An exploratory study of the psychosocial experiences of parents of infants diagnosed with Infantile Spasms

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Abstract

Infantile Spasms is a severe form of infantile epilepsy with a variable, but typically poor, long-term prognosis. The lived experiences of parents of children with this condition have never previously been examined. However, it is well understood that parents of children with other paediatric conditions, such as health or developmental conditions diagnosed in infancy or paediatric epilepsy, experience a range of stressors.

This thesis explores the lived experience of mothers who care for their child who has been diagnosed with Infantile Spasms. The qualitative study design, based upon principles of phenomenology, utilized semi-structured interviews with a small sample of mothers, in order to identify in-depth narratives via a process of thematic analysis.

The study highlighted three major themes of experience for mothers of children with this condition. These themes were; the process of seeking and experiencing the diagnosis of Infantile Spasms, adjusting to the child’s prognosis from Infantile Spasms and living with and making meaning from a diagnosis of Infantile Spasms. Mothers described the distress and guilt associated with the diagnosis, particularly if it was delayed. Many mothers described communication by healthcare professionals at the point of diagnosis as important, and shared positive and negative examples of communication. Mothers related that adjusting to their child’s refractory seizures or developmental deficits from this condition was challenging, and many had limited supports to assist them in doing so. However, many mothers were determined to make positive meaning from the experience, by assisting others or contributing to research about the condition.

This study is the first to outline the experience of mothers of children diagnosed with Infantile Spasms. Considerations for further research and clinical practice are outlined in the study.
Declaration

1. This thesis comprises only my original work towards the Master of Advanced Social Work by Research degree except where indicated in the preface;

2. (ii) due acknowledgement has been made in the text to all other material used;

   and

   (iii) the thesis is 29,799 words as approved by the Research Higher Degrees Committee, exclusive of tables, maps, bibliographies and appendices.
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# Table of Contents

Abstract .............................................................................................................................. 2
Declaration .......................................................................................................................... 3
Acknowledgements ........................................................................................................... 4
Table of Contents .............................................................................................................. 5
Chapter One: Introduction ............................................................................................... 7
  2.1. Caring for a healthy and developmentally normal infant ........................................... 11
  2.2. Caring for an infant with developmental or medical issue ........................................ 12
  3.1 How biological issues shape the parental experience of paediatric illness or disability...... 19
  3.2 How the experience of accessing healthcare shapes the parental experience of paediatric illness or disability ................................................................. 22
  3.3 How psychosocial issues shape the parental experience of paediatric illness and disability: ................................................................. 25
  3.4 The impact of a paediatric health or developmental issue on the parent-child relationship .............................................................................................. 27
Chapter Three: How the experience of caring for a child with a health or developmental issue is shaped ..................................................................................... 31
  4.1. Theoretical framework: ............................................................................................ 31
  4.2. Ethical issues: ............................................................................................................ 32
  4.3. Design considerations ............................................................................................... 32
  4.4. Recruitment: ............................................................................................................. 33
  4.5. The process of seeking and experiencing the diagnosis of Infantile Spasms .............. 40
  4.6. Data analysis ............................................................................................................ 36
  4.7. Confidentiality ......................................................................................................... 37
  4.8. Sample ....................................................................................................................... 39
  5.1. Caring for a child with paediatric epilepsy ................................................................. 15
  5.4. Chapter summary: ................................................................................................. 17

Chapter Four: Methodology ............................................................................................ 31
  5.4. Chapter summary: ................................................................................................. 17

Chapter Five: The experiences of mothers of infants affected by Infantile Spasms ........ 40
  5.1. The process of seeking and experiencing the diagnosis of Infantile Spasms .......... 40
  5.2. The impact of the child’s health or developmental condition of infancy on the parent-child relationship ................................................................. 27
  5.3. The impact of health or developmental conditions of infancy on the parent-child relationship ................................................................. 28

Chapter Six: The impact of a health or developmental issue on the parent-child relationship ........................................................................................................ 40
  6.1. Voluntary participation .......................................................................................... 35
  6.2. Data storage ........................................................................................................... 38
  6.3. Sample .................................................................................................................... 39
  6.4. Chapter summary: ................................................................................................. 39

Chapter Seven: The impact of Infantile Spasms on the parent-child relationship .......... 41
  7.1. Caring for a healthy and developmentally normal infant ........................................... 11
  7.2. Caring for an infant with developmental or medical issue ........................................ 12
  7.3. Infantile Spasms: Psychosocial implications for parents ........................................ 15
  7.4. Caring for a child with paediatric epilepsy ................................................................. 15
  7.5. Infantile Spasms: Psychosocial implications for the child relationship ................. 17
  7.6. The impact of health or developmental conditions of infancy on the parent-child relationship ..................................................................................... 22
  7.7. The impact of the child’s health or developmental condition of infancy on the parent-child relationship ................................................................. 27
  7.8. The impact of health or developmental conditions of infancy on the parent-child relationship ..................................................................................... 28
  7.9. Chapter summary: ................................................................................................. 29

Chapter Eight: The impact of a health or developmental issue on the parent-child relationship ........................................................................................................ 31
  8.1. Theoretical framework: ............................................................................................ 31
  8.2. Ethical issues: ............................................................................................................ 32
  8.3. Design considerations ............................................................................................... 32
  8.4. Recruitment: ............................................................................................................. 33
  8.5. The process of seeking and experiencing the diagnosis of Infantile Spasms .......... 40
  8.6. Data analysis ............................................................................................................ 36
  8.7. Confidentiality ......................................................................................................... 37
  8.8. Sample ....................................................................................................................... 39
  8.9. Chapter summary: ................................................................................................. 39

Chapter Nine: The impact of a health or developmental issue on the parent-child relationship ........................................................................................................ 40
  9.1. Voluntary participation .......................................................................................... 35
  9.2. Data storage ........................................................................................................... 38
  9.3. Sample .................................................................................................................... 39
  9.4. Chapter summary: ................................................................................................. 39

Chapter Ten: The impact of health or developmental conditions of infancy on the parent-child relationship ..................................................................................... 41
  10.1. Caring for a healthy and developmentally normal infant ........................................... 11
  10.2. Caring for an infant with developmental or medical issue ........................................ 12
  10.3. Infantile Spasms: Psychosocial implications for parents ........................................ 15
  10.4. Caring for a child with paediatric epilepsy ................................................................. 15
  10.5. Infantile Spasms: Psychosocial implications for the child relationship ................. 17
  10.6. The impact of health or developmental conditions of infancy on the parent-child relationship ..................................................................................... 22
  10.7. The impact of the child’s health or developmental condition of infancy on the parent-child relationship ................................................................. 27
  10.8. The impact of health or developmental conditions of infancy on the parent-child relationship ..................................................................................... 28
  10.9. Chapter summary: ................................................................................................. 29

Chapter Eleven: The impact of a health or developmental issue on the parent-child relationship ........................................................................................................ 31
  11.1. Theoretical framework: ............................................................................................ 31
  11.2. Ethical issues: ............................................................................................................ 32
  11.3. Design considerations ............................................................................................... 32
  11.4. Recruitment: ............................................................................................................. 33
  11.5. The process of seeking and experiencing the diagnosis of Infantile Spasms .......... 40
  11.6. Data analysis ............................................................................................................ 36
  11.7. Confidentiality ......................................................................................................... 37
  11.8. Sample .................................................................................................................... 39
  11.9. Chapter summary: ................................................................................................. 39

Chapter Twelve: The impact of health or developmental conditions of infancy on the parent-child relationship ..................................................................................... 41
  12.1. Voluntary participation .......................................................................................... 35
  12.2. Data storage ........................................................................................................... 38
  12.3. Sample .................................................................................................................... 39
  12.4. Chapter summary: ................................................................................................. 39

Chapter Thirteen: The impact of a health or developmental issue on the parent-child relationship ........................................................................................................ 41
  13.1. Theoretical framework: ............................................................................................ 41
  13.2. Ethical issues: ............................................................................................................ 41
  13.3. Design considerations ............................................................................................... 41
  13.4. Recruitment: ............................................................................................................. 41
  13.5. The process of seeking and experiencing the diagnosis of Infantile Spasms .......... 40
  13.6. Data analysis ............................................................................................................ 41
  13.7. Confidentiality ......................................................................................................... 41
  13.8. Sample .................................................................................................................... 41
  13.9. Chapter summary: ................................................................................................. 41
A delay in the diagnosis of Infantile Spasms: .................................................................42
The emotional impact of a delay in diagnosis of Infantile Spasms: ..........................44
The experience and impact of the diagnosis of Infantile Spasms .............................45
Mothers receiving support and information at the diagnosis of Infantile Spasms ....47
  Communication by medical professionals ........................................47
  Information and support provided by nursing and social work staff .................49
5.2. Mothers adjusting to their child’s prognosis from Infantile Spasms ..................51
  Achieving seizure control ........................................................................52
  Developing a secondary seizure disorder .................................................52
  Developmental stagnation or regression .................................................54
  Medication side effects: .........................................................................55
The impact of Infantile Spasms on the relationship between the mother and child ...56
5.3. Living with and making meaning from a diagnosis of Infantile Spasms ............57
  The avenues by which mothers accessed support ....................................58
  The father of the child with Infantile Spasms ..........................................58
  Extended family and friendship networks .................................................60
  Early Childhood Intervention Services ....................................................62
  Professional counselling ........................................................................63
  The desire to ‘give back’ and contribute to further knowledge regarding Infantile Spasms: ....................64
  Participation in research .........................................................................64
  Contributing to peer support forums: ......................................................65
  Financial and in-kind contributions ........................................................66
Chapter Six summary: ..................................................................................66
Chapter Six: Discussion ..................................................................................68
  6.1. Study strengths and limitations ..........................................................68
  6.2. Discussion and clinical practice implications ........................................69
  The process of seeking and experiencing the diagnosis of Infantile Spasms ........70
  The distress experienced by mothers when their child’s diagnosis is delayed ....71
  The provision of medical information at diagnosis ....................................73
  Mothers adjusting to their child’s prognosis from Infantile Spasms ...............75
  How the child’s health and developmental outlook influences the parental relationship with the child: 76
  6.3. Living with and making meaning from a diagnosis of Infantile Spasms .........78
  Informal sources of support: ....................................................................78
  Formal sources of support: ......................................................................79
  Furthering knowledge: ............................................................................80
Chapter Seven: Conclusion ............................................................................81
References: ....................................................................................................83
Appendices: ...................................................................................................110
  Appendix 1: Literature review method: ..................................................110
  Appendix 2: HREC approval letter ..........................................................112
  Appendix 3: HREC modification approval letter ......................................113
  Appendix 4: Study Design Diagram ........................................................115
  Appendix 5: Recruitment cover letter ....................................................116
  Appendix 6: Plain Language Statement ...................................................117
  Appendix 7: Consent form .......................................................................121
  Appendix 8: Interview schedule ...............................................................122
  Appendix 9: Thank you letter ...................................................................123
Chapter One: Introduction

This thesis details the psychosocial experiences of parents who have cared for their child who has been diagnosed with Infantile Spasms. Infantile Spasms, also known as West Syndrome, is a generalized form of epilepsy that occurs within early infancy (Goodkin & Bertram, 2009). It is considered “one of the most devastating neurological disorders of infancy and early childhood” as seizures are unlikely to respond to treatment and there is likelihood of a poor cognitive outcome (Sakakihara, 2011, p. 202). As a result, Infantile Spasms is commonly referred to as a ‘catastrophic epilepsy’ or an epileptic encephalopathy (Iwatani et al., 2012).

Infantile Spasms is diagnosed by a hypersarrhythmEEG; a specific pattern of chaotic brain waves on electroencephalography testing, and the presence of myoclonic-tonic seizures; which are sudden and brief muscle contractions that may occur singly, repeatedly or continuously, involving either the whole body or individual limbs or muscle groups (Appleton, 2001; Goodkin & Bertram, 2009). Children may or may not present with developmental delay at the time of diagnosis (Wong & Trevathan, 2001) or the spasms may occur in the context of tuberous sclerosis, another seizure disorder (O’Callaghan, 2004, as cited in Kopp, Muzykewicz, Staley, Thiele, & Pulsifer, 2008). The peak onset of the condition is between three to seven months of age and prevalence is stated at 3.5/10,000 live births (Wheless et al., 2012).

A child’s prognostic outcome from Infantile Spasms is typically defined by the impact of spasms on development and whether the spasms respond to treatment, or evolve into a secondary seizure disorder. Children may either suffer severe intellectual impairment and ongoing seizures throughout their lives, or experience remission from the spasms and develop normally from this point (Appleton, 2001). This wide range in prognostic outcome is related to the underlying aetiology of each child’s condition, which may not be immediately evident at diagnosis (Lagae et al., 2010; Wheless et al., 2012). An unclear atieology and normal development prior to spasm onset are associated with a more positive outcome from Infantile Spasms (Lagae et al., 2010; Shields, 2006). Delay in diagnosis and late commencement of treatment is common and is likely to contribute to a poor medical outcome (Auvin et al., 2012; Napuri, Le Gall, Dulac, Chaperon, & Riou, 2010).

Patients receive treatment from a paediatric neurologist, potentially a paediatrician and are typically referred to Early Childhood Intervention Services (ECIS) for monitoring of their
developmental progress. There are different international perspectives regarding the optimal treatment regime for Infantile Spasms (Pellock et al., 2010; Sakakihara, 2011) however medications commonly used include midazolam, prednisolone, vigabatrin and adrenocorticotropic hormone (ACTH) (Mackay et al., 2004). These medications have a range of side-effects including hypertension, increased risk of infection, sedation, irritability, insomnia, hypotonia and concentric visual field defects (Mackay et al., 2004).

This study was informed by my clinical social work experience with parents of children diagnosed with Infantile Spasms. I have worked as a paediatric hospital social worker for ten years, and have been employed at the Royal Children’s Hospital (RCH), Melbourne, as a social worker for seven years. I was allocated to the Neurology Unit for three years of this period, during which time I provided social work assessment and intervention to several parents of infants diagnosed with Infantile Spasms. I hypothesized from my clinical observations that parental adjustment to this condition may be complex; particularly due to the uncertain prognosis and unclear treatment regime, early onset of symptoms and potential for delayed diagnosis. I provided support to several couples who were highly distressed at the time of their child’s diagnosis. However, I was unable to locate any research relating the parental experience or psychosocial support needs of this population. Additionally, due to the scope of practice of a paediatric social worker, I had limited opportunity for outpatient follow up of these patients and families, leading to my own uncertainty regarding their ongoing experience and adaptation. This motivated me to conduct the research study, to develop an understanding of the experience of this unique population.

This study aims to answer the broad, exploratory research question, ‘what are the psychosocial experiences of parents who provide care to an infant diagnosed with Infantile Spasms?’ Secondary lines of enquiry, based upon the above research question, were,

- To explore parents’ adjustment to the diagnosis of Infantile Spasms in their child, including any impact of delayed diagnosis and treatment on this adjustment, for example delayed recognition of symptoms by professionals or parents.
- To explore parents’ perceptions of their relationship with their infant who has been diagnosed with Infantile Spasms.
- To outline informal and professional supports accessed by parents of infants with Infantile Spasms, including from the RCH and their perceived usefulness.

Semi-structured interviews commencing with an open, unstructured question were conducted
with nine parents of children diagnosed with Infantile Spasms to allow participants to define the priorities of their narratives. Phenomenological principals underpin the study, and this perspective was selected for multiple reasons, as outlined below. Interviews were transcribed and thematically coded and illustrative points were selected to highlight salient themes.

The thesis addresses these questions within the six chapters outlined below.

This chapter, the introduction to this thesis, details the medical context of Infantile Spasms, including the diagnostic and prognostic information that is relevant to the parental experience.

Chapters Two and Three provide an overview of the literature that relates to the present study. Chapter Two examines the context of the diagnosis of Infantile Spasms, firstly by considering the experience of parents in raising healthy infants, before considering the impact of a health or developmental issue diagnosed in infancy. The lack of studies addressing the Infantile Spasms population from a psychosocial perspective is then identified. Due to this lack of directly relevant research, a broader examination of literature relating to the experiences of parents of children with other forms of epilepsy was conducted. This includes conditions with an onset during infancy. This is due to the clinical similarities between patients with Infantile Spasms and other forms of paediatric epilepsy, despite some variances in symptoms and ages of onset.

Chapter Three utilizes a biopsychosocial conceptualisation of health to discuss the factors that contribute to the parental experience of childhood illness and disability. Issues that place additional strain or serve to mediate the impact on parents are highlighted. Finally, the influence that these stressors have on the interactions between parents and their children are examined.

Chapter Four outlines the method of the study, which aims to address the previously undocumented experience of this population. The selection of a phenomenological approach to underpin the study is explained, along with its congruence with the research question and study population. The chosen method, of semi-structured interviews, which were then subjected to thematic analysis, is outlined in close detail. Methodological and ethical considerations relating to recruitment, confidentiality and informed consent are detailed. Finally, characteristics of the sample who participated in the study are noted in order to contextualize responses.

Chapter Five outlines the themes that emerged from the responses of mothers from the coding
and analysis of transcripts. The super ordinate themes of the study are described with illustrative quotes.

Chapter Six firstly contextualizes the study findings within the limitations and strengths of the study design. The responses of participants in the study are then located within the theoretical context outlined in the first and second chapters and current clinical practice. Considerations and recommendations for future practice are suggested.
Chapter Two: The parental experience of raising a child

This chapter orientates the reader to the experience of parents who care for their child with Infantile Spasms. In order to do this, literature that is directly and contextually relevant to the developmental and health profiles of these children has been considered. The chapter commences by briefly identifying how parents experience the early infancy period when their child is healthy, as the diagnosis of Infantile Spasms can occur within this context. The typical experience of early parenting is then compared to that of caring for an infant with a health or developmental condition. This literature is relevant to the study population for several reasons. Firstly, children may be diagnosed with Infantile Spasms on a background of a developmental delay and therefore this literature provides the direct context for a portion of this population. Additionally, there are commonalities between the parental experiences of Infantile Spasms and those associated with a broader range of conditions diagnosed in infancy. In summary, this literature may form a point of comparison for the experience of parents with a child diagnosed with Infantile Spasms, or it may describe the context within which they face the diagnosis. Comparisons are then made between these relevant domains of literature and the available literature regarding the psychosocial implications of Infantile Spasms. It is established that no qualitative, psychosocial research has been undertaken with this population.

To conclude the chapter, the examination of literature is broadened from the narrowed focus on the Infantile Spasms population to a wider range of studies relating to paediatric epilepsy diagnoses. Other forms of epilepsy that are diagnosed in infancy are first examined, before more general forms of paediatric epilepsy are considered. This body of knowledge has direct relevance to the patient population despite some variances in the prognostic outcomes, diagnostic pathways and treatment regimens of these conditions. Experiences of parents of children with epilepsy that are likely to be similar to the Infantile Spasms group are identified. Areas of enquiry with limited application to the study population, such as behavioral issues for adolescent patients with epilepsy, were excluded from the study review despite their dominance within the literature.

2.1. Caring for a healthy and developmentally normal infant

The birth of a healthy infant is typically a challenging but joyous time for parents (Hwu & Yang, 2002, as cited in Lee, Lin, Huang, Hsu, & Bartlett, 2009). At the time of the birth, the parents’ fantasies and lived experience of the fetus merge with the born infant (Vreeswijk, Rijk,
Maas, & van Bakel, 2015) who is fully dependent on caregivers (Mendes, 2007). Acquiring the skills to successfully parent an infant is a task that most parents approach with a sense of anxiety, however the majority are able to successfully adjust to the new role (Smith, Akai, Klerman, & Keltner, 2010). Mothers may grow in parenting confidence at a faster rate than fathers (Hudson, Elek, & Fleck, 2001, as cited in Fonseca, Nazare, & Canavarro, 2013) which may be in part due to having more opportunities for caregiving encounters with the infant (The Organisation for Economic Co-Operation and Development, 2005; Seah & Morawska, 2016). However, in a Western context, it is acknowledged that fathers have an increasing role in the parenting of children (Marrs, Cossar, & Wroblewska, 2014). Social support is a strong mediating factor in the transition to parenthood (Bost et al., 2002, as cited in Fonseca, Nazare, & Canavarro, 2014) particularly for mothers (Seah & Morawska, 2016). However, adjusting to the new role is demanding even for those with strong support networks and limited pre-existing stressors (Cowan & Cowan, 1992).

The typically developing infant is experiencing a period of significant developmental growth between the ages of three to seven months, the period when the diagnosis of Infantile Spasms is made. At this developmental stage, infants start to develop vocalizations, begin to roll and sit with support and develop their fine motor skills (Zeanah, 2012). The infant can also sustain periods of joint engagement with a caregiver during this stage of their development (Adamson, Bakeman, Deckner, & Nelson, 2012). However, at this age the infant remains developmentally vulnerable as they are pre-verbal and have a lack of gross motor control that may highlight a delay in development (Zeanah, 2012). Parents of infants who do not settle, demonstrate a lack of persistent weight gain and do not respond to stimulus with eye contact, in addition to not attaining the developmental milestones listed above, are recommended to seek a review by a health professional (Better Health Channel, 2015).

