the information yourself, no one says 'You should be doing this, you should be doing that' …a little bit more help and guidance would be good, helpful" (Participant 12). Although some parents received some information from health professionals about services available, parents also described that the information provided was not comprehensive or ongoing. Similar to their experiences of learning about their child's needs, parents frequently described that they found out information and guidance from other parents at opportunistic moments or from the internet. Parents who had had more positive experiences of navigating the systems described that they linked in, early on, with a network of comprehensive services that were able to meet their needs, and that that service remained consistent throughout the child's childhood:

> I found that whole network thing of, you know, under the direction of the paediatrician; all of the other services have all been linked in. Everyone's known very much about (child)'s situation. (Participant 8)

The process of navigating the systems was also made more difficult by onerous paperwork, limited eligibility criteria and/ or stretched services which limited the child being able to access some services available. Although parents were eventually able to access the care that was needed, the process of knowing where to go or who to contact to access the service they needed was a challenge for almost all parents.

> ...because we found that… we don't know who to approach to get the care that we're requiring. It all comes from us and we don't know what exactly we need. And how long to wait before we should be get some direction on what we should be doing. And … yeah, that's … it's really difficult… (Participant 2)

Parents' experiences of the processes of learning as you go and navigating the systems occurred concurrently and impacted on each other. For example, the more the parents learnt about their child's need and the services available, the easier it was for them to find the help they need, and the more likely they were then able to learn more about their child's needs. Conversely, the less the parent knew about their child's needs, the more difficult it was for them to know what services they might need, and how to access them. Unfortunately, for most of the parents in the study, the latter example was more commonly described: "…a lot of parents are going alone because of, maybe, not knowing what is available in utilising the amount of therapy or services that we have in the area" (Participant 1).

6.2.4 Meeting needs through partnership

Children with cerebral palsy and their families did eventually get the help that they needed. However, parents described that their preferred approach for having the needs of their child and family met was through a partnership with health care professionals: "I think that's what works; you've got to make it personal. We don't want to feel like a number or just another case; we want to feel like you care" (Participant 11). Parents' perceived that a partnership developed through their interactions and relationships with health care professionals. The concept of a partnership, for some parents, also extended to a partnership with health care services and the local community: "…we've been to a couple of forums… we were one of about three parents, I think, and quite a large contingency of other people involved in the disabilities services and the government" (Participant 1). Parents perceived that a partnership with health professionals and health care services was a key aspect of care that ensured that the needs of their child and family are met.

Parents' descriptions of their interactions with health care professionals and services indicated that specific attitudes, values and processes contributed to their experiences of partnership. Parents' described a need for mutual regard and respect between the parent and the health care worker, and for the role each had in the process of health care for the child with cerebral palsy. Parents needed to perceive that they were being respected, regarded and listened to as a parent who knows their child and family best. Equally important, parents wanted to perceive that health professionals and services respected and regarded their child with cerebral palsy as a person who has potential and should have opportunity to experience life like any other child. Parents considered that they had primary responsibility for meeting the needs of their child. Therefore, parents felt that the needs of the child and family should be considered from their perspective, and that they, as parents, held the responsibility for making decisions about the care required. Parents want to be asked their opinion and to believe that they have a voice in the care of their child:

> I'm willing to listen to what the doctor's got to say, but I want him to listen to what I've got to say as well. So usually I come to a middle ground somewhere where I go "ok, yeah, I'm happy with that, we've compromised, he's said no AFO, I said I wanted an AFO, so we've compromised and we want him to wear it only during school hours". You know, so we've come to a compromise that works for both of us and we're all happy. (Participant 11)

Although they indicated their preference for a partnership, parents in this study did not always experience having their needs met this way. Parents frequently described experiences in which they felt that their knowledge of their child and their child's needs were disregarded by health professionals: "…it has been a very stressful time just getting people to listen, to support. I just know when things aren't right with him and yes, it's very frustrating when you're not listened to" (Participant 5). Some parents, particularly those whose children were more physically disabled, described experiences in which they thought that their child's well-being and potential was not valued by the health care professional or health care service:

> I asked that something be placed in his stomach because I could already see that the button was closing, the hole was closing. They said "We've got a major accident" and I said "I don't care what you've got. I've got a son in there. If you

> don't get something in that hole right now, we're going to end up in a major operation our self, having another button put in." (Participant 5)

Parents also identified organisational aspects of health care services and systems that impacted on having their needs met through partnership. Some parents whose children were less physically disabled explained that the limited availability of services for their child impacted on having their needs met: "Because he's, I guess, technically considered mild, the services? There not there, he's way, way down on the list. Lots of things don't seem to be as important where he's concerned, because he walks, he talks" (Participant 6). In contrast, another parent whose child had very high needs described a lack of partnership with the school system because of the limited scope of service the school system provided:

> Pretty much the school was all about education and not about (child)'s mobility and (child)'s ability… and fair enough they're an education department, but a special (education) unit for me means doing the things it needs for these children to be able to help their bodies to perform and do what needs to be done and help maintain these children. (Participant 5)

Parents who lived in the rural areas of the study area also experienced a lack of partnership due to the limited availability of services:

> I know that they've got a speech therapist in this building – she's only allowed to see children that aren't school age, which I think, if you've got somebody in a small town like that, can't it be opened up to (all) children who require it?... because (child) needs that. (Participant 6)

A lack of partnership in the process of having their needs met impacted directly on how parents experienced subsequent processes in the cycle of health care for their child with cerebral palsy. Parents reported that not being listened to or having their child's needs disregarded resulted in the needs of the child or family being overlooked, the child missing out, or having unmet needs. Parents described the impact this lack of partnership had on their interactions with the health care systems as a fight or a battle they had to deal with to have their needs met:

> It's been a constant fight and battle. I'm still fighting to get a standing frame in the school…then it was a constant battle of fighting for therapy… it doesn't matter what we do, we have to fight and challenge everyone on everything. (Participant 5)

This added stress in the parents' life also impacted on their own well-being and the well-being of the family: "…it's not until it actually creates a problem that they do something about it, and that's really upsetting because of the stress that it puts on us as a family…" (Participant 7).

6.2.5 Being empowered or disempowered

Parents described that their experiences of being empowered or disempowered occurred as a result of their experiences of health care for their child with cerebral palsy. Parents experienced of empowerment or disempowerment through developing confidence in themselves as parents who had the ability to meet the needs of their child with cerebral palsy, which reflected their sense of responsibility for this role in their child's life. However, parents relied on health care professionals and health care services to work with them to achieve this goal. This placed parents in a position of dependence, in which their capacity to meet the needs of their child relies on the partnership between them and the health professional or health service.

Parents described being empowered or disempowered as a result of their sense of trust and confidence in their child's health care workers and services, which in turn, developed from their interactions with health care professionals and health care services who were partnering with them to meet their needs. For example, when parents were given guidance and support, if they knew where to get help, and felt like they had a voice in their child's care, then the parents felt empowered in helping their child to get the care that they needed. One parent described her sense of confidence in the professionals and processes when an intervention was being organized for her child:

> Everything was available right there…You felt like something was being done. You didn't get sent home with no answers… you got sent home with every bit of information you needed… And every time you left they said "Any concerns before your next appointment, call us." (Participant 11)

However, when the parents perceived a lack of support, if the parents' concerns were disregarded, or if the parent found it difficult to get the help that they need, then parents experienced a process of disempowerment. One parent explicitly described this process of disempowerment during their interview:

> Because we're experiencing that (lack of partnership) with that service, and (also) with the health service, I think (father) and I kind of, at times, …myself more than (father), …start to feel we don't have the capacity to act in her best interests… (Participant 13)

Parents reported that their experiences of being empowered or disempowered had significant impact on their current and future experiences of the health care situation. If a parent had been empowered or disempowered in one health care situation, then this impacted their confidence and trust of new or future health care situations.

> … I think that at every turn we feel that (child) is, or that we're really vulnerable in our role as her caregivers, so that if we're giving any feedback that isn't going to be constructive or positive, that it's just going to actually make everything worse. (Participant 13)

Parents' experience of being empowered or disempowered occurred concurrently and interacted with the process of finding a balance.

6.2.6 Finding a balance

Parents' accounts of finding a balance reflected a process of decision making. Finding a balance was described by the parents in this study as a process of continuous evaluation, prioritization and management of the needs of their child with cerebral palsy in the context of all the other needs and challenges in the life of child and the family.

The process of finding a balance was influenced by parents' understandings of the challenges they were dealing with. The challenges that parents experienced could be separated into those that they accepted or at times even took for granted and those that they didn't accept and were caused by externally imposed factors. Parents accepted or took for granted challenges that they understood as being part of life of having a child with cerebral palsy or challenges that they felt they had made a choice about. For example, one parent explained the challenge of having access to limited services in the regional area, a challenge associated with a choice they have made: "I know we're a small place. If we moved to (capital city), yes, we'd probably have it more accessible, but, you know, not everyone can live in (capital city)". Another parent explained her acceptance of the physical challenges associated with caring for her son:

> I've got to lift him in the car. I've got to lift his wheelchair in the car…He's 38.9 kilos. The chair's 44 kilos. So there's lots of things – I had a lady come out with me the night we were fundraising, …it took us half an hour to get him sorted because we had to suction, lift chairs in, and she was just shocked on what I have to do to actually go out… and I said "well we're used to it." It's just how it is and it's just that we have to do this. (Participant 5)

However, parents understood situations that they perceived to be created by external factors outside of their control differently. Parents did not take for granted external factors such as supports and services that were of benefit to their child and their family.

> …it's just been phenomenal, what we've had done. If we hadn't have moved here, we wouldn't have got onto this (specialist), like we'd tried for years…I can't say enough about being up here, and what it's done for us as a family, and for (child). (Participant 7)

> I think that... overall he was lucky, the… programme he was part of was the head of its field when he was first diagnosed so we got in on the ground floor with a great doctor, I just happened to have a really good physio that knew about what was happening at (that programme) and put us straight through to them. (Participant 11)

In a similar way, parents did not accept added challenges that were created or existed because of external factors outside their control. Parents did not accept having appointments scheduled at inconvenient times, barriers to accessing services such as limitations in terms of eligibility and availability, or a lack of support or services, including both physical care and financial support.

> So it really has put an extreme amount of stress on us as a family here, not being able to just go and see a therapist in our area… when it really should not have been like that. And we went to our local minister and we got told that if we want those sort of services we need to leave the area, because we'd probably never have them. They said that's just part of living in a remote area, and I just thought well, that's not acceptable. (Participant 5)

It was these added challenges because of external factors that parents seemed to express most dissatisfaction about or had the most difficulty dealing with.

Parents described that the process of finding a balance encompassed consideration of the benefits and disadvantages of health care for their child with cerebral palsy as they impacted on the whole family. For example, parents described that the siblings might miss out on school photos or sporting activities because the parents had to take the child with cerebral palsy to an appointment. Alternatively, the parents themselves described being emotionally and physically tired from trying to do the best for their child with cerebral palsy. In many situations, the needs of the child with cerebral palsy predominated:

> You have to make sacrifices all the time. People always say “Well, how do you do it?” and “You shouldn’t do it.” I say “But we have to. That’s how we live.” We make our lives around that, because it’s all around (child). She’s the centre, and that’s just how we have to be. We wouldn’t survive as a family if we didn’t. (Participant 7)

However, at other times parents prioritized the needs of other family members or siblings, for example, when fitting health care appointments around work times for the parents or school hours for the other siblings: “… as a family you have to think of these things as well, it’s not just about getting everything for your child, you’ve got other kids to care for as well that are going to miss out.” As a result, some parents explicitly explained the need for health care services to consider the needs of the whole family to help them find a balance:

> I think sometimes the health care needs to be around the family a little bit more… the parents need to be cared for a bit more… (and) something to embrace the other siblings, because we get tired, we get stressed, and then that comes out impacting on the family circle. (Participant 7)

Parents constantly made decisions based on their evaluation of the impact on the child and on the family.

The processes of being empowered or disempowered and finding a balance were closely linked. When a parent felt like their child’s needs were not being met, they felt disempowered as a parent and were more likely to prioritise the needs of the child with cerebral palsy over the needs of the rest of the family. In contrast, if the parents felt confident that their child’s needs were being met, they subsequently felt more empowered and had opportunity to make decisions that balanced the needs of everyone in the family. However, according to the parents in this study, the lack of information and lack of support contributed to them more frequent experiencing difficulties with balancing the needs of the child and the family.

> It’s been a very interesting journey, but… I feel that we could’ve had a lot easier run... We haven’t had a really great opportunity, and we do, we absolutely adore our son, and we enjoy our lives, we try to enjoy it the best we can, but it’s very hard to with all the stress and the problems that we entail… (Participant 5)

6.2.7 Core category: “Making the most of their body and their life”

As is illustrated by the model in Figure 6.1, “making the most of their body and their life” was how parents in this study experienced the overall purpose of health care for their child with cerebral palsy, and underpinned their experiences of every other process in the cycle of health care. Parents explained that “making the most of their body and their life” incorporated maximizing the child’s physical and developmental skills, their independence and preventing deterioration, but that this was balanced with maximizing opportunity for their child to lead a rich, happy and personally fulfilling life. Parents wanted their child to be the best they can be, but not to the detriment to the child’s enjoyment of life.

