COMPLEXITY AND SERVICE PROVISION
IN THE ROYAL CHILDREN’S HOSPITAL’S
FAMILY CHOICE PROGRAM

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Abstract

Due to continued advancement in medical care and technology, the number of children living with complex medical care needs is increasing. Despite this, understandings of this group of children and the programs that support them are limited.

This research aimed to understand the medical and psychosocial complexity of the children and families access the Royal Children’s Hospital, Family Choice Program (FCP) and how this complexity impacts on service provision, including respite and case management services. In doing this, the thesis uses an exploratory approach to understand the documented medical complexity of the children and the documented psychosocial complexity of their families. The thesis explores the service provided within the FCP, specifically the respite and case management services. The thesis considers the relationships between these variables to explore the relationship between medical and psychosocial complexity and the provision of service within the FCP.

The study reviews the files of 65 children accessing the program over a six-month period (October 2014 – March 2015). A clinical data mining approach was used to collect the data, which involved collecting quantitative data from three program-based sources: The Family Choice Program Plan (FCPP), psychosocial assessment, and The Care Manager (TCM) a documentation system used by the program. The descriptive data were explored initially in three categories; medical complexity, psychosocial complexity, and service provision (incorporating respite and case management involvement). This descriptive data was then analysed further through a one-way repeated measures of analysis of variance (ANOVA) test to explore the differences between multiple variables to understand their impact on the dependent variable. Doing this meant it was possible to understand the impact of medical and psychosocial complexity of the provision of service within the FCP.

The thesis provides new understandings and knowledge from an exploratory program-based perspective on the medical complexity of children; reviewing the type and frequency of the medical interventional care needs of the children accessing the FCP. It also provided information about the medical ‘vulnerability’ and/or ‘intensity’ of the child’s care needs in line
with the program definitions. A review of the documented psychosocial complexity of the families of children with complex medical care needs found 27 documented stressors over ten psychosocial themes. The study also found how frequently these psychosocial stressors were documented for the group. Additionally, the study provides understanding of the service provision within the program; including respite and case management involvement. Respite was reviewed by considering the number of children accessing respite and the hours of respite allocated each week. Further, it explored the level of case management involvement provided to the families accessing the program.

This study found a relationship between the documented medical complexity of the children, the psychosocial complexity of their families, the presence of respite and the level of case management involvement provided. This knowledge provided an understanding of how medical and psychosocial complexity impact on service provision within the program, also providing further understanding on children with complex medical care need internationally. The implication of these findings for program research and practice are considered.
Declaration of Authorship

This is to certify that

(i) the thesis comprises only my original work towards the Master of Advanced Social Work,
(ii) due acknowledgement has been made in the text to all other material used,
(iii) the thesis is less than 30,000 works in length, exclusive of tables, maps, bibliographies and appendices

Signed:

Katherine Maughan
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Chapter One – Introduction

This thesis explores service provision within the complicated environment of home-based care for children with complex medical care needs. The thesis is focussed on the Royal Children’s Hospital’s Family Choice Program (FCP), a program I was a member of for over five years. During my time in this program I became interested in how we provide a service for children with complex medical care needs and what impacts on this. In practice, we, as social workers, often identify the increased complexity of families as one of the major impacts on our workload or the level of involvement we have with families. The FCP supports children with complex medical needs, but coming from a social work background, I am also aware of the psychosocial complexities families face. Working in a team that focussed solely on the ‘complex’ I initially became interested in how we define or explain complexity within the program, which led to the development of this study.

The Family Choice Program (FCP)

The FCP provides case management supports, by social workers, to children with complex medical needs across the state of Victoria, Australia. These children are often referred to as the most medically complex children in the state. Their care needs are diverse and may involve life-threatening seizures, complex respiratory conditions which result in the dependence on a tracheostomy or mechanical ventilation (or at times both), continuous dependency on oxygen therapy or many other medical interventions. The FCP provides support for between 100 and 120 children at any one time. Many of these children have rare or less common conditions and diagnoses that result in complex medical interventions, making them eligible for the program. This diversity represents the first challenge in considering case allocation and managing workload; understanding this within the FCP became the initial focus of the thesis.

The children also come from vastly diverse social situations. Their conditions occur across a range of socio-economic groups. This means the FCP case managers face an especially individualised group of families. Further complicating this is the impact of the child’s medical
condition on family functioning. In practice I have observed many families who face additional financial pressures as one parent is unable to work due to the child’s care requirements, additional relationship stress between couples with many resulting in separation, additional stress on accommodation and access to formal supports and many more concerning psychosocial stressors. Further to this, I have worked alongside families working through what seems at times to be a revolving door of grief and loss: loss of the ‘healthy child’; loss around changes to hopes and wishes for the child’s life; loss around further impairment and change in function; as well as the anticipatory grief associated with having a child with a life limiting condition.

In describing the children as medically complex, the experience of practice suggests their families also have psychosocial complexity. In the development of the FCP, questions around managing diversity and complexity were considered. The program, which was developed in 1995 in consultation with the Victorian Department of Human Services, includes the provision of in home respite support, with support workers trained by the program’s nursing staff on the child’s specific care needs. Further, the program covers the cost of funding of medical equipment and the related consumables. Both of these components are considered on an individual basis and take into consideration the intensity and vulnerability of the child’s medical care needs; that is, the child’s medical complexity. Whilst over time some structure has been placed around this to ensure equitable service delivery within budget constraints, the program has kept true to its model of individualised approaches to the provision of respite based on the child’s medical complexity. Understanding this, I became interested in the relationship between respite provision and case management involvement within the FCP.

**Development of the study**

In considering how to explore service provision within the case management team, I considered the components with the greatest impact on care. Firstly, this program is about supporting the medical complexity of the children at home. As this was the key purpose for the development of the program it felt important to include this in the study. Understanding how the program defines complexity was the first challenge. Medical complexity cannot be scored and the diversity of conditions means it is not possible to rank interventions or diagnoses above others.
Instead, this thesis explores medical complexity by the way it is documented within the FCP, by the number of medical interventional care needs the child has and through the use of two key terms ‘vulnerability’ and ‘intensity’. In considering medical complexity I hoped to understand whether it is the children considered to be vulnerable; or whether it is the medically intense children that required greater case management involvement; and if medical complexity affects case management involvement at all.

The second area considered in the study relates to psychosocial complexity. This is the core of the work done by the case management team, making it a vital area of review. Similarly to medical complexity, this is a challenging area to rank or score. Key stressors affect all individuals differently and gauging the impact across the group is near impossible. In considering what psychosocial complexity meant to this group, I considered the number of stressors a family might face. While we know in practice that one stressor may, at times, consume a family, my practice experience told me that it was the families with the greatest number of psychosocial stressors that had the greatest impact on the involvement of the case manager.

The third and final stage I considered in reviewing case management involvement was the allocation of respite. As mentioned above, in home respite is allocated to families based on the medical complexity of the child. Whilst based on a medical need, the coordination of respite is one of the key tasks of the case manager. This includes the recruitment of suitable support workers through various support worker agencies, coordination and facilitation of support worker interviews with families, development of respite rosters alongside the family and support worker agency and the ongoing coordination of respite shift changes. In discussion with FCP case managers, many will discuss the amount of time they spend coordinating respite and the significant impact this has on their workload. Respite also presents as the link between medical and psychosocial support in the program, respite is based on medical need but can be seen as a service that assists in the psychosocial support for families, allowing a break from the caring role. Given this, for this thesis it was important to consider the relationship between medical and psychosocial complexity on the allocation of respite, as well as the impact of level of respite allocated on the involvement of the case manager.
In deciding on the areas to focus on in answering this question of service provision, it is important to consider previous research and knowledge. Staff in the FCP have not completed any research of this nature previously. As discussed in Chapter Two, there is limited research on the provision of service for children with complex medical care needs. Much of the literature to date has focussed on the how we define this population and there is some beginning information on the programs developed to support these children and their families. However, as medical care and technology continue to improve the number of children living with complex medical conditions will only grow, requiring services to adapt to this growing demand and consider how we continue to provide a service to these children and their families. This thesis aims to provide exploratory-based understanding and literature to start a conversation about how these complexities impact on service provision.

**Research aims and questions**

In consideration of these key components of the FCP, this thesis aims to explore the following research questions:

1. What is the documented medical complexity of children accessing the FCP, as documented in the Family Choice Program Plan?
2. What is the documented psychosocial stress experienced by the families of children with complex medical care needs, as documented in the FCP Psychosocial Assessment?
3. How does respite provision relate to medical and psychosocial complexity in the FCP?
4. And, what is documented frequency and duration of case management contact within the FCP? And, how what is the relationship between this and medical complexity, psychosocial complexity and the provision of respite?

In exploring these four key areas, this thesis answers the overarching research question: what is the relationship between medical and psychosocial complexity and the provision of case management and respite services for children and families accessing the FCP?

Within the FCP, not all case managers are qualified social workers, therefore, given the scope of this thesis, a decision was made to focus more generally on a program-based understanding
of what impacts on service provision, including the level of involvement of the case manager, rather than the social work practitioner understanding.

**Study design**

In order to address the research questions, an audit of the files of children (n=65) accessing the FCP from October 2014 to March 2015 was completed. This file audit followed the clinical data mining approach (Epstein, 2010); that is, a retrospective file audit, using routinely collected information and guided by an audit tool. As discussed later in Chapter Three, this approach was applied as it provided an unbiased and non-invasive approach to data collection. Data were analysed using SPSS to understand the impact of medical and psychosocial complexity on service provision within the FCP.

**Overview of the thesis**

The thesis is presented in six chapters, including this introductory one. Chapter Two provides further background to the FCP and an introduction to the existing literature on children with complex medical care needs, the documented psychosocial stressors for their families and the potential impacts on service provision. Chapter Three discusses the research design of the study, including the ethical considerations, method and approach for data analysis. Chapter Four provides an overview of the study results on medical and psychosocial complexity; providing the exploratory data around the description of complexity within the program. Chapter Five provides an overview of the study results around service provision, including the allocation of respite and the level of case management involvement. This chapter then explores how these three areas impact on service provision within the program through the completion of a one-way repeated measure of analysis of variance (ANOVA) test. Finally, Chapter Six includes the discussion of the results in relation to the existing literature, a review of the limitations and implications of the study and a conclusion to the thesis and a final overview of the study.
Chapter Two – Children with Complex Medical Care Needs:  
Background and Literature

The Family Choice Program (FCP) represents one approach to supporting children with complex medical care needs at home. This chapter provides an overview of the key areas of this thesis from the perspectives of international literature, as well as on a program level within the FCP. In addressing the program’s background and the literature guiding the thesis, this chapter discusses the model of care for children with complex medical care needs, the current understanding of medical complexity, followed by the understanding of psychosocial complexity for families of children with complex medical care needs, and finally a consideration for the impact on service provision.