2.2. Caring for an infant with developmental or medical issue

The profile of health and developmental conditions of infancy

It is within the context outlined above that the diagnosis of a health or developmental condition of infancy occurs. A medical condition may be diagnosed antenatally (Coates et al., 2007) immediately post-partum (Marshall, Tanner, Kozyr, & Kirby, 2015) or on the emergence of symptoms later in infancy. Post-natal diagnosis can occur in a range of tertiary or community medical settings by emergency evaluation or as a result of planned investigations (de Groot-van der Mooren, Gemke, Cornel, & Weijerman, 2014; Harnett, Tierney, & Guerin, 2009).
Medical advances, particularly in relation to newborn screening programs, have resulted in a timelier diagnosis for some conditions that typically occur in infancy, for example deafness and cystic fibrosis (Coates et al., 2007; Tattersall & Young, 2006).

**The impact of a delay in the diagnosis of a health and developmental condition of infancy:**

Medical and developmental conditions may be particularly difficult to diagnose in a timely manner in infancy (Morley, Thornton, Cole, Fowler, & Hewson, 1991; Smaldone & Ritholz, 2011) due to the subtle presentation of symptoms (Bingham, Correa, & Huber, 2012) which the infant is unable to identify or report (Launay et al., 2014). Despite advances in antenatal and newborn screening technology, it is severe health conditions and disabilities with overt symptoms that are more likely to be identified in a timely way (Tuominen-Eriksson, Svensson, & Gunnarsson, 2013). Conditions that may escalate into a medical crisis, such as diabetes (Smaldone & Ritholz, 2011) are also identified quickly. However, equally serious conditions such as paediatric tumours and seizure disorders may not escalate into an immediate medical crisis, making detection more challenging for caregivers (Brasme et al., 2012; Sivberg, 2003). Psychosocial features of the parental situation may also influence detection timeframes, as the children of parents who are of younger age or who experience economic disadvantage are more likely to be delayed in receiving their diagnosis (Briggs-Gowan & Carter, 2008; Mandell, Novak, & Zubritsky, 2005). However, some studies do contest the notion that parents do not detect their child’s developmental delay in a timely manner (Cepanec, Lice, & Simlesa, 2012; Dixon, Badawi, French, & Kurinczuk, 2009). Additionally, one study specifically found that infants were not at increased risk for delays to diagnosis, suggesting that there were no increased risks of delays due to patient age (Sundaram, Day, & Kirk, 2009).

It is also common for health professionals to fail to prevent a delay in diagnosis in a range of paediatric health conditions (Brasme et al., 2012; Sundaram et al., 2009). Factors that may contribute to this occurring include standardized assessment instruments not being consistently utilized (Smith et al., 2010) and clinicians not having paediatric specialty training (Brasme et al., 2012). However, other studies contend that delays also occur in paediatric hospitals (Eckerle et al., 2015). Communication issues between medical professionals and parents may also increase the risk of a delayed diagnosis in a child. Within some studies that report a delay, parents describe feeling that their parental instincts have been ignored by doctors who minimize their observations or imply anxiety within the parent (Clarke & Fletcher, 2003; Tierney, Blackhurst, Scahill, & Callery, 2015).
Regardless of the cause, a protracted journey to diagnosis may provoke significant anxiety and distress in a parent (Tluczek, Koscik, Farrell, & Rock, 2005; Clarke & Fletcher, 2003). Parents may also carry an ongoing sense of guilt for not noting symptoms earlier (Evans, Wakefield, McLoone, & Cohn, 2015). This distress may be particularly fueled by the belief that timely medical treatment and developmental intervention are critical to maximizing outcomes for young children (Uus, Young, & Day, 2015).

The impact of a health or developmental issue of infancy on parents:

No matter the pathway to diagnosis, the very presence of a medical or developmental issue in an infant is known to be a major strain for parents, in addition to those associated with the raising of a healthy child (Darraht, Evans, & Adkins, 2002; Tierney et al., 2015). The literature describes a process of grieving the loss of the expected, healthy or “idealized” child (Gul et al., 2016). It is likely that parental quality of life, mental health and socio-economic status will be negatively impacted (Hartshorne, 2002). Parents must also meet the typically high care requirements of these children (Goodwin et al., 2015; Hallberg, Oskarsdóttir & Klingberg, 2010; Kandel & Merrick, 2003) which may involve intensive medical treatment via lengthy hospitalization (Jordan et al., 2014) or daily management of symptoms in an outpatient setting (Berg, 2011; Keren, 2011). Infants may have increased care needs in relation to areas such as feeding (Atzaba-Poria et al., 2010; Faugli, Emblem, Veenstra, Bjornland, & Diseth, 2008) movement and positioning (Hattier, Matson, Belva, & Kozlowski, 2012) or airway management (Miller, 2011). The symptoms of these conditions may be visually confronting (Berg, 2011; Keren, 2011) or may have few visible indicators (Jordan et al., 2014).

Whilst these negative aspects of the lived experience of paediatric illness for parents feature prominently in the literature, emerging narratives reveal the potential for resilience and positive adaptation. Resilience can be defined as “a dynamic process encompassing positive adaptation within the context of significant adversity” (Luthar, Cicchetti, & Becker, 2000, p. 543). Parental psychological distress and physical health improves in the six-month period post diagnosis for most parents (Fonseca, et al., 2013) with parents demonstrating a broader range of coping styles (Utens et al., 2002). The biological and psychosocial features of the infant and family profile that promote this resilience are of significant interest to researchers, and will be addressed in Chapter Three.
2.3. Infantile Spasms: Psychosocial implications for parents

As described above, the diagnosis of Infantile Spasms occurs at a time when parents are adjusting to the role of parenting the well, or medically or developmentally compromised infant. However, a closer examination of the literature related to the psychosocial implications of Infantile Spasms is required in order to locate this study. A thorough search of this literature was conducted, however, no studies that specifically assessed and addressed the lived experiences of these parents by involving them in research could be located.

The only references to the potential for Infantile Spasms to affect the parents of children diagnosed were located in a small number articles focused on the medical treatment of the condition. However, these statements were brief, located within the concluding statements of the articles and were not informed by consultation or research directly involving families. It was suggested that witnessing “daily clusters of distressing spasms” or developmental stagnation or regression resulted in unresolved, complex grief reactions in parents (Appleton, 2001, p. 688). There is also acknowledgement of the distressing nature of a delayed diagnosis, which typically occurs when a parent or professional fails to identify seizures or related symptoms in the child (Appleton, 2001; Ziegler, Erba, Holden, & Dennison, 2000). The role of psychological support for mothers of children diagnosed with Infantile Spasms was identified in a singular case study, where the provision of grief counselling and strategies for self-care management were discussed (Ziegler et al., 2000). Several medical articles address the need for a multidisciplinary approach to psychosocial care, identifying nurses, counsellors, clinical psychologists (Appleton, 2001) paediatricians, psychiatrists, rehabilitation service professionals, neuropsychologists, social workers and pharmacists (Pellock et al., 2010) as key professionals.

Research with the parents of children diagnosed with Infantile Spasms is therefore warranted given their anticipated acute needs and the lack of specific research with this group.

2.4. Caring for a child with paediatric epilepsy

As there is a knowledge gap regarding the psychosocial impact of Infantile Spasms on parents, studies relating to a broader range of paediatric epilepsy diagnosis’ may provide insights as to the lived experience of these parents.

As previously identified, Infantile Spasms is one of several forms of epilepsy that occur in
infancy. Dravet Syndrome and Ohtahara Syndrome are severe forms of epilepsy that are comparable to the Infantile Spasms population, due to their similar age of onset. Tuberous Sclerosis is a multi-systemic, genetic disorder where growths in the Central Nervous System can cause seizures (Curatolo, 2003, as cited in Kopp et al., 2008). Tuberous Sclerosis has also been previously identified as being a potential direct cause for Infantile Spasms. Some children initially diagnosed with these conditions may also go on to develop Infantile Spasms. However, children diagnosed with these conditions experience explosive onset of seizures in the first year of life that is often immediately refractory to treatment, unlike Infantile Spasms which often responds to treatment initially (Samia, Donald, Schlegel, & Wilmshurst, 2014). There are no psychosocially focused studies relating to the lived experience of parents of children with Ohtahara Syndrome, however Dravet Syndrome and Tuberous Sclerosis have been afforded attention in the literature. Parents of children diagnosed with these conditions experience similar issues to parents of children with other forms of epilepsy, for example grief responses, negative impacts on family quality of life, and limited access to supports, which are discussed further below (Graffigna, Bosio, & Cecchini, 2013). However, the intractable and relentless nature of seizures in these conditions creates great burden for parents (Camfield, Camfield and Nolan, 2012; Kopp et al., 2008) in addition to associated issues, such as medication side effects (Roth et al., 2011). Therefore, unique aspects of the experiences of parents of children with these conditions include the management of the refractory seizures (Nolan, Camfield, & Camfield, 2008) and particular challenges of accessing medical information at diagnosis (Whitehead & Gosling, 2003). Peer support groups, often facilitated over the internet, are particularly important avenue of support for parents of children with these rare conditions (Skluzacek, Watts, Parsy, Wical, & Camfield, 2011). Studies did not reference the diagnosis occurring in infancy as an issue of particular note, however this may be due to the extremely poor prognosis of these forms of epilepsy.

Parents of children diagnosed with generalized forms of epilepsy are confronted with a serious, chronic and episodic condition (Hodbell et al., 2007; Schuengel et al., 2009). It is common for paediatric epilepsy to be misdiagnosed or not detected in a timely way by parents or professionals (Berg, Loddenkemper, & Baca, 2014) particularly forms that are diagnosed in infancy (Bremer, Lossius, & Nakke, 2012). Epilepsy has an episodic nature of symptom onset, similarly to other conditions, such as diabetes and asthma, and it is hypothesized that this unpredictability may contribute to parental anxiety (Duffy, 2011; Thompson & Upton, 1992) and impaired family functioning (Buelow, McNelis, Shore, & Austin, 2006). Parents also
report social isolation (Camfield et al., 2012), sleep deprivation (Cottrell & Khan, 2005; Wood, Sherman, Hamiwka, Blackman, & Wirrell, 2008a) and financial hardship (Thomas & Bindu, 1999). Mothers of children diagnosed with epilepsy experience higher rates of depression (Ferro, Avison, Campbell, & Speechley, 2011b; Nolan et al., 2008; Wood, Sherman, Hamiwka, Blackman, & Wirrell, 2008b) compared to mothers of children with other health conditions (Rutter, Graham, & Yule, 1970, as cited in Ellis, Upton, & Thompson, 2000), women of childrearing ages (Beyond Blue, 2011) and the general population (Shore, Austin, Huster, & Dunn, 2002). However, in contrast to this argument, one identified study described rates of maternal depression in mothers of children with epilepsy as being consistent with those found in the general population (Nolan et al., 2008).

Parents of children with epilepsy experience a reduced quality of life and higher stress levels compared to parents of children with other chronic conditions, such as diabetes (Hoare, Mann, & Dunn, 2000; Moreira et al., 2013) or asthma (Chiou & Hsieh, 2008) and the general population (Iseri, Ozten, & Aker, 2005). However, quality of life for parents of children with epilepsy is similar to that of parents of children with cerebral palsy (Mezgebe et al., 2015), whilst parents of children with cancer experience more rumination and defense than their epilepsy counterparts (Goldbeck, 2001).

Whilst paediatric epilepsy clearly has a negative impact on the lives of the parents of these children, the capacity for adaptation to the diagnosis is acknowledged within the literature. Generalist trauma theory highlights that resilience is common amongst adults who have experienced a trauma; such as the diagnosis of epilepsy in their child (Bonanno, 2004, as cited in Ferro, Avison, Campbell, & Speechley, 2011a). In a small, phenomenological study of parents of children with epilepsy, participants maintained a sense of hope for the child’s prognosis, yet realistically incorporated the condition into their lives (Mu, 2008). Another study identified communication within the family unit as being key to promoting resilience and positive adaptation to the child’s condition (Ziegler et al., 2000).

2.4. Chapter summary:

This chapter has addressed the context of the study and provided insight to the possible experiences of the study population via relevant domains of research. The experience of raising a healthy or developmentally or medically compromised infant was first explored, in order to contextualize the diagnosis period. The experiences of parents raising a developmentally or
medically unwell infant were clearly identified as having possible parallels to the Infantile Spasms group. The lack of evidence-based research specifically outlining the psychosocial impacts of Infantile Spasms on parents was then identified; however, the brief references within medical literature and closely related studies were reviewed. Given this lack of directly applicable research, parallels were then drawn with the expanse of literature relating to paediatric epilepsy, as a relevant source of comparison to the Infantile Spasms population.
Chapter Three: How the experience of caring for a child with a health or developmental issue is shaped

This chapter explores how the parental experience of childhood illness or disability is shaped by a range of biological, psychological and social factors. The impact of this parental adjustment on the quality of the parent to infant interaction is then examined.

As described in Chapter Two the diagnosis of a medical or developmental condition in a child is challenging for the affected parents; however, some demonstrate the ability to adjust and cope relatively well. The factors that predict this capacity for adaptation are of interest to researchers, as they may be used to highlight vulnerable individuals and promote resilience within the population. A biopsychosocial model of health, originally outlined by Georg Engel, which states that biological, psychological and social factors influence health related outcomes for patients and their families, may be useful in conceptualizing these complex interactions (Engel, 1977).

The biological factors that will be discussed in this chapter are the type and severity of the child’s condition and the timing of the diagnosis. Socially constructed and experienced factors that are related to the medical condition include the quality of communication from medical professionals and the experience of accessing support services that are directly related to the management of the condition. Psychosocial factors that will be addressed include the parental socio-demographic profile, pre-existing mental health vulnerability and access to informal social supports. Finally, the influence that biopsychosocial factors have on the interaction between the infant and their parent and consequences of this potentially compromised relationship are discussed.

3.1 How biological issues shape the parental experience of paediatric illness or disability

When an infant or child is diagnosed with a health or developmental condition, the experiences for their parents are typically associated with the biological features of the condition. The severity of the child’s condition, as defined by the intensity and frequency of symptoms, the level of associated care needs and overall prognosis, are the factors most closely associated with poor quality of life for parents.
The severity of the child’s health or developmental condition

Studies examining paediatric epilepsy generally concur with the argument that disease severity is associated with impaired parental adjustment. Parents of children with severe forms of epilepsy are likely to experience challenges in their adjustment to and management of their child’s condition (McCusker, Kennedy, Anderson, Hicks, & Hanrahan, 2002) as discussed in the previous chapter. Maternal depression may be correlated with the number (Nolan et al., 2008) and severity (Shore et al., 2002) of seizures the child experiences. The presence of co-morbid behavioral issues (Shore et al., 2002; Wood et al., 2008a) and a reduced cognitive capacity (Ferro et al., 2011a) in the child is also strongly correlated with depression in mothers. However, a number of researchers contend that the severity of a child’s seizure disorder does not predict maternal depression (Wood et al., 2008b), parental chronic sorrow (Hodbell et al., 2007; Williams et al., 2003) or stress levels (Cushner-Weinstein et al., 2008). Additionally, determining the impact of epilepsy severity on parental coping is made challenging by evidence that parents can struggle to accurately report their child’s seizures (Ryan, Speechley, Levin, & Stewart, 2003; Wagner, Smith, Ferguson, & Wannamaker, 2009). However, Cottrell and Khan (2005) contest this notion, stating in their research that parents have a strong understanding of their child’s epilepsy and seizure patterns.

The inverse relationship between condition severity and parental adjustment is further confirmed by studies relating to paediatric developmental and health conditions more broadly. A range of research identifies a strong relationship between the type, and particularly the severity, of a child’s health condition and parental adjustment (Glasscock, 2000; Kandel & Merrick, 2003). One study compared maternal depression to rates of re-presentation to hospital for verified medical concerns, concluding that there was a correlation between the severity of the child’s medical condition and maternal depression (Miles, Holditch-Davis, Schwartz, & Scher, 2007). However, some researchers contest the presumed certainty that illness severity and visibility are the sole predictors of parental adjustment (Berant, Mikulincer, & Florian, 2003; Pelchat et al., 1999). Studies that considered levels of parental concern (Simons, Ritchie, & Mullett, 1998), and maternal post-traumatic stress disorder (PTSD) symptoms (Holditch-Davis, Bartlett, Blickman, & Miles, 2003) found that they were not related to the medical condition of premature infants admitted to hospital.

In summary, a breadth of literature identifies disease severity as a lead contributor to parental adjustment to childhood illness; however, it is not the sole predictive factor. As Infantile
Spasms has previously been identified as a catastrophic epileptic encephalopathy of infancy, it is reasonable to hypothesise that the parental experience of this condition may be challenging.

**The age of the child at the time of diagnosis**

The age at which the child is diagnosed with the health or developmental condition is another biological factor that have been shown to impact on parental adjustment. There is increasing interest in the role of age of seizure onset in determining patient and family outcomes, however limited research has been conducted in this area. It is widely acknowledged, however, that early age of seizure onset is highly associated with more severe intellectual impairment, refractory seizures and associated behavioural issues (Manor et al., 2013). As discussed above, this is likely to compromise parental adjustment and adaptation. However, other research contends that the diagnosis of epilepsy occurring at a younger age does not increase the risk for parental depression or maladjustment (Cushner-Weinstein et al., 2008; Shore et al., 2002) or reduce patient quality of life (Manor et al., 2013). In fact, the parental experience of childhood epilepsy may worsen the older the child is at diagnosis as the child is more aware of their situation (Behrouzian & Neamatpour, 2010; Greeff & Nolting, 2013).

In contrast to the finding above, research relating specifically to infants has found that the diagnosis of a health condition in the infancy period, as opposed to at an older age in childhood, has negative implications for the parental experience. Even the specific age at which the diagnosis is made in the infancy period may have an impact on how the condition is experienced by the parents. As previously discussed, infants diagnosed with health conditions may receive the diagnosis in the antenatal period, immediately after birth or within the first months of the infants’ life (Coates et al., 2007; Marshall et al., 2015). Whilst antenatal diagnosis is not directly relevant to the Infantile Spasms population, studies examining antenatal diagnosis often make highly relevant comparisons to the experience of postnatal diagnosis in order to quantify the impact on their population. These studies report mixed outcomes of these comparisons, some declaring that antenatal diagnosis increases the grief experienced by parents (Hunfeld, Tempels, Passchier, Hazebroek, & Tibboel, 1999) whilst others suggesting that it improves the quality of life of mothers (Fonseca, et al., 2013) and allows parents to refine coping strategies prior to the child’s birth (Glidden, Billings & Jobe, 2006).

The specific complexities associated with the diagnosis of a health condition in infancy, in comparison to later in childhood, have previously been addressed in Chapter One. In contrast
to the evidence highlighted regarding paediatric epilepsy, parents may be negatively impacted by meeting the care needs of the infant, who is medically and developmentally more vulnerable as a result of their age (Franich-Ray et al., 2013; Nagata, Nagai, Sobajima, Ando, & Honjo, 2004). There is also evidence that children diagnosed at younger ages are likely to engage less with their medical treatment and have more significant psychological issues into the future (Goldston, Kovacs, Obrosky, & Iyengar, 1995, as cited in Popp, Robinon, Britner, & Blank, 2014).

In summary, there is little overall consensus regarding the impact of the age at which a child is diagnosed with a health issue on their parents; as researchers disagree on whether an earlier age of diagnosis increases or reduces parental stress. The age of the child at diagnosis is a particularly relevant consideration for this study, due to the specific and relatively homogenous age at which Infantile Spasms is diagnosed for all patients.

3.2 How the experience of accessing healthcare shapes the parental experience of paediatric illness or disability

The communication of information to parents by medical professionals

In addition to the biological features of their child’s health condition, aspects of the lived experience of accessing healthcare may influence overall parental adjustment. One component of the healthcare journey that is particularly relevant to this study is the manner in which healthcare professionals communicate with parents at the time of their child’s diagnosis and throughout ongoing treatment. Good communication is defined within the literature as the combination of “knowledge and interpersonal skills” (Nelson, Caress, Glenny, & Kirk, 2012).

Parents of children with epilepsy have consistently reported that they require clear medical information regarding their child’s condition (Aytch & White, 2001; McNelis, Buelow, Myers, & Johnson, 1998; Shore et al., 1998) particularly due to the unpredictable nature of epilepsy (Mu, 2004). The delivery of this information can also influence the ability of the parent to adjust to the new diagnosis (Psenka & Holden, 1996). Unfortunately, parents regularly report that they receive inadequate information from health professionals, and that this forms a source of considerable anxiety for them (Buelow et al., 2006; Ziegler et al., 2000). Saburi (2011) reported that parents felt their child’s physician maintained a singular focus on medication related issues, as opposed to discussing broader subjects such as the impact of epilepsy on peer interaction and relations within the family. Other parents report that they received inaccurate
information regarding the seizure disorder itself. It is suggested that nursing case management services may be able to reduce parental stress by the provision of information (Mu, Kuo, & Chang, 2005) whilst psychoeducational programs have been demonstrated to reduce parental educational needs (Austin, 2006).