> … I’m trying to reach that middle ground of making sure that (child) has the best opportunities to reach that ceiling that’s there… and also to have that ceiling raised if it can be in terms of her development, but that’s not what life is about. Her life is about living, and doing those things with her and for her is going to be something that enriches her life and help her to grow and develop as a human being. (Participant 13)

Parents perceived that health care professionals and health care services were there to help facilitate this purpose: “... giving them the steps … to make the most of themselves, to some degree. Providing a fun way that she can actually make the most of her body and her life” (Participant 2).

An important understanding of how parents experienced “making the most of their body and their life” was how the parent experienced that their child was perceived by others. Parents wanted their child to be perceived as a child first, and as having a disability second. Parents wanted their child to be perceived by others as having the same right to opportunities to maximize their potential, but also the same right to joy, independence, desires, happiness and sense of fulfillment as other children without disability. Parents wanted their child to be given the same opportunities as any other child, and to be respected as a person, rather than be treated as something that is ‘broken’ or that ‘needs to be fixed’.

> The initial consultation with (the paediatrician), for example, was around us presenting the issues so it was all kind of issue-based – “She’s this, she’s that, she’s that”, you know, and as parents finding that really difficult because… it all becomes around (child) being this thing with all these issues that need to be addressed. (Participant 13)

> I would so love that people become far, far more enlightened to see past that and see that (child) is a strong, spirited little girl who deserves to have every opportunity to achieve the best that she can and to have the support to do that… (Participant 13)

Parents' understandings of "making the most of their body and their life" underpinned and impacted their experiences of all other aspects of their child's health care. Throughout the process of health care, parents made choices and took opportunities that they considered would provide their child with opportunities to be the best person they could be. Parents learnt about their child's needs and navigated the systems to find the help that they needed. Parents who had their needs met through partnership then developed a sense of empowerment. Parents who were empowered were more likely to believe that they could meet their child's needs, and therefore were more able to find a balance. As a result of all these processes, the parents felt they were able to find opportunities for their child and family to lead a balanced, happy life. Every stage of the process of health care the parents experienced was motivated by this purpose, and every stage of the process of health care fed into this overall goal of "making the most of their body and their life".

> I'm trying to reach that point where I feel confident that professionals involved with her are helping her to achieve her potential as much as possible … And helping her to develop that sense of "I'm a little girl. I'm a little girl who's got an unusual situation because I have to have all these people involved …but I'm a little girl. I'm not a patient all the time and having to do all this is just… a very small part of who I am". (Participant 13)

6.3 Chapter summary

Parents of children with cerebral palsy living in a regional area of Australia experience health care for their child as constantly evolving cycles of "making the most of their body and their life". Key processes that contributed to parents' experiences of health care were evolving needs, learning as you go, navigating the systems, meeting needs through partnership, being empowered or disempowered, and finding a balance. This is the first study to provide inductive understanding of parents' experiences of health care for their children with cerebral palsy living in a regional Queensland area.

Chapter 7 Discussion

7.1 Introduction

In the previous chapter, the findings of the grounded theory study into parents' experiences of health care for their children with cerebral palsy in a regional area of Queensland, Australia were presented. According to the findings of this study, parents experienced health care for their children with cerebral palsy as a constantly evolving cycle that consisted of six key processes: evolving needs, learning as you go, navigating the systems, meeting needs through partnership, being empowered or disempowered, and finding a balance. The core category and purpose for health care in the child's life was "making the most of their body and their life". In this chapter, the findings of the study are discussed in relation to other relevant literature relating to health care service delivery for children with cerebral palsy or children with other similar disabilities and their families. The purpose of this discussion is to position the findings and conceptual model in the context of current understandings of health care service delivery for this population and to describe the contribution to the literature.

In the first section, the six key categories and the core category are discussed in relation to the relevant literature. The relevance and similarity of each of the categories to key principles of health care service delivery approaches is demonstrated. These approaches include family centred care, the concept of a partnership relationship between parents and their children's health care providers, and empowerment. Parents' experiences of each of the categories are also similar to the findings of previous literature that examines issues with health care service delivery for this population. However, four new concepts have also been identified through this study which are less well explored and understood in the literature, and the contribution of these concepts to new understandings of health care service delivery for children with cerebral palsy are discussed in detail. These concepts include the temporal nature of needs evolving over time as the child develops; the concept of being empowered or disempowered through the interactive processes of health care; the importance of having a community or network of supports for receiving information and guidance, and; the importance of the attitudes and values of health care professionals and services to parents' experiences of partnership and empowerment. In the second section, the conceptual model is compared to the previously identified guidelines and standards of care. Key differences between the conceptual model and the guidelines and standards are identified and explored. The discussions in this section provide identification of new understandings of parents' experiences, as well as aspects of health care service delivery that can be improved for this population.

7.2 Comparisons of study findings to the literature

7.2.1 Evolving needs

Parents' experiences of health care as an ongoing cyclical process that evolves over time reflects a temporal process. For the parents in the current study, the need for health care was constant, but the focus of health care changed over time in response to the evolving needs of the child and the family. The evolving nature of the cycles of health care also had an apparent cumulative effect - parents' experiences in one cycle of health care impacted on their experiences in the next cycle. Although the current literature relating to health care service delivery for children with cerebral palsy does acknowledge that cerebral palsy is a lifelong condition, the evaluation of health care for children with cerebral palsy often focuses on evaluation of individual episodes of care or of services at a single point in time (Baird, McConachie, & Scrutton, 2000; Capjon & Bjørk, 2010; Garwick et al., 1998; Iversen et al., 2009; Karande et al., 2008; Law et al., 2011; Phua et al., 2005; Ziviani et al., 2011). This approach to the evaluation of health care for this population does not explicitly reflect or acknowledge the temporal nature of health care as identified in this study.

Parents' experiences of health care as a constant in the child's and family's life are synonymous with the concept of consistency of care. Consistency of care is recognized in the literature as an important aspect of health care service delivery for children with chronic illnesses and disabilities (Fereday, Oster, & Darbyshire, 2010; Murphy et al., 2011; Nuutila & Salanterä, 2006; Rossiter, Fowler, Hopwood, Lee, & Dunston, 2011). Consistency of care was described by the parents in this study as seeing the same person, having regular reviews, and having consistency of service eligibility and accessibility across different services and throughout the child's different ages and developmental stages. Parents in this study perceived that consistency of care contributed to improved understanding for both the parent and the health professional of the child's and family's needs, improved relationships with health care professionals, and more chance of having their needs met. These findings are consistent with previous literature that identifies links between consistency of care and the development of a partnership relationship between health care professionals and parents of children with special health care needs (Kieckhefer, Kratz, Trahms, Uding, & Villareale, 2009; Knapp, Madden, & Marcu, 2010; Nuutila & Salanterä, 2006). In contrast, these findings challenge the use of an episodic care model, in which services are only provided for a finite periods of time for a specific issue, following which families are discharged and must be re-referred for the next episode of care (Comino et al., 2012). In addition, despite the importance of consistency of care to their experiences of health care, parents in the current study indicated that this was often difficult to maintain, and a lack of consistency of care contributed to difficulties in the processes of learning as you go, navigating the systems, and subsequently meeting needs through partnership. These findings are in line with the results of previous research that demonstrate that inconsistent care, particularly from different health care providers, contributes to a lack of mutual trust between parents and health professionals, decreased access to appropriate and timely care, and decreased satisfaction with services (Knapp et al., 2010; Law et al., 2003a; Nuutila & Salanterä, 2006). However, parents in the current study indicated the importance of consistency of care to all categories in the cycle of health care, including the processes of being empowered or disempowered, finding a balance and "making the most of their body and their life". The impact of consistency of care on these other aspects of health care have not previously been recognised, and require consideration for health care service delivery practices for this population.

7.2.2 Learning as you go and navigating the systems

Parents' experiences of the processes of learning as you go and navigating the systems involved learning about their child's needs, as well as searching for and finding the appropriate health care services who could then meet their needs. A key aspect of care that contributed to positive experiences of these processes was receiving information and guidance. For the parents in this study, receiving information and guidance incorporated knowledge of their child's and family's needs, both now and in the future, and of services and supports available to them including how to access them. Having both theoretical and practical knowledge has been shown to help parents to feel more confident and therefore empowered (Kieckhefer et al., 2009; Staples, 1990). However, many parents in the current study reported a lack of information and guidance from health professionals and services, and instead reported that they received most of their information from other parents at opportune moments. These findings are consistent with previous research identifying that provision of information is an important but often unfulfilled need for parents of children with disabilities or special health care needs (Bellin et al., 2011; Jeglinsky et al., 2011; Nuutila & Salanterä, 2006).

The need information and guidance described by parents in this study continued over time and changed in response to the evolving needs of the child and the family. This continued need for information and guidance over time has been identified in previous research evaluating health care service delivery practices for children and their families requiring ongoing care (Nuutila & Salanterä, 2006; Palisano et al., 2009; Rossiter et al., 2011). One study suggested that one reason parents might continuously need to know more information could be due to a parental perspective that they can never have too much information (Palisano et al., 2009). However, the findings of this study, which indicate that health care is experienced as a constant but evolving process, provide an alternative interpretation for parents' ongoing need for information: each time a new need arises, parents re-enter the cycle of health care and the categories of learning as you go and navigating the systems. Therefore, the parents' continuous need to know more information occurred in response to the changing or evolving health care needs for their child and family. These findings are consistent with that of another study that demonstrated that parents caring for children with long term illnesses experienced an ongoing and changing need for information and support throughout the different phases of learning to care for their child (Nuutila & Salanterä, 2006).

Parents in the current study also identified that another important source for sharing and receiving information and guidance was through having links to a network or community of other parents. The concept of what constitutes a support network or a community support, although not clear in the health and disability literature, appears to refer to individual people, or services and organisations, available in the community who provide support to families but are separate to any health care system. The benefits of having links to community supports are mentioned in two relevant studies. In the first study, the principle of having links with community supports in order to support the well-being of the child and the family is explained in relation to the family centred care approach to health care service delivery (Rosenbaum et al., 1998). In the second study, parents reflecting on their experiences of raising a child with cerebral palsy described that they benefited from both formal support provided by specific community services and informal community support provided by extended family members, friends, other parents of children with cerebral palsy, and other community members (Reid et al., 2011). Both of these studies describe that the primary benefit of having links with community supports is that it contributes to the child's and family's well-being. In contrast, the parents in the current study identified that the primary benefit of having links with other parents was to receive information and guidance. This benefit of having links to community supports, particularly other parents of children with cerebral palsy, has not been identified in previous literature and provides a new understanding of the importance of these links for this population.

The organisation of health care services was a second key aspect of health care that parents described as contributing to challenges in their experiences of navigating the systems and finding the help they needed. For example, parents' in the current study described experiencing variations in the eligibility and organisation of services across different services, geographical areas, or ages, which subsequently impacted on the availability and accessibility of these services. The impact of the organisation of health care services is considered in some literature relating to approaches to health care service delivery, such as family centered care and collaborative, community-based primary care. Family centred care recognizes the central role that the parents and family play in the child's health care, and advocates for their involvement in the health care interaction and the development of services (Jeglinsky, Autti-

Rämö, & Brogren Carlberg, 2011; King et al, 2004; Law et al, 2003b). Collaborative, community-based primary care advocates for all health care services for the child and their family to be delivered in the community by a single physician in collaboration with other health service providers (Cooley, 2004; Liptak et al., 2011). Both these approaches advocate for coordinated and collaborative care across different services, and where possible, from as few different health care providers as possible (Farmer, Clark, Sherman, Marien, & Selva, 2005; Law, Hanna, et al., 2003; Nijhuis et al., 2007; Sloper, Jones, Triggs, Howarth, & Barton, 2003). Receiving services from an increased number of different providers has been associated with decreased parent perceptions of family centeredness of services and decreased parental satisfaction with services (Law et al., 2003a). The findings of the current study extend on this understanding. Parents in the current study described that having to receive services from a number of different health care providers over time due to changes in eligibility and accessibility contributed to challenges when learning about their child's needs, navigating the systems and decreased consistency of care. One model identified in the literature that may address this issue is the key worker model. In the key worker model, one health professional involved in the care of the child acts across service boundaries as a single point of contact, and ensures that access and delivery of services from the different agencies are coordinated and meet the various needs of the family (Sloper et al., 2003). The findings of the current study support the use of a key worker model to potentially improve parents' experiences of consistent, coordinated and collaborative health care service delivery across service boundaries and over time.