2.1 Models of care for children with complex medical care needs

The Medical Home

The development of alternative and community based models of care has been vital in providing appropriate support to an expanding population of children with complex medical needs. One of the models of care, which has been accepted internationally, is the concept of a medical home. The medical home is seen as being critical to the health care system (Nageswaran, Ip, Golden, O'Shea, & Easterling, 2012) and has been embraced as an official policy by many governments and private business organizations (Stille et al., 2010). As the size and complexity of the population of children with complex medical care needs grows, further service development demands the acceptance of the medical home model (Peter et al., 2011). With existing formal services unable to provide appropriate support within the hospital, policy changes have led to complex medical and nursing care being provided by parents within the family home (Kirk, 2001).

The development of the medical home has been well accepted by paediatricians (Manhas & Mitchell, 2009; Turchi, Gatto & Antonelli, 2007) and literature has documented its various successes and benefits. At a government or organisational level, the medical home model has
been responsible for improving the use of hospital resources. The medical home reduces the average length of stay by children with complex medical care needs (Kelly, Golnik, & Cady, 2008). The improved use of Paediatric Intensive Care Units was also noted (Farasat & Hewitt-Taylor, 2007; Hewitt-Taylor, 2008), as prior to the development of the medical home, children with complex medical care needs whose health and required medical interventions were relatively stable were residing in intensive care units (Farasat & Hewitt-Taylor, 2007). Since the development of the medical home the psychosocial, emotional, educational and development needs of the children have arguably been better met and they continue to receive high quality medical support but in the more suitable environment of the family home (Farasat & Hewitt-Taylor, 2007). From a family centred perspective, the benefits of a medical home for families have also been explored. Family stress was noted to have reduced through the support of the medical home (Kelly et al., 2008). The medical home was also found to have a positive impact on family functioning by decreasing family strain (Farmer, Clark, Sherman, Marein, & Selva, 2005).

Whilst the health system and families benefit from the development of a medical home model, the documented advantages for children with complex medical care needs are also well accepted. Kelly et al. (2008) have suggested that a medical home may improve children’s health. Children receiving supports through a medical home model have been found to be half as likely to experience a delay in necessary medical care (Strickland et al., 2004). The development of a medical home can benefit two groups of children. Firstly, children whose care needs are particularly complex and who frequently present to hospital (Cohen, Friedman, Nicholas, Adams, & Rosenbaum, 2008); and secondly, children who require technical and logistical resources, which are not present in the child’s community or home (Cohen et al., 2008). The medical home model has allowed for improved health delivery to this group of children who require additional resources and time, and is now seen to be the standard in caring from children with complex medical needs (Turchi et al., 2007).

The development of medical home programs has been recognised as an emerging need (Smith, 2011). Given this, there has been an increased emphasis on personalized care, care management, and reduced hospital stays (Law, McCann & O’May, 2011) all of which has improved the service delivery for children with complex medical needs. Whilst the rationale
and justifications for the development of medical home models has been accepted internationally, the implementation and the service frameworks differ between countries and regions and across various health services.

The medical home is a conceptual model which is used to describe a holistic approach to care (Cohen et al., 2008). The characteristics of a medical home generally include comprehensive, coordinated and continuous care, which is compassionate, culturally effective and family centred (Turchi et al., 2007). In order to achieve this level of care, the medical home is seen to adopt a systems approach, which provides a service across the patient’s journey from the hospital to the home (Peter et al., 2011). Several models have been applied in medical home programs Cohen et al. (2008) compare two models, generalist and specialist. The specialist model involves multidisciplinary teams who work with groups of children with clinically common conditions such as cystic fibrosis and cancer. In comparison, the generalist model supports care that is not focussed on specific organs or diseases, but rather the range of chronic childhood conditions. A generalist approach to the medical home aims to avoid the possibility of neglecting the range of needs of children and their families, as can occur through a specialist approach (Cohen et al., 2008).

Despite the various approaches in the application of the medical home model, it is acknowledged throughout the literature that a medical home provides a single point of care (Stille & Antonelli, 2004) and acts as a central hub (Nageswaran et al., 2012) that supports families by providing a one-stop shop (Kelly et al., 2008). To achieve the concept of the one-stop shop or central hub, the roles of the parent in these programs has evolved from the provision of personal care to the performance of clinical procedures (Kirk, 2001).

To assist families in their newfound roles, the medical home model has incorporated the provision of supports to meet family’s needs. One of the key elements of the medical home is the care coordination provided to families (Stille et al., 2010). Care coordination involves the integration of health and other related systems of care (Kelly, Kratz, Bielski, & Mann Reinhart, 2002), and often includes the development of care plans, appointment scheduling, referrals to community resources, provision of information, and linking families to required services and
equipment (Turchi et al., 2007). The role of care coordination can also be to provide families with emotional support and encourage the empowerment of children and their families (Farmer et al., 2005). Another approach, which aims to provide assistance to families caring for children with complex medical needs at home is respite support (Olsen & Maslin-Prothero, 2001). An education approach has been used to train people within the community to care for these children at home providing the family with respite (Kelly et al., 2008). Parents have welcomed and valued the support of respite, explaining this time gave them the opportunity to catch up on sleep, have a bath and recover the required emotional strength (Olsen & Maslin-Prothero, 2001).

To achieve the level of support required by the medical home model, a strong multidisciplinary team is required, in addition to effective partnerships with families (Stille & Antonelli, 2004). In the Farmer et al. (2005) study, the team consisted of a physician, office and administration staff, a nurse, the child and family, and a paid parent consultant. The involvement of primary care physicians in the program is seen to be paramount (American Academy of Pediatrics, 1999) and it is considered essential that the paediatrician embraces the medical home model (Turchi et al, 2007). Given the number of external agencies and systems involved in the care of a child, another important role is that of the key worker (Cohen et al., 2008) or case manager to assist in the care coordination and in meeting the psychosocial needs of the families and children (Kelly et al., 2008). An effective application of the medical home model promotes and develops a team of professionals capable of identifying the strengths and abilities of an individual or family, whilst coordinating resources and complicated information to ensure children with complex medical care needs can be successfully Transitioned from the hospital to home (Kelly et al., 2002).

**The Family Choice Program**

As discussed in Chapter one, the FCP is an example of the medical home model. The program is state-wide within Victoria and funded by the Department of Health and Human Services, with services organised and provided by the FCP team at the Royal Children’s Hospital (RCH). The FCP provides support to the families of children and young people aged 0-17 years with
high levels of complex long-term medical care needs. The FCP has been supporting families since 1995 through a model of case management and home care nursing, and with the provision of trained support workers, respite, equipment and consumables. This enables children to be cared for safely at home and avoids unnecessary admission to hospital.

The team at RCH, with the support of the Department of Human Services, first designed the FCP to facilitate the discharge of a small number of long stay patients. The development of the FCP required a shift in the hospital’s approach to these medically complex children, whose care had previously been considered too complex to be managed anywhere except in a hospital and by trained nurses. Since this time, the program has grown, along with this population of children. The FCP provides support to between 100 and 120 children and their families; this number fluctuates based on the demand for the program with no set limit for the number of children accessing the program. These children and their families are supported by a team of professionals within the program including: a medical director, nurse unit manager, a senior case management liaison, two case management liaisons, three nurse liaisons, six case managers and a team of home care nurses. In addition to the internal team based at RCH, services such as home care nursing and case management are contracted to external service providers. The use of external service providers occurs mostly in the regional areas of the state to ensure these families receive similar access to supports as metropolitan families.

Whilst the FCP has some differences to the medical home models discussed earlier, it shares many of the same aspects. Using the analogy of the iceberg, the FCP aims to service the very tip of the iceberg: meaning the children who qualify for the FCP could be considered amongst the most medically complex in the state. The availability of resources and the decision to provide a service for the children at the very peak of the iceberg means that eligibility for the program is stringent, and given the ever-changing nature of children with complex medical care needs eligibility at a program level is reviewed every sixteen weeks.

As noted in the previous chapter, the group of children with complex medical care needs vary greatly on an individual nature, meaning that whilst these children are grouped together under a definition of ‘complex medical care needs’, many of them have unique or rare conditions and care needs that an individualised approach is required. Through its design, the FCP focusses on the medical interventional care needs of the child rather than the diagnosis of the child’s condition. In considering the implications for practice, this means that the program considers
the individualised impact of the child’s condition rather than considering the ‘usual’ trajectory of the child’s illness or diagnosis.

The FCP relies on a strong multidisciplinary team, including case managers, to implement the model of care. The FCP is based on a medical model to care, meaning many of the staff within the program are of medical or nursing background. However, as discussed above, one of the key elements of the medical home model is care coordination, which is a key aspect of the role of a case manager within the FCP. As discussed further below, many children with complex medical care needs also have complex social situations. The use of case managers within the program aims to address the key elements of care coordination as well providing much needed social and emotional support.

The FCP assists parents in caring for their child within the home environment. In doing this, it considers the main impact having a child with complex medical care needs may have on family life. Children with the level of complexity of those of the FCP often have difficulty accessing mainstream services, even those services developed for children with disabilities. For example, the care needs these children require would be outside of the experience and skill set of an untrained support worker, meaning that these children are unable to access mainstream disability facility or in home respite services. To assist in addressing this, the FCP provides respite with a trained support worker. Respite is funded and sourced through the FCP and selected support workers are then trained individually in the specific care needs of the child. The provision of respite allows families a break from the twenty-four hour care these children require, it aims to give them time to rest and spend time with the child’s siblings or to attend to ‘normal’ aspects of life. Another component of service provision comes through the funding of medical equipment and consumables. Many of the children on the FCP are dependent on medical technology, most of which is costly to purchase and maintain. The FCP provides the funding of medical equipment and consumables, reducing the financial burden placed on families.
2.2 Understanding medical complexity

Defining Medical Complexity

Internationally, children with complex medical care needs have piqued the interest of health researchers. The interest is due to the advancements in medical care and technology, which resulted in an increase in the number of children surviving complex, chronic and previously fatal conditions (San Tucker & Roberts, 1990), an increase which we continue to see in practice today. Improvements in care for children and infants have led to an epidemiologic shift, which led to children living with care needs considered medically complex (Wise, 2004). Continued advances are only likely to result in more neonates and children surviving; as the number of children and infants surviving critical illness, congenital abnormalities and trauma increases, so will the number of children in the community who are dependent on technological support (Murphy, 2008) and who live with complex conditions (Turchi et al., 2007). Home based care for these children with complex medical care needs has also been supported throughout the literature, suggesting that this change is occurring at an international level, across the industrialised world (Olsen & Maslin-Prothero, 2001). The advances in medical care have been met with similar advancements in medical technology allowing for children with complex medical needs to be cared for at home (Manhas & Mitchell, 2009). Specifically, an increasing number of children are living at home receiving technological support, in the form of mechanical ventilation (Dybwik, Tollali, Nielsen, & Brinchmann, 2011). Whilst the impact of medical and technological development on the survival prospects for children with complex medical care needs is generally agreed upon throughout the literature, the diversity of this group makes it a difficult population to define (Farasat & Hewitt-Taylor, 2007).