Studies addressing a broader range of paediatric health conditions also provide insight into the quality of healthcare professional communication, and the impact that this has on parents. Similar to their epilepsy counterparts, parents of children with a range of health and developmental conditions report that clear, concise and empathic communication with a focus on essential medical information is important at diagnosis (Bingham et al., 2012; Cabral, Ingram, Hay, & Horwood, 2014; Patistea & Babatsikou, 2003; Zierhut & Bartels, 2012). Parents require the timing and delivery of information to be individualised (Tierney et al., 2015) and framed with consideration of the pre-existing knowledge and the potential misconceptions that they bring to the interaction (Psenka & Holden, 1996). It is therefore important for parents to have the capacity to express their concerns and expectations early within the relationship with the physician (Howells & Lopez, 2008). In contrast to the studies conducted relating to epilepsy, research suggests that parents are generally satisfied with communication by doctors on the diagnosis of a condition in their child (Nelson et al., 2012). However, critiques suggest that the structure and content of information may be unclear (Goin-Kochel, Mackintosh & Myers, 2006, as cited in Osborne & Reed, 2008) or incomplete, outdated and lacking for some individuals (Marshall et al., 2015). It is important to note, however, that clinical information may be unclear to physicians at the time of diagnosis, making it challenging for them to provide clarity to parents. Similarly, reassurance and support from medical professionals is important yet often reported to be absent (Tierney et al., 2015) with parents reporting with an over-emphasis by doctors on the negative aspects of the diagnosis (Skotko, 2005, as cited in de Groot-van der Mooren et al., 2014).

Strong communication by medical professionals is important in supporting the lived experience of parents of children with a health condition. Sensitive and thorough communication has been identified as facilitating parental adjustment to diagnosis, (Choi, Lee, & Yoo, 2011) satisfaction with healthcare provision (Howells & Lopez, 2008) and strengthens the relationship between the parents of the child with a disability (Taanila, Jarvelin, & Kokkonen, 1998). Delays in the provision of medical information after the diagnosis has been made can increase parental stress levels (Most, Fidler, Laforce-Booth, & Kelly, 2006; Tluczek et al., 2005). The clear delivery
of information is particularly important as parents often have a reduced capacity to process complex information at the time of diagnosis. However, the process of seeking and receiving information may be immediately containing and assist some parents to develop skills for independent management of the condition in the future (Patistea & Babatsikou, 2003).

The experience of accessing formal supports related to the child’s condition

Another aspect of the paediatric healthcare experience that has been seen to assist parental adjustment is the quality and accessibility of professional services that monitor and support the affected child and family. There are a range of formal, non-medical, community based support services that parents of children with epilepsy may access specifically in relation to the child’s condition, including counselling and early intervention (EI) services. As seizures risk a child’s development, young children with epilepsy within Victoria, Australia, typically access EI services, locally referred to as Early Childhood Intervention Services (ECIS). ECIS is publicly funded through the Department of Education and Training to “support children with a disability or developmental delay from birth to school entry and their families. ECIS provides special education, therapy, counselling, service planning and coordination, assistance and support to access services such as kindergarten and child care” (Department of Education & Training, 2017, para 1). However, current ECIS services will transfer to Early Childhood Early Intervention services (ECEIS) via the staged roll-out of the National Disability Insurance Scheme (NDIS). ECEIS pledge to offer a family-centered approach by developing plans that are individualized to each child’s development and maximize the timely delivery of supports to children under seven years of age (Raising Children Network, 2016). However, due to the absence of psychosocially focused research relating to infants and young children with seizures, there are limited references to how these parents experience accessing EI services. One relevant study indicated that in addition to promoting developmental gains in the child, EI services were demonstrated to improve parents’ understanding of their child’s seizure disorder (Aytch & White, 2001).

A wider body of literature exists in relation to the use of EI services for infants and young children with a broader range of health and developmental issues. The effectiveness of EI services is not well understood (Guralnick, 1998) however, it is suggested that they improve parenting (Salisbury & Copeland, 2013) and developmental outcomes for children (Tuominen-Eriksson et al., 2013). These benefits are more likely to be evident if EI is delivered in an inclusive, ‘family centered’ manner; which empowers the family to work in partnership with
professionals (Wang et al., 2006). However, there can be extended delays in gaining access to ECIS in Victoria (McManus, Carle, & Rapport, 2014), which is consistent with the limited supports that are available for children with disabilities in Western countries (Burton-Smith et al., 2009; Hiebert-Murphy, Trute, Wright, 2011; Marcenko & Meyers, 1991). International research indicates that socio-economic status may also present as a barrier to accessing EI; (McManus et al., 2014): however, maternal depression did not prevent access in the same way (Feinberg, Donahue, Bliss, & Silverstein, 2012).

Individual, professional counselling may also be of benefit to this population given the extent of possible grief and the frightening nature of witnessing seizures (Galletti & Sturniolo, 2004). Counselling may also be helpful for parents of children with any form of developmental delay, health condition or disability (Haugstvedt, Graff-Iversen, Bukholm, Haugli, & Hallberg, 2013). There are no consistent approaches to therapeutic intervention with parents of affected children, however some approaches may include psychodynamic guidance to support acceptance of the child’s development (Capozzi, 2010) or cognitive behavioural therapy or problem solving therapy to incorporate the diagnosis into the parents’ life (Eccleston, Palermo, Fisher, & Law, 2012).

3.3 How psychosocial issues shape the parental experience of paediatric illness and disability:

The parental experience of paediatric illness is not solely predicted by the biological features of the child’s condition or the lived experience of accessing healthcare. Psychosocial factors, which are typically pre-existing strengths or vulnerabilities of the parents that they bring to the health experience, have also been shown to have a significant role.

Psychosocial issues relating to paediatric epilepsy

Pre-existing psychosocial vulnerabilities within the parent’s situation have been shown to impact on their adjustment to the diagnosis of epilepsy in their child. For example, mothers of children with epilepsy are more likely to experience depression if they are younger (Ferro et al., 2011b) and have a lack of family support (Ferro & Speechley, 2009; Shore et al., 2002). Several authors identified socioeconomic status as having an equal or greater influence on parental adaptation than epilepsy severity (Mitchell, Scheier & Baker, 1994; Thomas & Bindu, 1999). Other studies are less conclusive regarding the impact of maternal socio-economic status and education level, some pointing to their correlation with maternal depression (Shore
et al., 2002) with others indicating no link (Chiou & Hsieh, 2008; Wood et al., 2008b). These findings are highly consistent with the psychosocial risk factors that impact upon parents of children with a broader range of health conditions. Similarly to the epilepsy group, factors such as the mother’s age (Northrup, Evans, & Stotts, 2013), being unmarried (Miles et al., 2007) and having less education and income (Northrup et al., 2013; Zaidman-Zait & Jamieson, 2007) are more likely to predict maternal depression than their child’s diagnosis. Some studies relating to infants and young children even contend that psychosocial factors have an equal or more significant role than biological factors (McCusker et al., 2002; Stephens, Bann, Poole, & Vohr, 2008).

Access to adequate informal, social supports is a psychosocial factor known to mediate the negative impacts of childhood illness or disability on parents. A primary source of practical and emotional support in the care of the child with epilepsy is located in the relationship between the parents of the child. Unfortunately, there is limited research in relation to the role fathers play in caring for their children with epilepsy (Harden, Black, & Chin, 2016) likely due to the difficulty associated with recruiting fathers to participate in research (Moreira et al., 2013). At the point of diagnosis, evidence suggests that mothers experience a greater burden of care and higher levels of stress than fathers (Ramaglia et al., 2007). Fathers are also less likely to reduce hours or resign from employment as a result of their child’s diagnosis (Riechmann et al., 2015). However, it is also understood that fathers experience ongoing uncertainty and distress regarding their child’s epilepsy (Mu, 2005) and may be more likely to experience depression than mothers (Reilly, Taft, Nelander, Malmgren, & Olsson, 2015). Family functioning may also be impaired in this cohort, in comparison to the general population (Thornton et al., 2008).

**Psychosocial issues relating to health or developmental conditions of infancy**

Literature addressing the role of fathers in relation to parenting their children with a broader range of disabilities and health conditions provides a clearer sense of their influence. Whilst there is a similar, growing interest in the contribution that fathers make to caregiving within this context (Laxman et al., 2013) it is generally accepted that women typically undertake the primary caregiving role of a child with a disability (Tsibidaki, 2013). There are clear benefits to fathers actively supporting their partners in the care of the unwell child. Fathers who are responsively engaged in the care of their children have partners with less depressive symptoms (Laxman et al., 2013) and parenting stress levels (Song, Chun, & Choi, 2015). The marital
relationship also benefits if contributions to the caring role are even (Ozyazicioglu & Buran, 2014; Seah & Morawska, 2016). However, performing the role of a secondary caregiver can negatively impact on socio-economic status, with partners or fathers experiencing limited access to flexible working conditions and experiencing reduced work fulfillment (Ferro et al., 2011a). Fathers who do engage actively in the care of their disabled children typically have higher levels of education, fewer gender-stereotyped beliefs, a more internal locus of control and higher levels of empathy (Bragiel & Kaniok, 2014). Having a similar or complementary coping style to their partner also aides a collaborative approach to parenting for this group (Goldbeck, 2001; Zierhut & Bartels, 2012).

Parents also access support from their extended families, particularly the grandparents of the child. Parents of children with a disability elicit both instrumental (for example, financial and childcare support) and emotional support from grandparents to assist them in their caring role (Canary, 2008; Katz & Kessel, 2002). In some studies, grandmothers have been found to provide more support than grandfathers (Canary, 2008; Hall, 2004).

Another avenue that parents may access for support is peer support groups (Ziegler et al., 2000). An increasingly popular medium for parents to access peer support is via internet support groups, which allow parents to interact with specific populations in a relatively anonymous manner (Camfield et al., 2012; Lewis, Noyes, & Hastings, 2015).

3.4 The impact of a paediatric health or developmental issue on the parent-child relationship

As previously discussed, a complex interaction of bio-psychosocial factors determines the parental experience of their child’s illness or developmental disability, including epilepsy. This experience, and the related capacity to adjust to the diagnosis, has been demonstrated to impact on the parents’ interactions with their child. A parent’s ability to develop a meaningful, coordinated and connected relationship with their young child, primarily through their interactions, is of significant benefit to both the child and parent. These interactions may be compromised by biological issues that relate to the child or psychosocial features of the family’s situation, as discussed below.

The impact of paediatric epilepsy on the parent-child relationship

Literature relating to paediatric epilepsy clearly shows a correlation between the parental
adjustment to the condition and the quality of the interaction that the parent has with their child. Parents who demonstrate a constructive adaption to the diagnosis employ more positive behaviour strategies in their parenting than those with negative beliefs about the condition (Williams et al., 2003). Parents who experience depression are more likely to act intrusively, meaning they override the autonomy of the infant, and confine the activities of their child with epilepsy (Austin & McDermott, 1988, as cited in Behrouzian & Neamatpour, 2010). They are also likely to struggle with establishing routines (Rodenburg, Meijer, Dekovic, & Aldenkamp, 2007; Thomas & Bindu, 1999) and experience difficulty managing their child’s epilepsy (McCusker et al., 2002; Otero & Hodes, 2000; Rodenburg, Wagner, Austin, Kerr, & Dunn, 2011). It is also suggested that the stigma associated with epilepsy may potentially lead to maladaptive parenting (Ellis et al., 2000; Pal, 2002). In addition to the contribution of parental adaption, the inherently unpredictable nature of the condition may result in parents using more intrusive parenting techniques (Seidenberg and Berent, 1992, as cited in Chiou & Hsieh, 2008; Wood et al., 2008a).

The impact of health or developmental conditions of infancy on the parent-child relationship

Infants and young children with a broader range of medical or developmental conditions, aside from epilepsy, also encounter challenges in the interaction with their parents, as a result of the condition. Infants with a health condition or disability are likely to be less responsive toward the parent (Singer et al., 2003), have less engaging facial expressions than their counterparts with no delay (Levy-Shiff, 1986, as cited in Becker, Engelhardt, Steinmann, & Kane, 1997) and are less responsive to maternal cues in vocalizing (Becker et al., 1997; Holditch-Davis, Schwartz, Black, & Scher, 2007). As outlined previously, medication side effects from commonly used steroid medications may also contribute to a flat and disengaged affect in an infant. This reduced capacity of the infant to engage and respond to the parent is detrimental to the infant to parent relationship (Rempel, Ravindran, Rogers, & Magil-Evans, 2013; Sealy & Glovinsky, 2016; Torowicz, Irving, Hanlon, Sumpter, & Medoff-Cooper, 2010; Troutman, Moran, Arndt, Johnson, & Chmielewski, 2012). Parental confidence in their caregiving ability may be reduced (Miles, Holditch-Davis, Burchinal, & Brunssen, 2011) which may compromise their ability to read the cues of their infant (Barrera, Kitching, Cunningham, Doucet, & Rosenbaum, 1991). Caregivers of infants with disabilities are likely to be more intrusive (Forcada-Guex, Pierrehumbert, Borghini, Moessinger, & Muller-Nix, 2006) and directive (Becker et al., 1997; Laing et al., 2010) in their interactions with their child. Conversely, research has also found that parents of disabled infants touch their children less than parents of
non-disabled infants (Atzaba-Poria et al., 2010).

In addition to the biological factors that influence the developing relationship between infant and parent, psychosocial factors also hold influence (Becker et al., 1997; Muller-Nix et al., 2004). It is well established that parents who are experiencing depression in the early period of their infant’s life are likely to have impaired relations with their children (Atkinson et al., 2000; Britton, 2005). Parents with depression are likely to demonstrate less warmth (Lovejoy, Graczyk, O’Hare, & Neuman, 2000) or responsiveness in their interactions with their child (Milgrom, Ericksen, McCarthy, & Gemmill, 2006) and initiate less developmentally enriching behaviours (Campbell, Matestic, von Stauffenberg, Mohan, & Kirchner, 2007). Mothers experiencing depression also describe their infants as being more difficult than they are independently rated as being (Pauli-Pott, Mertesacker, Bade, Bauer, & Beckmann, 2000). Parental depression may hold even more influence over the parent to child relationship than the child’s medical condition (Gray et al., 2013). As previously outlined, this is especially relevant as maternal depression is particularly common amongst mothers of children with health or developmental issues including those diagnosed with epilepsy.

However, in contrast to the discourse that the parenting of a disabled infant is inherently compromised, some studies demonstrate that there are no differences between the parenting of disabled children and their developmentally normal counterparts. Several studies have found that parents do not alter (Gul et al., 2016; Schermann-Eizirik, Hagekull, Bohlin, Persson, & Sedin, 1997) or become more directive (Cress, Moskal, & Hoffman, 2008) in their parenting of children with a range of medical issues or developmental delays. Additionally, the literature challenges the negative characterization of behaviours as either ‘intrusive’ or ‘directive’. Active engagement with a less responsive infant can be reframed from being an ‘intrusive’ behaviour to a sensitive and accommodating response to the child (Becker et al., 1997; Goldberg & DiVitto, 2002, as cited in Singer et al., 2003; Minde, 2000, as cited in Laing et al., 2010).

3.5. Chapter summary:

This chapter has utilized a bio-psychosocial model of health to explore how the parental experience of their child’s illness or disability is shaped. The chapter has summarized studies pertaining to paediatric epilepsy and developmental and health conditions of infancy and early childhood in order to contextualize the main themes of the study. The biological, psychological
and social factors that are key influences on these experiences were addressed. Whilst the results of studies are mixed, the literature generally suggests that biological and psychosocial factors contribute equally to the parental experience and their adjustment. The detrimental impact that these influences have on the relationship between the caregiving parent and infant was then highlighted. Due to the lack of specific research addressing Infantile Spasms, it is likely that the experience of these parents will be located at the junction of the experiences of parents of children with epilepsy or health or developmental issues diagnosed in infancy.

This chapter has detailed how various bio-psychosocial issues engage to influence how parents experience paediatric illness or disability. These complex interactions provide indications as to how this overall experience may be for parents, however it is important to note that they do not comprise the lived experiences of these parents. Parents who detail their lived experience of caring for their child with a health issue, including epilepsy, are likely to reference some of the major contributing factors to adjustment that are discussed above. However, the perspective from these narratives is those of parents providing accounts of their own lived experience of caring for their children. Research that promotes the narratives of parents allows their experience to be articulated in the way that reflects the issues of most significance to them. These studies also allow for a more in-depth, nuanced account of the journey that parents face when their child is diagnosed with a health or developmental issue.
Chapter Four: Methodology

A consideration of the literature, outlined in Chapter One and Two, highlights a gap in understanding relating to the experience of parents of young children with seizures; of which the Infantile Spasms population is a sub-group. Given this lack of knowledge, an exploratory study, based on principles of phenomenology was devised in order to answer the broad research question ‘what are the psychosocial experiences of parents who provide care to an infant diagnosed with Infantile Spasms?’

This chapter addresses the methodological and ethical considerations that framed the design of this study. Initially, the chapter outlines the theoretical context and human research ethics committee approval that guided the research. The design of the study is then articulated, namely semi-structured interviews with a small number of participants, seeking in-depth narratives regarding the lived experience of this phenomena. The strategy utilized to recruit participants to the study is detailed, and the demographic profile of participants who were successfully recruited by this method is outlined. Design considerations that were implemented to ensure ethical research practice with the above participants are discussed, for example strategies to ensure informed consent and confidentiality of study information. Finally, the process by which these interviews were then subjected to thematic analysis, in order to identify the study findings, is then outlined in detail.

4.1. Theoretical framework:

This study is an examination of the ‘life-worlds’ of parents of infants diagnosed with Infantile Spasms, based upon principles of phenomenological research. Phenomenology is a philosophical and research method originated by German philosopher Edmund Husserl that aims to comprehensively articulate a phenomenon as perceived by those experiencing it (Grbich, 2013). Phenomenological research aims to explore individuals’ personal perceptions of their experiences in order to understand human phenomena. Due to the lack of any previous research addressing the experiences of this population and the rare incidence of the condition, a qualitative method based on principles of phenomenological research was selected to guide the study design. This approach allowed in-depth narratives to be uncovered on this little known subject, with participants being valued as the experts of their lived experiences.
This study may not be considered a purist phenomenological study due to the use of a semi-structured interview schedule, which will be detailed further below. However, the principles above were fundamental to the development of the study and shaping the aim of detailing the lived experience of this population.

### 4.2. Ethical issues:

Prior to commencing the study, ethics approval was granted in 2016 by the Human Research Ethics Committee Ethics (HREC) of the Royal Children’s Hospital. A modification of the original HREC approval was granted in April, 2016, in order to allow telephone interviews to occur. I undertook monthly supervision at The University of Melbourne under the Principal Researcher and secondary supervisor, for discussion and management of ethical issues arising from the study, as recommended in the literature (Ahern, 2012; Dickson-Swift, James, Kippen, & Liampittong, 2007).

The major ethical consideration in conducting this study was the risk of causing participants psychological harm as a result of their participation. Participants did not experience any risks to their physical safety, however it was anticipated that the highly sensitive nature of the interviews may place some participants at risk of feeling upset and distressed. Whilst there has been debate regarding the potential risks of qualitative research on participant’s psychological wellbeing (Hadjistavropoulos & Smythe, 2001) there is increasing acknowledgement of the therapeutic value of face-to-face interviewing, with distress anticipated to be relatively short term (Ahern, 2012; Dickson-Swift et al., 2007; McCoyd & Shdaimah, 2007). Potential positive outcomes for participants include a sense of ‘catharsis’, empowerment in telling their story and a sense of contributing to awareness or positive change in relation to the issue (Birch & Miller, 2000; Peel, Parry, Douglas & Lawton, 2006). Strategies implemented to ameliorate these risks are detailed whilst discussing the process of obtaining ‘informed consent’.

### 4.3. Design considerations

The study is comprised of a face-to-face or telephone interview with parents, with both mothers and fathers targeted for recruitment, of children diagnosed with Infantile Spasms. In keeping with a phenomenological approach, the interview was conducted as an open question to participants, requesting that they speak to their lived experience of their child’s Infantile Spasms. An interview schedule was devised, however, to encourage discussion with participants who may have struggled to engage with an open ended query, which was overtly
requested by one participant. The interview schedule was devised in close consultation with University of Melbourne supervisors. Questions were based on the primary study objectives outlined in the introduction chapter, in addition to open questions seeking participant priorities. The semi-structured interview guide was carefully constructed to commence with general, basic questions in order to establish rapport prior to addressing more sensitive and potentially challenging aspects of the participant’s experience (King & Horrocks, 2010). A series of brief questions collecting participant demographic information were asked at the beginning of the interview to contextualise participant responses. Participants were also asked if their child had developed any additional medical conditions, including associated seizure disorders, in order to provide further context to the interview. An audio recording device recorded interviews, which were then transcribed prior to deleting the audio-recordings.

Interviews were conducted at the Royal Children’s Hospital in a private interview room in the Family Hub, and several later interviews were conducted over the phone. In person and telephone interviews were offered at a time that was most convenient to the participant. The initial Plain Language Statement only offered the option of interviews in person, however several potential participants who declined to participate voluntarily articulated that the option of a telephone interview would assist them to participate, and that they felt strongly motivated to do so. A HREC ethics modification was sought to allow both in person and telephone interviews to occur. Approval was granted after the first five individuals were interviewed, and telephone interviews were offered to those who had expressed interest. This offer of telephone interviews resulted in additional participation meeting required recruitment targets, therefore no amended Plain Language Statements were sent to additional potential participants. To ensure participant and student researcher safety, interviews occurring at the participant’s home were not offered. The study was unable to provide childcare facilities to participants, therefore several participants brought additional caregivers to care for their children whilst the interview occurred.

Participants were sent a thank you letter that summarised the study results.