7.2.3 Meeting needs through partnership

Meeting needs through partnership was a key process that enabled parents to get the help that they needed. The concept of a partnership relationship between parents and their child's health care providers has been widely described and supported by previous studies (Cooley, 2004; Davis et al., 2002; Fereday et al., 2010; Haas, Gray, & McConnell, 1992; Lipson Aisen et al., 2011; Murphy et al., 2011; Nuutila & Salanterä, 2006). The concept of a partnership between parents or families and their children's health care providers is at the centre of the principals of family centred care and the family partnerships approach to care (Davis et al., 2002; Rosenbaum et al., 1998). These approaches encourage family involvement in decision making, collaboration with parents, and respectful and supportive interactions between health care providers and families (Davis et al., 2002; Rosenbaum et al., 1998). Elements of health care service delivery that are demonstrated in research studies to contribute to a partnership relationship include provision of family centred care, receiving consistency of care from the same health care provider, the health care provider having respect for the child and for the parents' role in the health care of their child, and the development of trust between the health care professional and the parent (Fereday et al., 2010; Galil et al., 2006; Murphy et al., 2011; Nuutila & Salanterä, 2006). These elements reflect that specific behaviours, attitudes or values demonstrated by health care professionals and services contribute to parents' experiences of partnership, which are consistent with the findings of this study. Parents in this study emphasised the importance of the attitudes and values of health care workers and services to their experiences of partnership. Parents wanted to feel respected and regarded as a parent, and for their child to be respected and regarded as a child and a person whose worth was valued by their health professionals and services. Parents identified specific processes that contributed to their experiences of being respected and valued by health care workers – these included taking the time, such as taking time to listen to concerns, answer questions or explain issues; being listened to, and; being accommodated, such as providing flexible care that accommodated the specific needs of the child and family. Not having a partnership relationship contributed to parents experiencing unmet needs, overlooked needs, missing out, or being disregarded. Therefore, parents' experiences of the category of meeting needs through partnership support the use of a partnership between health care professionals and parents of children with cerebral palsy. However, for the parents in this study, the development of a partnership also extended to their interactions with the wider health care services and organisations. For example, parents identified that organisational aspects of care, such as service eligibility criteria, service priorities or the limited availability of local services, especially in rural areas, contributed to difficulties in meeting needs through partnership. Only the importance of receiving consistency of care from the same health professionals to parents' perspectives of partnership with health care providers has been identified in previous studies (Murphy et al., 2011; Nuutila & Salanterä, 2006). The impacts of other organisational aspects of care on parents' experiences of partnership, as identified in this study, have not previously been identified.

7.2.4 Being empowered or disempowered and finding a balance

Parents' descriptions of empowerment in this study reflect that empowerment occurs through a number of processes and has a number of impact or outcomes, and that their experiences of empowerment can change over time due to the evolving nature of health care. The concept of being empowered or disempowered through the process of health care has previously been discussed in literature relating to health care service delivery for families of children with disabilities. Although the definition of empowerment is not entirely clear in this literature, there is some general understanding and consensus as to how empowerment occurs and what contributes to individual empowerment of parents of children with disabilities (Dempsey & Dunst, 2004; Dunst, Trivette, & Deal, 1988; MacMullin, Viecili, Cappadocia, & Weiss, 2010; Zimmerman, 1995; Zimmerman & Warschausky, 1998). At an individual level, empowerment is conceptualised to consist of intrapersonal, interactional and behavioural components (Zimmerman, 1995). The intrapersonal component refers to how parents perceive themselves, and includes their sense of self-efficacy, competence, motivation and perceived control over their life situations (Zimmerman & Warschausky, 1998). The interactional component refers to how people perceive and relate to their social environments, such as their awareness of how to access and utilise resources and to participate in the social environment in order to achieve a specific goal (Zimmerman & Warschausky, 1998). The behavioural component refers to the specific behaviours and actions that an individual takes when attempting to exercise influence on their social environment, such as participation in activities, managing problems or coping with stress and change (Zimmerman & Warschausky, 1998).

The concept of empowerment, and the conceptualisation of each component contributing to individual empowerment, resonates with the findings of this study. The intrapersonal component of empowerment is reflected in parents' experiences of being empowered or disempowered as a result of developing a sense of confidence in themselves as parents who could ensure that their child's health care needs were met and their sense of control in being able to "…make the most of their body and their life". The interactional component of empowerment is reflected in parents' experiences of being empowered and disempowered as a result of their interactions with health professionals and services, during the processes of learning as you go, navigating the systems and meeting needs through partnership. Through these processes, parents developed knowledge of their child's and family's needs and the steps and strategies required to access the care that they required. Finally, the behavioural component of individual empowerment is reflected in the processes of meeting needs through partnership and finding a balance. Through these processes parents reported taking specific actions, such as advocating for their child's needs or making decisions about their child's needs in the context of the rest of life, in their attempts to ensure that their child's health care needs are met. Parents in the current study described multiple aspects of care that contributed their experiences of being empowered or disempowered, which is consistent with the conceptualisation of individual empowerment in the disability literature (Dunst, Trivette, & Deal, 1988; Zimmerman, 1995; Zimmerman & Warschausky, 1998).

Much of the literature describing strategies to foster empowerment in parents of children with disabilities focuses on the imparting of knowledge and skills to parents and parents' participation in their child's care (Dempsey & Dunst, 2004; Dunst et al., 1988; Itzhaky & Schwartz, 2001; MacMullin et al., 2010; Reio & Fornes, 2011). For example, the impact of a parent intervention program that focused on imparting knowledge and skills, the performance of tasks, and enhancement of parents' self-esteem and sense of mastery is described in one study (Itzhaky & Schwartz, 2001). These types of strategies primarily address the intrapersonal and behavioural components of the concept of individual empowerment - that the parents' perception of their control of the situation and the actions they take to exercise influence on their situations. However, while parents' experiences of being empowered or disempowered in this study also support these understandings, the interactional component of empowerment - that is, parents' interactions with health care professionals and services - were particularly emphasised by parents as being important to their experiences of being empowered or disempowered. Only one previous study could be identified that demonstrated this link between parents' perceptions of their relationship with health professionals and their experiences of empowerment (Dempsey & Dunst, 2004). In this study, parents' perceptions of their level of participation in the child's care and of the nature of the relationship with the health care provider as one that promoted self-efficacy of the parent were both predictors of their experiences of empowerment (Dempsey & Dunst, 2004). The findings of this current study exploring parents' experiences of health care for their children with cerebral palsy, therefore, provide additional support to the understanding of the importance of the interactional aspects of health care to parents' experiences of empowerment.

Finally, parents' experiences of finding a balance were consistent with the principals of family centred care. The process of finding a balance involved evaluation, prioritisation and decision making that considered the needs of the child in the context of all other challenges in life. Parents constantly considered the benefits and disadvantages of health care for the child as it impacted on the whole family. This finding is consistent with the family centred care approach which recommends that the needs of all family members should be considered when delivering care to children with disabilities and their families (King et al., 2004; Law et al., 2003b). The importance of addressing the needs of all family members is also addressed in literature relating to the development of partnerships between parents and health care providers (Murphy et al., 2011). An additional understanding developed through this study is how parents' perceptions of the challenges involved in their child's health care impacted on their experiences of finding a balance. Parents described that the process of decision making depended on their experiences of the challenges they were dealing with. Parents accepted challenges that they perceived were part of life or that they had had a choice in, but did not accept challenges that they perceived were created by externally controlled situations, such as challenges in accessing care for their child due to limited service eligibility and availability. This understanding provides new insight into the importance of parents' perceptions of the various challenges they face, and the impact parents' sense of control or empowerment has on their decision making and their experiences of finding a balance.

7.2.5 “Making the most of their body and their life”

Understanding parents’ experiences of the overall purpose of health care for their child with cerebral palsy – as explained by the core category “making the most of their body and their life” – is a key outcome of this study that provides new insights for health care service delivery for this population. Parents in this study considered that the process of “making the most of their body and their life” incorporated maximising the child’s potential, but that this is balanced with maximising opportunities to lead a rich, happy and personally fulfilling life. Parents also considered that the role of health care professionals and services in the life of their child and family was to facilitate this process. These findings resonate with the results of two previous studies. Parents’ reflecting on their experiences of raising a child with cerebral palsy identified the importance of promoting children’s independence, as well as the importance of accessing community programs for a source of inclusion, socialisation, self-realisation, responsibility and enjoyment for their child with cerebral palsy (Reid et al., 2011). Similarly, adolescents with cerebral palsy reflected on the importance of participation in activities of their preference to their experiences of quality of life, which was supported by their experiences of being perceived as capable and supported by others (Shikako-Thomas et al., 2009). These reflections are consistent with parents’ experiences and understandings of “making the most of their body and their life” as identified in the current study. However, parents’ experiences of “making the most of their body and their life” relied on their experiences of all the processes or important aspects of care within the cycle of health care illustrated by the conceptual model. These wider impacts, particularly in relation to the organisational and interactive aspects of care, have not been identified or explored in previous research relating to health care service delivery for children with cerebral palsy and their families.

7.2.6 An Alternative Interpretation

An alternative interpretation of this study is that the findings could also reflect short-comings in health care service delivery practices within the regional area. For example, the difficulty parents’ perceived with meeting needs through partnership could be because of the limited availability of health care services for children with cerebral palsy and their families and the behaviours of the health professionals working in the regional area. Therefore, the importance the parents in this study placed on meeting needs through partnership could reflect their negative experiences with this process. Accordingly, the findings of this study also support previous research demonstrating that clinical practices do not always reflect the theoretical ideals of health care service delivery for this population, and that improvements in health care service delivery practices are required in the regional area (Darrah et al., 2002; Darrah et al., 2010; Garth et al., 2009; Jeglinsky et al., 2011; Nijhuis et al., 2007). However, the theoretical sampling strategy used in this study specifically included interviewing parents who had had positive experiences of the regional health care services, questioning parents about both positive and negative experiences of health care, and interviewing one parent who had recently moved from a metropolitan area whose stories on health care for their child with cerebral palsy predominantly related to care received in the metropolitan area. These sampling strategies allowed comparison of parents' experiences, and allowed identification that the aspects of care that contributed to positive experiences of health care were the same aspects of care that parents reported as lacking or difficult and subsequently contributing to negative experiences of health care. These comparisons across different experiences add strength to the subsequent interpretations of parents' perspectives of important aspects of care for their children with cerebral palsy within the health care service region.

7.3 Comparisons of findings to guidelines and standards of care

The findings of this study contrast with the structure and content of the guidelines and standards of care for children with cerebral palsy that were reviewed in the narrative review in Chapter Three (Bakheit et al., 2001; Berker & Yalçin, 2010; Koops et al., 2008; Nickel & Desch, 2000; Ohio Department of Health, 1995; Seattle Children's Hospital, 2011; Wilson & Cooley, 2000). The reviewed guidelines and standards of care list potential health care needs by age or developmental stage (Nickel & Desch, 2000; Seattle Children's Hospital, 2011; Wilson & Cooley, 2000), by body system (Koops et al., 2008), or by potential presenting problems (Bakheit et al., 2001; Berker & Yalçin, 2010; Ohio Department of Health, 1995). The structure of the guidelines and standards of care according to lists of problems suggest an episodic care model, which is in contrast with parents' experiences of health care as a constant but evolving process. In addition, the guidelines and standards of care focused primarily on the biomedical aspects of the child's health care, and had little incorporation of the current approaches to health care service delivery and little information about how health care services should be provided. This is in contrast with the findings of this study, in which parents considered that the important aspects of health care for their children with cerebral palsy related primarily to the interactive and organisational aspects of care. The important aspects of care described by parents as important in this study are consistent with the understandings of issues of health care service delivery that contribute to parental dissatisfaction with care identified in previous research (Darrah et al., 2002; Irochu-Omare, 2004; McKay & Hensey, 1990; Reid et al., 2011). Therefore, the findings of this study support the conclusions of the narrative review that the guidelines and standards of care for children with cerebral palsy should incorporate principals of the current approaches to health care service delivery and information about how health care services should be delivered (Hayles et al, 2014). Subsequently, it may be reasonable to consider that incorporation of the conceptual model developed from this study, which explains parents' experiences of important aspects of care, into future guidelines and standards of care could contribute to improved satisfaction with care for parents of children with cerebral palsy.

7.4 Chapter summary

Parents' experiences of health care for their children with cerebral palsy described in this study that are consistent with previous literature include:

- The importance of consistency of care
- The importance of information and guidance
- The importance of a partnership relationship with health care providers
- The concept of being empowered through the process of health care
- Principals of family centred care that recommend the development of a partnership and consideration of the needs of the whole family

New contributions to understanding of parents' experiences of health care identified through this study include:

- The ongoing and evolving nature in which parents experience health care
- The benefits of having links to a network or community of other parents for the purposes of sharing and receiving information and guidance
- The impact of the organisational and interactive aspects of care to parents' experiences of care and empowerment
- How parents understand challenges and make decisions relating to the health care of their child with cerebral palsy
- The overall purpose of health care in the life of the child and family as "making the most of their body and their life".