Commonly, the literature refers to the term ‘Children with Special Health Care Needs’ or ‘Children with Medical Complexity’ who are described as children who have or are at risk of chronic physical, developmental, behavioural or emotional conditions and require medical and other services beyond that of children generally (McPherson et al., 1998 and Kuo et al., 2014). This definition encompasses a broad range of conditions, and with the diverse nature of the chronic conditions experienced by children there is a requirement for an individual approach (Stille & Antonelli, 2004 and Cohen et al., 2008). Kelly et al. (2008) argue that this broad
definition includes children with relatively routine medical needs who may be at risk of developing a chronic condition as well as children currently experiencing complex medical care needs (Kelly et al., 2008).

Bramlett, Read, Bethell and Blumberg (2009) explored the subgroups encompassed in this definition, focusing on the more complex and diverse of the population. These subgroups differ in regards to the expected medical expenditure, the impact of the child’s condition on the family unit and are also based on specific health problems and their known complexity (Bramlett et al., 2009). To qualify as having complex medical care needs, children were required to be experiencing at least one of five health consequences: functional limitations, ongoing prescription medication, ongoing specialist care, ongoing need for additional medical and other support above that of children generally, and the presence of developmental, behavioural and emotional conditions (Bramlett et al., 2009). Another study used a similar approach to identify children with complex medical care needs. Participants in the Farmer et al. (2005) study all experienced a chronic health condition with an expected illness trajectory of twelve or more months and at least one of the following criteria: a biological health condition impacting on one or more body systems, involvement with medical specialists, three or more hospitalisations each with a length of stay greater than fifteen days within the previous twelve months, dependence on medical technology and the ongoing need for the coordination of home based services (Farmer et al., 2005).

Throughout the literature, children with complex medical care needs are explained across various medical, development and psychosocial areas. Within my practice I have noted a need to develop a clear definition based on the practice wisdom of those who work with this group of children. Bringing Children Home (Smith, 2011) explains the population of children with complex medical care needs accessing their medical home service are most commonly experiencing conditions related to respiratory functioning, injuries and peri-natal complications (Smith, 2011). In comparison, the UK Children’s Outreach Service identifies children with complex medical care needs as most frequently being children who also have a diagnosis of Cerebral Palsy, Epilepsy or a developmental delay (Olsen & Maslin-Prothero, 2001).
In practice some services have recognised the common use of technology within the complex medical needs population and have defined children by their dependence on medical technology and medical fragility (Nageswaran et al., 2012; Hewitt-Taylor, 2008). In exploring the role of dependence on technology, as a defining factor for children with complex medical needs, both Farasat and Hewitt-Taylor (2007) and Olsen and Maslin-Prothero (2001) refer to child’s requirement for medical technology as a form of describing the complexity of children needs. Farasat and Hewitt-Taylor (2007) explain that complex medical care needs include long term mechanical ventilation, oxygen therapy, tracheostomy, dialysis and gastrostomy feeding, whereas Olsen and Maslin-Prothero (2001) also include nasogastric tube feeding, intravenous antibiotics and other medications in their definition.

The discrepancies in the definitions of children with complex medical needs have led to the development of a proposed framework by Cohen et al. (2011). This proposed framework consists of four domains to characterize chronic childhood conditions. The first domain is based on the needs of the child and includes medical, therapy and educational needs. Secondly, children are required to have one or more chronic, diagnosed or unknown conditions. Thirdly, to be classified as having complex medical care needs children would typically experience severe functional limitations and may be dependent on medical technology. The final domain defining this population is the utilization of health care and medical services, which is typically more frequent and prolonged than the general paediatric population. Whilst this proposed framework has not been accepted internationally, it provides a definition that encompasses key components recognised as identifiers of children with complex medical care needs.

**Defining medical complexity within the Family Choice Program**

Whilst much of the work discussed above was occurring, the team at the Royal Children’s Hospital, in consultation with the Department of Human Services, was also trying to determine how the program would define medical complexity in the development of the FCP. The FCP depends on the program’s self-designed eligibility tool to assist in determining whether child meets the level of medical complexity required for acceptance onto the program.
Similar to many of the definitions discussed in this chapter, the FCP does not use a diagnostic approach to assess eligibility and medical complexity, meaning it is not the diagnosis of the child’s condition that is assessed; rather the impact of this condition on the child’s care. This approach provides the scope for a more individualised approach to determining medical complexity as children are not grouped based on their diagnosis. In application, this means that the program reviews the medical interventional care needs of the child, that is, tracheostomy dependence, suctioning requirement, seizure management, airway repositioning and other medical interventions. In assessing these medical interventional care needs the program uses two terms ‘vulnerability’ and ‘intensity’.

‘Vulnerability’ refers to the medical fragility of the child, which is the risk of sudden and severe deterioration if the child was not to receive immediate medical intervention. An example of a child considered eligible based on ‘vulnerability’ would be a child who is dependent on a tracheostomy and who does not have an alternate airway, meaning they are unable to breathe effectively through their mouth or nose. A child like this may experience sudden and severe deterioration if their tracheostomy was to become blocked and needed to be either changed or cleared through the use of a suction machine. If the necessary medical intervention this child requires is not received in a timely manner the child will be unable to breathe, which may result in respiratory arrest and subsequently death. Medical ‘intensity’ on the other hand refers to children who have frequent care needs. An example of a child considered eligible for medical ‘intensity’ would be a child who requires frequent airway support. This may be a child who has poor airway management due to poor muscle tone and who has a risk of aspiration. For this child to be considered ‘intense’ they may be requiring airway reposition or suctioning every thirty minutes during the day and multiple times overnight. Whilst likely to still be uncomfortable, this child may not deteriorate as rapidly or severely as the child considered vulnerable, however the intensity of their care needs makes care for this child equally challenging. Further to this, there are also many children on the FCP who are considered both medical ‘vulnerable’ and ‘intense’; these children would be considered the ‘tip of the iceberg’ of medical complexity within the program and the hospital.

While the FCP has done extensive work on the development of the eligibility tool and guidelines, a review of how this impacts on the pattern of the complexity has not been
completed. The present study used the FCP eligibility guideline to develop a file audit to understand the documented medical complexity of the children accessing the program. Completing this provides further understanding of the number of children with specific medical interventional care needs, the frequency of children described as ‘vulnerable’ or ‘intense’, as well as knowledge of the mix of medical complexity within the program, which will add to existing literature on this topic.

2.3 Understanding psychosocial complexity

Psychosocial complexity amongst medical complexity

As highlighted earlier, families and children with complex medical care needs face additional challenges on a daily basis. These children require a higher and more consistent level of care giving, often involving situations that demand immediate intervention (Rosenblum & Ross, 2013). The impact of caring for a child with complex medical care needs may include three main effects on family life: time required, multiple roles of the parent and the impact on the family unit (Whiting, 2014). In considering the effects on time, Whiting (2014) discussed the additional time it takes for the child to complete activities of daily living; in many cases the child is fully dependent on the parent or care giver unlike children of similar age. In addition to supporting the day to day care of the child and the technical care the child requires, further time is spent attending medical appointments and participating in meetings and discussion with professionals involved in the child’s care. The additional time burden experienced by families of children with complex medical care needs results in having less time for social activities and reduced the time parents spent with their other children (Whiting, 2014). Because of the increased care demands these children require many families have at least one parent who has decreased employment to care for the child, leading to increased financial burden for the family (Bramlett et al., 2009).

In caring for a child with complex medical care needs, many parents report having to take on multiple roles (Whiting, 2014). Parents explain that they are required to be the ‘parent’ and the ‘nurse’ for the child (Whiting, 2014; Hewitt-Taylor, 2008). In practice, the parents of children with complex medical care needs are often referred to as being the ‘experts’ in their child’s
care. This may have an impact on parent’s willingness or trust in another caring for the child, in both formal and informal settings (Whiting, 2014). This can be further complicated when the expectations of parents and health professionals are not clear to one another, resulting in conflicting perceptions on the role of the parent in caring for a child with complex medical care needs at home (Kirk, 2001).

The third main effect on the family, as discussed by Whiting (2014) focuses on the impact on the family unit. The concept of the ‘disabled family’ refers to the adverse effects the child’s disability or care needs have on social engagement, employment opportunities and general household life (Whiting, 2014). San Tucker and Roberts (1990) raised similar concerns in discussing the discharge of children with complex medical care needs from the hospital to the home, exploring not only the concerns for the child but also the impact on the family. In some cases, families have reported not feeling completely aware of the long term implications caring for their child would have, not only on themselves but the family unit (Kirk, 2001).

In addition to the increased burden or demands placed on families caring for a child with complex medical needs, literature has also recognised that many of these children also have complex social situations (Kelly et al., 2008). Complex social needs for these families include inadequate housing, lack of transportation, the presence of behavioural issues and in some instances a single caregiver (Kelly et al., 2008). These psychosocial stressors are on top of the provision of home care, care coordination, and financial burden related to the child’s condition and care needs (Kuo, Cohen, Agrawal, Berry & Casey, 2011). Also, literature has highlighted that the more complex the child’s care needs the higher the rate of unemployment or underemployment (Kuo et al., 2011; Kuo et al., 2014; Hewitt-Taylor, 2008), leading to more than half of the families, as documented in Kuo et al. (2011), reporting financial difficulties, suggesting a possible link between medical and psychosocial complexity. Additionally, children with complex medical care needs are also understood to have a higher percentage of unmet health care needs than those without medical complexity (Kuo et al., 2014).

Given that families all adjust and manage in different ways, studies have also considered the level of resilience amongst these families. A study completed by Woodson, Thakkar, Burbag,
Kichler and Nabours (2015) explored the concept of ‘hardiness’ or resilience of families with children with complex and chronic health care needs. A finding of this study linked the age of the child with the level of family ‘hardiness’; the older the age of the child the lower the level of family ‘hardiness’ (Woodson et al., 2015). This may be due to the long term nature of these conditions and the cumulative burden this places on the family unit (Woodson et al., 2015), which is further understood when considering the exhaustion and anxiety facing parents of children with complex medical care needs, which is further exacerbated when the child requires twenty-four hour care and medical monitoring (Dybwik et al., 2011).