4.4. Recruitment:

The study aimed to recruit ten parents of children diagnosed with Infantile Spasms prior to 2011. Exclusion criteria included patients who had died, parents who did not speak English and families who had had clinical contact with the student researcher. These criteria were
selected to ensure no undue distress to parents of bereaved children and the lack of resources to provide appropriate interpreters to families. Parents whose infants were diagnosed between January 2005 and January 2011 were contacted in reverse order of date of diagnosis in sequential groups of fifteen. This timeframe was selected to reduce the likelihood that the student researcher had had any clinical contact with participants, due to the student researcher being allocated as the Neurology team social worker after this time. This meant that participants were reflecting upon their historical experience from several years prior. This may have had benefits in reducing the risk of the interview becoming psychologically distressing and allowing participants time to have reflected upon their experiences. It was proposed that if both parents from a couple wished to participate in the study they would be interviewed individually. Joint interviews were considered however there are additional complexities relating to the analysis and depth of information sourced from conducting joint interviews (Morgan et al., 2013). I aimed to recruit up to ten participants due to the exploratory nature of the study. The design of the study does not attempt to produce generalizable results and interviews aimed to yield comprehensive transcripts for thematic analysis.

Recruitment was conducted sequentially to ensure that all individuals who responded positively to recruitment materials were included in the study. This was due to the emotive nature of the study and the wish to honor the volunteered time of individuals who agreed to be interviewed. Fifteen families were sent information packages regarding the study in the first round of recruitment and eleven further packages were mailed as indicated by the number of initial participant responses. I planned to interview all parents who consented to participate in the study, even if this had numbered all fifteen parents.

Potential participants to the study were initially identified via a RCH EEG results database by RCH technician staff. Home addresses of potential participants were sourced from the IBA computer patient information system, utilising the patient’s UR number. Participant information sourced for the study was crosschecked with the IBA system to ensure that the student researcher has not had clinical contact with the parents prior to study information being mailed. A covering letter was signed by the Head of the Neurology Department, due to her rightful access to the patient data. In conjunction with the covering letter, a Plain Language Statement and consent form were sent to eligible parents. The information package material was reviewed by the Plain Language Advisor of the Royal Children’s Hospital. A self-addressed, stamped envelope was included for consent forms to be returned to the student
researcher. These forms allowed potential participants to consent to participate or decline further contact; contact with the student researcher was also welcomed by telephone or email. Potential participants were also invited to meet at an outpatient appointment to take written consent. The letter also stated that a telephone call would be made to families who did not respond to the letter within two weeks of anticipated receipt.

Parents approached for the study who did not make contact within two weeks of anticipated receipt of the study information by mail were called on the telephone number listed on IBA. The study was explained to these parents and those who indicated a wish to participate were mailed additional information packages and/or appointments scheduled to meet. Potential participants were not required to provide a reason for declining involvement.

Informed consent

Informed consent was obtained through the provision of clear information in the Plain Language Statement outlining the risks and benefits of participation, confidentiality and voluntary nature of participation. Participants were provided opportunities for verbal clarification with the student researcher prior to the signing of the consent form. Efforts were made to ameliorate the lack of clarity for participants regarding the content of the semi-structured interview by disclosing the themes anticipated for discussion. (Hadjistavropoulos & Smythe, 2001).

The plain language statement sent to parents acknowledged that the subject matter for in-depth interviews may cause distress for some participants. Participants were reminded that they were free to cancel or postpone the interview at any time, or request that the audio-recording device was switched off. Whilst I distinguished between the research interview and providing a counselling service, skills utilized in clinical practice as a social worker such as active listening, containment and psychological first aid were utilized to support participants (Birch & Miller, 2000; McCoyd & Shdaimah, 2007). Counselling services were available for participants if required in addition to the psychosocial services available at the RCH. No participants requested information or referral to a counselling service after interviews concluded. It was intended for this action to be recorded on the interview transcript for any participant who received a referral for additional support.

Voluntary participation

Participants were advised that their choice not to participate or to withdraw from the study at
any time, without providing a reason, would not affect the provision of healthcare to their child. This included psychosocial services such as social work. Participants were able to withdraw by informing the student researcher in writing or verbally. It was planned that qualitative transcripts and/or audio recordings of participants who withdrew from the study would be shredded/destroyed and data sets that had been analyzed in NVivo would be withdrawn. However, no participants withdrew and therefore this did not need to occur. It was intended that any participants who withdrew from the study would not be replaced, due to the qualitative and non-representative nature of the data.

4.6. Data analysis

The process of thematic analysis was selected to synthesize and present the themes that represent the experience of parents in rich detail. Thematic analysis is consistent with the phenomenological framework of the study. This process is acknowledged as interpretive, in that these ‘life worlds’ are not directly accessible to the researcher and therefore must be carefully deciphered and interpreted (Giorgi, 2009; Smith & Osborn, 2003). The model of thematic analysis offered by Braun and Clarke (2006) was used to guide data analysis for this study. This six-step process has been condensed into a five-step process, as the transcription of data by the student researcher has already occurred.

Each transcript was read multiple times and analyzed individually. The student researcher made annotations and highlighted pertinent words or passages, connected similar themes across different sections of the transcript and marked issues that appeared to be missing or incomplete. NVivo was utilized to capture the student researcher’s impressions regarding the emerging themes (Braun & Clarke, 2006; Creswell, 2009).

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<th>Step</th>
<th>Process of thematic analysis</th>
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<td>1</td>
<td>Initial codes were generated from the data, which consisted of the most basic segments of information, which were used to develop themes</td>
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<tr>
<td>2</td>
<td>The most central codes for each individual transcript were grouped into themes and arranged into a table utilizing NVivo. The identification of themes and salient quotations were reviewed in supervision between the student and principal</td>
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Further revision of themes then occurred, prior to the definition of themes. The main themes of each interview were compared with those identified in the other transcripts. Commonalities, differences and prevalence of themes were identified and themes without significant data were discarded.

The revised themes were then distilled into superordinate themes. Subordinate themes, e.g. variations of experience of a superordinate theme, assisted to develop a more comprehensive expression of the phenomena. Quotes from each transcript were selected that represented the superordinate themes.

Adapted from (Braun & Clarke, 2006; Creswell, 2009; Smith, Flowers, & Larkin, 2009).

The process of thematic analysis was facilitated via the Computer-Assisted Qualitative Data Analysis Software (CAQDAS), NVivo. Whilst there has been debate regarding the rapidly increasing use of CAQDAS in qualitative research, proponents of the technology highlight that it can improve the quality of analysis, whilst being more efficient and increasing the security of data storage (Goble, Austin, Larsen, Kreitzer, & Brintnell, 2012).

The model offered by Braun & Clarke (2006) also offers the framework for the reporting of the superordinate themes in Chapter Five of the thesis. Themes with 2-3 respondents are defined as having ‘a few’ respondents, themes with 4-5 respondents are defined as having ‘some’ respondents whilst themes with 6 or more respondents are cited as being articulated by ‘most’ respondents. Quotations were edited for superfluous or repetitious language for the purpose of clarity.

Extrapolated themes of data analysis were discussed monthly in supervision at The University of Melbourne and consensus was reached on the identification of themes.

**4.7. Confidentiality**

I informed participants of their rights to confidentiality prior to the commencement of interviews. Efforts were made to ensure participant confidentiality, as small participant
numbers increase the possibility of an individual being recognized (Bryman, 2012). Participants have been ensured anonymity by the allocation of numerical codes to their responses, e.g. ‘Participant 1’. The names of healthcare providers or other individuals, for example extended family, specifically identified by participants were anonymized to ensure their confidentiality. Information that was likely to lead to the identification of a participant or related individual, such as geographical locations, was also anonymized. This was indicated in the quotations included in Chapter Five by underlining text and using single quotation marks.

Participants were informed that I was mandated to waive confidentiality as required by law, for example the disclosure of significant parental mental health issues and family or child abuse and/or neglect by participants. These criteria were discussed with the Chief Social Worker, who agreed to these thresholds of risk being utilized. It was planned that in the above circumstances, I would inform the Chief Social Worker of the RCH Social Work Department who would allocate the participant to another social worker for clinical intervention. This may have involved a referral to Child First, a parenting and family support service or a notification to the Department of Health and Human Services, Child Protection, the statutory child protection service in Victoria. These procedures were not required as no participants disclosed issues potentially resulting in child neglect or abuse to the student researcher.

**Data storage**

The data that has been retained and stored from this study are the interview transcripts and consent forms signed by parents. The interview transcripts were re-identifiable, to ensure that participants could select to withdraw from the study prior to the publication of the thesis. Transcripts of the qualitative interviews conducted with participants were immediately de-identified and assigned a numerical code that correlated to the patient medical UR. A code-sheet that matched the numerical code to a hospital UR was stored separately to my password protected home computer in a de-identified format. Transcripts were also held on a password protected external hard drive as a precautionary backup of the data. This was and continues to be stored in the locked filing cabinet at the RCH, alongside the re-identifiable hard-copy transcriptions. Both the project file within the NVivo program and the home computer were password protected to prevent unauthorized access.

All research data and the completed thesis is stored in the RCH Social Work Department in a locked filing cabinet designated for research material. Participant information will be kept for seven years after the publication of the Masters thesis, in accordance with the Health Records
Act. The research data will then be destroyed.

4.8. Sample

Twenty-six families were contacted by the research team, in two rounds of recruitment between October 2015 and June 2016. Eight potential participants were excluded from participation due to either having had contact with myself in a clinical capacity or being of non-English speaking background. One patient’s family was excluded as their child was deceased. Eleven participants consented to participate in the study, however only nine were able to finalize their participation. Thirteen participants were unable to be reached on contact phone numbers provided on IBA on their follow up phone call which occurred two weeks after the anticipated receipt of Plain Language Statement. Three participants declined to participate in the study when contacted in the follow up phone call, volunteering that child-caring duties precluded them from participating. No approached individuals returned the consent form declining participation.

Participants had children ranging in ages from four to nine years, with a median age of six years. Seven children of participants had pre-existing medical conditions prior to the diagnosis of Infantile Spasms, including Down Syndrome, stroke from birth related trauma, metabolic and genetic disorders and encephalopathy at birth. The remaining two were diagnosed in the context of otherwise normal development. All families recruited had ongoing medical contact with the Royal Children’s Hospital.

The study approached both parents and/or caregivers of children diagnosed with Infantile Spasms, however only mothers participated in the study.

4.9. Chapter summary:

This chapter explored how the study was designed and implemented. The ethical considerations that first guided the design of the research were outlined. The design considerations that framed the study, a semi-structured interview with mothers of children diagnosed with Infantile Spasms, were outlined. The method and considerations of recruiting potential participants was identified. The thematic analysis process of analyzing the interview transcripts was outlined. Finally, the sample of participants that were included in the study was identified and explained.
Chapter Five: The experiences of mothers of infants affected by Infantile Spasms

This chapter outlines the themes identified from the interviews of mothers of children diagnosed with Infantile Spasms. Themes will be presented in the order of how frequently they featured in the thematic analysis process of the mothers’ responses. This generally reflects the chronological order of how these narratives emerged in the interviews, although for a minority of mothers the order presented below does not reflect the significance of their issues. Relevant quotations have been used to highlight salient themes and provide deeper insight to the experience of these mothers.

The primary finding of this study relates to the experience of mothers of the process of their child receiving a diagnosis of Infantile Spasms. Particular attention is afforded to sub-themes such as the experience of mothers when a delay occurred, the emotional impact of the diagnosis on mothers and communication by health professionals at the time of diagnosis. Another finding of this study was how mothers experienced their child’s prognosis from the Infantile Spasms, particularly their developmental outcome and whether they experienced remission from seizures. Mothers also provided mixed reflections on the impact that the Infantile Spasms had had on their interaction or relationship with their infant. The final major theme was the ways in which mothers lived with the Infantile Spasms and made meaning from the experience of doing so. This chapter particularly addresses the support received by mothers and how this contributed to their ongoing experience of the condition. Mothers also described contributing to paediatric healthcare services and research as an important part of making meaning of their child’s diagnosis of Infantile Spasms.

A finding of this study is that whilst the recruitment strategy attempted to recruit both mothers and fathers to participate, only mothers consented and completed interviews. No fathers indicated interest in participating, despite recruitment invitations specifically addressing both mothers and fathers. This finding will be discussed further in Chapter Six in light of current understandings of fathers’ participation in research relating to childhood disability.

5.1. The process of seeking and experiencing the diagnosis of Infantile Spasms

Mothers spoke at length about their experience of their child’s diagnosis of Infantile Spasms. This was the primary and initial narrative raised by all mothers in the study, in response to the
first interview question asking them to speak in an unstructured manner about their experience of this phenomena. Within this key narrative, each mother appeared to value or assign meaning to different aspects of the journey. The primary theme relates to the process of the diagnosis being made; with a particular focus on the experience of any delays in this process, the emotional impact of the diagnosis and communication by health professionals at the time of diagnosis.

All mothers in this study raised the complex process of seeking and obtaining the Infantile Spasms diagnosis for their child. Although a few mothers in the study identified that they quickly received the diagnosis of Infantile Spasms after seeking medical treatment after first noting symptoms, most mothers reported that they experienced challenges with obtaining their child’s formal diagnosis by a health professional. The causes of these challenges varied; for some mothers the cause related to the parents identifying the symptoms of Infantile Spasms in their infant, whereas other mothers experienced difficulty in noting the symptoms in their child or communicating these observations to health professionals for further investigation. A few mothers experienced delays due to a health professional not noting the symptoms when the mother sought medical assessment. Mothers who described a delay in presentation or diagnosis all described an acute sense of distress about the fact that this had occurred, regardless of the circumstances of how it occurred.

A straight-forward process to obtaining the diagnosis of Infantile Spasms:

Mothers within this study described the indications of spasms as including the rhythmic movements of the arms, head nodding, eye rolling and emerging behavioral and sleep issues:

And then when she started having the seizures, ah, well first of all we didn’t realize what they were...her eyes just started to roll. – Mother 4

A few mothers reported an uncomplicated journey to diagnosis by their quick identification of symptoms and straightforward process of accessing treatment. Mothers who attended a pediatrician or a tertiary, pediatric hospital initially did not experience any delay to their child’s diagnosis. For example:

It’s a hard thing to describe to someone because...when you’re trying to describe to them...and then, to a doctor, and then you’re like...I thought if I was to bring her to a GP then they would have no idea, so I thought the best thing to do was to bring her to
a hospital and then, when I was waiting in the waiting room it actually happened. So, um, they quickly rushed us in and obviously monitored him straight away. – Mother 8

For another mother, the use of the internet to search for information aided this process:

My mum actually looked it up on the internet...and from there she said to me...well, came up with something for it...the same actions for it and she’d already said it and then when, and when the doctor actually said Infantile Spasms we knew what they were talking about. – Mother 4

A delay in the diagnosis of Infantile Spasms:

However, most mothers experienced some delay in obtaining the diagnosis of Infantile Spasms for their child. Mothers’ narratives indicated that they identified the symptoms of Infantile Spasms and became aware of their significance all at different times. A few mothers witnessed seizures for extended periods prior to seeking medical care due to misinterpreting this symptom, whereas several attended a GP or hospital on first recognition of the symptoms. A few mothers could retrospectively recognize that they had noticed the spasms in their child but had not known what they were, and therefore did not seek medical treatment immediately. These mothers had postulated a number of alternative explanations for the spasms at the time, for example being a startle reflex or the infant gesturing to be picked up:

‘Patient 3’ had always been very low toned so, hypotonic, very low tone, didn’t have much movement and her arms were the weakest. And then every now and again when she was lying down, she would put her arms up and then put them down again. And it might have happened once today, not for a couple of days...once again, and we started thinking ‘she’s wanting to be picked up’. And it was a weird kind of movement that we kind of went, ‘that’s a bit odd...’ but again, first child...nothing to compare it to...we’ve been told she’s got a movement problem she’s really low toned, she’s not moving very well...so we didn’t think anything of it... – Mother 3

Some mothers experienced delays to the diagnosis of their child due to a health professional not noting or correctly interpreting the spasms when medical treatment was sought. This included attending the emergency department of another hospital, a general practitioner or utilizing nurse on call telephone advice services. These mothers had attended health care services specifically for the evaluation of the spasms symptoms:
She was just making these movements with her head, nodding. And this kept up for a while so we took her to the doctor, our local doctor in 'suburb', and she said “Oh that’s just behavioural”, because she was doing it so frequently she was doing it in the doctor’s office while we were there. And um, we said ‘ah okay’ that was somewhat reassuring, but not really because there was a bigger picture forming with her behaviour and her sleep. – Mother 6

I think it was the unknown, because we had first seen the GP and been told “It’s probably gas” or wind or something like that, and he actually had a seizure in the office, with the doctor, and they didn’t have any idea of what it was. – Mother 1

One mother articulated her concern that the health professional evaluating her child did not take her concerns regarding her child seriously due to her being a first time mother:

Yeah, they really don’t take it, like they just believe ‘new mum, doesn’t really know what’s going on...’ so yeah...they really don’t trust the mother’s instinct. But I knew something was wrong with ‘patient 7’, you know, first thing when he was born. Nobody believed me. – Mother 7

Issues of coordination and timeliness of communication between health services were also noted by one mother as contributing to the delay:

When we were at ‘Name’ Hospital they did organize an EEG here...and we came here for an EEG here, and the Children’s wanted to keep her, they didn’t want to send her back to ‘Name’ but ‘Name’ fought to have her back...so we went back to ‘Name’, because they were having a back and forth of ‘argy-bargy’ about territorial, whatever....so, we could have been on board with the Children’s for a couple of weeks because in between, because by the time I went ‘nah’ to my GP, there was probably a delay of a couple of weeks. – Mother 5

A few mothers highlighted that articulating the symptoms that they had noted in their child was only possible in a face to face consultation with a medical professional. One mother experienced difficulty in conveying her child’s symptoms to her doctor in a face to face consultation, and speculated that this would be even more challenging via other means of communication, for example telephone or email.
The emotional impact of a delay in diagnosis of Infantile Spasms:

Most mothers who spoke about a challenging and delayed diagnosis process for their child expressed significant distress and a sense of guilt about this occurring. A few mothers expressed that they felt that they should have known that the seizures were occurring because of their role as the child’s mother and primary caregiver:

_Horrendous…I… I… I was devastated. Because I left it for so long. I believed, my husband who said it was probably nothing, so I believed him. My GP said don’t worry and hubby said “Listen to the GP” and I felt awful when he did get a diagnosis because, you know in your gut when you know something is really, really wrong and you kick yourself afterwards for not listening to myself, that’s what I’ve been doing for the next three years._ – Mother 9

Another mother reflected on the experience of seeking and not immediately receiving their child’s diagnosis during a hospital admission as ‘traumatic’:

_Yeah…unfortunately it’s, um, a very traumatic experience. It sticks with you. The anger never goes away…I tried to forget it but…you just push through it I guess._ – Mother 7

A few mothers articulated their fear that the delay from the time from spasm onset to the diagnosis being made may have impacted their child’s development, and that this exacerbated their sense of personal guilt. Mothers appeared to have differing perspectives as to whether their child’s development had been affected by the delay, with some mothers being told that there was no impact whilst others were uncertain or felt that they would never know the extent of impact:

_I’m obviously very aware of the impact that Infantile Spasms has on children’s development who don’t have any other issues to start out with and I can and never will know the impact of this on ‘patient 5’s’ development. And that’s where I am mad that I didn’t know about it sooner to have it addressed sooner. Because she had a couple of months where she was having the seizures where I didn’t know that’s what they were. Um, I can’t change it…it just is. And here she is now she’s doing beautifully and we celebrate her – what she can do, not look at what she can’t do. But I know, in contrast to other kids with Downs Syndrome, even who are younger than her, her speech is not as well developed and you know, different elements of her development are not there._
You know, um, so that’s hard…that’s just tough. You know, I wish it was different but you can’t change it. – Mother 5

One mother deduced the potential impact directly from the medical clinician’s urgency in commencing treatment for her child:

*I think the thing that bothers me the most when I look back…is how slow it was when I think about it, it was probably a matter of two months…that’s always bothered me, I mean what if I had got her seen in the first instance, when it first happened…you know because I know the more it goes on…the more damage it does…so I always stress about the period where they were looking and whether that was damage that I could have avoided because they...you know what I mean, like when you get hospitalized and they say “We have to start this today…” And you go ‘well, this has been going on for months’. – Mother 2

The experience and impact of the diagnosis of Infantile Spasms

All mothers highlighted the shocking and often distressing nature of the diagnosis; aside from the difficult aspects of delayed diagnosis. Some mothers highlighted feeling shock at the diagnosis, which appeared particularly relevant to those who also experienced delays to their child’s diagnosis:

*I was sitting in the chair I had ‘patient 5’ on me, she was nine months old, I was thinking ‘isn’t this lovely, it’s a darkened room…I’m getting to have a little relax with ‘patient 5’, she was asleep on me; this is beautiful!’ And I didn’t even notice the technician go out of the room, which would have been a flag for ‘oh, what’s going on here…?’ So I just got the shock of my life when a doctor came back in and said “Oh this is not great” and “You need to go down to the Emergency department immediately and be admitted…” blah blah blah, so I spent the day with ‘patient 5’ in Emergency. – Mother 5

Other mothers had no prior knowledge or understanding of epilepsy from their own personal networks or experience, and this appeared to contribute to their sense of shock at the diagnosis:
medical conditions or epilepsy or anything so it just...came from nowhere I suppose. – Mother 6

Mothers also shared highly individual, personal and profound responses relating to their own sense of guilt for their child’s diagnosis. These were in addition to the narratives of guilt that were expressed in relation to a delayed diagnosis. Mothers felt guilt for a number of reasons, including a generalized sense of responsibility for causing their child’s Infantile Spasms:

*He was only six months old so, you know, um, obviously my main concern was what was going on and why it was happening and...um...is it something I’ve done? You know, you blame yourself.* – Mother 8

Another mother expressed a deep and long lasting sense of guilt due to her choice to have a home birth, which may have contributed to her child’s acquired brain injury which pre-dated the Infantile Spasms diagnosis:

*(crying) I’ll just spend the rest of my life trying to make it okay...I’ve been through so many psychologists and psychiatrists, they all tell me it’s not good...and I listen to them and I say “I know you’re trying to help me...but...it’s my fault...and no one can tell me it’s not....nobody”. So many psychiatrists and psychologists have said it to me and I’m like... ‘nup’...I made the decision to have a home birth...I was putting my needs in front of hers...so...it’s my fault...I get teary every now and again...and it does affect my mental health to a degree...but, I’m absolute...if I had made different decisions she wouldn’t be in the position that she’s in that no one can do anything.* – Mother 2

Expressing these accounts of the sense of guilt carried by mothers caused many of them distress during the interview. A few mothers were unable to speak due to crying, however no mothers requested that the interview be paused or terminated.