These findings provide new understanding of parents' experiences and insight into the aspects of health care service delivery that may be improved for this population.

Chapter 8 Summary, conclusions and recommendations

8.1 Introduction

This study was undertaken to explore parents' experiences of health care for their children with cerebral palsy living in a regional area of Queensland, Australia. Prior to this study no previous research had explored parents' experiences of health care for their child with cerebral palsy, including what aspects of care they think are important and how they want health care services to be delivered. This lack of understanding of parents' experiences, along with the lack of parental input into the guidelines and standards of care (Bakheit et al., 2001; Berker & Yalçin, 2010; Koops et al., 2008; Nickel & Desch, 2000; Ohio Department of Health, 1995; Seattle Children's Hospital, 2011; Wilson & Cooley, 2000), may be one reason why parents continue to be dissatisfied with their child's health care (Darrah et al., 2010; Irochu-Omare, 2004; McKay & Hensey, 1990). The aim of the study conducted for this thesis was to address this gap in knowledge by using grounded theory methodology to generate a conceptual model that explains parents' experiences of health care for their children with cerebral palsy. The findings of this study provide new understandings of parents' experiences from their perspectives, and insight into the aspects of health care that can be improved for this population. The purpose of this chapter is to summarise the thesis, summarise the study findings and subsequent clinical implications, to outline the study limitations, and to provide recommendations for future research and clinical policies and practices.

8.2 Thesis summary

The background and rationale for the development of the study into parent's experiences of health care for their children with cerebral palsy was provided in Section One. In Chapter One, the clinical and theoretical context that guided the development of the study, as well as the study aims and design and the thesis structure and style were outlined. Following this chapter, the background knowledge and understandings that guided the purposes of the study were outlined in Chapters Two and Three. In Chapter Two, the wide ranging and variable impact of cerebral palsy on children and the health care interventions available for this population were summarised. In Chapter Three, a narrative review exploring the current approaches to health care service delivery and the available guidelines and standards of care for children with cerebral palsy and their families was presented. From this narrative review, it was identified that clinical practices and currently available guidelines and standards of care do not consistently incorporate the current approaches to health care service delivery. In particular, the guidelines and standards of care have been developed with no or limited the input of parents or families. No previous research had explored how parents experience health care for their children with cerebral palsy. This gap in the literature formed the basis for the aims and purposes of the study conducted for this thesis.

In Section Two, which comprised of Chapter Two and Three, the justification for the study design and the study processes and methods were provided in detail. In Chapter Three, the aspects of the research purposes and clinical context were discussed in detail, which guided the study design which included a relativist approach, social constructivist viewpoint, and grounded theory methodology. A relativist approach suited the need to explore variability in the parents' experiences. A social constructivist viewpoint fit the purpose to explore parents' experiences of health care for their children, which was considered a social process with multiple interactions between parents, their children and the health care providers and services, as well as the dual role of the thesis author as both researcher and clinician. Grounded theory methodology addressed the need to generate new information that reflected parents' experiences, and for the study outcomes to be useful in clinical practice. Chapter 4 included a detailed account of the processes and methods used in the study. The key methods of grounded theory methodology, which included constant comparative analysis, theoretical sampling of participants and data, and memoing, sorting and diagramming, facilitated the development of a conceptual model that explained parents' experiences of health care for their children with cerebral palsy.

Finally, in Section Three, which comprised Chapters Six and Seven, the findings of the grounded theory study and were presented, and compared to relevant literature. In Chapter Six, the findings of the study demonstrated that parents living in a regional area of Queensland, Australia, experienced health care for their child with cerebral palsy as an evolving and cyclical process of "making the most of their body and their life". The categories of the conceptual model included evolving needs; learning as you go, navigating the systems, meeting needs through partnership, being empowered or disempowered, and finding a balance, and represented key aspects of care in the process of health care for children with cerebral palsy as experienced by their parents. In Chapter Seven, comparisons of the study findings to relevant literature identified that the findings are consistent with current literature supporting consistency of care, partnership approaches, family centred care and the importance of information and guidance and empowerment for parents of children with cerebral palsy. In addition, new understandings identified from the study included parents' experiences of the temporal nature of health care, the benefits of having links to a network of parents for information and guidance, the impact of the organisation of health care services, and parents' experiences of the overall purpose of health care in the life of the child and the family.

A summary of thesis chapters and associated main findings is provided as a Table in Appendix 17.

8.3 Summary of main findings

The aim of this thesis was to explore parents' experiences of health care for their child with cerebral palsy in a regional area of Queensland. The answers to the research questions, which are derived from the findings of the grounded theory study are summarised below.

8.3.1 How do parents living in a regional area of Queensland perceive health care for their children with cerebral palsy?

Parents in this study experienced health care for their children with cerebral palsy as an evolving and cyclical process of trying to help their child to make the most of their body and their life. Parents' descriptions of an evolving process reflected their experiences that while the need for health care is constant, the specific health care needs of the child and family vary, due to changes over time or new needs arising. In addition, parents' reported that health care for their child with cerebral palsy impacted on the whole family and so health care should incorporate and address the needs of the whole family.

8.3.2 What do parents think are important aspects of their child's health care?

Parents' experiences of important aspects of their child's health care are identified in the key categories of the conceptual model. Important aspects of health care according to the parents in this study included having care that was could meet the evolving needs of the child and the family, being able to learn as you go and navigate the systems, meeting needs through partnership, being empowered or disempowered, and finding a balance. The findings of this study also identified specific processes that were important to parents' experiences of every category within the conceptual model. These included receiving consistent care over time and across organisational boundaries, receiving health care services that considered and addressed the needs of the whole family, receiving information and guidance from health professionals but importantly also through other parents, and the impact of the attitudes and values of health care workers and services to their experiences of partnership and empowerment. Each of these processes or aspects of care are discussed in detail in Chapters Six and Seven. Parents' experiences of each of these important aspects of care contributed to their overall experiences of being able to help their child to make the most of their body and their life.

8.3.3 How do parents want their child's health care needs to be met?

Parents in this study identified that their preferred method for having their child's health care needs met is through a partnership with health care professionals and health care services. In order for this to occur, parents emphasised the importance of the interactive and organisational aspects of care. In their interactions with both health care professionals, but also with the wider health care services, parents want to feel respected and regarded, and they want their child to be respected and regarded as a child and a person whose worth and potential was valued. Key aspects of care that contributed to these experiences included their perceptions of the attitudes and values of health care professionals and the wider health care services, as well as receiving care that is consistent over time, but flexible enough to meet the evolving needs of the child and family.

8.4 Clinical recommendations

Health care services for children with cerebral palsy and their families should be organised and delivered to reflect parents' experiences that health care is a constant but evolving process

The findings of this study demonstrate that receiving consistent but flexible care was frequently difficult due to the organisation of health care services, which limited consistency of care and access to care. Strategies to facilitate consistency of care include the introduction of uniform eligibility criteria, accessibility processes and service delivery models to health care services for this population across different services and throughout childhood. Parents' experiences of the need for consistency of care challenges the use of the episodic care model (Comino et al., 2012). An alternative suggestion in line with the conceptual model of parents' experiences from this study is that episodes of care could still be provided for each evolving need, but children with cerebral palsy and their families could also receive regular reviews and access to services be made easier, which might meet their need for consistency of care. In addition, the use of a key worker model, in which a key health professional provides consistent contact and support to the family, both over time and across organisational boundaries (Carpenter, 2000; Greco, Sloper, Webb, & Beecham, 2007; Sloper et al., 2003), could also improve parents' experiences of consistency of their child's health care. A shift toward focusing on the organisational aspects of care when reviewing, redesigning, and researching health care services for this population is required to facilitate a move towards health care service delivery models that reflect parents' experiences of a consistent but evolving process of health care for their children with cerebral palsy and their families.

Health care professionals and services should consider the needs of the whole family when delivering services to children with cerebral palsy.

The findings of this study support the introduction of health care service delivery strategies that consider and address the needs of all members of the family. Health care services could consider introducing standardised screening for family health and well-being. This screening might incorporate the health and well-being of the parents and siblings, as well as exploration of family relationships and coping. In addition, health care services could offer specific support services for parents and siblings of children with cerebral palsy. These support services could be provided in a group format to facilitate information sharing, problem solving and social support. Other strategies that health services could implement that consider and address the needs of all members of the family include offering flexible appointment times to fit in with parents' work commitments and siblings' participation needs. According to the findings of this study, by addressing the needs of the whole family, health care services and professionals can assist parents and families to better find a balance, and therefore contribute to their experience of being able to help their child with cerebral palsy to make the most of their body and their life.

Health care professionals and services should consider and implement strategies that increase the provision of information and guidance to parents of children with cerebral palsy

The need for information and guidance experienced by parents in this study indicates that health care services could consider the use of interventions that focus primarily on education and information sharing between health professionals or services and families. These interventions might include general information sharing through parent education sessions or forums or through flyers, handouts or newsletters for parents and families. Specific information could also be provided through provision of written summaries following appointments to explain new information. A suggestion from one of the parents in this study was the provision of "diagnosis packages" at the time of diagnosis, which could contain general information about the child's condition and a directory of services and funding available, as well as personalised information about the child's potential outcomes and needs. In addition, parents in this study reported that they often received a wealth of information through other parents that was not otherwise available through their interactions with health care professionals or health care services. As a result, health care services could also consider facilitating opportunities for social networking, information sharing and problem solving between parents of children with cerebral palsy through the use of parent support groups or networking forums. Finally, access to information could also be improved through the use of electronic means such as web-based information, or online discussion forums that are supported or attended by health care professionals.

Health care services and professionals should consider the impact of their attitudes and values on parents' experiences, and implement strategies that promote parent empowerment when

delivering health care services to children with cerebral palsy and their families.

Parents in this study identified the importance and the impact of the attitudes and values of both individual professionals and wider health care services and organisations to their experiences of health care for their child. At a health care service or organisation level, this finding indicates a need for health care service delivery models that reflect respect and regard for the worth of children with cerebral palsy, as well as the role of their parents and family in their life and overall health care. Health care services could consider the use of eligibility criteria and access processes that acknowledge the worth of children and their parents in the health care interaction, or flexible service delivery models that can better address the individual needs identified by families of children with cerebral palsy. In addition, services and professionals should encourage parents to have a strong voice in their child's health care. At an organisational level, this might involve the inclusion of parent advisory groups or parent representatives on organisational boards or committees. At an individual health professional level, this finding indicates a need for training that focuses on advanced communication skills, interpersonal interactions and behaviours, and empathetic car, such as is incorporates in the family partnership and parent advisor model (Davis et al., 2002; Keatinge, Fowler, & Briggs, 2008; Law, Hanna, et al., 2003).

Future guidelines and standards of care should incorporate parents' experiences and perspectives of health care for their children with cerebral palsy

This thesis was commenced as a result of identification that the current guidelines and standards of care for children with cerebral palsy did not incorporate parents' viewpoints. The study conducted for this thesis provides new understanding of parents' experiences of important aspects of care for their children with cerebral palsy that had not previously been explored. Subsequently, parent's experiences of health care as identified in this thesis should be incorporated into future guidelines and standards of care for children with cerebral palsy. By doing so, implementation of any updated guidelines and standards of care may potentially contribute to improved experiences and satisfaction with care for parents of children with cerebral palsy.

8.5 Importance of clinical practice changes for new health care service delivery strategies and funding programs

The current climate of health care service delivery and funding programs has seen a shift towards the introduction of individualised funding packages and increased consumer choice in care (Department of Families, 2013; DisabilityCare Australia, 2013). Under these programs, parents of children with cerebral palsy will have the opportunity to choose which health service they require, as well as which health care professional they would like to provide that service. It will be important for parents to have a high level of knowledge of their child's needs, as well as good information and direction about the services available to them and which services might be most useful in their individual circumstances, because parents will have increased responsibility for managing and directing their child's care. As a result, health care services and professionals may need to ensure that parents are provided with sufficient education and regular holistic reviews to monitor changes in health care needs over time and to help parents to develop knowledge and to feel empowered to make decisions about their child's and family's needs. In addition, parental experiences and satisfaction with care will potentially have a significant impact on parents' choices regarding which health care service they choose to access and spend their funding on. Therefore, the findings of this study and the clinical practice implications suggested should be considered carefully by health care services and professionals who provide care to children with cerebral palsy and their families, and rely on this population as consumers of their services.

8.6 Limitations and future research directions

The limitations of this study need acknowledgement and consideration in terms of interpreting the understandings and implications of the study. However, the limitations identified also provide scope for future investigation and research directions.

This study has only addressed experiences of parents of children with cerebral palsy aged 16 years or younger. Children can have different experiences of health care than their parents; this requires further exploration. In addition, young adults with cerebral palsy and their parents, who were not included in this study, might have rich experiences of health care in late childhood and early adolescence not captured by the participant sample. Although some parents touched on issues relating to this period of childhood, such as future navigation of services and independence of the child with cerebral palsy, other issues such as emotional needs and sexuality were not discussed by parents in this study. Further research is required to explore children's and parents' experiences of health care in what can be a challenging period in life of any adolescent or young adults and their family.