Further to the importance of assessing and understanding the psychosocial needs of children and their families, another important factor in addressing psychosocial needs of families is through the provision of practical support. The inclusion of care resources and financial assistance to lessen family stress was seen to be beneficial in supporting the psychosocial needs of families (San Tucker & Roberts, 1990), as was the provision of practical support in the form of respite (Olsen & Maslin-Prothero, 2001). Programs that had incorporated a psychosocial focus into practice found that the majority of care coordination was related to non-medical needs such as referrals to community service, supporting psychosocial concerns, and consulting with educational services (Kelly et al., 2008). Recommendations to support the families of children with complex medical care needs suggest the role of professionals is to provide families with the long term support they require (Manhas & Mitchell, 2009), so they can appropriately care for their child at home.

**Psychosocial complexity within the Family Choice Program**

Knowledge of families of the children accessing the FCP suggests they face similar concerns to those raised throughout the literature. Whilst not currently acknowledged through research, the staff within the FCP recognise the psychosocial complexity of many of the families accessing the program. Farmer et al. (2005) found that programs similar to the FCP were helpful in addressing the psychosocial needs of families by supporting relationships as well as the emotional and behavioural needs of the child. Whilst eligibility for the FCP does not consider the psychosocial issues impacting the child or their family, once accepted onto the program this is considered and there are supports in place to support these issues.
All children and families accessing the FCP are allocated a case manager, who is of social work or similar background. The decision to utilise professionals with social work or similar training was to ensure the complex psychosocial needs as well as the grief and loss these families face were suitably supported. Case managers are involved in the assessment of the psychosocial needs of families accessing the program and provide supports around this. Manhas and Mitchell (2009) suggest there needs to be an emphasis on greater consideration of social and psychological needs by professionals, the involvement of case managers within the program aims to address this. Documentation within the program promotes the sharing of psychosocial information between the team. Case managers are required to complete psychosocial assessments for all new children, reviewed annually throughout the child’s involvement with the program. Psychosocial assessments are made available to all staff on the FCP team, and summaries of these assessment and any updates are documented on the child’s program care plan, the FCP Plan. This document is completed by the case manager and home care nurse with the family every sixteen weeks and is then presented to the programs management team. This process allows for psychosocial concerns to be discussed with the wider team, allowing for a greater knowledge and understanding of the child and family’s situation but also promotes a multi-disciplinary approach to decision making.

While practice wisdom and the literature discussed earlier identify the increased psychosocial complexity of these families, a review of the specific stressors faced by the families of children with complex medical care needs has not been documented in the literature. Given the documented impact having a child with complex medical care needs has on psychosocial function, it was important to understand what these stressors are. The present study reviewed this, providing an understanding of the psychosocial stressors of these families, as documented in the FCP Psychosocial Assessment. Further, the study considers the relationship between medical and psychosocial complexity to understand whether the level of medical complexity or the care needs of the child result in an increased level of psychosocial stress.
2.4 Impact of service provision

Understanding the impact of medical and psychosocial complexity on service provision

Whilst internationally literature is unable to provide a consensus on the definition for children with complex medical care needs, the issues facing this diverse population and the impact of the health system and resources are internationally acknowledged. Children with complex medical care needs are generally recognised as having a greater risk of hospitalisation, intensive care admission and are likely to have increased school absences (Cooley & McAllister, 2004). In addition to the increased hospital utilization, children with complex medical care needs resource use is above that of the general paediatric population (Simon et al., 2010).

As this population continues to grow so does their influence on costs to the health care system (Kuo et al., 2011). The predicted costs to the health care system and the epidemiological changes of this populations represent a challenge for governments to develop community based models of care that are responsive to the needs of these children and their families (Bramlett et al., 2009).

As discussed earlier, the role of a case manager or care coordinator is seen as a vital component of the medical home and is a key role within the FCP. However, literature on the role of the case manager within these models and programs is limited. Moore (2016) discusses the use of case managers for people who are vulnerable, including both children and adults. In the case of the FCP and similar medical home model, this may be linked to the increased pressures of caring for a child with complex medical care needs. As discussed above, the level of care these children require has been seen to relate to further psychosocial stress, causing greater social vulnerability for these families (Moore, 2016). The role of a case manager generally is understood to be a professional who oversees the provision of community based support, for those who may otherwise rely on institutional based care (Thompson, 2005). This is true of the FCP case managers, who implement the program’s model of care, including the provision of respite supports. Further, the role of the case manager is understood in relation to a systems
based approach, where the case manager assists in developing and maintaining systems and linking clients to the systems in place (Jones & May, 1992). Finally, the role of a case manager includes direct clinical intervention with clients, perhaps counselling or other forms of psychosocial support (Jones & May, 1992). Within the FCP, these components of care are all seen within the work of the case manager, who supports families to link with appropriate service systems as well as the direct clinical work, supporting the complex psychosocial needs of the families of children with complex medical care needs.

Whilst the threat of additional burden on the service system has been acknowledged, there has been limited research on how this group of children and their families impact the provision of service within medical home models. As complexity continues to increase, we can assume that the stress on the system will also increase, making it a vital time to consider the impact on the system so we can develop processes to best support these children and their families. Within the FCP, many case managers comment on the increasing complexity of the children and families they support. Whilst numbers of children may not have increased over the last five years, many hypothesise that complexity has. If numbers do not change but complexity does, this brings us back to the question of equity within workloads and how we develop a model that considers the impact of the complexities rather than a balance of caseloads across a team.

Children with complex medical care needs may be considered one of the future challenges to health care systems internationally, one which will only continue to emerge with improvements in medical care and technology. However, whilst this group developing quickly the challenges are still young and within the FCP we are only just starting to see children ‘graduate’ from the program due to their age. As discussed throughout this chapter, research about this group of children and their families is limited and has predominantly focussed on established models of care and the medical definition of children with complex medical care needs.

As the number of children with complex medical care needs continues to grow, it is vital to understand the potential impact on the existing service system. This thesis explores the relationship between the documented medical complexity of the child and psychosocial
complexity of the families and the provision of service within the FCP, including respite and case management involvement. Understanding this will add to the literature by starting a conversation on the complexities of these families and consideration about how services can adapt to continue to support the growing needs of children with complex medical care needs.

Chapter overview

As presented in this chapter, the understandings about children with complex medical care needs and their families are still limited. Whilst the team at RCH were beginning to design the FCP, many others around the world were also considering similar models to care for children at home. Having started as a somewhat reactive approach in response to a growing issue within the international paediatric health care system, years on many are now beginning to review these care models, question how we define medical complexity, as well as understand the psychosocial needs of these families. However, as discussed throughout this chapter the literature around the impact on service provision is limited. This thesis aims to add to this literature and to assist in starting the conversation by understanding how the medical and psychosocial needs of these children and their families impact on service provision.
Chapter Three - Methodology and Research Design

This chapter provides an overview of the ethical and methodological considerations and the research design implemented in the present study. A clinical data mining approach (Epstein, 2010) was selected for the research method. This chapter explores reasons behind selecting this approach and the use of this method to collect data on medical and psychosocial complexity, respite provision and case management involvement. Finally, this chapter provides an overview of the approach to data analysis.

As outlined in Chapter One, the aims of this research were to explore: the documented medical complexity of the children accessing the FCP, the documented psychosocial stressors experienced by the families of children with complex medical care needs, the relationship between respite provision and medical and psychosocial complexity, the level of case management involvement and the relationship between case management involvement, medical complexity, psychosocial complexity and the provision of respite. In exploring these, the study sought to answer the overarching research question: what is the relationship between medical and psychosocial complexity and the provision of respite and case management services for children and families accessing the FCP?

3.1 Ethical considerations

In considering the method for the study, the first consideration was to implement an ethical approach to research, ensuring no harm to the participants (Rubin & Babbie, 2011). This was particularly necessary when completing research with a vulnerable group, including children, and when the researcher was an employee of the program at the time it was being studied. Considering the risks and benefits of undertaking a study of the FCP, its staff and the children and families accessing the program was essential in determining the methodological approach of the study.
Children and families accessing the FCP

Firstly, in considering the risks it was important to consider the indirect subjects of this research: the children and families accessing the program (Hugman, 2010). By applying a data mining approach (Epstein, 2010) to the study, the risks were considered negligible according to the RCH Research Ethics and Governance Department, as all information being collected for the purpose of this thesis was routinely collected and documented, and no direct contact with children and families was required. As I was an employee of the program at the time of data collection, I routinely accessed the information.

Another consideration was the anonymity of the children and families as well as the case managers. To address this, all data were coded to avoid the possibility of individuals being identified (Moyse Steinberg, 2015). Given the relatively small size of the program and the individualised nature of many of the children’s conditions, it was important also to ensure children and families could not be re-identified through the results. To manage this, data have been presented in an aggregate format, rather than as individualised data (Dodd & Epstein, 2012).

Whilst it was important to acknowledge the potential risks of the research, it was also important to consider the benefits to the children and families accessing the program. As discussed in Chapter Two, knowledge is limited on children accessing the FCP, as well as the wider population of children defined as medically complex. This thesis provides additional literature and knowledge of how medical complexity was defined by the FCP through a program-based review. In addition to improved understanding of medical complexity, the research also provided information of the psychosocial stressors families experience and reviewed whether identified stressors correlated with medical complexity. Finally, this thesis considered the impact on the medical complexity of children and the psychosocial complexity of children on service provision. In adding to the knowledge in this way, this thesis will assist programs, specifically the FCP in adapting to the changing needs of children and families to provide the best care possible.
Case managers

Another one of the risks considered for this thesis was the role of the researcher within the program and the relationships with the case managers. As a member of the team there was a risk that this relationship could impact on the interpretation of the data, specifically around the level of case management involvement; this guided the decision to use quantitative data for the study. As noted by Dodd and Epstein (2012), providing a quantitative approach to the study reduces the risk for the interpretation of data to be biased. It was important to review what this meant for the case management team, whose notes were being audited for the study, as the application of a data mining model (Epstein, 2010) relies on the presence of accurate documentation. As discussed, the study focused on the documented medical and psychosocial complexity of children and families, but also reviewed the level of case management involvement. Specifically reviewing the level of involvement of the case management team may have posed a risk of staff feeling their work was being scrutinized (Moyse Steinberg, 2015). It was important to recognize the impact of this. To address this, I provided multiple opportunities to discuss concerns with individual staff. I also ensured that the aims of the study, to improve knowledge of the impact of medical and psychosocial complexity on service delivery, were understood by case managers to eliminate concerns of being critiqued.