Only one mother in this study reflected that she and her husband were not distressed at the time of their child’s diagnosis, as they were not aware of the implications of the condition at that stage. This mother also reported a narrative of no delays to her child’s diagnosis and having strong family support:

*When the doctor actually said Infantile Spasms we knew what they were talking about. Yeah...at that point...so when they said, I guess we just...we knew but we didn’t really...*
Mothers receiving support and information at the diagnosis of Infantile Spasms

An aspect of the diagnosis journey consistently raised by mothers was their experience of receiving information and support at the time of diagnosis. Most mothers described the role of the doctor, usually a Pediatric Neurologist, as being the primary source of information about their child’s condition:

‘Patient 5’ was the first to join the international study on Infantile Spasms and so people were very keen for us to join the study but didn’t want us to feel as though they were coercing us so they spent a lot of time with us as a result, not realizing that I would have happily done that. But what it was useful for was that I needed to understand all the literature that there was and what the parameters of that study were just from an interest point of view because I want to know what I’m doing for my own daughter. – Mother 5

Mothers were eager for clear, concise information regarding their child’s condition, treatment and prognosis. However, some mothers were willing to trust the expertise of the doctor treating their child:

think there were two types of treatment at that stage, and ‘Neurologist’ and I think it was either where you choose or there was a study at that time as well…and it was kind of like, put it in his hands, kind of thing. And I think what happened, I think we kind of thought ‘well you probably know best so we’d put it in his hands to choose what he thought was best for patient 8 at the time. – Mother 8

Several mothers spoke of reading literature relating to the poor prognosis of Infantile Spasms at diagnosis, despite being forewarned not to ‘google’ internet search by medical professionals:

For us, it was frightening um, it was very unexpected because we didn’t know what Infantile Spasms was and ‘Dr Google’ is a very, very awful thing, um to try and get any level of research or information online, you’re bombarded with the most horrific imagery and, you know, stories of diagnoses that are just dreadful. – Mother 1

Communication by medical professionals

Mothers described that the quality of communication by medical professionals at the time of
diagnosis had a significant impact on their experiences of this period. Mothers had numerous examples of communication from health professionals that they perceived to be either positive or negative. Again, the primary role of the medical physician was highlighted by all mothers who spoke about communication at this time.

Some mothers identified that communication from medical professionals at the time of diagnosis was positive. Mothers within this group reflected that they felt information was presented as clearly as was possible when the aetiology of the condition and treatment plans may have been uncertain. One mother reflected that the medical professional she met appeared to intentionally control the delivery of information to ensure that she understood and retained it. Several mothers recalled the exact words said to them by the medical clinicians despite the number of years that had passed since the diagnosis. Some mothers particularly noted the sensitivity and empathy of the clinician involved:

‘Neurologist 2’ sat next to me and did the “We need to talk to you, we need to tell you this – she’s got epilepsy, um, they call it Infantile Spasms. That’s what this was (gestures spasm). It’s not going to hurt her but we need to look at how we can stop it. What you saw…” and he’s brought [the EEG recording] back up, “This is not normal, this should be in a nice pattern. What that’s telling us that she’s got electrical activity…” like he went through it all very calmly, did the whole hold the hand, “We’ve spoken to ‘Neurologist 1’ he’s in ‘location’…he’ll be back tomorrow, I’m with you until he’s back” very, very good bedside manner, ‘Neurologist 2’, having dealt with a few of them now. – Mother 3

The time and energy that was spent by doctors in answering their question was also appreciated by mothers:

I don’t know how they could do anything different…um, I would say…like I said, they were great, the doctors. They explained themselves perfectly…they gave me information. I’m just trying to think, there was nothing that they could really have improved upon. – Mother 8

Conversely, some mothers provided examples of poor communication that they experienced from medical professionals at the time of diagnosis. Several of these mothers had previously noted other aspects of the communication by health professionals as being positive. Mothers provided examples of non-sensitive delivery of information regarding the prognosis and the
potentially refractory nature of Infantile Spasms:

*The hardest thing at the time wasn’t that...Neurology were very calm...unfortunately we had someone on the weekend who I don’t think understood what the process had been, that this had been a shock to everybody, and was very cut and dry about it, and went “Oh well, Infantile Spasms...there’s your death sentence...they won’t stop, she’ll seize for the rest of her life”. That was not fun to be told.-- Mother 9*

Another mother identified the casual manner of the delivery of the diagnosis as distressing:

*I remember we had to go back into hospital and have 24 hour ECG monitoring and the doctor coming in with an entourage of student doctors saying, um, “Yep great, we’ve confirmed it is epilepsy...I’ll come back and talk to you later.” And that was just devastating for me...um...that there was nothing great about that (crying).– Mother 5*

A few mothers in particular noted the non-verbal communication of clinicians during the immediate period leading up to diagnosis as a strong memory. Silences, looks and physical movements of clinicians were recalled and considered important in the memory-making relating to diagnosis:

*And the staff there in MRI recovery went “Why didn’t you tell us she was an epileptic?” And I’ve looked at them and gone “She’s not an epileptic...” and I reckon the whole room went dead silent and they’ve all just looked at me...and um, no one would say anything at this point, no one was speaking to me, they were all doing everything they needed to be doing and they were very quiet about it.-- Mother 3*

*Information and support provided by nursing and social work staff*

Some mothers made references to the support and information that was or was not provided by health care staff who were not doctors, such as nurses and social workers. However, the support provided by these professionals featured less prominently than that provided by doctors. The majority of mothers related that they did not meet a non-medical health care professional at the time of diagnosis, via the RCH or externally. Only one mother described meeting an allied health or nursing care professional, i.e. social worker, nurse coordinator, at the time of diagnosis. Several mothers volunteered that they did not feel that contact with a social worker would have been helpful at the time, for a number of reasons:
We didn’t have any counsellor given to us at the time, given to us...because we’d been with the metabolic team, ‘metabolic social worker’ is the metabolic counsellor, and we’d kind of spoken to ‘metabolic social worker’ here and there about metabolic stuff but this wasn’t her thing, she didn’t know anything about...and we didn’t see her, there wasn’t a counsellor offered...I think I got more out of the mothers in the room at the time in the room, which sounds really silly but...speaking to other mothers...I think was better because it was more, for us, I think if we’d been given a counsellor at the time it would have been ‘oh no, not another staff member to deal with...’ Yeah...almost, you know, just... ‘oh no, another lanyard.’ (laughs) ‘What now?’ – Mother 3

One mother identified being offered social work services during their admission to hospital when the Infantile Spasms was diagnosed. This mother expressed that she had found the notion of speaking to a social worker about her experience too distressing:

*They were really good at accommodating, they had a social worker there for me in case I wanted to talk to anyone, and yeah it was good...the nurses were my one connection with reality. They tried to get me to talk to a social worker, um, but every time I tried to even open my mouth I would just break, I would just blubber (laughs). I was an absolute total train wreck.* – Mother 7

As detailed above, some mothers speculated that accessing peer support and information from other mothers in similar circumstances was more beneficial than the anticipated gains of meeting a social worker. Several mothers recalled the shared patient rooms that existed in the old RCH building and felt that they may have been more conducive to peer support than the single rooms of the new RCH building.

One mother hypothesized that a social worker may have been able to coordinate the provision of information, referrals and support in order to facilitate her understanding of and adjustment to the condition. This appeared to be in contrast to her lived experience of attempting to self-source information:

*For me it was even when she was unwell in the beginning...I had services ringing me saying “We can offer you this...you need to take this number down and ring this and do that” and I was just like ‘urgh’. In the end I was just like...’yep...yep...yep’ (mimics nodding head), I just stopped writing! ‘Yep yep, thank you’. – Mother 2*
One mother reflected that she had received the support of a social worker at the Royal Women’s Hospital immediately post birth and had found this to be helpful, particularly in relation to navigating communication with healthcare professionals. She then identified that she did not have similar social work contact at the Royal Children’s Hospital:

I think the contrast, I think when we were in the Women’s Hospital when she was born, I was assigned a social worker and if I ever needed anything that’s who I contacted. And she did the ground work and got whatever I needed sorted…and was there and I had her card and if I needed her, and that for me, was this one point of contact you know what I mean, and I had an issue with the way that one of the doctors you know, the way he addresses us, not intentionally, when he was giving us information when she was very little in the NICU, and she was the one who went and spoke to the doctor and then things changed…you know what I mean? Because you just don’t want confrontation, you don’t want to say anything…but it was would just come out in the course of general conversation. – Mother 2

5.2. Mothers adjusting to their child’s prognosis from Infantile Spasms

A theme that emerged consistently in the study was the concern that mothers had regarding their child’s prognosis from the Infantile Spasms. Mothers appeared to define their child’s prognosis in various ways, most commonly by whether seizures were refractory and/or the child developed a secondary seizure disorder after the Infantile Spasms ceased. Mothers were also concerned regarding their child’s developmental outcome, specifically either short or long term developmental stagnation or regression as a result of spasms or treatment. As previously highlighted, narratives regarding prognosis emerged at varying time-points across the illness trajectory. All mothers in this study identified their child experiencing a poor outcome from Infantile Spasms, from both a seizure control and developmental perspective.

Mothers also separately reflected on the impact that the Infantile Spasms had had on their interaction or relationship with their infant. Several identified that medication side effects, ongoing seizures or developmental delay negatively affected their ability to interact with their infant. The majority felt that the Infantile Spasms had made them more protective of their infant, which they framed as a positive impact on the relationship. This question appeared to be challenging for mothers to answer, particularly for those who participated in telephone based interviews, based on their non-verbal communication and for some, limited response.
Achieving seizure control

Seizure control was a significant indicator of their child’s prognosis for most mothers, and this was often only revealed over a period of time. Mothers reported differing experiences and outcomes of seizure medications, however the children of all study mothers had experienced refractory seizures since diagnosis. A few patients in this small sample were described by mothers as achieving initial success in stopping seizures in the treatment of Infantile Spasms. One child did not experience any remission from seizures, which may have been due to the diagnosis of a genetic/chromosomal disorder which increased their risk of refractory seizures. It was unclear from the narratives of a few interviews whether the patients had experienced any period of remission from spasms before the onset of a secondary form of epilepsy. However, this was not universally or systemically explored in interviews. However, at the time of interview, all of these children were continuing to live with refractory seizures. This was distressing for mothers, some of whom had trialed multiple medications in their children in the hope of remission from seizures:

I guess the biggest thing was when ‘Dr Neurologist’ said he’d tried everything...after about 5 or 6 medications plus the ketogenic, he said he’d exhausted all of his options and he was going to refer us on to another neurologist in the hospital...and I think that’s when it hit us the hardest...when we realized that we’re not going to be able to help her with this. – Mother 4

The successful use of medications to control spasms was described by mothers as being positive and worthy of celebration. However, one mother acknowledged her complex emotional reaction to the immediate cessation of spasms on commencement of treatment:

Yeah, so with the heavy dose steroids, the seizures did stop...we couldn’t see them obviously after we left the hospital...which was scary too, you know? Because when you’re in hospital with your baby, with something that you never ever could picture, you know, um, you never think of the worst. – Mother 8

Developing a secondary seizure disorder

The development of a secondary seizure disorder in patients was a source of considerable distress for most mothers. A few mothers were aware of the theoretical risk of this occurring but maintained hope that their child would not develop a secondary seizure disorder:
Her being diagnosed with epilepsy and that was not so much the Infantile Spasms but that was the start of it, but when she was diagnosed with secondary form of epilepsy that was another whole new and separate level of grief for me (crying). – Mother 9

Another mother was aware of the risk but felt that the diagnosis of a secondary form of epilepsy was more likely to be made further into the future than when it was. The timing of the subsequent diagnosis was a source of considerable shock for this mother:

We knew that there was a risk that she would develop another form of epilepsy but I guess, you know, you unwittingly have expectation and I clearly had one in my head that that would be years in the future and something we would worry about in future years. But she actually developed a secondary form of epilepsy while she was weaning from the medication from Infantile Spasms so that was a big shock. – Mother 5

A few mothers commented that they felt ill-prepared by medical staff about the strong likelihood of their child developing a secondary seizure disorder, and that this compounded their sense of stress:

Mother 6: And then we were lucky, we had a follow up EEG a couple of weeks later at the Children’s and um, they said “Perfect EEG no sign of any, hypstathymia pattern on the EEG”, and she was...really... Yeah cause we hadn’t seen any clinical seizures, that’s right, for a few days. So everyone was really happy... ‘Neurologist 3’ was thrilled, he said “This is fantastic!” And we thought, ‘oh...all right, this is great we’re home free...’ And we probably didn’t realise, we didn’t really get told that the spasms could return, that she could have a relapse, but um...yeah...I think the statistic we were told was maybe one in ten kids relapse, but I think it’s more like...50% from what I now know...but...yeah, anyway, I don’t know if that’s true or not...so we um....

Interviewer: Do you feel like, in some ways you weren’t prepared? As well as you weren’t expecting it?

Mother 6: Yeah, probably...I think everyone, we were certainly like – crack open the champagne, we’re done with this! And um, I don’t think we were prepared.

One mother commented that she was able to transfer skills from managing Infantile Spasms to
her child’s secondary form of epilepsy, and implied that this prior knowledge was helpful:

*He didn’t have seizures for about, I think it was about 6 weeks to 2 months...and then it came back after he was eight months...I mean what do you do? But at least this time I knew what I was dealing with, so you know, as soon as I saw it I rushed him back to hospital.* – Mother 8

**Developmental stagnation or regression**

Another indication of their child’s prognosis for mothers was the impact of Infantile Spasms or its treatment on their child’s development. Some mothers reflected, with hindsight, that their child’s development regressed when the spasms started, or when treatment commenced. The infant’s regression or stagnation of development appeared to be a cause of significant distress for those mothers who raised it. Mothers used strong language to highlight the importance of this subject, with several becoming distressed and tearful in discussing this aspect of their child’s journey:

*So I guess with ‘patient 4’, when she was diagnosed, um, that was one thing, but when she started having the seizures at five months, that’s when she regressed and if anything, that’s when it hit us the hardest...because she was progressing...* – Mother 4

Developmental progression was highlighted as an indicator of successful treatment by another mother. She appeared to have a strong emotional reaction to her child’s developmental progression on medication, as it indicated to her the extent of the developmental stagnation her child had been experiencing prior to this shift:

**Mother 5:** *So we were very lucky she was you know, matched into the intervention group, which wasn’t trialling diff...unused drugs, they were both very known and used drugs...and she responded instantaneously you know...she...the day that she was admitted they started her on the mediation that night and she basically slept for 14 hours...and then woke up and smiled at me...* (crying, pause).

**Interviewer:** *Was that something that she had been struggling to...*

**Mother 5:** *Which she had stopped doing, she had regressed. So that just felt completely like a miracle to us, um...*

One mother acknowledged that she was unsure whether the diagnosis had impacted on her
child’s development:

*He’s not, um, we’re having a few problems at school in terms of his writing...so, um, I’m not sure if he’s got any developmental issues but...his school is really good, they’re onto everything.* – Mother 8

Whilst another mother felt assured by her child’s doctor informing her that her child’s development would not have been affected by the onset of Infantile Spasms:

*Because I’ve seen his cognitive development go so far downhill and take so long to recover, um, but then talking to another Neurologist who I met recently, they said “Nothing you could have done”, you know, “Delaying it, did nothing”, “Even if you had taken a different type of drug other than the steroids, wouldn’t have mattered” (laughs) you know?* – Mother 1

One mother recalled that her attendance at her child’s first Neurology outpatient clinic was initially a distressing experience. She described that observing other patients who were attending the same clinic as her child, who had significant disabilities, made her consider the potential future prognosis of her child’s condition:

*When we first got into the Neurology outpatient area and seeing children that were really disabled and their mothers and you just think ‘oh gosh, Neurology, so this is what it’s all about...’ and um, so it’s...it’s a bit hard to talk about... (crying).* – Mother 6

Medication side effects:

The negative impacts of steroid based medications on development was discussed by most of mothers in this study. Whilst these were framed as short term medication side effects as opposed to indications of longer term deficits, mothers described them as being distressing. Mothers noted that steroid medication temporarily resulted in significant weight gain, lack of engagement by the infant, compromised immune system function and reduced motor skills:

*She was just very big, she blew up and, um, as a result there was no emotion there. She never cried...she was just, I mean to us she was a little bit of a vegetable in a sense, I know that sounds horrible...but she just...she just did nothing. And, um, yeah so she didn’t um, didn’t show emotion...didn’t move.* – Mother 4
There was a significant emotional impact on mothers who observed the loss of specific developmental skills in their children:

...and we also lost all of his development through Infantile Spasms...and then the steroids...so 'patient 1' went from a child who could roll over, start eating solids...to a child who was basically like a baby again...so we lost, um, swallowing...we lost our smile...we lost our babble, rolling over, sitting up...the whole lot. Everything was gone back to normal. It was, to put in bluntly, horrendous. – Mother 1

The impact of Infantile Spasms on the relationship between the mother and child

A theme that emerged from mothers’ narratives was the impact that Infantile Spasms had on the relationship between the mother and the infant. A few mothers described unexpected positive impacts of the diagnosis of Infantile Spasms on the relationship between them and their child. Several mothers described feeling more protective of their child with Infantile Spasms, as they felt the child was vulnerable. In the case of these mothers, this perception of vulnerability was directly related to the seizures in the child:

If anything I still just wanted to comfort her and basically promise her that I’d never leave her side, when she’s having a seizure, I wanted someone to be at her side at all times...you know, if we can...I think there were one or two occasions where, um, um, she’s had a seizure through the night and I couldn’t bear to get up...and that’s difficult because when you’re asleep you’re not thinking clearly...so she’s probably experienced that once or twice in her whole lifetime. – Mother 4

Additional monitoring of the child due to seizures or related treatments was often framed as protective parenting, which was invoked due to a sense of attachment to the child and identification of their vulnerability.

One mother described feeling conflicted between a sense of protectiveness and fear which affected how she physically engaged with her child:

In the beginning I was afraid to hold him. As much as I wanted to cling to him and just to have him in my arms I was terrified at the same time, I didn’t want to break him or drop him or have him be frightened by it...I was more protective. I was way more protective of him, it’s kind of hard...because I didn’t get that initial bonding with him.
– Mother 7
However, a few mothers identified that the Infantile Spasms caused strain in their relationship with their child. One mother could identify the impact of her child’s Infantile Spasms, in addition to her child’s pre-morbid delays, on her connection with her child. She acknowledged her sense of loss of the anticipated child, without health and developmental issues, and this appeared to have significant ramifications on the couple’s planning for additional children:

Yeah…I kept thinking I wanted a baby and I’ve got a chemistry lab...you know, because she was tube fed at that time as well, so we had syringes and um, yeah just...we were only going to have two children, so when everything happened with her we were considering ‘should we go back for a third?’ And for me it was, I was telling the psychologist, I feel like I just want two typical children....and I’m petrified because if anything goes wrong I don’t know how I’m going to cope...um, so for, I mean do have the vision of your life set out, your kid is going to do this and then go do that…dah dah dah, and then it completely changes...so I was nervous about um, ‘okay I can accept her more if I can have the two kids that I always wanted…that had no issues...” – Mother 2

A few mothers identified that the impact of sleep deprivation may have impacted on their mood and subsequently the relationship with their child. One mother identified that her child needed additional overnight monitoring and comfort due to their spasms, which resulted in her experiencing fatigue and frustration:

The only time it had an impact was I got resentful of the lack of sleep, so at three o’clock in the morning when he’s making noise it's not fun, but I think that would happen with any child and when you’re sleep deprived it’s a form of torture, and you can get resentful of a child when they keep you awake for months on end...so at that stage I was probably living on 2-3 hours of sleep per night...um, mind you now I’m only getting 4-5 so there’s not big improvement on that...um, but that was the only time – Mother 1

One mother did, however, acknowledge that the sleep deprivation she experienced may have been similar to that experienced by mothers of similarly aged children without Infantile Spasms.

5.3. Living with and making meaning from a diagnosis of Infantile Spasms

The final major theme identified by the study is the ongoing experience of mothers living with
Infantile Spasms and its’ consequences. This chapter particularly addresses the support received by mothers after the initial diagnosis period of Infantile Spasms and how this contributed to their ongoing experience of the condition. Support was received from formal or informal sources, with the primary sources being within the relationship with the child’s father and family or friends or Early Childhood Intervention Services (ECIS). Mothers reported varying degrees of the quality and accessibility of the support they received. Mothers also described participating in research or contributing to paediatric healthcare services as an important part of making meaning of their child’s diagnosis of Infantile Spasms.