The setting for this study was a single regional health service district. The findings of this study appear to be transferable to other regional areas in Western countries, in which philosophies around health care service delivery practices are potentially similar. However, families' experiences of health care for their children with cerebral palsy will also be influenced by the organisation, availability, and accessibility of health care services in their local area, which might differ compared to the region in which this study was conducted, and from that of other regions and in metropolitan areas. The findings of this study might, therefore, reflect the specific nature and health care service environment and characteristics of the regional area in which this study was conducted. For this reason, the study setting has been described in detail to enable readers to assess the transferability of the study findings to other regions and health care environments. The participant sample for this study did include two parents who had moved to the regional area from a metropolitan area, and these parents' experiences in metropolitan areas were included in the analysis. However, further research is required to investigate the experiences of families who live in other regional and metropolitan areas.

The availability of participants with variations in certain demographics and personal experiences was limited due to the voluntary nature of the recruitment strategy for this study. The parents who volunteered for this study could be assumed to already be somewhat empowered. It will be important for future researchers to seek out parents who are possibly less empowered, for example, those from lower socioeconomic backgrounds and those with their own health problems such as disability or mental health conditions. The participant sample for this study also did not include any parents from indigenous backgrounds or other cultures. The experiences of these parents may differ from those of the parents in this study due to different understandings of the concepts of health and disability and different viewpoints about the role of health care in the life of the child and family, and therefore require further exploration. Finally, although the participant sample for this study included one foster care parent and one adoptive parent, the experiences of parents and children living in non-'standardised' families, such as with grandparents or gay/ lesbian couples requires further exploration. In addition, some children with cerebral palsy may live in institutionalised care. Further research is required to investigate how best to deliver services to children whose care arrangements do not fit the typical Western description of 'family'.

To develop a broader theory around health care service delivery for children with cerebral palsy, further research could also explore the perspectives of health care professionals, health service managers and policy makers. Subsequently, comparisons of these perspectives with the experiences of parents and children might allow identification of differences in viewpoints and potential barriers to the alignment of clinical health care service delivery practices with families' perspectives and experiences of important aspects of care. Finally, the use of a participatory action research design, in which children, parents and health care professionals from different geographical areas in Australia compare their various experiences of health care, could facilitate the development of an Australian standard of care for children with cerebral palsy that might bring about improvements in health care experiences and satisfaction with care for this population.

8.7 Conclusions

This thesis and research study is the first to explore parents' experiences of health care for their children with cerebral palsy. The main findings include:

- Parents living in a regional area of Queensland, Australia, experience health care for their children with cerebral palsy as an evolving and cyclical process of "making the most of their body and their life":

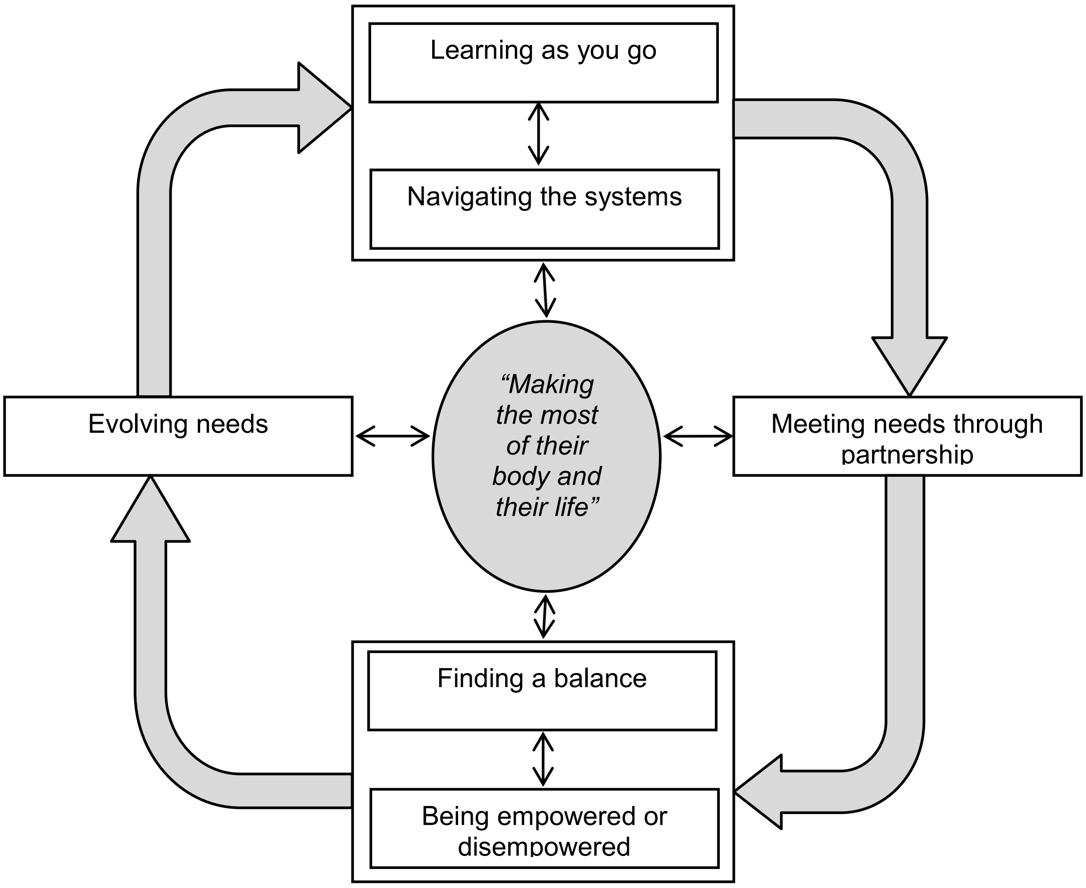

Figure 8.1 Parents' experiences of the process of health care for their children with cerebral palsy.

- The core category of "making the most of their body and their life" underpins and motivates all experiences in the cycle of health care
- The cycle of health care for parents consists of six key categories or processes: evolving needs, learning as you go, navigating the systems, meeting needs through partnership, being empowered or disempowered, and finding a balance.
- Parents' experiences of each of the key categories develop as a result of their experiences in the previous category, and impact on their experiences of the subsequent category.

- Key aspects of care for parents of children with cerebral palsy include: having consistent but flexible care that can meet the evolving needs of their child and family; receiving health care that considers and addresses the needs of the whole family; receiving information and guidance from health professionals, but importantly through links with other parents; and, the attitudes and values of health care workers which impact on how parents experience the process of health care for their child with cerebral palsy. These aspects of care can be used to inform clinical practice changes for health care professionals and services providing care to this population.
- Further research investigating children's and young adult's experiences of health care is required, as well as comparison of experiences in different geographical areas, with different models of service delivery, with families of different cultural and family backgrounds, and with health professionals and policy makers, to develop a broader theory around health care service delivery for children with cerebral palsy and their families.

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Appendices

Appendix 1 Co-author agreement on candidate's contribution to papers

Thesis Title: "Making the Most of their Body and their Life": Parents' experiences of health care for their children with cerebral palsy

Name of Candidate: Emily Hayles

Chapter No.	Details of publications on which chapter is based	Nature and extent of the intellectual input of each author, including the candidate	I confirm the candidates contribution to this paper and consent to the inclusion of the paper in this thesis
2	Hayles, E., Jones, A., Harvey, D., Plummer, D. & Ruston, S. (2014). Delivering health care services to children with cerebral palsy and their families: a narrative review. *Health and Social Care in the Community.* (Manuscript accepted for publication).	• E. Hayles was the chief investigator. She was responsible for developing the study design, searching and screening the literature for inclusion, analysis of the literature and manuscript preparation. • S. Ruston was involved in developing the conceptual design of the narrative review. • A. Jones, D. Harvey and D. Plummer contributed to the study design and review of the draft manuscript.	**Emily Hayles** Signature: **Anne Jones** Signature: **Sally Ruston** Signature: **Desley Harvey** Signature: **David Plummer** Signature:

4	Hayles, E., Harvey, D., Plummer, D. & Jones, A. (2014). Focusing on families experiences of health care: Choosing a qualitative research design. (Manuscript submitted for publication).	• E. Hayles was responsible for review of the literature, research concept and design, and preparation of manuscript. • D. Harvey, D. Plummer and A. Jones contributed to the study design and review of the draft manuscript.	**Emily Hayles** Signature: **Anne Jones** **Desley Harvey** Signature: **David Plummer** Signature:
6	Hayles, E., Harvey, D., Plummer, D. & Jones, A. (2014). Parents' experiences of health care for their child with cerebral palsy. (Manuscript submitted for publication).	• E. Hayles was the chief investigator. She was responsible for review of the literature, research concept and design, participant recruitment, data collection, data analysis and manuscript preparation. • D. Harvey, D. Plummer and A. Jones contributed to the study design, data analysis and review of the draft manuscript.	**Emily Hayles** Signature: **Anne Jones** Signature: **Desley Harvey** Signature: **David Plummer** Signature:

Appendix 2 Summary of literature included for review in narrative review (Chapter Three)

	Authors	Year	Type of literature	• Study design • Data collection method	Approach to health care service delivery	Article or document focus	Type of health service (Country of study)	Peer-reviewed (Y/N)
Articles related to approaches to health care service delivery								
1	Buran et al.	2009	Journal article	• Quantitative population-based evaluation of need • Standardised survey	ICF	Needs identified by parents of children with CP for information, services, and access to treatment	Multi-disciplinary CP clinic at children's hospital (USA)	Yes
2	Cooley	2004	Journal article	• Clinical report • Summary of clinical evidence and opinions	Collaborative, community-based primary care	Specific aspects of care for children with CP that a medical home should provide	Community primary care (USA)	Yes
3	Darrah et al.	2010	Journal article	• Exploratory service investigation • Interviews with managers and therapists; focus groups with parents	Family centred care & ICF	Evidence of FCC, functional goal setting and transition planning in therapy services	Not specified (Canada)	Yes
4	Darrah et al.	2011	Journal article	• Description of therapy protocol used in randomized controlled trial	ICF	Training program and intervention protocol using context therapy approach	Not specified (Canada)	Yes
5	Dirks & Hadders-Algra	2011	Journal article	• Systematic review and analysis • Analysis of literature of early intervention programs for children with CP	Family centred care	Nature of family involvement in early intervention programs for children with CP	Not specified	Yes
6	dos Santos et al.	2012	Journal article	• Narrative review of literature • Summary of clinical evidence	ICF	Evaluation of the literature reviewing components of the ICF in children with CP	Not specified (Brazil)	Yes
7	Garth, Murphy &	2009	Journal article	• Qualitative grounded theory study • Separate semi-structured interviews	Family centred care	Experience of doctor-parent-child partnership and nature of child's	Paediatric teaching hospital	Yes

	Authors	**Year**	**Type of literature**	• **Study design** • **Data collection method**	**Approach to health care service delivery**	**Article or document focus**	**Type of health service (Country of study)**	**Peer-reviewed (Y/N)**
	Reddihough			with children with CP, their parents and paediatricians		involvement in this partnership	(Australia)	
8	Iversen, Graue, & Clare	2009	Journal article	• Qualitative phenomenology • In-depth interviews with parents of children with CP	Family centred care	Parents' experiences when their child with CP was going through a surgical procedure	Inpatient (Norway)	Yes
9	Jeglinsky, Autti-Rämö & Brogren Carlberg	2011	Journal article	• Qualitative service evaluation • Standardised parent and service provider questionnaires	Family centred care	Comparing parents' and service providers' views and experiences of FCC	University hospitals (Finland & Sweden)	Yes
10	Karande, Patil, & Kulkarni	2008	Journal article	• Pre-post intervention evaluation • Parent knowledge questionnaire	Family centred care	Impact of educational program on parental knowledge of CP	Educational program (India)	Yes
11	King et al.	1999	Journal article	• Quantitative analysis with structural equation modelling • Multiple scales and outcome measures completed by parents of children 3-6yo with non-progressive neuro-developmental disorder	Family centred care	Relationship between parents' perceptions of FCC and parent emotional well-being	Community based children's rehabilitation services (Canada)	Yes
12	King et al.	2004	Journal article	• Narrative review	Family centred care	Evidence for FCC in regards to child with cerebral palsy, their parent/family, and service system outcomes	Community based children's rehabilitation services	Yes
13	LaForme Fiss, McCoy, Chiarello & Move & PLAY Study Team	2012	Journal article	• Quantitative comparison of parents' and therapists' perceptions • Services Questionnaire	Family centred care & ICF	Comparison of parent's and therapists perceptions of focus of therapy, collaboration and provision of services that reflect principals of FCC	Community or outpatient children's rehabilitation services (USA)	Yes