Family Choice Program and the Royal Children’s Hospital

In considering the risks and benefits and the design of the study it was necessary to consider the impact on the FCP as well as the RCH at an organisational level. The study applied a data mining approach (Epstein, 2010) to a practice-based research model (Dodd & Epstein, 2012). Undertaking a practice-based research approach to the FCP meant there was a risk of collecting data that may not reflect positively on the program or the organisation. For example, there was a risk that the data collected on the involvement of the case manager may be incorrectly interpreted and used to adjust staffing levels across the program. As mentioned earlier, as an employee of the program it was important to minimise the potential risk to the program and organisation, but provide honest and accurate results. Again, the application of the data mining approach reduced the risk of results being biased by the researcher (Epstein, 2010). However, to manage the risk of negative findings on the program or organisation, it was important that the data provided an exploratory understanding, rather than acting as a program evaluation (Moyse Steinberg, 2015).
3.2 Method

The research followed a data mining approach within an exploratory program based review (Epstein, 2010 and Moyse Steinberg, 2015). It focused on obtaining information and understandings that will be helpful in the future planning of the program and aims to improve the implementation of services. Epstein (2010) describes clinical data mining as a method of practice-based research that is retrospective in approach, realistic in results and non-intrusive to the group being researched.

The FCP has extensive data stored through routine documentation and case records. In using a clinical data mining approach, this previously unexplored resource has been reviewed and re-interpreted to generate new knowledge and understandings (Epstein, 2010). This method has been selected due to its non-intrusive approach and as it allows for the use of pre-existing data without intruding on practice (Epstein, 2010).

This study was approved by the RCH Human research Ethics Committee on 7th July 2014 (HREC No. 34065A). Refer to Appendix One for details.

Data collection methods

The clinical data mining approach for the study involved a review of routinely completed documents for each child registered with the FCP (see inclusion/exclusion criteria on p. 41), including the FCP Plan (FCPP) and the Psychosocial Assessment, as well as a review of case management involvement as documented on The Care Manager system. Figure 1 below provides an overview of the data collected and the relevant data source.

The data collection for this study incorporated three data sources and used a data mining approach. Clinical data mining provided a review of what has occurred (Epstein, 2010), and focuses on what decisions have been made with regard to medical complexity and respite allocation, as well as the level of case management involvement. Four topic areas were explored: medical complexity, psychosocial complexity, respite allocation and case management involvement. As this study is about the records of children accessing the FCP, the
use of terms ‘records’ and ‘children’ will be used interchangeably throughout the thesis to refer to the data collected.

<table>
<thead>
<tr>
<th>Data Collected</th>
<th>Data Source</th>
<th>Abbreviation</th>
<th>File completed by</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of medical interventional care needs and type</strong></td>
<td>Family Choice</td>
<td>FCPP</td>
<td>FCP Nursing staff every sixteen weeks</td>
</tr>
<tr>
<td></td>
<td>Program Plan</td>
<td>FCP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(medical interventions table)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Medical vulnerability and / or intensity</strong></td>
<td>Family Choice</td>
<td>FCPP</td>
<td>FCP Nurse Unit Manager, Nurse Liaison and Consultant every sixteen weeks</td>
</tr>
<tr>
<td></td>
<td>Program Plan</td>
<td>FCP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(Eligibility Statement)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Number and type of psychosocial stressors</strong></td>
<td>FCP Psychosocial Assessment</td>
<td>Psychosocial Assessment</td>
<td>FCP Case Manager an acceptance to the FCP and updated every twelve months</td>
</tr>
<tr>
<td><strong>The number of respite hours allocated and received</strong></td>
<td>Family Choice</td>
<td>FCPP</td>
<td>FCP Case Manager every sixteen weeks</td>
</tr>
<tr>
<td></td>
<td>Program Plan</td>
<td>FCP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(Respite table)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Frequency and duration of case management contacts</strong></td>
<td>The Care Manager</td>
<td>TCM</td>
<td>FCP Case Manager updated with every contact documented</td>
</tr>
</tbody>
</table>

Figure 1
*Overview of sources of data collection*

*Medical Complexity:*

Medical complexity was reviewed in two stages. Reported, medical complexity was considered by exploring the number of medical interventions required for each child i.e. suctioning, CPAP, oxygen therapy, PEG/NGT. The data on the number of medical interventions was drawn from the medical intervention table on the FCPP document (see Appendix Two for audit tool). This
table is completed by the Home Care Nurse every sixteen weeks and is used by the management team when considering and assessing ongoing eligibility and the level of support required.

In addition to exploring the medical complexity from an interventional review, the assessed vulnerability and intensity of children accessing the program was examined. As noted in Chapter Two, children accessing the FCP are defined as ‘vulnerable’ and/or ‘intense’ medically by the medical director and nurse unit manager in conjunction with the team, as per the eligibility criteria. The audit reviewed the number of children described as ‘vulnerable’, ‘intense’ or ‘both’ (see Appendix Two for audit tool). This provided additional information about how this group was defined by the program and is considered in conjunction with the data on the medical interventional care needs, as described above. The data for this stage of the research was also drawn from the FCPP document, using the eligibility statement at the end of the document. This statement is based on the RCH@Home FCP Access Policy, and is determined and documented by the medical director and nurse unit manager, in consultation with the allocated case manager and regional nurse liaison, at the completion of the sixteen week eligibility and service provision review.

Data collected on medical complexity were entered on an excel spreadsheet, indicating the medical interventions the child requires, and assessment of vulnerability and intensity as per the FCPP documents (see Appendix Two for audit tool). The coded data were exported to SPSS for analysis.

*Psychosocial Complexity:*

Psychosocial complexity included the number of psychosocial stressors and the types of stressors, and was collected from the FCP Psychosocial Assessment. This assessment is completed by the case manager for every family, with information collected over several contacts with the child and family. The FCP Psychosocial Assessment covers key themes, including: medical diagnosis; current level of function (includes home environment, equipment needs, self-care, access to community and services); parent/guardian presentation, genogram; summary of social situation; information supports; formal supports; income/financial situation; safety and risk issues; legal status; parent/guardian’s response to the child’s health condition and associated care needs; summary of key psychosocial stressors; and summary of assessment.
This assessment is completed to determine the key psychosocial stressors for the family and to guide the intervention plan for the case manager.

To collect the data the FCP assessment of each child and family was reviewed, with the key psychosocial themes recorded on an excel spreadsheet (see Appendix Three for audit tool). Stressors were recorded under themes such as accommodation, employment or financial stress. The number and type of stressor was entered on an excel spreadsheet. The coded data were exported to SPSS for analysis.

**Respite Allocation:**

Information regarding respite support provided through the FCP has been drawn from the FCPP, using the respite table. Completed by the case manager, each FCPP contained details on the level of respite that has been approved and is being accessed for each child. The completion of this table is routine practice for all case managers and is presented and discussed every sixteen weeks at the FCP review. A review of all internally case managed respite tables was used and separated into five-hour groups i.e. 1-5 hours, 6-10 hours etc.

Data on respite allocation was entered on a spreadsheet, stating whether the child has respite allocated, if the family accesses all available respite, and the number of hours of respite used weekly (see Appendix Four for audit tool). This was then totaled across the sample group and averages formed. The coded data were exported to SPSS for analysis.

**Case Management Involvement:**

The level of case management involvement was sourced through an audit of the documentation database, The Care Manager (TCM). Staff members are required to complete all documentation on TCM. All entries require the duration of contact to be recorded and are identified as either direct client contact or indirect contact. Within the FCP and for this thesis, direct contact refers to any direct contact with a child or family, whereas indirect contact refers to any contact outside of this, for example with an external service provider or a member of the multidisciplinary team. To understand the level and provision of case management involvement, an audit of all internal case managers’ documentation was completed to determine the frequency and duration of both direct and indirect contact for each child in the
sample group. This was completed over a six-month period to provide an average monthly level of intervention.

Data on case management involvement was entered on an excel spreadsheet, and indicated the frequency and duration for both direct and indirect contact per child for each month of the six-month period (see Appendix Five for audit tool). A summary of the six-month period was included to average out the level of case management involvement over this period. The coded data were exported to SPSS for analysis.

Data analysis

As outlined above, the data generated through this research were quantitative. The quantitative data were coded and entered into SPSS (version 23) for analysis. Analysis was initially univariate. This provided the descriptive data set for the sample (Rubin & Babbie, 2011). In consultation with the University of Melbourne Statistical Consulting Centre, it was determined that the sample size was representative of the program.

Where appropriate, throughout the thesis, a review of the correlation and statistical significance of the results was reviewed using the Pearson’s Correlation Coefficient. For this thesis, a p value of less than 0.05 has been considered statistically significant.

The descriptive data were explored initially in three categories: medical complexity, psychosocial complexity, and service provision (incorporating respite allocation and case management involvement). Firstly, data analysis on medical complexity considered the number of medical interventional cares needs per child, the type and frequency of these care needs, and the number of children described a ‘vulnerable’ and/or ‘intense’. Following this, the relationship between the number of medical interventional care needs and the description of ‘vulnerable’ and/or ‘intense’ was considered. Secondly, psychosocial complexity was explored the type and frequency of documented psychosocial stressors, the data analysis then reviewed the relationship between psychosocial stressors and the age of the child. Finally, the analysis of psychosocial complexity explored the relationship between the data collected on medical complexity and psychosocial complexity.
Data analysis at this point in the thesis was completed as descriptive data only. In consultation with the University of Melbourne Statistical Consulting Centre, it was agreed that as the data collected on medical and psychosocial complexity was for descriptive purposes only, further statistical analysis was not necessary. Also, as both medical and psychosocial complexity considered documented information only and it was not within the scope of the thesis to determine the weighting of complexity any more thoroughly any further statistically analysis could produce inaccurate results.

The third component of the data analysis explored service provision. Starting with respite allocation, this thesis explores the number of children with respite allocated, the number of children utilizing all allocated respite and the numbers of hours of respite received each week. Relationships between respite allocation and the age of the child, medical complexity and psychosocial complexity were then explored. Continuing under the service provision data, the frequency and duration of case management involvement over a six-month period was also explored. Similar to respite allocation, the relationship between case management involvement and the age of the child, medical complexity, psychosocial complexity and respite allocation were explored.

Again, the data collected on respite allocation and case management involvement was for descriptive purposes only. Therefore, following consultation from the University of Melbourne Statistical Consulting Centre, it was determined that further statistical analysis of these variables should not be completed and was not within the scope of this thesis.

After a review of these three categories, an analysis was conducted of the relationship between all variables, through a univariate analysis of variance to provide the estimated marginal means. Further consultation with University of Melbourne Statistical Consulting Centre indicated that it was feasible to complete a one-way repeated measures of analysis of variance (ANOVA) test. ANOVA statistics test for differences between multiple variables to understand their impact on the dependent variable (Allen, & Bennet, 2012). Completing the ANOVA tests explored the impact of medical and psychosocial complexity and respite allocated on the provision of case management services. This comparison assisted in determining how each factor impacted of the provision of service through the FCP. Based on consultations with University of Melbourne Statistical Consulting Centre, the power of the sample was determined to be sufficient to complete this level of statistical analysis.
Inclusion and exclusion criteria

At the time of data collection (06.01.2014), 116 children were receiving supports through the FCP. With new referrals discussed weekly, the number of children accessing the program varies slightly. The data mining sample was selected based on the active client numbers on a set date (06.01.2014), and included all children who had been on the FCP for six months or more to ensure sufficient numbers for data mining (n=65). As the review of case management service delivery involved data-mining, the frequency and duration of case management involvement, the selection of a six-month period (October 2014 to March 2015) provided the opportunity for an average to be generated, thereby taking into consideration that case management involvement may vary between months.