The avenues by which mothers accessed support

The father of the child with Infantile Spasms

The level of support available for mothers within the relationship with the father of the child with Infantile Spasms was a consistent theme raised by all mothers. Partners of these mothers were exclusively male and all were the father of the child with Infantile Spasms. Most mothers highlighted that their partner did not provide them with a high degree of support in the care of their child with Infantile Spasms:

“But then again it was all me…my husband was just looking on as this was all happening…so…he didn’t have much to do with it so…I mean he gave her the medication and those kinds of things but…all the hospitalizations, all the appointments was me.” – Mother 2

Several mothers acknowledged the anger, distress or depression that the child’s father experienced due to their child’s diagnosis. These mothers hypothesized that these reactions may have informed their capacity to assist or support them as the primary caregiver:

“I’ve always dealt with the medical side of things better than ‘father’; ‘father’ really just, he had severe depression from the day she crashed…um, very angry still at that stage, angry with the world; “Why aren’t you fixing it? Why aren’t you doing something?” you know, and um…I guess too...even looking at the doctors, I guess it’s the male versus the female approach.” – Mother 3

In addition to the stressors associated with the diagnosis, a few mothers described their partners as having pre-existing clinically diagnosed or tendencies towards depression or anxiety. A few
fathers were also described as experiencing other psychosocial stressors at the time of diagnosis, for example unemployment. Mothers felt that these issues exacerbated fathers’ reactions to the diagnosis and their ability to be supportive:

All of this had a very significant toll on him and I firmly believe that the level of trauma that he also experienced, not just through all of what I’ve recounted today and others that were happening around us. He has probably always had a tendency towards anxiety but he ended up with acute panic disorder and was hospitalized and has been on a significant journey ever since in recovery from that and I really believe it’s because (gestures with hand a level) he only had this much level of stress in his life but when he hit major, major stress he did not have the coping mechanisms. – Mother 5

A few mothers also stated that their partners struggled with the lack of support and attention they received from them during their child’s period of treatment, and that this was a cause for tension and stress in the relationship:

But yeah it was a pretty tough time…I wasn’t well at the same time my husband wasn’t well…he had a period where he wasn’t dealing well with my lack of attention…because I was so focused on her…and yeah… – Mother 2

Two mothers described the father of the child with Infantile Spasms as an ex-partner at the time of interview. Both reported similar narratives of limited provision of support by their ex-partner in the adjustment to the condition:

Yeah…yeah it’s kind of scary, I mean it was kind of scary at the time. And my husband, well my ex-husband now, but he was not a very supportive person either. – Mother 8

In contrast to this narrative of limited support, one mother described her relationship with the child’s father as fluctuating between being a source of teamwork and support to the opposite of this:

My husband and I…went through phases where we would be awesome and work beautifully together in supporting each other and then the complete and utter opposite of that, because the only one who understands and can support you is your partner. And so, we would either tear each other apart or be amazingly supportive. – Mother 5

One mother described that their partner had a different yet complementary attitude towards
their child’s prognosis:

I think I was always optimistic but my husband, he’s always been a bit more of a cautious one out of the two of us. – Mother 6

Extended family and friendship networks

Mothers also reflected on the quantity and quality of support that they received from their immediate family and their friends as they cared for their child. Extended family, typically comprised of the mother’s parents and siblings, were the primary and first support avenue raised by some mothers. Of those mothers who addressed the issue of support provided by family or friends, most mothers reported that this support was limited. For some, family were present but had limited capacity to assist with caring for an infant with such high care needs:

I’d have to say, um, there was always support in the way of people there but I wouldn’t say we’ve had a lot of support in the way of, helping with ‘patient 4’, um, my expectations might be different to what everyone else thinks but, um, we definitely don’t get the time out cause she’s pretty easy overall, but we don’t really get that time out. At the start actually, for the first sort of, one to two years, no one would be confident enough to look after her...and I too wasn’t confident to let anyone look after her because she was only having certain amount of midazolam if we need to and at the beginning we were calling the ambulance every time, and now that’s just...I look back now and think it’s unnecessary. – Mother 4

For others, extended family were unable to provide additional support due to experiencing their own stressors:

Family is hard...we’ve got our four kids...um....my husband’s family is not supportive, at all, um, and, um, in my family my father is quite ill. My Mum does so much to help...but she can’t, she doesn’t want to be a baby sitter because she baby-sits my father and, um, my brother is not paternal at all and he is a truck driver who drives nights, and so he only sees the kids when he can and my other sister has three young kids so, yeah we were fighting on our own. – Mother 1

One mother described her child’s immunosuppressed condition post treatment via steroids as limiting their capacity to elicit support from their family:
We were on high dose prednisolone and so she was immuno-compromised and we were going into Christmas, and this was her first Christmas, when she also had Downs Syndrome and so we had a lot of extended family functions and that was really tough, um, that we had to keep her away because of her immune system, that she was recovering from Infantile Spasms and was on some pretty hefty medications at a time when it would have, you wanted people to see and share her, well and just the added, sort of, it’s other people’s awkwardness around Downs Syndrome and so you wanted her out there to go ‘yes this, is our baby’ and we had to go ‘no sorry, don’t come near us…’ and you know, keep her away. – Mother 5

However, a few mothers cited a strong network of support from family, referencing their assistance with practical tasks such as the provision of childcare to the infant or cooking and cleaning. There was limited discussion of the emotional support that was provided by or elicited from these family members:

But it was just that constant...she was just constantly upset or, you know, yeah...just a lot at the start but got to the point where she wouldn’t sleep at all, so we, we were rocking the pram for twenty hours of the day...giving her baths. At that stage we were really lucky and family really stepped in and helped out and um... yeah look Mum and Dad, who were away in (overseas location) at the time, came home when they realised how serious things were. – Mother 6

One mother cited the lack of support she received from her in-laws as upsetting, although she perceived that lack of support offered by her own mother as more distressing:

And my partner’s family didn’t know how to approach the situation so they said “If you need anything.... phone credit, we can buy you some ‘phone credit’”. I don’t need phone credit; I need my son home with me. So, feed me positive stuff – but they didn’t know. So I was pretty much on my own, trying to push him and myself. – Mother 7

The support offered by friends of the mothers was discussed less than the theme of family support. One mother identified that she had only received support from friends, however did not discuss in detail what this support looked like. Another mother acknowledged the contribution of friends in the same phrase as family, providing examples of contributions of food, phone calls and messages of support.
One mother raised that she felt a sense of isolation from her friendship group since her child’s diagnosis. She conveyed a sense of disappointment regarding the limited support she had received from them:

*Interviewer: And you said that it was hard to talk to your friends at times…*

*Mother 1: Absolutely, because they knew something was wrong…and you’d say it was Infantile Spasms, but then what is it? Well it’s seizures, well it’s just epilepsy…well no it’s not…and you’d have to go through try to explain to them in layman’s terms what it actually meant when I didn’t actually know what it really meant. So I think from our perspective we probably could have used a little more backup from our circle of friends.*

One mother related that her friends did not support her, and she perceived that this was due to their fear of her situation:

*No, yeah, my friends didn’t know how to approach me. They were all working, I mean I was working before this. So they couldn’t really come out of their jobs to come down, except for weekends to come down and they were terrified of me because I was just clinging.* – Mother 7

*Early Childhood Intervention Services*

Only a few mothers discussed accessing Early Childhood Intervention Service (ECIS) for their infant with Infantile Spasms and perceiving this to be a support. One patient was referred prior to the diagnosis of Infantile Spasms due to a pre-morbid condition whilst another was referred in direct relation to the Infantile Spasms diagnosis. Both mothers related that this service provided essential therapy to promote their child’s development:

*Yeah…we were lucky that we didn’t have to make additional trips to Melbourne for therapies, on top of everything else – not that we are never here, we were often at appointments every, two or three months these days so it’s not too much for sure – but we’re lucky that we’re not there every week for hydrotherapy or speech or something…because that would be tricky…yeah…um, but they are really good, they give home visits or we can go to them…so we’re really lucky…in that sense…that that’s all available to us…* – Mother 6

One mother initially reported not having access to any supports due to her child not having a
formally diagnosed condition, but subsequently identified that her child was linked with an ECIS service where she gained support largely from other families. Another mother had a positive experience with a local service who provided interim support to families waiting a place in an ECIS service:

‘Patient 6’ was referred to Kids Plus, which were our local – well they used to be run as a charity, I don’t know if you know Kids Plus, but they do physio, speech, OT all of those services. And they were run just by a couple of people in Geelong – which was quite an incredible story because they just, you know, ‘clinician name’ was one of them she was a physio, saw a need where babies were needing to wait weeks and months on end for intervention when, you know, weeks and months were not what they had because they were only tiny babies. So that was set up to allow people with immediate access to that service, and it was all free, it was run as a charity, they never charged anyone. – Mother 6

Professional counselling

Most mothers interpreted the researcher asking about their access to formal supports as relating specifically to counselling by a professional, despite subsequent clarification of other possibilities from the researcher. A few mothers had attended counselling, one on the suggestion of a Paediatrician and the other via self-referral post the diagnosis period. The mother who self-referred to counselling found the process helpful, whilst the mother who was referred did not:

Mother 4: Um, not through the Royal Children’s…probably through the Pediatrician…she suggested that perhaps, um…um…going to see counselling. We probably went to one session and…yeah…that was it. I don’t think we needed that…I think we just had to get through it…I mean it was just what she had, it was what we had…so...

Interviewer: So you didn’t find that particularly helpful?

Mother 4: No…not really. No, not really I’m not sure why really…I guess we just felt like we were living it on our own and we just had to deal with it how we could.

Other mothers did not access a counsellor, with one feeling that she did not require counselling
assistance at the time:

Oh no, nothing like that. I didn’t need it, I wanted to be next to my kid (laughs). I wanted to be by his side all the time. I had my family and they were awesome, I’ve got two sisters and a Mum, my mothers, are my...like...um...support network. – Mother 8

Another mother reflected that she had not accessed or been made aware of counselling at the time of her child’s diagnosis however she retrospectively felt that it may have been helpful and had subsequently engaged a counsellor to address other issues.

The desire to ‘give back’ and contribute to further knowledge regarding Infantile Spasms:

Some mothers within the study reflected on a sense of wishing to give back to those who had assisted them through the journey of Infantile Spasms, and extend knowledge regarding the condition. Mothers had different experiences of contributing, with multiple mothers citing participation in research studies, particularly medical research studies, participating in advisory committees or contributing financially to charities. Participation was also often framed as seeking to contribute to the understanding of the condition in order to improve outcomes for both their children, and others.

This theme appeared to merge, for some mothers, with the concept of mothers being experts within the field of their child’s condition and care. The narratives of how these mothers contributed to varying causes related to their child’s condition were all raised by the mothers themselves, with no prompting by the researcher.

Participation in research

Participation in research studies was mentioned by some mothers of this study during the interview. However, mothers also discussed their previous experiences and motivations in participating in research in discussions whilst arranging the interview with the researcher. Some mothers felt that their participation was important to potentially improve treatments and/or outcomes for their own child as well as future patients. This was especially due to the rare nature of Infantile Spasms, with several mothers being aware of the small pool for potential recruitment to studies. There was some acknowledgement of the stress associated with the decision to participate in a clinical trial relating to treatment; as it was perceived that this may have an impact of their child’s clinical outcome:
When we were finally on the ward being approached to be part of the study, which was again, it was a very interesting space to be in, where you were being told that you couldn’t choose the treatment, it was a random draw as to either she gets one drug she gets the other drug or she gets both at the same time and that was the study, to see whether or not one drug on its own would be better than the two. So we had to decide at that point whether we were going to do it or not. So I looked at the detail of the study and thought, ‘okay, well you need 400 people over four years given it is so rare, to try and gather the number of people you needed to get, so fine we’ll do it, but it was terrifying thinking ‘What if I’m not giving her the best option…? What if my decision makes it worse for her?’ – Mother 2

One mother was actively involved in a peer support organisation for her child’s specific secondary seizure disorder, which had direct links to international genetic studies. Another mother felt motivated to participate in research by the particular distress associated with her child’s developmental regression at the time of the Infantile Spasms commencing:

*Did the Infantile Spasms have something to do with that [developmental regression]? I don’t know….um, could they have? Who knows, but I don’t think they do know…but that’s one of the reasons why we’re so happy to be a part of researching or finding out…treating it.* – Mother 1

**Contributing to peer support forums:**

A few mothers felt compelled to advocate for others by joining or leading peer support forums. Several mothers reflected on their ability to assist others through these mediums. For example, one mother described joining the Royal Children’s Hospital Family Advisory committee in order to advocate for other families; however this was not described as a positive experience:

*After our early experiences at the Royal Children’s I actually joined the Family Advisory Committee, because that’s what I do. And I’m not a quitter, but it’s one of the first things where I actually went to three or four meetings and went ‘I’m not spending my time on this, I’ve got limited time but I’m not going to have clinicians come and tell me what they want to tell me – this is a family advisory committee, counsel whatever, you should be listening to us, and you need to listen to us.’* – Mother 5

Another mother held a leadership position in a peer support organisation for mothers of
children. This mother spoke at length about assisting others in a peer support manner:

*We almost need to have a mother advisory group that kind of comes in speaks to mothers with no medical information given but just a, “Hey do you know what..? I’m a volunteer or a mother but I’m just a mother talking to another mother.” Because we look at it differently when you’ve lived it...you now; 'How am I going to get my kid to school? How am I going to do this, how am I going to get them in the car? What if they seize in the car?’ All these things that doctors kind of...that’s not their thing (laughs).*

– Mother 3

As a result, whilst support was also gained from peer support services, these mothers described that a primary aim in engaging in these activities was being able to offer support to other families.

*Financial and in-kind contributions*

Finally, some mothers mentioned donating money to relevant charities in order to contribute to services or research. Mothers attributed this to either the care that they received at the Royal Children’s Hospital or via external, related organizations; for example, the Epilepsy Foundation. Donation was described as being meaningful and a reflection of their experience:

*When she was in hospital in the home, someone came and door knocked from the Epilepsy Foundation, and ‘Father’ just goes, “Here’s fifty bucks” (laughs) and the guys like “Oh, alright thank you thank you...we’ll get your details..” And now we’re on their mailing list because they think we’re a good donor...and we’re like, “No no, you just got us on a good day” (laughs). We were just dealing with that very thing at that very moment...which we didn’t go into. – Mother 2*

One mother reflected that she often contributed time by providing learning opportunities to staff of the Royal Children’s Hospital, for example allowing her child to be examined by medical students on the ward. She identified her own definition of the importance of this task, which was for the development of future medical professionals and potentially improving outcomes for her or other children in the future.

*Chapter summary:*

This chapter has outlined the primary themes identified through thematic analysis of interview
transcripts. The major theme identified within the study was the process of seeking the infant’s diagnosis of Infantile Spasms; with most mothers relating complex journeys to diagnosis often characterized by delays. These delays caused mothers significant emotional distress. Other aspects of the diagnosis journey that were discussed include the emotional reaction of the mother to the diagnosis and their experience of the communication of health professionals, primarily doctors.

Other major themes identified by the thematic analysis include the grief experienced by parents in relation to their child’s uncertain prognosis from Infantile Spasms, particularly due to the refractory nature of seizures and the impact of Infantile Spasms on development. The impact of Infantile Spasms on the relationship between the parent and infant was also considered. Finally, specific aspects of the experience of living with a diagnosis of Infantile Spasms were highlighted, particularly the experience of mothers of accessing formal and informal supports and contributing to research. The process by which mothers made meaning from the diagnosis, typically by contributing towards further research or assisting other families with a child with the condition, was also discussed.
Chapter Six: Discussion

This thesis has articulated the lived experience of a small sample of mothers of children diagnosed with Infantile Spasms. In order to accurately locate the contribution of this study, this chapter commences with a critical examination of the strengths and limitations of the study. The three major themes of the study are then reiterated, namely: the process of seeking and experiencing the diagnosis, adjustment to the impact upon the infant, and living with and making meaning from the experience. These themes are contextualized within the literature that was previously identified in Chapters Two and Three, and within current clinical practice.

6.1. Study strengths and limitations

The results of this study should be considered in the context of several limitations.

Firstly, the results of this study should be considered in the context of the small numbers of participants in this study. Due to the small sample size, the findings below are not easily generalizable to other populations, despite the rarity of the condition. Additionally, the study method that was granted Royal Children’s Hospital HREC approval stipulated that ten participants would be recruited to the study, however only nine mothers finalized their participation in the time constraints for completion of the thesis. Further research with a larger sample, however, is recommended in order to attempt to generalize findings. However, a sample of nine mothers is appropriate both to the incidence of this condition and the study design, which aimed to capture in-depth narratives. The narratives of nine mothers still facilitates a valid and comprehensive understanding of the experiences of mothers of children with this rare condition.

Secondly, the sample recruited to the study represents a somewhat homogenous group of Infantile Spasms patients in comparing their disease-related outcomes. The children of all mothers recruited to this study experienced ongoing seizures and had poor developmental outcomes, whereas not all patients with Infantile Spasms fit this profile. In particular, the narratives of mothers of children who experienced remission from seizures after treatment for Infantile Spasms are not present. This homogenous study population is likely due to the recruitment design of the study, in that patients were recruited retrospectively from the Royal Children’s Hospital based on their diagnosis. It is plausible to suggest that patients with more regular contact with the RCH would be more likely to participate in this study, both for
convenience and motivational reasons. However, it is important to note that the homogenous nature of the recruited sample may also offer strengths to the study. Firstly, this population in somewhat reflective of patient prognostic outcomes from Infantile Spasms, in that the majority of patients experience refractory seizures and intellectual disability. Additionally, the homogenous patient group does allow the study to provide an in-depth account of the specific experiences of mothers who have children who do not respond to treatment. In particular, themes relating to adjustment and grief are explored in great detail due to the variety of narratives.

Finally, the responses garnered from the telephone interviews were consistently to be more brief than responses obtained from interviews in person. This finding is strongly supported within the literature, and was highlighted as a known potential consequence of this interviewing strategy in the HREC application.

6.2. Discussion and clinical practice implications

This study answered the broad, exploratory research question, ‘what are the psychosocial experiences of parents who provide care to an infant diagnosed with Infantile Spasms?’ The study also examined the following secondary lines of enquiry, based upon the above research question,

- To explore parents’ adjustment to the diagnosis of Infantile Spasms in their child, including any impact of delayed diagnosis and treatment on this adjustment, for example delayed recognition of symptoms by professionals or parents.
- To explore parents’ perceptions of their relationship with their infant who has been diagnosed with Infantile Spasms.
- To outline informal and professional supports accessed by parents of infants with Infantile Spasms, including from the RCH and their perceived usefulness.

The initial finding of this study is that despite attempts to recruit both mothers and fathers, only mothers participated in this research. It is widely acknowledged within the literature that recruiting fathers to participate in research about their experiences of their children’s health issues can be challenging (Harden et al., 2016; Moreira et al., 2013). This is likely to reflect the previously discussed, lived experience of fathers, in that they are still likely to be less engaged in directly caring for an infant (The Organisation for Economic Co-Operation and
Development, 2005; Ramaglia et al., 2007; Riechmann et al., 2015; Seah & Morawska, 2016; Tsibidaki, 2013) despite evidence highlighting the benefits of their involvement in caregiving (Laxman et al., 2013; Özyazıcıoğlu & Buran, 2014; Seah & Morawska, 2016; Song et al., 2015). However, participation in the study exclusively by mothers allows the findings to reflect their experiences in a cohesive series of narratives. Recommendations for future research within this area include ongoing attempts to recruit fathers to research relating to paediatric epilepsy, potentially within studies solely tasked with determining their experiences.

The process of seeking and experiencing the diagnosis of Infantile Spasms

This study found that the experience of seeking and obtaining the diagnosis of Infantile Spasms for their child was the most significant experience for these mothers. This over-arching theme was comprised of two distinct sub-themes of experience, with each being directly located within the diagnosis period.

The first sub-theme is the experience of mothers when their child’s diagnosis of Infantile Spasms was delayed. Most mothers in the study experienced a delay in the diagnosis of their child’s Infantile Spasms, which is consistent with the medical literature outlined in Chapter One (Appleton, 2001; Auvin et al., 2012; Napuri et al., 2010; Ziegler et al., 2000). This finding is further supported by literature detailed in Chapter Two that identifies that health or developmental conditions of infancy are at increased risk of not being diagnosed in a timely manner (Launay et al., 2014; Morley et al., 1991; Smaldone & Ritholz, 2011). This study provides some unique insights regarding the specific ways in which a delayed diagnosis of Infantile Spasms occurs. Two clear circumstances were identified: namely that mothers retrospectively acknowledged that spasms’ symptoms were overlooked or incorrectly interpreted and not acted upon, or that medical professionals failed to identify symptoms during consultations. Mothers spoke about noting symptoms of Infantile Spasms but did not seek immediately medical treatment is a particularly unique finding of this study; both in providing an account of the circumstances in which this occurred and describing the resulting impact on the mother. These mothers described witnessing spasms but believing that they were developmentally appropriate tasks for the infant to be attempting, such as physically engaging with the parent or moving independently. The symptoms of Infantile Spasm onset are subtle, and as previously outlined, it is common for conditions with a subtle onset of symptoms to be difficult for caregivers to identify, resulting in late presentation for diagnosis (Bingham et al., 2012; Bland & Young, 1991; Brasme et al., 2012; Sivberg, 2003). However, reducing the risk
of non-identification of seizures by caregivers is a challenging task. Infantile Spasms is a rare condition, therefore broad educational or awareness raising campaigns, in the context of over-recognition of non-epileptic seizure like events in the community, may increase anxiety and inappropriate presentations for healthcare assessment (Berg et al., 2014). However, targeted education can easily be offered to populations at risk of developing Infantile Spasms, such as patients with Tubular Sclerosis. This currently occurs at the Royal Children’s Hospital, via showing parents educational videos demonstrating spasms to increase their capacity to identify them, which is supported in the literature (Lim Fat, Doja, Barrowman, & Sell, 2011).