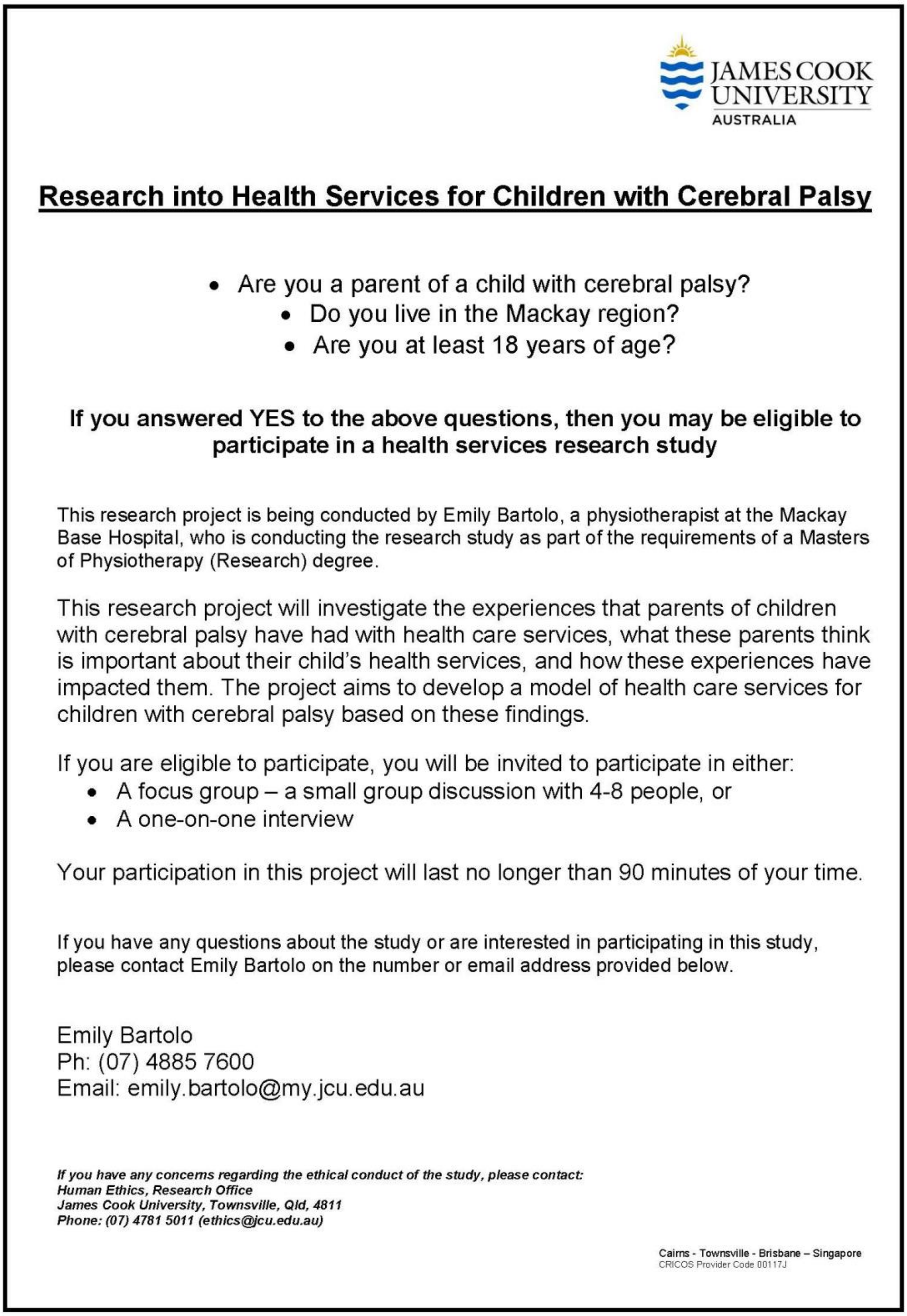
	Authors	**Year**	**Type of literature**	• **Study design** • **Data collection method**	**Approach to health care service delivery**	**Article or document focus**	**Type of health service (Country of study)**	**Peer-reviewed (Y/N)**
14	Law et al.	2011	Journal article	• Randomised controlled trial • Multiple outcome measures	ICF	Efficacy of child-focused intervention vs context-focused intervention on improving performance of functional tasks and mobility in young children with CP	Children's rehabilitation centres (Canada)	Yes
15	Lindstrand, Brodin & Lind	2002	Journal article	• Summary and comparison of three different studies • Parent interviews or parent questionnaire and interviews	Family centred care	Parent/carer expectations of achievements through therapy for their child with a disability	Not specified (Sweden)	Yes
16	Liptak, Murphy & Council on Children with Disabilities	2011	Journal article	• Clinical report • Review of clinical evidence and opinions	Collaborative, community-based primary care	Review of aspects of care specific to CP that medical home should provide beyond routine health care	Not specified (USA)	Yes
17	Lipson Aisen et al.	2011	Journal article	• Clinical report • Summary of clinical evidence and opinions	Collaborative, community-based primary care	Clinical management of CP including transition, patient-centred and FCC, integrated care, and neuroplasticity	Not specified (USA)	Yes
18	Morgan & Tan	2010	Journal article	• Qualitative exploration using multiple case-study strategy • Semi-structured individual or small group interviews with parents of children with CP	Family centred care	Parents' perceptions of family centred rehabilitation in Cambodia	Community based therapy (Cambodia)	Yes
19	Msall & Park	2008	Journal article	• Clinical report • Summary of clinical evidence and opinions	Family centred care & ICF	Management strategies for children with CP with neuro-developmental, FCC and ICF approach	Not specified (USA)	Yes
20	Nijhuis et al.	2007	Journal article	• Policy document review and evaluation • Analysis of policy documents and team conferences according to	Family centred care	Evaluation and analysis of national views and organisational policies on collaborative care for children with CP and their parents	Paediatric rehabilitation centres and associated	Yes

	Authors	Year	Type of literature	• Study design • Data collection method	Approach to health care service delivery	Article or document focus	Type of health service (Country of study)	Peer-reviewed (Y/N)
				checklist			schools for special education (Netherlands)	
21	Reid et al.	2011	Journal article	• Qualitative exploratory analysis • Parent interviews	Collaborative, community-based primary care & ICF	Experiences of parents of children with CP with community recreation programs, therapy services and medical interventions	Not specified (Canada)	Yes
22	Saleh et al.	2008	Journal article	• Cross-sectional survey • Structured telephone interviews with OT's and PT's working in paediatric rehabilitation	ICF	OT and PT practices for children with CP	Not specified (Canada)	Yes
23	Trabacca et al.	2012	Journal article	• Single case study • Application of the ICF to neurorehabilitation assessment and planning for child with dyskinetic CP	ICF	Illustrate the use of the ICF in the neurorehabilitation assessment and planning of child with CP	Neurorehabilitation Unit (Italy)	Yes
24	Young et al.	2006	Journal article	• Qualitative exploratory analysis • Semi-structured interviews with children with CP and their parents; focus groups with health care practitioners who work with children with CP.	Family centred care	Childrens, parents and health practitioners experiences of shared decision making	Community-based physiotherapy services (UK)	Yes
25	Ziviani, Feeney & Khan	2011	Journal article	• Quantitative cross-sectional evaluation • Parent/ carer surveys and outcome measure	Family centred care	Relationship between family and child characteristics and perceptions of FCC with satisfaction with care	3 early intervention services provided through non-governmental organisations (Australia)	Yes

	Authors	Year	Type of literature	• Study design • Data collection method	Approach to health care service delivery	Article or document focus	Type of health service (Country of study)	Peer-reviewed (Y/N)
Guidelines or standards of care								
1	Bakheit et al.	2001	Journal article	• Two stage opinion consensus • Multi-disciplinary working groups developed statement, reviewed by professional bodies and voluntary organisations	N/A	Standards of healthcare in CP	Not specified (UK)	Yes
2	Berker & Yalcin	2010	Guideline	Not described	N/A	Care of children and young adults with cerebral palsy	Not specified (Turkey)	Not specified
3	Koops, Burdo-Hartman & Dodge	2008	Guideline	Not described	N/A	Guide to chronic care management for children with CP and their families	Not specified (USA)	Not specified
4	Ohio Department of Health	1995	Guideline	Not described	N/A	Care of children with cerebral palsy	Not specified	Not specified
5	Nickel & Desch	2000	Guideline	Not described	N/A	Care of children and adolescents with CP	Not specified	Yes
6	The Center for Children with Special Needs, Seattle Children's Hospital	2011	Guideline	• Consensus by state-wide multidisciplinary team, included primary and tertiary care providers, family members and health plan representative • Revisions made using best evidence based practice recommendations available	N/A	Critical elements of care of children with CP	Not specified (USA)	Not specified
7	Wilson & Cooley	2000	Guideline	Not described	N/A	Checklist for the preventative medical management of children with CP	Not specified	Not specified

CP = cerebral palsy

Appendix 3 Participant Flyer



JAMES COOK UNIVERSITY
AUSTRALIA

Research into Health Services for Children with Cerebral Palsy

- Are you a parent of a child with cerebral palsy?
- Do you live in the Mackay region?
- Are you at least 18 years of age?

If you answered YES to the above questions, then you may be eligible to participate in a health services research study

This research project is being conducted by Emily Bartolo, a physiotherapist at the Mackay Base Hospital, who is conducting the research study as part of the requirements of a Masters of Physiotherapy (Research) degree.

This research project will investigate the experiences that parents of children with cerebral palsy have had with health care services, what these parents think is important about their child's health services, and how these experiences have impacted them. The project aims to develop a model of health care services for children with cerebral palsy based on these findings.

If you are eligible to participate, you will be invited to participate in either:

- A focus group – a small group discussion with 4-8 people, or
- A one-on-one interview

Your participation in this project will last no longer than 90 minutes of your time.

If you have any questions about the study or are interested in participating in this study, please contact Emily Bartolo on the number or email address provided below.

Emily Bartolo
Ph: (07) 4885 7600
Email: emily.bartolo@my.jcu.edu.au

If you have any concerns regarding the ethical conduct of the study, please contact:
Human Ethics, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 5011 (ethics@jcu.edu.au)

Cairns - Townsville - Brisbane – Singapore
CRICOS Provider Code 00117J

Appendix 4 Participant Information Sheet

INFORMATION SHEET

PROJECT TITLE: **What are parents' experiences of health care for their children with cerebral palsy living in regional Queensland?**

INVESTIGATOR: Emily Bartolo, Physiotherapist, Mackay Base Hospital, Queensland Health
Masters of Physiotherapy (Research) student, James Cook University

SUPERVISORS: 1. Anne Jones, Senior Lecturer and Research Supervisor, School of Physiotherapy, James Cook University
2. Desley Harvey, Senior Research Fellow, Cairns and Hinterland Health Service District, Queensland Health
3. Professor David Plummer, Professor of Health Research, Northern Area Health Service, Queensland Health

Thank you for your interest in participating in this research project. This study is being conducted by Emily Bartolo and will contribute to her Masters of Physiotherapy (Research) degree at James Cook University.

This information sheet tells you about the research project. It explains what is involved to help you decide if you want to take part. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Participation in this research is voluntary. If you don't wish to take part, you don't have to.

What is the purpose of this research project?

Children with cerebral palsy often have complex and multiple health care needs. It is considered best practice to include parents and children in making decisions about the child's health care needs. However, the current guidelines and standards of care for children with cerebral palsy were developed by health care professionals or medical experts - without the involvement of parents. Parents have not previously been asked what they think is important about their children's health care needs.

This project aims to discover what parents of children with cerebral palsy think are important aspects of health care for their child and why these are important. It will develop a model of health care for children with cerebral palsy based on the information that parents provide. This research may help health professionals to better understand the needs of children with cerebral palsy and their families, and may be used in the development of future models of care that better meet their specific needs.

What does participation in this research project involve?

If you agree to be involved in this study, you will be invited to participate in either:

- a small group discussion with 4-8 people, (a focus group), or
- a one-on-one interview

The focus group or interview, with your consent (and the consent of the other participants if taking part in a focus group), will be audio-taped and should take no more than 90 minutes of your time. Focus groups will be held in a community venue. One-on-one interviews will be held either in your own home or at a community venue, depending on your preference. During the focus group or interview you will be asked questions about:

- Your previous experiences and interactions with health care professionals and health care services,
- How these experiences and interactions have affected the way you think about health care services for your child, and what are important aspects of your child's health care needs,
- How you think health care services for your child with cerebral palsy should be delivered, and
- General information to describe your child.

The information gathered during the focus group/ interview will be kept highly confidential. The audiotape of the focus group/interview will be transcribed, and all personal information will be removed at this time. Names and personal information will be kept strictly confidential. Any written records will be kept in a locked filing cabinet at the James Cook University, and any electronic computer records will be kept in a password locked computer at the James Cook University's Mackay Campus building.

Your participation in this project will not have any impact on the health care services you currently receive or may receive in the future, nor your relationship with the health care professionals you see.

What are the possible benefits?

Your participation in this project may not be of direct benefit to you, your child with cerebral palsy or your family.