Children whose case management was provided by an agency external to the RCH were excluded from the study due to differences in documentation and provision of service.

Chapter overview

This chapter has provided an overview of the research design including the methodological considerations of the study. The research design was chosen to be non-intrusive to the families and children accessing the program by exploring retrospective data that is routinely collected by the FCP team. By completing the study in this way, the aim was to give an unbiased understanding into the FCP.
Chapter Four – Exploring Medical and Psychosocial Complexity

This chapter describes the medical complexity of the children on the program, exploring data collected from the children’s files on the number of medical intervention care needs they require and the assessed intensity and/or vulnerability of their medical care needs. It describes the results of the thematic analysis of psychosocial assessments to explore documented psychosocial complexity.

4.1 Medical complexity

As discussed in Chapter Three, medical complexity was reviewed in two ways: by exploring the number of medical interventional care needs each child required and by reviewing their documented reason for eligibility and the use of the terms ‘vulnerable’ and/or ‘intense’.

4.1a Demographics

The age of the children whose files were reviewed in the study ranged from one to eighteen years of age.

As shown in Table 1 (overleaf), most of the children on the program were aged one to four years (40%), with four years of age being the most frequently represented. The second most frequently represented group was those between twelve and eighteen years.

The majority of the children were male (61.5%). Whilst exploration around the reason behind this was not undertaken in this thesis, this may be due to the greater number of genetic conditions that affects males compared to females.
### Table 1

<table>
<thead>
<tr>
<th>Years of Age</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - 4</td>
<td>26</td>
<td>40</td>
</tr>
<tr>
<td>5 - 11</td>
<td>18</td>
<td>27.7</td>
</tr>
<tr>
<td>12 - 18</td>
<td>21</td>
<td>32.3</td>
</tr>
<tr>
<td>Total</td>
<td>65</td>
<td>100</td>
</tr>
</tbody>
</table>

#### 4.1b Medical interventional care needs

As shown in Table 2 (overleaf), the number of medical interventions ranged from one to seven. Many children in the study had more than one interventional care need, with the greatest percentage of children being in the group with two interventional care needs (32.3%). The majority of children had between two to four interventional care needs (69.2%). This result provides great insight into the level of care these children require, with parents or care givers expected to manage multiple care needs and potential multiple pieces of equipment. Given this, it is reasonable to expect that children with a high number of medical interventional care needs have a high level of medical complexity.

In considering the types of medical interventional care needs, oximetry monitoring was the most frequently recorded, with 61.5% of children with this care need documented as shown in Table 3 (overleaf). This intervention is often required in addition to other interventional care needs, accounting for the majority of children having at least two interventional care needs.

The second most commonly documented intervention was gastrostomy or nasogastric feeding (55.4%). Eligibility for the program does not solely consider feeding, however this may be considered for children with multiple care needs with high intensity; therefore, all children with gastrostomy or nasogastric feeding will also have at least one other medical interventional care need.
Table 2

**Total number of medical interventional care needs per child**

<table>
<thead>
<tr>
<th>Number of Medical Intervenional Care Needs</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>6</td>
<td>9.2</td>
</tr>
<tr>
<td>2</td>
<td>21</td>
<td>32.3</td>
</tr>
<tr>
<td>3</td>
<td>13</td>
<td>20.0</td>
</tr>
<tr>
<td>4</td>
<td>11</td>
<td>16.9</td>
</tr>
<tr>
<td>5</td>
<td>8</td>
<td>12.3</td>
</tr>
<tr>
<td>6</td>
<td>5</td>
<td>7.7</td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Total</td>
<td>65</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 3

**Medical interventional care needs by type**

<table>
<thead>
<tr>
<th>Medical Intervention</th>
<th>Frequency</th>
<th>Percentage with Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oximetry Monitoring</td>
<td>40</td>
<td>61.5</td>
</tr>
<tr>
<td>Percutaneous Endoscopic Gastrostomy (PEG) / Percutaneous Endoscopic Jejunostomy (PEJ) / Nasogastric Tube (NGT) / Nasojejunal Tube (NJT) Feed</td>
<td>36</td>
<td>55.4</td>
</tr>
<tr>
<td>Tracheostomy Dependence</td>
<td>26</td>
<td>40</td>
</tr>
<tr>
<td>Other</td>
<td>23</td>
<td>35.4</td>
</tr>
<tr>
<td>Suctioning Requirement</td>
<td>16</td>
<td>24.6</td>
</tr>
<tr>
<td>Oxygen Dependence</td>
<td>16</td>
<td>24.6</td>
</tr>
<tr>
<td>Bi-level Positive Airway Pressure (BIPAP) / Continuous Positive Airway Pressure (CPAP)</td>
<td>14</td>
<td>21.5</td>
</tr>
<tr>
<td>Seizure Management</td>
<td>14</td>
<td>21.5</td>
</tr>
<tr>
<td>Airway Positioning</td>
<td>8</td>
<td>12.3</td>
</tr>
<tr>
<td>Prostacyclin</td>
<td>5</td>
<td>7.7</td>
</tr>
<tr>
<td>Mechanical Ventilation</td>
<td>3</td>
<td>4.6</td>
</tr>
<tr>
<td>Total Parenteral Nutrition (TPN)</td>
<td>3</td>
<td>4.6</td>
</tr>
<tr>
<td>AIRVO Dependence</td>
<td>2</td>
<td>3.1</td>
</tr>
<tr>
<td>Epidermolysis Bullosa (EB) Care</td>
<td>2</td>
<td>3.1</td>
</tr>
</tbody>
</table>
The two least frequently documented care needs within the sample were EB care and AIRVO dependence. EB care relates to the care of children with Epidermolysis Bullosa. This is a particularly rare condition and only children with an especially high level of intensity are eligible for the program. Children in this category will most likely only have this one interventional care need, which was supported in the results. AIRVO dependence relates to the use of a specific piece of medical equipment that delivers high flow oxygen. At the time of data collection, this was a relatively new piece of technology being used at home for these children, therefore explaining the low frequency.

4.1c Medical vulnerability and intensity

In addition to the review of the number and type of interventional care needs the child requires, this analysis of medical complexity also included the children’s eligibility for the program due to the ‘vulnerability’ or ‘intensity’ of their care needs.

As shown in Table 4, the majority of children were documented as being medically ‘vulnerable’ (52.3%), meaning they were considered to be at risk of sudden severe deterioration. Whilst in the general sense of the word ‘vulnerable’ all of the children accessing the program would be considered ‘vulnerable’ in comparison to the general population, for the FCP this relates to the child’s relative vulnerability based on program eligibility. Based on practice knowledge of the FCP this result is not surprising as the eligibility for the program requires a high level of ‘vulnerability’ for a child to be accepted onto the program.

The number of children considered to be medically ‘intense’ (13.8%) by the FCP was the lowest represented group. Again, whilst most of these children would be consider ‘intense’ when compared to the general population, this classification is relative to the group of children accessing the program. A lower number of children documented as ‘intense’ only is not surprising from a program perspective. This is because of the challenges in confirming the intensity of a child’s care needs. ‘Intensity’ refers to the number of medical interventions the
child requires throughout a day, something which can change regularly and is therefore harder to define.

Children considered to be both ‘vulnerable’ and ‘intense’, meaning they had frequent medical interventions and were also at risk of sudden severe deterioration, were the second most frequently represented (16.9%). Children in this ‘both’ category could be considered the most medically complex of the sample.

While staff members are asked to assess as either ‘vulnerable’ or ‘intense’ some were not using this terminology. Given this, 16.9% of files were unable to be coded and they make up the ‘neither’ category. This group represents both inconsistencies in documentation, but also includes children who may no longer be eligible for the program and are currently being transitioned to other, more appropriate, services.

Table 4

<table>
<thead>
<tr>
<th>Medical Eligibility Category</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vulnerable</td>
<td>34</td>
<td>52.3</td>
</tr>
<tr>
<td>Intense</td>
<td>9</td>
<td>13.8</td>
</tr>
<tr>
<td>Both Vulnerable and Intense</td>
<td>11</td>
<td>16.9</td>
</tr>
<tr>
<td>Neither Vulnerable nor Intense</td>
<td>11</td>
<td>16.9</td>
</tr>
</tbody>
</table>

These two components of data collection, medical interventional care needs and medical vulnerability and intensity, were reviewed together to establish a deeper understanding of the documentation of medical complexity of the children. In considering the number of medical interventional care needs, there was no significant variation between the categories of ‘vulnerable’, ‘intense’, ‘both’ or ‘neither’ as seen in Figure 2. Each category had a similar range of medical interventional care needs, with intensity being the only category to include the full range from one to seven medical interventional care needs. The greatest difference in medical interventional care needs can be seen between the ‘vulnerable’ and ‘both’ categories with a difference of two care needs between the averages.
Figure 2

*Medical interventional care needs by medical vulnerability and/or intensity*

The type of interventional care need in each category, as shown in Table 5, indicates a more complex finding. In considering the ‘vulnerable’ category, children in this group were mostly those with oximetry monitoring, gastrostomy and/or nasogastric feeds, and tracheostomy dependence. As mentioned above, oximetry monitoring generally supports another interventional care need, and is used to alert carers to a sudden deterioration in the child’s oxygen saturations, heart rate or respiratory rate. Tracheostomy dependence was an expected high frequency group within the ‘vulnerable’ category given the nature of their condition; many children have a tracheostomy inserted due to structural issues with their trachea. Many of these children do not have an alternate airway, meaning they are completely dependent on the tracheostomy to maintain a patent airway. These children can experience sudden severe deterioration if their tracheostomy tube becomes blocked or dislodged.
The ‘intense’ category showed a different group of medical interventional care needs, with the most frequently represented being: gastrostomy/nasogastric feeds, suctioning, seizure management and other. The other category included care needs that are outside of the available options on the program’s medical intervention table, perhaps indicating a particularly rare condition or new interventional care need that has not previously been noted by the program. This included chest physiotherapy and dependence on the cough assist machine. Eligibility for the program for children with suction or seizures relates to the number of times the carer is required to perform the intervention in a 24-hour period. Therefore, to be eligible for the program with these care needs, a child needs to be considered ‘intense’; so it is expected that these care needs are the most frequently represented in this group.