Another finding of this study was that some mothers perceived that medical professionals had failed to identify the diagnosis of Infantile Spasms in their child in a timely way. This occurred when children were physically examined and evaluated in person or a verbal description of the spasm symptoms were conveyed to a doctor. This finding is supported in the literature, which particularly identifies seizure disorders, rare conditions and conditions diagnosed in infancy as being more likely to be incorrectly diagnosed by a medical professional (Napuri, Gall, Dulac, Chaperon, & Riou, 2010; Wheless et al., 2012). A finding of particular note is that delays in diagnosis reduced when medical evaluation occurred in a paediatric, tertiary medical setting compared to a non-paediatric emergency department clinician or a General Practitioner. As previously discussed in Chapter Two, there are mixed views regarding the importance of paediatric specialty assessment. However, the risk of misdiagnosis generally appears to be reduced in this setting (Brasme et al., 2012; Eckerle et al., 2015).

As identified above, further education of medical practitioners is essential to reduce the risk of delayed diagnosis in this condition, due to the limited capacity to educate the wider population effectively. This notion is supported within literature that identifies recommendations for General Practitioners, Paediatricians and other health professionals, to consider the diagnosis of Infantile Spasms in evaluating patients and undertake ongoing training where possible (Howell, 2017; Wheless et al., 2012).

The distress experienced by mothers when their child’s diagnosis is delayed

This is the first study to document the significant maternal distress and sense of personal guilt associated with a delay in diagnosis of this condition, which was present regardless of the cause of the delay. The highly personal narratives detailed in this study are the first systematically gathered collection of experiences of this phenomena.
However, these grief and adjustment reactions having been experienced by mothers of children who experience a delay in their diagnosis of other medical conditions (Clarke & Fletcher, 2003; Evans et al., 2015; Tluczek et al., 2005; Uus et al., 2015). Whilst distress was present regardless of the circumstances in which the delay occurred, it appeared that mothers who failed to detect symptoms themselves experienced considerable distress and felt an increased sense of personal guilt. Several mothers appeared to conceptualize themselves as the protector of their child, and the subsequent delay in identification of symptoms reflected on their capacity as a caregiver.

Mothers of infants who were not delayed in receiving their diagnosis were still distressed about the diagnosis of Infantile Spasms being made. This typically related to these mothers’ understanding that Infantile Spasms has a variable, but typically poor, prognosis. It is clearly identified within the literature discussed in Chapter Two that the diagnosis of a health or developmental condition in a child results in profound grief responses from a parent (Darraht, Evans, & Adkins, 2002; Gul et al., 2016; Tierney et al., 2015). In contrast to some narratives within the literature, this study did not present any findings to indicate that parents had a sense of disbelief regarding the condition (Bingham et al., 2012) or conversely that they felt relieved to be given a diagnosis that confirmed the symptoms noted (Tierney et al., 2015). This may be due to the fact that Infantile Spasms is a condition requiring immediate, intensive treatment with a poor prognosis still being a possibility. It is therefore likely that the prognostic outcome would mitigate any sense of relief experienced by the parent upon receiving the diagnosis. The sense of grief in mothers often originated at the point of diagnosis, but was further confirmed and worsened by their observation of their child’s symptoms persisting or worsening over time. As a result, this theme will be discussed further in relation to the finding of mothers’ experience of and adjustment to their child’s prognosis from Infantile Spasms.

The literature acknowledges the importance of supporting all caregivers at the point of the diagnosis of a condition in a child (Austin, 2006; Aytch & White, 2001; Laxman et al., 2013; Mu, Kuo, & Chang, 2005; Salisbury & Copeland, 2013; Song, Chun, & Choi, 2015). Whilst mothers in this study did not commonly seek out support from healthcare professionals, such as social workers or nurse coordinators, it has been demonstrated that they can be helpful in supporting parents at diagnosis. However, mothers within this study preferred to access their informal networks of support and prioritized obtaining the relevant medical information as a source of containment and support. It is therefore important to individualize care based on the preferences and needs of patients and their families. Whilst social workers may not have been
identified as key professionals whose support was sought by mothers within this study, social workers in Paediatric hospitals are systemic and patient focused in assessing how families wish to access support. They may also be able to provide secondary consultation to healthcare professionals regarding the interplay of psychosocial factors on health outcomes, if their direct contact is not welcomed by parents at the point of diagnosis.

The provision of medical information at diagnosis

Another theme related to the diagnostic journey of mothers of children with Infantile Spasms was the experience of communication by health-care professionals. Parents of children diagnosed with a wide range of medical conditions frequently relate the importance of and the process by which they seek information at the time of diagnosis (Aytch & White, 2001; Bingham et al., 2012; Cabral et al., 2014; McNelis et al., 1998; Patistea & Babatsikou, 2003; Shore et al., 1998; Starke & Moller, 2002; Zierhut & Bartels, 2012). It is clearly demonstrated within the literature that this information may act as a mediating factor of parental distress and facilitate their ongoing coping (Most et al., 2006; Psenka & Holden, 1996; Taanila et al., 1998; Tluczek et al., 2005). The findings of this study were consistent with these results, as mothers strongly identified the need for clear, concise information at the time of diagnosis. Information about the medical condition was considered most important and mothers primarily sought for it from doctors.

Mothers in this study articulated a range of experiences of communication from their child’s doctor towards them, both positive and negative. These narratives were emphatically expressed to the researcher with great clarity, despite the passage of time since the events had occurred. The majority of mothers within this study appeared satisfied with the structure and content of information provided at diagnosis, somewhat in contrast to the literature previously identified (Buelow et al., 2006; Nolan et al., 2006; Saburi, 2011; Ziegler et al., 2000). This may be due to the fact that for mothers who participated in this study, their child’s diagnosis was typically confirmed by a specialist Paediatric Neurologist; an expert medical physician in the field of paediatric epilepsy. This finding is particularly commendable given the potentially unclear aetiology of the condition at the point of diagnosis, which may have impacted on the ability of the Neurologist to consistently provide clear and detailed information to mothers.

However, mothers reported that medical physicians demonstrated varied levels of empathy and sensitivity at the time of diagnosis. The absence of these components of communication
appeared to have negative impacts on mothers, who clearly recalled examples of insensitive delivery of information. This finding is consistent with literature previously outlined in Chapter Three of the thesis which clearly outlines the importance of sensitive communication by healthcare professionals in facilitating parental adjustment to a diagnosis of a condition in their child (Choi et al., 2011; Galil et al., 2006; Howells & Lopez, 2008). Mothers also appeared to have different preferences for the style of interpersonal communication of their child’s doctor, with some requesting a warm, empathic style from physicians whilst others preferring a direct style that prioritised transmission of information.

It relation to practice, it is therefore important for medical physicians to consider both the content of and manner in which information is communicated to parents at diagnosis. As indicated by this study, this communication has a lasting impact on how mothers view the diagnosis period, and doctors are within a particularly powerful position to shape these memories. Other health professional disciplines, such as social workers, may also have a role in supporting specialist medical professionals in conveying diagnostic and prognostic information sensitively to families. Social workers may be able to influence medical professionals by being present during particularly sensitive medical consultations and gathering psychosocial information from the family which may inform communication styles of doctors.

The way that parents experience communication by health professionals is also shaped by the context in which the interaction occurs, in addition to the actions of an individual clinician. It is therefore relevant to consider the context in which the diagnoses of Infantile Spasms occurred in the study population, as the clinical management of these patients at the Royal Children’s Hospital has evolved since the patients in this study were diagnosed. The children of mothers of this study were treated for Infantile Spasms at the RCH prior to the development of a Criteria Led Discharge (CLD). The CLD expedites the discharge of patients with Infantile Spasms from hospital when they are first admitted and diagnosed with the condition, by establishing discharge planning goals that may be completed by a nurse. In comparison to the study population, patients who are now diagnosed with Infantile Spasms can be discharged within two days of admission and may have less interface with a Paediatric Neurologist during this time. The findings of this study indicate that mothers appreciated thorough and sensitively delivered information regarding their child’s newly diagnosed condition from a Paediatric
Neurologist it would therefore be important to consider whether new guidelines focused on streamlining care do reduce opportunities for the transmission of information.

Mothers adjusting to their child’s prognosis from Infantile Spasms

This study also found that mothers of children who experienced a poor outcome from Infantile Spasms experienced considerable distress and grief. The children of all mothers within this study had a poor developmental outcome and continued to experience refractory seizures. This finding is somewhat consistent with medical literature outlining the disease trajectory of Infantile Spasms, as it is considered to be a ‘catastrophic epilepsy of childhood’ (Iwatani et al., 2012). However, as previously discussed, this homogenous patient group is not representative of the entire population, likely due to the recruitment strategy utilized.

This is the first study to discuss the emotional responses of mothers to Infantile Spasms that is refractory to treatment; aside from assumptive statements made within medical research studies. These mothers articulated or demonstrated their distress during the interview when they confronted the issue of the impact of Infantile Spasms on their child’s health. They were deeply concerned about ongoing seizures that were refractory to treatment, and the development of a secondary seizure disorder. High levels of distress were also demonstrated in discussing any developmental delay or regression in the child. These narratives contribute to findings from quantitative research, highlighted in Chapter Three, that discuss the relationship between the biological severity of the child’s condition and the maladjustment of their parent (Ferro et al., 2011b; Glasscock, 2000; Kandel & Merrick, 2003; Kerr & McIntosh, 2000; McCusker, Kennedy, Anderson, & Hanrahan, 2002; Miles, Holditch-David, Schwartz, & Scher, 2007; Nolan et al., 2008; Shore et al., 2002; Wood et al., 2008a). Whilst the methodological design of this qualitative study did not aim to measure the impact of disease severity, mothers clearly identified within their narratives that they were affected by the degree of their child’s impairment. This study offers a more personal, in-depth account of the experience of mothers’ grief surrounding the potential poor outcome of Infantile Spasms; as opposed to quantitative studies that examine causal relationships but do not provide insight to the lived experience. It is important to consider, as noted in Chapter Three, that psychosocial factors may be as important as biological factors in influencing the parental experience. However, mothers within this study did not identify that pre-existing psychosocial stressors impacted on their experiences, aside from issues relating to the availability of support via partners or extended family which will be discussed shortly.
These mothers also highlighted their lived experience of the side effects of medication used to treat Infantile Spasms. These side effects are well understood, and were discussed in Chapter One of the thesis (Mackay et al., 2004). However, this is the first study to describe the lived experience of these side effects for parents, in the context of their use to treat Infantile Spasms. Side effects, such as decreased engagement from the infant, bloating, irritability and reduced immunity, were generally described in relation to the associated caregiving tasks or the impact they had on the interaction with the child, rather than provoking an acute sense of distress. This may be due to the shorter term nature of these side effects, compared to the permanent nature of prognosis from the condition itself. Considerations for practice may include increasing access to supports within the community to mitigate the impact of these distressing symptoms on caregivers.

*How the child’s health and developmental outlook influences the parental relationship with the child:*

Mothers within this study were mixed in their views as to whether the diagnosis of Infantile Spasms impacted on their relationship with their child or their parenting. It is important to note that this study did not attempt to measure the impact of Infantile Spasms on attachment or parenting, but to glean an understanding of mothers’ own perceptions of this phenomena. Questioning mothers directly on their relationship with their child may have been confronting, and responses to the direct query on this subject in the majority were brief. However, mothers also referenced their relationship with their child indirectly throughout their narratives. Some mothers felt that the presence of the Infantile Spasms facilitated some unanticipated and subtle benefits to their connection with their child. This was typically demonstrated by the provision of additional care and monitoring to the child, due to a sense that the child was particularly vulnerable due to their seizures. Traditionally, in the context of the literature outlined in Chapter Three of the thesis, the provision of additional care to a child with a health or developmental issue may be viewed as intrusive or directive parenting (Becker et al., 1997; Forcada-Guex, Pierrehumbert, Borghini, Moessinger, & Muller-Nix, 2006; Laing et al., 2010). Literature specifically considering paediatric epilepsy identified that parents may restrict the autonomy of the child and act intrusively towards them (Austin & McDermott, 1988, as cited in Behrouzian & Neamatpour, 2010). However, mothers within this study framed these acts of caregiving as an accommodation of the child’s additional needs and a reflection of their sense of attachment and affection towards the infant. Infantile Spasms, as per paediatric epilepsy
generally, is an unpredictable and serious condition; often requiring intervention from the
caregiver to assess child wellbeing following a seizure. Therefore, whilst objective analysis of
these interactions is not possible, it is reasonable to suggest that the acts of additional care
provided to the child with Infantile Spasms were typically indicative of a positive infant/parent
relationship. This is in keeping with an increasing body of literature that interprets acts of
additional caregiving as an appropriate accommodation to the child’s developmental or health
needs (Becker et al., 1997; Goldberg & DiVitto cited in Singer et al., 2003; Minde 2000 cited
in Laing et al., 2010).

However, other mothers could acknowledge that the symptoms or management of Infantile
Spasms placed some strain on their relationship with their child. Several mothers described
grieving the loss of the healthy child that they anticipated having; a phenomenon that is well
described in the literature and summarized in Chapter Two of the thesis (Appleton, 2001;
Galletti & Sturniolo, 2004; Gul et al., 2016). Several mothers acknowledged that they had at
times viewed the infant as an over-medicalized entity. Other mothers framed the challenges to
the relationship as being compounded by frustration associated with sleep deprivation. Sleep
deprivation is widely acknowledged in the literature, and identified in Chapter Two, as being
a significant stressor for parents of children with disabilities and epilepsy (Cottrell & Khan,

Whilst some mothers could overt these challenging aspects to the parent/infant relationship,
others appeared to struggle to articulate these even though they may have been present.
Mothers within this study commonly identified the physical impacts that Infantile Spasms and
its’ associated treatment had on the capacity of the infant to communicate and engage.
However, limited connection was overtly made between this reduced capacity and the parent
to infant relationship. There is a significant body of literature that identifies the impact of caring
for an infant with a less engaging manner on the parents’ bond with and parenting of the child,
as summarized in Chapter Three of the thesis (Holditch-Davis, Schwartz, Black, & Scher,
2007; Rempel, Ravindran, Rogers, & Magil-Evans, 2013; Sealy & Glovinsky, 2016; Singer et
al., 2003; Torowicz, Irving, Hanlon, Sumpter, & Medoff-Cooper, 2010; Troutman, Moran,
Arndt, Johnson, & Chmielewski, 2012). Interestingly, some mothers initially stated that the
Infantile Spasms had not affected their relationship with their child, before providing examples
of both positive and negative impacts. This result has been found in another study (Jordan et
al., 2014) that specifically examined the influence of healthcare provision on the parent to
infant relationship.

Social workers should consider attachment based screening and intervention to establish the presence of a medical condition impacts on the parent to infant relationship. Psychoeducation, counselling and referral onto specialist services for families with increased vulnerability may be appropriate for the families of patients diagnosed with Infantile Spasms.

6.3. Living with and making meaning from a diagnosis of Infantile Spasms

This study also identified the way in which mothers of children with Infantile Spasms sought to cope, adjust and to assist their peers to do the same. Mothers expressed receiving varying levels of support from a range of sources throughout the ongoing process of caring for their child.

Informal sources of support:

The majority of mothers spoke at length about the support they received from a spouse or partner who was the father of the child diagnosed with Infantile Spasms. These narratives portrayed wide-ranging experiences, however the overwhelming majority of mothers described having limited support from the child’s father. This is highly consistent with the literature previously outlined in chapter 3.2, which contends that mothers continue to play the dominant role in caring for children with disabilities (OECD, 2005; Ramaglia et al., 2007; Seah & Morawska, 2016; Tsibidaki, 2013).

The distress expressed by these mothers while describing this phenomena is reflected in studies that outline increased psychological risks to mothers of having limited access to a supportive partner (Laxman et al. 2013; Ozyazicioglu & Buran 2014; Seah & Morawska, 2016; Song et al., 2015). The importance of a complementary coping style with one’s partner was also identified in this study, as is noted in the literature (Goldbeck 2001; Zierhut & Bartels 2012). Mothers were not systematically questioned on the psychosocial profile of their families, and therefore it is difficult to comment on why some fathers actively assisted and supported these mothers.

Of note, however, is the fact that the several mothers who described having an unsupportive partner also identified them as having pre-existing psychosocial stressors, such as unemployment, mental health issues or complex family relations, whereas the few mothers
who described their partners as providing adequate support denied any pre-existing psychosocial complexity. The role of pre-morbid psychosocial stressors and a specific temperament for fathers, as described in Chapter Three, predicts the level of support that they provide (Bragiel & Kaniok, 2014).

The next most frequently reported source of support for mothers was their immediate and extended family members. As found within this study, parents of children with a disability elicited instrumental and emotional support from grandparents to assist them in their caring role (Canary 2008; Katz & Kessel, 2002). Mothers within this study typically described the availability of extended family to provide practical assistance, however reflected with great emotion on the times that they felt that this assistance was lacking. The support of grandmothers featured more prominently than that provided by grandfathers, as confirmed in the literature previously discussed (Canary, 2008; Hall, 2004).

This finding should be considered by health care professionals in the provision of care and information to families throughout treatment. Clinicians should maximize opportunities for fathers to engage in healthcare services related to their child, and where appropriate, extended family members. Additionally, clinicians, such as paediatric social workers, should potentially screen for relationship or psychosocial stressors throughout treatment, given their impact on the capacity of parents to cope.

*Formal sources of support:*

For participants in this study, formal supports were identified as counselling, peer support groups and Early Childhood Intervention Services. As found within this study, mothers of children with disabilities or epilepsy in Western countries typically do not receive adequate formal supports (Burton-Smith et al., 2009; Hiebert-Murphy, Trute, Wright, 2011; Marcenko & Meyers, 1991). Counselling was the primary formal support that parents raised either as having accessed, having considered accessing or being aware of but not engaging in. The limited uptake or interest in counselling services by the participants within this study is in contrast to the available literature which outlines the benefits of counselling for parents of children with disabilities, and generally moderate uptake within the community (Capozzi, 2010; Eccleston, Palermo, Fisher, & Law, 2012; Galletti & Sturniolo, 2004; Haugstvedt, Graff-Iversen, Bukholm, Haugli, & Hallberg, 2013).

Early Childhood Intervention Services (ECIS) were raised by only a small number of mothers
as a source of support for themselves. ECIS was typically discussed as a therapy service targeting the child’s development, but not as a source of emotional or practical support for the mothers themselves. This presents in contrast to the literature discussed in Chapter Three of this thesis, in which ECIS is clearly designed to provide support to parents (Department of Education & Training, 2017). ECIS services were not identified at all by a number of mothers within this study, however given the developmental profile of these children it is unlikely that the majority were not linked with ECIS. Therefore, it is reasonable to interpret that ECIS was not generally viewed as a support for these mothers.

This finding may also be impacted by the significant changes to service delivery of ECIS that will occur through the transition to ECEIS, via the implementation of the NDIS. The increased funding of these services may result in mothers of children diagnosed with Infantile Spasms in future cohorts acknowledging the role of ECEIS in a more significant way.

Furthering knowledge

Mothers conveyed a sense of wishing further knowledge and research regarding their child’s condition, both to benefit both their own children and others diagnosed with Infantile Spasms. This sub-theme emerged organically from mothers, and presented itself in varying manners – e.g. making financial donations to relevant charities, contributing to research or training for doctors or managing peer support forums for parents. Parents of children with a disability make significant contributions to this understanding of childhood illness and disability via their participation in research. A large focus of that contribution stems from participation in medical and drug trials seeking to advance treatment. This is particularly true of children with rare disorders, however little is known regarding their motivations for participation in research. This study provided personal insights to the motivations of mothers of children with a rare condition to participate in research, which typically stem from motivations to improve outcomes for all children diagnosed with Infantile Spasms.
Chapter Seven: Conclusion

This research explored the psychosocial experiences of parents who care for an infant diagnosed with Infantile Spasms. In-depth narratives from mothers were gathered, prioritizing the issues that were of most significance to them in summarizing this complex phenomenon. The study also explored their experiences of obtaining the child’s diagnosis, their relationship with their child and the informal and professional supports that they accessed in living with the condition. Only mothers participated in this study, despite recruitment invitations specifically addressing both mothers and fathers.

Three major themes emerged as findings of this study. The first major theme identified was the experience that mothers had of their journey to obtaining their child’s diagnosis. A particularly prominent issue within this narrative was that many mothers experienced a delay to their child’s diagnosis of Infantile Spasms, due to either themselves or a medical physician failing to quickly identify symptoms and commence treatment. This study provided detailed examples of the emotional toll and sense of personal guilt that this exacted upon affected mothers. Another significant issue identified by mothers was their experience of communication by health professionals at the time of diagnosis, and how this had the capacity to influence their experience of this time.