Your participation in this project will provide you with the opportunity to share your experiences, thoughts and opinions on your child's health care needs and health care services, and those of children with cerebral palsy in general. The potential long-term benefits of this project are improved delivery of health care services to children with cerebral palsy and their families; however, this study will not directly impact current health care service delivery.

What are the possible risks?

Some people may become distressed or upset when discussing their child's health care or condition. If this occurs, the researcher may arrange counselling or other appropriate support with your consent. Professionals who are not members of the research team will provide any counselling or support.

Do I have to take part in this research project?

Taking part in this study is completely voluntary. If you do not wish to take part, you do not have to and you can stop taking part in the study at any time without explanation. If you decide to withdraw, please notify Emily Bartolo as soon as possible.

Your decision whether to take part or not, or to withdraw, will not affect you or your child in any way, and will not impact your relationship with the researcher or with your child's health care service providers.

How will I be informed of the final results of the project?

At the completion of the study you will be invited to attend a feedback session with other participants. This feedback session will be held at a community venue, and the researcher will provide a summary of the outcomes of the study. A written summary of the research outcomes will also be sent to each participant at the conclusion of the study.

What will happen to information about me?

Your personal details will be kept strictly confidential. Direct quotes and comments, will be used to illustrate the outcomes of this research in publications for the James Cook University, Queensland Health, and in professional journals and conference presentations, however you will not be identified in any way.

Is this research project approved?

This study has been cleared by the Human Research Ethics Committees for the Townsville Health Service District and the James Cook University in accordance with the National Health and Medical Research Council's guidelines.

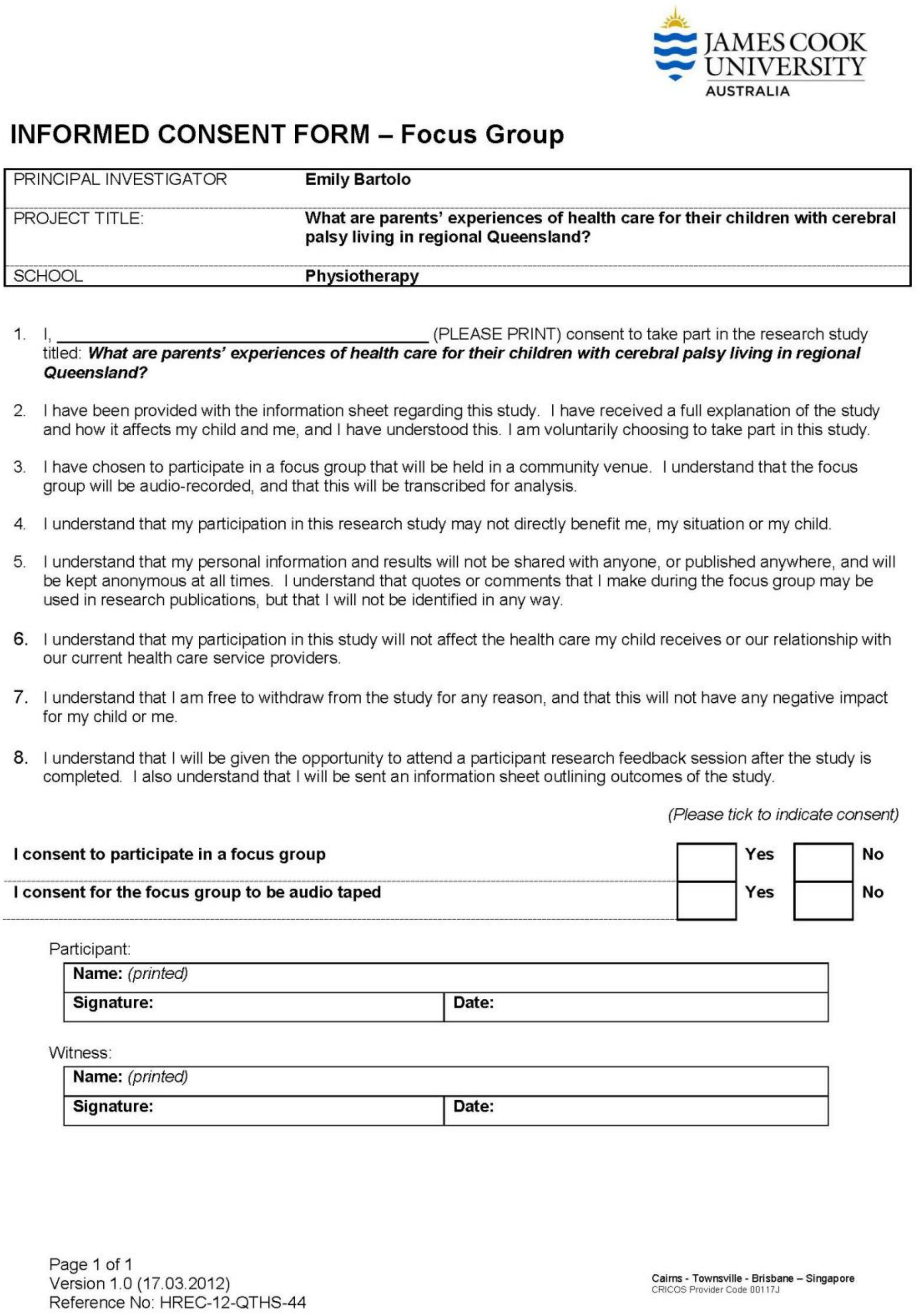
Who can I contact?

If you have any questions about the study, please contact Emily Bartolo or Anne Jones as listed below.
Thank you for your interest in this research project.

Principal Investigator:	***Supervisor:***
Emily Bartolo	**Anne Jones**
School of Physiotherapy	**School of Physiotherapy**
James Cook University	**James Cook University**
Phone: (07) 4885 7600	**Phone: (07) 4781 4085**
Email: emily.bartolo@my.jcu.edu.au	**Email: anne.jones@jcu.edu.au**

If you have any concerns regarding the ethical conduct of the study, please contact:
Human Ethics, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 5011 (ethics@jcu.edu.au)

Appendix 5 Informed Consent Form – Focus Group



JAMES COOK UNIVERSITY
AUSTRALIA

INFORMED CONSENT FORM – Focus Group

PRINCIPAL INVESTIGATOR	**Emily Bartolo**
PROJECT TITLE:	**What are parents' experiences of health care for their children with cerebral palsy living in regional Queensland?**
SCHOOL	**Physiotherapy**

1. I, ______________________________ (PLEASE PRINT) consent to take part in the research study titled: ***What are parents' experiences of health care for their children with cerebral palsy living in regional Queensland?***
2. I have been provided with the information sheet regarding this study. I have received a full explanation of the study and how it affects my child and me, and I have understood this. I am voluntarily choosing to take part in this study.
3. I have chosen to participate in a focus group that will be held in a community venue. I understand that the focus group will be audio-recorded, and that this will be transcribed for analysis.
4. I understand that my participation in this research study may not directly benefit me, my situation or my child.
5. I understand that my personal information and results will not be shared with anyone, or published anywhere, and will be kept anonymous at all times. I understand that quotes or comments that I make during the focus group may be used in research publications, but that I will not be identified in any way.
6. I understand that my participation in this study will not affect the health care my child receives or our relationship with our current health care service providers.
7. I understand that I am free to withdraw from the study for any reason, and that this will not have any negative impact for my child or me.
8. I understand that I will be given the opportunity to attend a participant research feedback session after the study is completed. I also understand that I will be sent an information sheet outlining outcomes of the study.

(Please tick to indicate consent)

I consent to participate in a focus group	☐ **Yes**	☐ **No**
I consent for the focus group to be audio taped	☐ **Yes**	☐ **No**

Participant:

Name: *(printed)*	
Signature:	**Date:**

Witness:

Name: *(printed)*	
Signature:	**Date:**

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Version 1.0 (17.03.2012)
Reference No: HREC-12-QTHS-44

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Appendix 6 Informed Consent Form – Interview

JAMES COOK
UNIVERSITY
AUSTRALIA

INFORMED CONSENT FORM - Interview

PRINCIPAL INVESTIGATOR	**Emily Bartolo**
PROJECT TITLE:	**What are parents' experiences health care for their children with cerebral palsy living in regional Queensland?**
SCHOOL	**Physiotherapy**

1. I, ______________________________________ (PLEASE PRINT) consent to take part in the research study titled: ***What are parents' experiences of health care for their children with cerebral palsy living in regional Queensland?***
2. I have been provided with the information sheet regarding this study. I have received a full explanation of the study and how it affects my child and me, and I have understood this. I am voluntarily choosing to take part in this study.
3. I understand that I will be participating in a one-on-one interview with the investigator that will be held in my own home or in a community venue, depending on my preference. I understand this interview will be audio-recorded, and that this will be transcribed for analysis. If the interview will be held in my own home, I understand that I need to ensure safe access for the investigator to my home for the interview, including restraining any animals I own.
4. I understand that my participation in this research study may not directly benefit me, my situation or my child.
5. I understand that my personal information and results will not be shared with anyone, or published anywhere, and will be kept anonymous at all times. I understand that quotes or comments that I make during the one-on-one interview may be used in research publications, but that I will not be identified in any way.
6. I understand that my participation in this study will not affect the health care my child receives or our relationship with our current health care service providers.
7. I understand that I am free to withdraw from the study for any reason, and that this will not have any negative impact for my child or me.
8. I understand that I will be given the opportunity to attend a participant research feedback session after the study is completed. I also understand that I will be sent an information sheet outlining outcomes of the study.

(Please tick to indicate consent)

I consent to be interviewed	☐ **Yes**	☐ **No**
I consent for the interview to be audio taped	☐ **Yes**	☐ **No**

Participant:

Name: *(printed)*	
Signature:	**Date:**

Witness:

Name: *(printed)*	
Signature:	**Date:**

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Version 1.0 (17.03.2012)
Reference No: HREC-12-QTHS-44

Cairns - Townsville - Brisbane – Singapore
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Appendix 7 Ethics Approvals

Townsville Hospital and Health Service Approval

This administrative form
has been removed

This administrative form
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James Cook University Human Ethics Research Committee Approval

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has been removed

Queensland Health Ethics Approval

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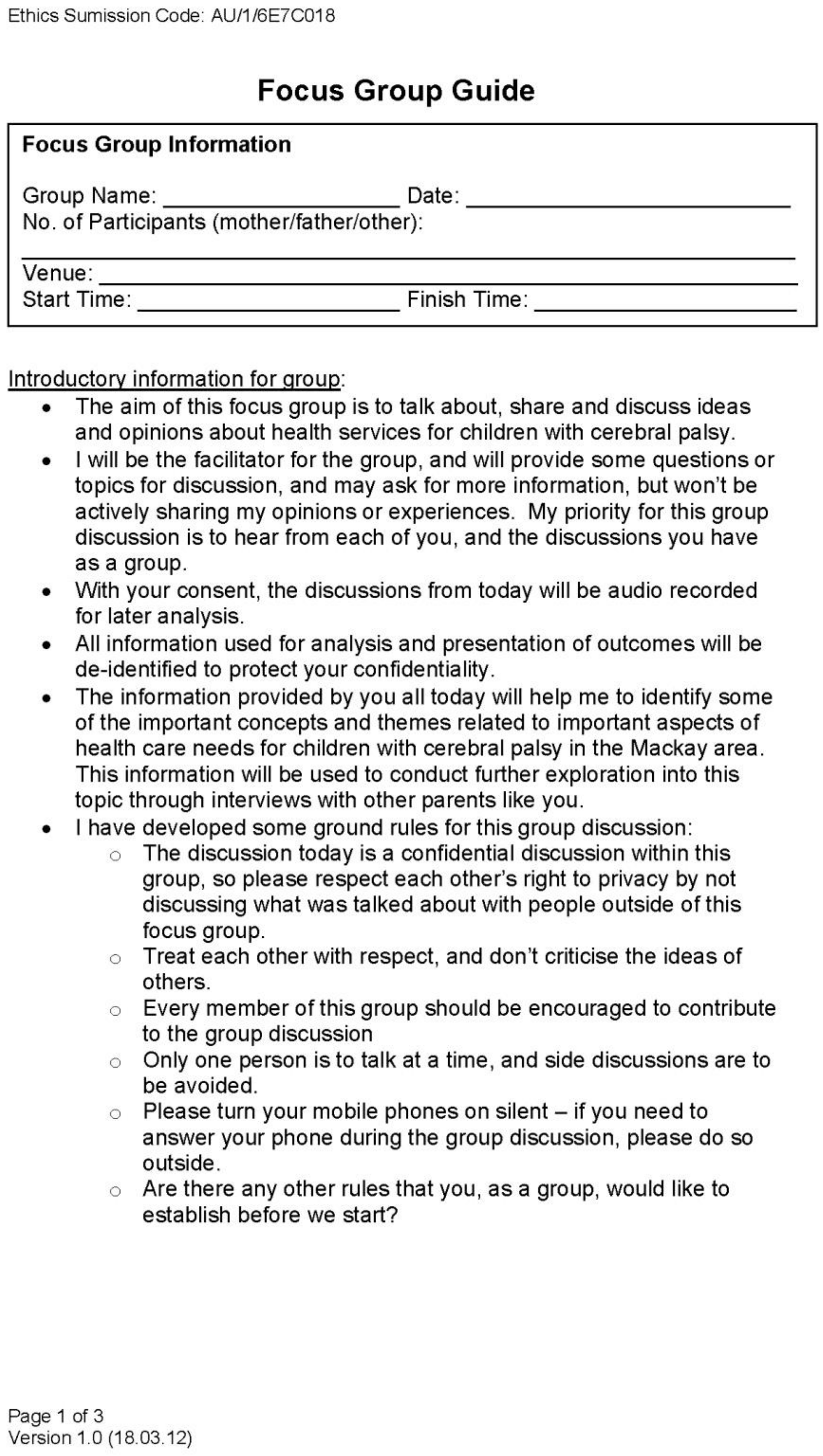
has been removed