The ‘both vulnerable and intense’ category showed a combination of the most frequently represented care needs from both the intensity and vulnerability category. The most frequently represented care needs within the ‘both’ category were gastrostomy / nasogastric feeds, oximetry monitoring, seizure management and suctioning. Given children in this category are

<table>
<thead>
<tr>
<th>Interventional Care Need</th>
<th>No. Vulnerable</th>
<th>No. Intense</th>
<th>No. Both</th>
<th>No. Neither</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tracheostomy Dependence</td>
<td>17</td>
<td>2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Suctioning Requirement</td>
<td>2</td>
<td>4</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Airway Positioning</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Mechanical Ventilation</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>AIRVO Dependence</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>BIPAP/CPAP</td>
<td>9</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Oximetry Monitoring</td>
<td>23</td>
<td>3</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Oxygen Dependence</td>
<td>7</td>
<td>2</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>TPN</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Prostacyclin</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Seizure Management</td>
<td>2</td>
<td>4</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>EB Care</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>PEG/PEJ/NGT/NJT</td>
<td>14</td>
<td>5</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
<td>6</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>
considered to be ‘both vulnerable and intense’ it was expected that the types of interventional care needs would cover those in each of the first two categories.

Finally, the ‘neither vulnerable nor intense’ category showed a range of interventional care need types, suggesting these children are either ineligible and are being transitioned from the program, or this was an inconsistency in documentation. Children on TPN only appeared in the ‘neither’ category, perhaps suggesting confusion or uncertainty around how to categorise these children. These issues are explored further in Chapter Six.

4.2 Psychosocial complexity

‘Psychosocial complexity’ in this study related to the stressors for families as documented by case managers. A review of each child’s psychosocial assessment was completed, collecting key categories of psychosocial stressors which have been grouped into themes.

4.2a Documented psychosocial stressors

A total of twenty-seven documented psychosocial stressors were identified (Table 6 - overleaf), which were coded into ten key themes.

The number of stressors identified and the variety of these stressors provides insight into the complexity of the case management role within the program. At any time a case manager may be required to respond to or provide support around any one of the stressors and is therefore required to demonstrate a high level of social understanding and social work skill base.
Table 6  
**Documented psychosocial stressors**

<table>
<thead>
<tr>
<th>Themes and sub-themes</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adjustment Reaction</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjustment to Diagnosis</td>
<td>43</td>
<td>66.2</td>
</tr>
<tr>
<td>Adjustment to care needs</td>
<td>17</td>
<td>26.2</td>
</tr>
<tr>
<td>Grief and Loss</td>
<td>10</td>
<td>15.4</td>
</tr>
<tr>
<td><strong>Supports - Informal / Formal</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Formal Supports</td>
<td>17</td>
<td>26.2</td>
</tr>
<tr>
<td>Informal Supports</td>
<td>35</td>
<td>53.8</td>
</tr>
<tr>
<td>Social Isolation</td>
<td>12</td>
<td>18.6</td>
</tr>
<tr>
<td><strong>Family Structure / Dynamics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single Parent</td>
<td>13</td>
<td>20</td>
</tr>
<tr>
<td>Relationship Stress</td>
<td>14</td>
<td>21.5</td>
</tr>
<tr>
<td>Relationship Breakdown</td>
<td>9</td>
<td>13.8</td>
</tr>
<tr>
<td>Family Conflict</td>
<td>5</td>
<td>7.7</td>
</tr>
<tr>
<td><strong>Parental Health</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental Mental Health</td>
<td>27</td>
<td>41.5</td>
</tr>
<tr>
<td>Parents Physical Health</td>
<td>9</td>
<td>13.8</td>
</tr>
<tr>
<td><strong>Siblings</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact on Sibling</td>
<td>4</td>
<td>6.2</td>
</tr>
<tr>
<td>Siblings Mental Health</td>
<td>4</td>
<td>6.2</td>
</tr>
<tr>
<td>Siblings Health / Sibling with Disability</td>
<td>6</td>
<td>9.2</td>
</tr>
<tr>
<td><strong>Accommodation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accommodation</td>
<td>15</td>
<td>23.1</td>
</tr>
<tr>
<td><strong>Financial / Employment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td>23</td>
<td>35.4</td>
</tr>
<tr>
<td>Financial</td>
<td>33</td>
<td>50.8</td>
</tr>
<tr>
<td><strong>Legal / Child at Risk</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Department of Human Services (DHHS) Child Protection Involvement</td>
<td>2</td>
<td>3.1</td>
</tr>
<tr>
<td>Family Violence</td>
<td>4</td>
<td>6.2</td>
</tr>
<tr>
<td>Legal Involvement (not DHHS)</td>
<td>4</td>
<td>6.2</td>
</tr>
<tr>
<td><strong>Access to Services</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transport</td>
<td>4</td>
<td>6.2</td>
</tr>
<tr>
<td>Geographical Location of Family</td>
<td>5</td>
<td>7.7</td>
</tr>
<tr>
<td>Transition to Adult Services</td>
<td>3</td>
<td>4.6</td>
</tr>
<tr>
<td>Non English Speaking Background (NESB)</td>
<td>7</td>
<td>10.8</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioural Issues for the child</td>
<td>6</td>
<td>9.2</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>7.7</td>
</tr>
</tbody>
</table>
As outlined in Table 6, a little over two thirds of records indicated families identify adjustment to diagnosis (66.2%) as a key psychosocial stressor. Given the complexity of these children’s diagnoses, a result indicating the high level of adjustment is not surprising, however as many of the children are potentially years from their initial diagnosis this does suggest a level of ongoing adjustment throughout the child’s life. This will be discussed in more detail in Chapter Six. Around half of the records indicated information supports and financial stress as a key psychosocial stressor, which was closely followed by parental mental health and employment. The least frequently documented stressors included: DHHS Child Protection involvement (3.1%), transition from Paediatric to adult services (4.6%), Family Violence (6.2%), impact of sibling (6.2%), transport (6.2%) and legal involvement (not DHHS) (6.2%).

When considering the documented stressors by theme, it is again clear to see that issues around adjustment reactions, including adjustment to diagnosis, adjustment to care needs and grief and loss, are the most noted source of psychosocial stress of the group. Other themes with high representation across the group were supports, family structure, financial/employment and parental health. The high frequency of results around adjustment reactions will be explored further in Chapter Six, as will these other themes.

As demonstrated in Figure 3, the number of stressors per child documented ranged from one to eleven, with the highest frequency being at five and six stressors. Whilst not comparable to the general population, as discussed in Chapter Two, this result is concerning but not unexpected; it indicates that in addition to the complex medical care needs these children experience, many also face complex social situations.
Table 7 (overleaf) shows that 61.5% of the sample had over five or more psychosocial stressors documented, at the higher end of psychosocial complexity.

Whilst the analysis considered the number of psychosocial stressors documented for each child and family, it could not consider the level of impact each stressor had on the family. In considering this, it is not possible to establish whether those with high number of documented stressors experienced greater impact of psychosocial stress than those in the lower group (i.e. four or fewer psychosocial stressors). Also, it is important to consider the impact the case managers have on these results. These issues are considered further in Chapter Six.
Table 7

*Total number of psychosocial stressors per child*

<table>
<thead>
<tr>
<th>Number of Stressors</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>6</td>
<td>9.2</td>
</tr>
<tr>
<td>2</td>
<td>5</td>
<td>7.7</td>
</tr>
<tr>
<td>3</td>
<td>7</td>
<td>10.8</td>
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<td>7</td>
<td>10.8</td>
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<td>5</td>
<td>11</td>
<td>16.9</td>
</tr>
<tr>
<td>6</td>
<td>10</td>
<td>15.4</td>
</tr>
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<td>7</td>
<td>6</td>
<td>9.2</td>
</tr>
<tr>
<td>8</td>
<td>7</td>
<td>10.8</td>
</tr>
<tr>
<td>9</td>
<td>5</td>
<td>7.7</td>
</tr>
<tr>
<td>11</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Total</td>
<td>65</td>
<td>100.0</td>
</tr>
</tbody>
</table>

4.2b Psychosocial stressors and the age of the child

The relationship between the age of the child and the number of documented psychosocial stressors was also explored, and is shown in Figure 4 (overleaf).

The review of age and documented psychosocial stress showed a weak positive correlation ($R^2=0.056$, $p=0.058$) indicating that there is not a direct relationship between these variables. In considering the population of children at pre-school age, less than five years, the number of psychosocial stressors ranged from one to nine stressors per family. Many families with children under five years of age had between three to six psychosocial stressors, similar to the spread across the broader group.
Children with the greatest number of documented stressors, eight and above, were generally between the ages of seven and eighteen years, with only two exceptions to this at two and three years of age. This may relate to the increased burden of care for families as children grow, especially about the ongoing impact to employment, financial stress and access to support.

4.2c Medical complexity and psychosocial complexity

As discussed in the Chapter Three, this study explores two aspects of complexity within the FCP: medical complexity of the child and psychosocial complexity of the family. Figure 5 explores the possible relationship between these two variables. In considering the number of medical interventional care needs the child requires, Figure 5 shows that there is no direct
relationship between the number of documented psychosocial stressors and the number of interventional care needs the child requires ($R^2 = 0.044$, $p=0.092$).

Figure 5

*Medical interventional care needs and psychosocial stress*

Similar to above, Figure 6 considers the relationship between medical complexity and psychosocial stress, this time exploring the recorded medical vulnerability and/or intensity of the child. As seen in Figure 6, psychosocial stress did not appear to have a direct relationship to the assessed vulnerability or intensity of the child.
Children considered to be medically ‘vulnerable’ ranged from having one to nine psychosocial stressors recorded, with an average of five documented stressors per child. The ‘intense’ group had a slightly smaller range, from two to eight stressors, but again had an average of five documented stressors per child. This is consistent with the rest of the sample. The group of children considered ‘both medically vulnerable and intense’ had a range that started slightly higher than the previous two groups at three psychosocial stressors, but reached the same maximum as the ‘vulnerable’ group of nine documented stressors. The average number of stressors for the ‘both medically vulnerable and intense’ group sat slightly higher at six stressors. However, in considering the rest of the group this was the second highest represented group so is not a surprising result. Finally, the group of children in the ‘neither’ category, meaning they were not documented as either ‘vulnerable’ or ‘intense’ medically, had the greatest range in psychosocial stressors from one to eleven stressors. Despite the large range in documented stressors across this group, the average number of stressor was five, consistent with the group as a whole.
Whilst medical complexity in both aspects, interventional care needs and medical vulnerability showed some variation in psychosocial stress, there does not appear to be a relationship between the two areas of complexity.