The second major theme of the study was how mothers’ experienced their child’s prognosis from the Infantile Spasms. The presence of ongoing, refractory seizures or developmental delay or stagnation were a cause for considerable distress in mothers of children with Infantile Spasms. Mothers’ related that the gradual unveiling of clinical symptoms became the clearest evidence of likely poor prognosis from this condition, due to the variable prognostic outcomes for this condition. Therefore, the emergence of these indicators was particularly distressing for these mothers. Mothers also reflected on the impact that Infantile Spasms had on their interactions and relationship with their child. For some mothers it engendered a sense of protectiveness of the infant, whereas for others it reduced their ability to connect with the child.

The final theme of the study was the ways in which mothers lived and sought to cope with the diagnosis of Infantile Spasms and make meaning from their lived experience. Mothers referenced the support that they received from informal sources, such as the relationship with the father of the child and their extended family, as more important than that offered by professional services. Mothers also described contributing to paediatric healthcare or charitable
services as an important part of making meaning of their child’s diagnosis of Infantile Spasms.

Whilst these are the first documented experiences of mothers of children who have lived with Infantile Spasms, they are supported by literature examining the experiences of parents of children with other paediatric health or developmental issues. Parental distress regarding a delay in diagnosis is common, even if there is no potential impact on prognosis - as there potentially is with Infantile Spasms. This study offers a unique insight to the distress experienced by this population, where prognostic outcome is impacted by treatment delay. This study also contributes to the expanse of literature outlining the importance of clear, empathic communication from doctors at the time of the diagnosis of a paediatric healthcare condition.

Whilst studies highlight that psychosocial factors have an equal influence on parental adjustment to paediatric illness as to biological factors, this study found that mothers cited the severity of their child’s condition as impacting on their experiences. This study offered highly personal and unique narratives highlighting that biological compromise in a child has a significant impact on parents. However, mothers who participated within this study primarily sought support from informal sources, such as family or friends, which should be further considered when providing psychosocial interventions in a clinical setting.

This study has recommended further research with this population or groups with similar clinical presentations, such as other forms of infantile epilepsy. As this exploratory study has identified key themes of experience above, further studies are indicated to ascertain how representative these are of the entire population.
References:


Cushner-Weinstein, S., Dassoulas, K., Salpekar, J. A., Henderson, S. E., Pearl, P. L.,


doi:10.1016/j.ajem.2015.04.006


doi:10.1038/bjc.2014.516


Holditch-Davis, D., Schwartz, T., Black, B., & Scher, M. (2007). Correlates of mother-


infants at 18 months. *Infant Mental Health Journal, 29,* 570-587. doi:10.1002/imhj.20196


Appendices:

Appendix 1: Literature review method:

A thorough literature review was conducted, initially attempting to locate studies specific to the psychosocial aspects of Infantile Spasms. The key words ‘Infantile Spasms’, ‘West Syndrome’, ‘psychosocial’, ‘adjustment’, ‘stress’ and ‘coping’ in the University of Melbourne SuperSearch function, MEDLINE, PsycInfo and CINAHL Plus. This search identified no studies that have examined the psychosocial experience of parents who provide care to an infant diagnosed with Infantile Spasms.

The range of search terms utilized were then widened to gather supporting literature from related fields. The research team brainstormed related fields and determined that literature relating to the following issues would be relevant to consider in developing the study, and the following key words

- The psychosocial issues for caregivers of infants with a disability, chronic or acute health issues.
- The psychosocial issues for caregivers of children diagnosed with epilepsy.

To identify related literature focusing on epilepsy, the search terms below were utilized in Medline, CINAHL and Psycinfo. This search strategy resulted in 1,757 journal articles, including duplicates. Relevant references in articles were also used to collect further information. Of the above, 80 articles were considered relevant and were reviewed and considered for inclusion.

- ‘Pediatric’/’Paediatric’ + ‘epilepsy’ + stress/ coping/ grief/ adjustment/ depression/anxiety/ QOL/ psychosocial.

To identify related literature focusing on infants, the search terms listed below were utilized in Medline, CINAHL and Psycinfo. Relevant references in articles were also used to collect
further information. Of the above, 65 articles were considered relevant and were thoroughly reviewed and considered for inclusion.

- Infant + illness + QOL/ depression/ adjustment/ parent/ psychosocial/ coping/ stress.
- Infant + disability + parent/ adjustment/ coping/ stress/ anxiety/ depression/ QOL/ psychosocial.
- Infant + parental + adjustment.
- Infant + parenting + disability.
- Infant AND ‘chronic health’.
- ‘Early Intervention’ AND grief.

Following the completion of interviews, a further literature search was conducted to expand on relevant themes. The Infant Mental Health journal years 2015 – 2016 was reviewed for relevant articles. In April, 2016 the databases Medline, CINAHL and Psycinfo were searched for the terms of,

- ‘Infant OR baby’ AND diabetes.
- ‘Infant OR baby’ AND Esophageal atresia.
- Cardiac AND infant AND parent.
- ‘Down Syndrome’ AND infant AND parent.
- ‘Down Syndrome’ AND diagnosis AND parent.
- Parenting AND epilepsy.
- ‘Delayed diagnosis’ AND infant/parent.
- Baby OR infant OR newborn AND cystic fibrosis AND parent/diagnosis
- ‘Developmental regression’ AND parent
- ‘Medical side effect’ AND infant
- Steroid side effect
Appendix 2: HREC approval letter

RCH HUMAN RESEARCH ETHICS COMMITTEE APPROVAL

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<td>A phenomenological study of the psychosocial experiences of parents of infants diagnosed with Infantile Spasms</td>
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<td>DOCUMENTS APPROVED:</td>
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<td>PIS and CF v2 dated 23 Mar 2015</td>
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<tr>
<td>PRINCIPAL INVESTIGATOR:</td>
<td>Menka Tsantekti</td>
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<tr>
<td>DATE OF ORIGINAL APPROVAL:</td>
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<td>DURATION:</td>
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SIGNED: 

[Signature]

COMMITTEE REPRESENTATIVE: 

[Signature] 17 April 2015

CONDITIONS:

APPROVED SUBJECT TO THE FOLLOWING CONDITIONS:

ALL PROJECTS:
1. The study must not commence until all Research Agreements have been executed (if applicable).
3. Any proposed change in the protocol or approved documents or the addition of documents must be submitted to the Human Research Ethics Committee (HREC) for approval prior to implementation, including:
   - flyers, brochures, advertising material
   - increase in recruitment target
4. The Principal Investigator must notify Research Ethics & Governance of:
   - any serious adverse effects of the study on participants and steps taken to deal with them.
   - any unforeseen events (e.g. protocol violations or complaints).
   - Investigators withdrawing from or joining the project.
5. A progress report must be submitted annually and at the conclusion of the project.
6. RCH HREC approval must remain current for the entire duration of the project. If the project is not completed in the allocated time a renewal request must be submitted to the Research Ethics & Governance. Investigators undertaking projects without current HREC approval risk their indemnity, funding and publication rights.

CLINICAL TRIALS:
7. Must comply with Good Clinical Practice (GCP).
8. Must report all internal (occurring in RCH participants) Serious Adverse Events (SAE) to the sponsor and the RCH HREC within 72 hours of occurrence.
9. Must report all Suspected Unexpected Serious Adverse Reactions (SUSARS) to the Therapeutic Goods Administration (TGA) (for sponsored studies the sponsor may take this responsibility).
Appendix 3: HREC modification approval letter

ETHICS APPROVAL & GOVERNANCE AUTHORISATION

12 April 2016

Menka Tsantefski
University of Melbourne

Dear Dr Tsantefski

Project Title: A phenomenological study of the psychosocial experiences of parents of infants diagnosed with Infantile Spasms

RCH HREC Reference Number: 35032B

I am pleased to advise that the below modification has received ethical approval from The Royal Children’s Hospital Melbourne Human Research Ethics Committee (HREC).

The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). This HREC is organised and operates in accordance with the National Health and Medical Research Council’s (NHRMC) National Statement on Ethical Conduct in Human Research (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

The modification has also received governance authorisation at the Melbourne Children’s Campus (incorporating The Royal Children’s Hospital, Murdoch Children’s Research Institute and the University of Melbourne Department of Paediatrics).

HREC Approval Date: 12 April 2016

Participating Sites:
Ethical approval for this project applies at the following sites:

- The Royal Children’s Hospital and Murdoch Childrens Research Institute

Approved Documents:
The following documents have been reviewed and approved:

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<th>Date</th>
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<td>V2</td>
<td>7 Mar 2016</td>
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<td>12 Apr 2016</td>
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<td>Recruitment letter</td>
<td>V1</td>
<td>1 Apr 2016</td>
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Conditions of Ethics Approval:
- You are required to submit to the HREC:
  - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.
  - A comprehensive Final Report upon completion of the project.
Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.

Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: Monitoring and reporting of safety for clinical trials involving therapeutic products May 2009.

Notify the reviewing HREC of your inability to continue as Coordinating Principal Investigator.

Notify the reviewing HREC of the failure to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.

Notify the reviewing HREC of any matters which may impact the conduct of the project.

If your project involves radiation, you are legally obliged to conduct your research in accordance with the Australian Radiation Protection and Nuclear Safety Agency Code of Practice ‘Exposure of Humans to Ionizing Radiation for Research Purposes’ Radiation Protection series Publication No.8 (May 2005)(ARPANSA Code).

The HREC, authorising institution and/or their delegate/s may conduct an audit of the project at any time.

Yours sincerely

[Signature]

Sophie Gatenby
Senior Ethics Officer (HREC Secretariat)
Research Ethics and Governance
The Royal Children's Hospital Melbourne
Phone: (03) 9345 5044
Email: rch.ethics@rch.org.au
Web: www.rch.org.au
Appendix 4: Study Design Diagram

Parents of eligible patients identified using EEG records identifying West Syndrome as diagnosis. Parents sent Plain Language Statement and Consent Form.

- **Positive response from parent/s**
  - Initial phone or email contact with parent/s to arrange interview time
  - Student researcher receives written consent
  - Interview conducted with parent/s

- **No contact received from parent/s**
  - Phone call made to listed phone number on CLARA/IBA system
  - Positive response from parent/s
  - Parent/s receive written consent
  - Interview conducted with parent/s

- **Parent/s decline involvement**
  - No further contact from parent/s
  - No further action
Appendix 5: Recruitment cover letter

DATE

Dear NAME/S,

Research Project Title: What are the psychosocial experiences of parents who provide care to an infant diagnosed with Infantile Spasms?

We are writing to let you know about a new research project that is taking place at The Royal Children's Hospital (RCH) that may interest you.

Why are you being asked?
We are sending you this information because your child has been treated for Infantile Spasms by the Neurology Department at RCH.

What is the research about?
We have enclosed an information statement and consent form describing the project. The form explains the research in detail, including:

What we aim to learn from the research
What is involved if you take part
What the risks and benefits of participation are
What happens to information collected and how confidentiality of information is protected

What do you need to do?
We would be grateful if you could take some time to read the information statement and consider taking part.

Please call or email Kelly O'Mara, the social work student researcher on 9345 9300 or Kelly.omara@rch.org.au to let us know if you are interested in taking part or not.

If we do not hear from you in the next two weeks, Kelly O’Mara will contact you to check you received this letter and to answer any questions you may have about the research.

Kind regards,

[Signature]

A/Prof Monique M Ryan M Med BS, FRACP
Director, Department of Neurology
Research Fellow, Murdoch Childrens Research Institute
The Royal Children’s Hospital Melbourne
50 Flemington Road Parkville 3052 Victoria
Appendix 6: Plain Language Statement

HREC Project Number: 35032 B
Research Project Title: What are the psychosocial experiences of parents who provide care to an infant diagnosed with Infantile Spasms?
Principal Researcher: Associate Professor Lou Harms
Version Number: 2
Version Date: 07.03.2016

Dear Mr/Mrs NAME,

Thank you for taking the time to read this Participant Information Statement and Consent Form. We would like to invite you to participate in a research project that is explained below. This document is 5 pages long. Please make sure you have all the pages.

What is an Information Statement?
These pages tell you about the research project. It explains to you clearly and openly all the steps and procedures of the project. The information is to help you to decide whether or not you would like to take part in the research. Please read this Information Statement carefully. Before you decide to take part or not, you can ask us any questions you have about the project. You may want to talk about the project with your family, friends or health care worker. If you would like to take part in the research project, please sign the consent form at the end of this information statement. By signing the consent form you are telling us that you:

- understand what you have read
- had a chance to ask questions and received satisfactory answers
- consent to taking part in the project.

We will give you a copy of this information and consent form to keep.

1. What is the research project about?

We are conducting a study about the experiences of parents who are raising a child who has been diagnosed with Infantile Spasms. There has been no research in this area before, but we understand there is a wide range of experiences for people who are raising a baby with a chronic health condition. There are also many stressors associated with caring for a child with a seizure disorder. We are hoping to gain an understanding of the positive and negative experiences that you have had in parenting and seeking healthcare for your son/daughter who
has been diagnosed with Infantile Spasms. We are hoping to recruit up to ten parents who are willing to share their experiences with us.

2. Who is funding this research project?

This project is not receiving any external funding and is being conducted by Kelly O’Mara as a component of the Master of Advanced Social Work course through The University of Melbourne.

3. Why am I being asked to be in this research project?

We are asking you to take part because your child was diagnosed with Infantile Spasms at The Royal Children’s Hospital (RCH) during or before 2011.

4. What does participation in this research involve?

We would like you to take part in a face-to-face interview, as the parent of a child with Infantile Spasms. This will take place at the RCH and can be arranged to coincide with upcoming medical appointments for your child, if this is convenient. Both mothers and fathers are welcome to participate in this study. The interview will take approximately one hour and will be conducted by Kelly O’Mara, the student researcher and social worker at the RCH. The interview will cover areas such as:

- The impact of your child’s diagnosis on your family and yourself.
- Your perception as to whether Infantile Spasms affected your relationship with your child.
- Your experience of care at the RCH and other services.

We will make a digital audio-recording of the interview so we can concentrate on listening to what you have to say rather than distract ourselves by taking notes. After the interview we will transcribe the recording. This means we will make a full written copy of the recording. This transcript will be securely destroyed after we have analysed the data.

5. What are my alternatives to taking part?

Participation in a research project is voluntary. It is your choice to take part in this research. You do not have to agree if you do not want to.

If you give your consent and change your mind, you can withdraw from the project. You do not need to tell us the reason why you want to stop being in the project. If you leave the project we will destroy any information collected from you.

Your decision will not affect any treatment or care your child gets, or your family’s relationship with The Royal Children’s Hospital.

6. What are the possible benefits for me and other people in the future?
We do not expect there to be any direct benefit to you. We believe the information that you share with us will help us to improve our understanding of the needs of families in your position and improve our services.

7. What are the possible risks, side-effects, discomfits and/or inconveniences?

We have framed the interview questions carefully, as we are aware that discussing this subject may be distressing for some families. However, if you would prefer not to discuss any questions asked you do not need to answer them. We are able to arrange a counselling service for you if this is required following the interview. We anticipate that the only inconvenience is the time required for you to participate.

8. What will be done to make sure my information is confidential?

Any information we collect for this research project that can identify you will be treated as confidential. We can disclose the information only with your permission, except as required by law.

All information will be stored securely in the Social Work Department at The Royal Children’s Hospital Melbourne (RCH).

The following people may access information collected as part of this research project:
- The research team involved with this project
- The RCH Human Research Ethics Committee

The information will be re-identifiable. This means that we will remove your name and give the information a special code number. Only the research team can match your name to code number, if it is necessary to do so.

We will keep the information for at least 7 years. After this time, it will be destroyed.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to access and correct the information we collect and store about you. Please contact us if you would like to access the information.

When we write or talk about the results of this project, information will be provided in such a way that you or your family cannot be identified.

9. Will I be informed of the results when the research project is finished?

At the end of the project, we will send you a summary of our findings. This will be of the whole group of participants, not your individual responses. We may also use the findings to publish a journal article or for any relevant conference presentations.

We hope that you will take part in this study. If you wish to do so, please either, Return the attached consent form in the self addressed envelope.
Contact Kelly O'Mara, Neurology social worker on 9345 9300 pager 7550 or via Kelly.omara@rch.org.au.

Yours sincerely,

[Signature]

Kelly O’Mara
Student Researcher
Social Worker
Royal Children’s Hospital

Associate Professor Lou Harms
Deputy Head, Department of Social Work,
School of Health Sciences
University of Melbourne

If you have any concerns and/or complaints about the project, the way it is being conducted or your rights as a research participant, and would like to speak to someone independent of the project, please contact:
Director, Research Ethics & Governance, The Royal Children’s Hospital Melbourne on telephone: (03) 9345 5044.
Appendix 7: Consent form

HREC Project Number: 35032 B

Research Project Title: What are the psychosocial experiences of parents who provide care to an infant diagnosed with Infantile Spasms?


- I have read, or had read to me in my first language, the information statement version listed above and I understand its contents.
- I believe I understand the purpose, extent and possible risks of my involvement in this project.
- I voluntarily consent to take part in this research project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by The Royal Children’s Hospital Melbourne Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007) – including all updates.
- I understand I will receive a copy of this Information Statement and Consent Form.
- I understand that the results from this research may be used in a masters thesis, journal publications and conference presentations.

Participant Name ___________________________ Participant Signature ___________________________ Date _______________ 

Declaration by researcher: I have supplied an Information Letter and Consent Form to the participant who has signed above, and believe that they understand the purpose, extent and possible risks of their involvement in this project.

Research Team Member Name ___________________________ Research Team Member Signature ___________________________ Date _______________ 

I do not wish to participate in this research study. I understand I will not be contacted again in relation to this study.

Participant Name ___________________________ Participant Signature ___________________________ Date _______________ 

Note: All parties signing the Consent Form must date their own signature.
Appendix 8: Interview schedule

Participant age: Age of patient at time of diagnosis:

Participant gender: Age of child at time of interview:

Relationship with patient:

Interview preamble/question:

Thank you for agreeing to be a part of this study. As we discussed on the phone/via email, I am looking to gain an understanding of the experience of parents who are caring for a child who was diagnosed with Infantile Spasms. In your own time, would you like to tell me about your experiences in raising child’s name, who was diagnosed with Infantile Spasms?

Interview prompts:

What was your experience of your child being diagnosed with Infantile Spasms?

What was your experience of receiving medical care for your child at the Royal Children’s Hospital?

What was your experience of receiving support for yourself in relation to your child’s diagnosis at the Royal Children’s Hospital?

Did the Royal Children’s Hospital refer you to any services for you or your child? If so, what was your experience of those services?

Has your child’s diagnosis of Infantile Spasms had an impact on your relationship with your child? If so, what has it been?

Has caring for your child with Infantile Spasms had an impact on other relationships in your life? If so, what has it been?

Is there anything more that you would like to tell me?
Appendix 9: Thank you letter

HREC Project Number: 35032 B
Research Project Title: What are the psychosocial experiences of parents who provide care to a child diagnosed with Infantile Spasms?

Dear Mrs/ Ms NAME

On behalf of the research team for the Infantile Spasms study, we would like to thank you for taking part in our research project. Your contribution, both in time and the personal insights you shared with us, was greatly appreciated.

We asked questions relating to your experience in caring for your child, with a diagnosis of Infantile Spasms. Responses from all participants have now been collated; we are pleased to be able to share the main themes of our results with you below,

- It was common for the diagnosis of Infantile Spasms to be delayed for the children of mothers who participated. This occurred when symptoms of spasms were subtle and difficult to detect, either by parents or health care providers. Whilst a delay in the diagnosis contributed to distress at the time of diagnosis, mothers who participated in this study found the diagnosis of Infantile Spasms to be shocking and upsetting. Mothers also spoke about their experience, either positive or negative, of communication by health professionals at the time diagnosis.

- The children of mothers who participated in our study had ongoing health issues after their child’s diagnosis of Infantile Spasms. These included ongoing seizures and developmental delay. Mothers spoke about how they lived with their child’s ongoing health challenges. It was often distressing for mothers when their child had ongoing impacts from the Infantile Spasms.

- Mothers of children diagnosed with Infantile Spasms accessed support from a variety of sources. Primary sources of support included their partner, or the father of the child with Infantile Spasms, extended family and friends and Early Childhood Intervention Services. Mothers described receiving varying levels of support from these sources. Many mothers of children diagnosed with Infantile Spasms also contributed to furthering knowledge regarding Infantile Spasms, for example through participation in research, donations or supporting other parents through similar circumstances.

If you would like any more information about the study or wish to discuss anything further, please do not hesitate to contact Kelly O’Mara on (03) 9345 9300.

Thank you again for your participation, without your family our project would not have been possible.

Yours sincerely

Principal Investigator
Associate Professor Lou Harms
Deputy Head, Department of Social Work
School of Health Sciences
University of Melbourne

Student Researcher
Kelly O’Mara
Social Worker
Royal Children’s Hospital
Minerva Access is the Institutional Repository of The University of Melbourne

Author/s:
O'Mara, Kelly

Title:
An exploratory study of the psychosocial experiences of parents of infants diagnosed with Infantile Spasms

Date:
2017

Persistent Link:
http://hdl.handle.net/11343/194148

File Description:
An exploratory study of the psychosocial experiences of parents of infants diagnosed with Infantile Spasms

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