Appendix 8 Focus Group Guide



Ethics Sumission Code: AU/1/6E7C018

Focus Group Guide

Focus Group Information

Group Name: ____________________ Date: ___________________________
No. of Participants (mother/father/other):
____
Venue: ____
Start Time: ______________________ Finish Time: ______________________

Introductory information for group:

- The aim of this focus group is to talk about, share and discuss ideas and opinions about health services for children with cerebral palsy.
- I will be the facilitator for the group, and will provide some questions or topics for discussion, and may ask for more information, but won't be actively sharing my opinions or experiences. My priority for this group discussion is to hear from each of you, and the discussions you have as a group.
- With your consent, the discussions from today will be audio recorded for later analysis.
- All information used for analysis and presentation of outcomes will be de-identified to protect your confidentiality.
- The information provided by you all today will help me to identify some of the important concepts and themes related to important aspects of health care needs for children with cerebral palsy in the Mackay area. This information will be used to conduct further exploration into this topic through interviews with other parents like you.
- I have developed some ground rules for this group discussion:
    - The discussion today is a confidential discussion within this group, so please respect each other's right to privacy by not discussing what was talked about with people outside of this focus group.
    - Treat each other with respect, and don't criticise the ideas of others.
    - Every member of this group should be encouraged to contribute to the group discussion
    - Only one person is to talk at a time, and side discussions are to be avoided.
    - Please turn your mobile phones on silent – if you need to answer your phone during the group discussion, please do so outside.
    - Are there any other rules that you, as a group, would like to establish before we start?

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Focus Group Questions

- Ice-Breaker:
    - Each participant introduces themselves, with short introductory discussion unrelated to research topic

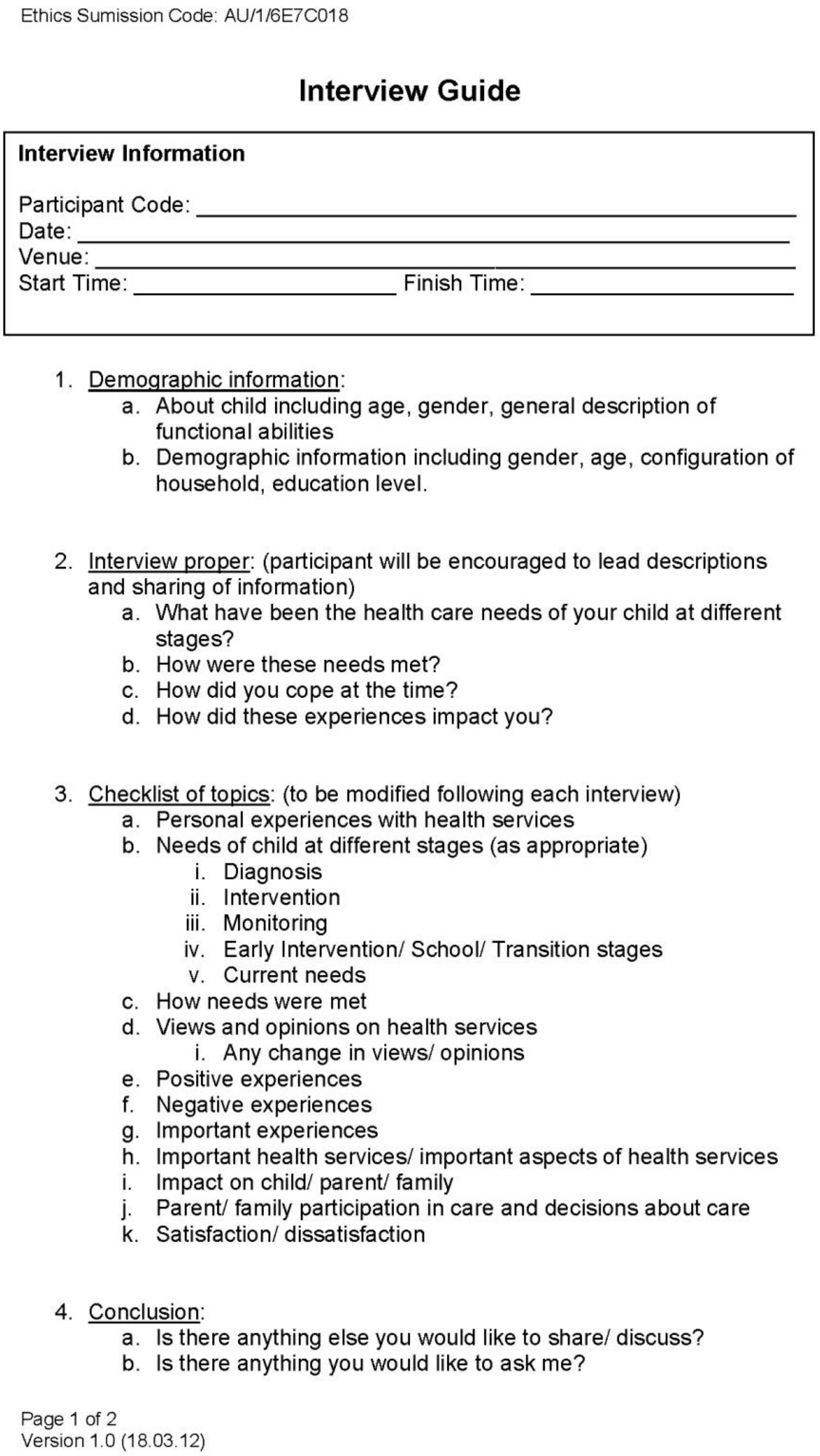
- Focus Group Discussion Topics:
    - What are the health care needs of children with cerebral palsy to live a good life?
    - At different stages?
    - How are these needs met?
    - What impacts do health care services have on you/ your child/ your family?

- *Checklist/ Topic Prompts:- (to be modified as required following initial focus group)*
    - *Experiences with health services*
    - *Needs of children with CP at different stages*
        - *Diagnosis*
        - *Intervention*
        - *Monitoring*
        - *Early Intervention/ School/ Transition stages*
        - *Current needs*
    - *How needs are met*
    - *Views and opinions on needs and health services*
    - *Positive experiences*
    - *Negative experiences*
    - *Important aspects of health care*
    - *Impacts on child/ parents/ family*
    - *Parent/ family participation in care and decisions about care*
    - *Satisfaction/ dissatisfaction*

- Probing questions: (to be used to encourage further exploration and reflection)
    - What happened in that situation?
    - How did that happen?
    - What occurred before that/ after that?
    - How often has ……. occurred?
    - How did that impact you?
    - What was that like for you?
    - What did that mean for you/ your child/ your family?
    - Can you give me an example of……?
    - Has there been other situations like that? How were they similar/ different?
    - What contributed to ………?
    - Can you explain ………. further?
    - How did you come to know/ understand/ decide that?
    - Why is that important?

- Conclusion
  - Thank you and acknowledge contribution to project outcomes
  - Briefly summarise what has been discussed, and explain how this information will be used to progress the research
  - Explain that the outcomes of the research will be shared with all participants at participant feedback sessions at the conclusion of the study, which will be late 2013 or early 2014. Will all be invited to attend, and will also receive a written summary of the outcomes in the mail
  - If you have anything specific you need to discuss with me in private, you can see me now as everyone is leaving, or contact me over the phone or by email.
  - Thanks again for your participation

Appendix 9 Interview Guide



Ethics Sumission Code: AU/1/6E7C018

Interview Guide

Interview Information

Participant Code: ____
Date: ____
Venue: ____
Start Time: ____________________ Finish Time: ____________________

1. Demographic information:
    a. About child including age, gender, general description of functional abilities
    b. Demographic information including gender, age, configuration of household, education level.

2. Interview proper: (participant will be encouraged to lead descriptions and sharing of information)
    a. What have been the health care needs of your child at different stages?
    b. How were these needs met?
    c. How did you cope at the time?
    d. How did these experiences impact you?

3. Checklist of topics: (to be modified following each interview)
    a. Personal experiences with health services
    b. Needs of child at different stages (as appropriate)
        i. Diagnosis
        ii. Intervention
        iii. Monitoring
        iv. Early Intervention/ School/ Transition stages
        v. Current needs
    c. How needs were met
    d. Views and opinions on health services
        i. Any change in views/ opinions
    e. Positive experiences
    f. Negative experiences
    g. Important experiences
    h. Important health services/ important aspects of health services
    i. Impact on child/ parent/ family
    j. Parent/ family participation in care and decisions about care
    k. Satisfaction/ dissatisfaction

4. Conclusion:
    a. Is there anything else you would like to share/ discuss?
    b. Is there anything you would like to ask me?

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Probing questions: (to be used to encourage further exploration and reflection)

- What happened in that situation?
- How did that happen?
- What occurred before that/ after that?
- How often has ……. occurred?
- How did that impact you?
- What was that like for you?
- What did that mean for you/ your child/ your family?
- Can you give me an example of……?
- Has there been other situations like that? How were they similar/ different?
- What contributed to ………?
- Can you explain ………. further?
- How did you come to know/ understand/ decide that?
- Why is that important?

Appendix 10 Summary of Thesis Chapters and Main Findings

Chapter	Content	Main Findings
Section One		
1. Introduction	Outline of thesis rationale, design and theoretical context, aims of research, and thesis structure	• The aim of the research conducted for this thesis was to explore parents' experiences of health care for their children with cerebral palsy in a regional Queensland area.
2. Background – Understanding Cerebral Palsy	Outline of cerebral palsy, its impact on children with cerebral palsy and their families, and types of interventions and health services available.	• Cerebral palsy is a complex neuro-developmental condition that has wide ranging impacts on children at the impairment, activity and participation levels of the ICF • Health care services for children with cerebral palsy can vary widely, but aim to support children and families to achieve the best possible health, functional, participatory and quality of life outcomes.
3. Background – Understanding the Gaps in the Literature	Narrative review of literature relating to health care service delivery for children with cerebral palsy and their families, and critical review of current guidelines and standards of care.	• Health care practices for children with cerebral palsy, and current guidelines and standards for care don't always reflect the current approaches to health care service delivery, which include family centred care, care delivered according to the ICF, and collaborative community-based primary care. • Parents' experiences of health care for their children with cerebral palsy have not previously been explored. This is the gap in the literature addressed by the study conducted for this thesis.
Section Two		
4. Justification of Research Design	In-depth discussion of research questions and clinical context that guided the research design.	• A relativist approach suited the need to explore parents' experiences, which will vary due to the variable nature of cerebral palsy and health care for children and families • A social constructivist viewpoint suited the need to explore the parents' experiences of the sociological process of health care, as well as the author's dual role as both researcher and clinician. • Grounded theory methodology allowed exploration of variations in parents' experiences, ensured

		the findings of the research reflected parents' viewpoints as closely as possible, and enabled the development of a clinically useful explanatory conceptual model.
5. Research Process and Methods	Outline of research processes and methods used in grounded theory research study.	• Key methods of grounded theory methodology, including constant comparative analysis, theoretical sampling of participants and data, and memoing, sorting and diagramming allowed the development of a conceptual model that explains parents' experiences of health care
Section Three		
6. Findings of the Grounded Theory Study	Findings of grounded theory research study exploring parents' experiences of health care for their children with cerebral palsy living in a regional Queensland area.	• Parents' of children with cerebral palsy experience health care for their child as an evolving and cyclical process of "making the most of their body and their life". • Key aspects of health care included evolving needs, learning as you go, navigating the systems, meeting needs through partnership, being empowered or disempowered, and finding a balance.
7. Discussion – Comparisons with the Literature	Comparisons of model of parents' experiences of health care with literature relating to health care service delivery for children with cerebral palsy	• Parents' experiences of health care are consistent with current literature supporting consistency of care, partnership approaches, family centred care, and the importance of information and guidance and the concept of empowerment for parents of children with cerebral palsy • New contributions to understanding include parents' experiences of the temporal nature of health care, the importance of receiving information and guidance, the benefits of having links to a network of parents, the impact of the organisation of health care services, and how parents' understand the overall purpose of health care in their child's life.