**Chapter overview**

This chapter has provided an overview of medical and psychosocial complexity for children and families in the FCP. Medical complexity was explored in relation to the number of medical interventional care needs the child requires and whether they are considered medically vulnerable and/or intense. Psychosocial complexity was explored in relation to the type and frequency of documented psychosocial stressors. This chapter then explored the relationship between these two complexities. Whilst the results did not indicate a direct relationship between medical and psychosocial complexity, the findings do assist in describing the high level of complexity experienced by these children and their families. In Chapter Five these results will be reviewed further, considering the relationship between medical and psychosocial complexity and service provision.
Chapter Five – Exploring Service Provision

As described in Chapter Three, service provision has been conceptualised in this thesis as respite allocation and case management involvement. In exploring service provision, the data provide a description of the respite received by children on the FCP and the level of case management involvement. This chapter explores potential relationships between this service provision and the medical and psychosocial complexity of the children and their families.

5.1 Respite

As noted in Chapter Two, in-home respite within the program is allocated depending on the medical and psychosocial needs of the child and family. Not all children on the program have respite allocated, and of those with respite allocated, not all families choose to access any or all of their allocated hours. In reviewing respite, the number of children with respite allocated, the number using all allocated hours, and the number of hours received by each child, were examined. As discussed in Chapter Three, this was used to explore relationships between respite and the medical complexity of the child and psychosocial complexity of the family.

Most children (73.8%) were allocated respite, as shown in Table 8. Respite may not be allocated for numerous reasons but it is often linked with the medical care needs of the child. For example, if a child requires medical interventions that are considered to be too complex to be taught to a support worker, in-home respite will not be allocated as the child’s health is considered to be too unpredictable or too complex.

<table>
<thead>
<tr>
<th>Respite Allocated</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>48</td>
<td>73.8</td>
</tr>
<tr>
<td>No</td>
<td>17</td>
<td>26.2</td>
</tr>
<tr>
<td>Total</td>
<td>65</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 8
Number of children with respite allocated
Table 9 shows the number of children who used all their allocated hours. The children who were not allocated respite, as mentioned above, are included also in the group of children using all allocated hours to avoid inflating the results around the number of children and families who were not receiving their complete level of support as assessed by the FCP. Of the 65 children included in the study a small percentage of 12.3% were not using all allocated hours. This may be at the family’s request or may be due to vacant shifts which may be a result of delays or difficulty in recruiting support workers.

Table 9  
**Number of children using all allocated respite hours**

<table>
<thead>
<tr>
<th>Using all Allocated Respite Hours</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>57</td>
<td>87.7</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
<td>12.3</td>
</tr>
<tr>
<td>Total</td>
<td>65</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Children in the study received from zero to over forty hours of respite per week. As outlined in Table 10 respite hours were broken down into five-hour groups. The most frequently represented group was those with zero hours respite each week, however, as noted above, this group includes the seventeen children without respite allocated.

Table 10  
**Total number of hours of respite received each week**

<table>
<thead>
<tr>
<th>Hours of Respite Received each Week</th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 hours respite per week</td>
<td>21</td>
<td>32.3</td>
<td>32.3</td>
</tr>
<tr>
<td>1-5 hours respite per week</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>6-10 hours respite per week</td>
<td>5</td>
<td>7.7</td>
<td>40.0</td>
</tr>
<tr>
<td>11-15 hours respite per week</td>
<td>11</td>
<td>16.9</td>
<td>56.9</td>
</tr>
<tr>
<td>16-20 hours respite per week</td>
<td>12</td>
<td>18.5</td>
<td>75.4</td>
</tr>
<tr>
<td>21-25 hours respite per week</td>
<td>5</td>
<td>7.7</td>
<td>83.1</td>
</tr>
<tr>
<td>26-30 hours respite per week</td>
<td>5</td>
<td>7.7</td>
<td>90.8</td>
</tr>
<tr>
<td>31-35 hours respite per week</td>
<td>4</td>
<td>6.2</td>
<td>96.9</td>
</tr>
<tr>
<td>36-40 hours respite per week</td>
<td>1</td>
<td>1.5</td>
<td>98.5</td>
</tr>
<tr>
<td>40 plus hours respite per week</td>
<td>1</td>
<td>1.5</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>65</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>
Of the children receiving respite, all were receiving six hours or above per week. This may be due to program guides for allocating respite, but also relates to the challenges of recruiting staff for less than six hours per week of work. For the children receiving respite, the highest represented group was those with sixteen to twenty hours of respite per week, closely followed by those with eleven to fifteen hours per week. On allocating respite at the time of eligibility, many children are initially allocated respite packages of between twelve to thirty hours so this result is not surprising. However, those with higher levels of respite per week (i.e. thirty hours or above) may be children with higher medical care needs or those who have been on the program for an extended time and whose respite packages are still based on historical decisions, explored later in this chapter.

Figure 7 (overleaf) shows the relationship between age and the number of hours respite received through the FCP each week. The most frequently represented group receiving respite was the group receiving sixteen to twenty hours of respite per week. The age range for this group was between one and seventeen years with the average age of five years. The average age for those receiving eleven to fifteen hours or six to ten hours was slightly older at seven and twelve years respectively. Often within the program, when children commence school, the respite they receive through the program reduces, which is supported by these results.

Children receiving higher levels of respite at twenty-one and above hours per week showed an increase in the average age. This may be related to the medical complexity and increased care requires of children as they grow. Typically, this group have additional disability based care needs, requiring increased assistance in the form of respite.
Figure 7
*Respite received by age of the child*

5.1a Medical complexity and respite received

Figure 8 (overleaf) shows the relationship between medical complexity and the level of respite received. Those receiving zero hours or sixteen to twenty hours per week showed the great range in the number of medical interventional care needs the child requires, ranging from one to six care needs. The average number of care needs varied across the groups of respite hours, ranging from two interventional care needs, seen in the zero and eleven to fifteen hours groups up to the highest average of five interventional care needs in the twenty-six to thirty hours of respite per week group. These results suggest there is not a relationship between the number of medical interventional care needs a child requires and the amount of respite they receive. This relationship will be explored further in Chapter Six.
Figure 8
Respite received by number of medical interventional care needs

Figure 9 (overleaf) shows the relationship between the hours of respite received by a family and the documented medical vulnerability and/or intensity of the child. Similar to the results seen in Figure 8, there was a substantial range in number of hours of respite received for each of the categories; however, the averages across the group showed less variation.

For the children assessed as ‘vulnerable’ the amount of respite received ranged from zero to over forty hours per week, with an average of between eleven and fifteen hours per week. Children assessed as ‘intense’ recorded a smaller range from eleven hours per week to thirty-six to forty hours per week. However, the average amount of respite received for this group was only marginally higher than the ‘vulnerable’ group at twenty-one to twenty-five hours per week. The group of children assessed as ‘both medically vulnerable and intense’ received the smallest range in respite hours each week, ranging from sixteen to twenty hours up to thirty-
one to thirty-five hours per week. The average number of respite hours for the children considered ‘both medically vulnerable and intense’ match those in the ‘intense’ group, at twenty-one to twenty-five hours per week, suggesting a relationship between the medical intensity of the child’s care needs and the respite the family receive. These issues will be discussed further in Chapter Six.

![Figure 9](image)

*Figure 9*
Respite received by medical vulnerability and / or intensity

**5.1b Psychosocial complexity and respite**

The number of psychosocial stressors documented for each child did not appear to have a direct relationship with the hours of respite received each week. However, there was a notable difference between the average number of psychosocial stressors documented for those with zero hours of respite per week in comparison to those with thirty-one hours or more of respite each week, as shown in Figure 10 (overleaf).
Figure 10

Respite received by number of psychosocial stressors

Families receiving zero hours of respite per week had the lowest average of psychosocial stressors. In considering the documented psychosocial stressors experienced by families not receiving respite through the program, the majority of this group (61.9%) have four or less documented stressors, as shown in Table 11 (overleaf).
Table 11

*Total Number of psychosocial stressors for those receiving zero hours respite per week*

<table>
<thead>
<tr>
<th>Total Number of Documented Psychosocial Stressors</th>
<th>Number receiving zero hours of respite</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
</tr>
</tbody>
</table>

Whilst still experiencing some psychosocial stressors, when compared to the rest of the group these families appear to have a lower level of active stressors, which may mean they have a lesser requirement for practical support from the program and have therefore declined respite. Those not receiving respite with nine or more psychosocial stressors represented 19.0% of the group with zero hours of respite. These families have relatively high level of documented psychosocial stress and are not receiving practical support in the form of respite through the program. As mentioned earlier, one reason a child may not be receiving respite through the program is due to delays or difficulties in carer recruitment, which may result in additional stress for the family and is often linked with other psychosocial stressors as discussed further in Chapter Six.
5.2 Case management involvement

In reviewing the level of case management involvement received by the child and family, several components of case management were examined, including: direct contact with the family, indirect contact with service providers or other health professionals, administration and travel time. In considering the level of case management involvement, the above areas were analysed in two ways, firstly by reviewing the number of contacts and then the total duration of these contacts. As discussed previously, these data were collected over a six-month period. Results have been averaged across the months to provide a monthly average for all areas.

Following a descriptive analysis of case management involvement within the program, the potential relationships between medical complexity, psychosocial complexity and respite provision, and on the level of case management involvement received, were analysed.

5.2a Level of case management involvement

Figure 11 (overleaf) shows the relationship between the total number of contacts involving a case manager and the total duration of these contacts over the six-month period of the study.

In Figure 11 the contacts include both direct and indirect contacts, but do not include administration time and travel. As seen in Figure 11, there was a strong positive correlation between the number of contacts a case manager is involved in and the duration of these contacts ($R^2=0.819$, $p=0.000$). This is not a surprising result and is likely to vary based on the work style of the case manager and possibly the family’s preferred style of communication. For example, some case managers and/or families may have multiple short contacts, whereas another may have one contact that is longer in duration.
As outlined in Figure 11, total duration of contacts involving a case manager ranged from 37 minutes to 4032 minutes over the selected six-month period. The majority of children and families received a total duration of contact up to 2000 minutes over the six-month period. Total contacts over the six-month also varied greatly, ranging from 4 to 285 contacts. Again, the majority of children were at the lower end of the scale receiving up to 100 contacts over the six-month period.

Figure 12 (overleaf) shows the relationship between case management contacts and the duration of these contacts (averaged over the six-month period).
Figure 12

*Average number of case management contacts by average duration of case management contacts per month*

Again, there was a strong positive correlation between the average number of contacts involving a case manager and the average monthly duration of these contacts ($R^2 = 0.819$, p=0.000).

The duration of contacts ranged from 6 minutes to 672 minutes per month, with the majority of children receiving an average duration of up to 300 minutes of case management involvement per month. The number of contacts per month varied again, ranging from 1 to 48 contacts per month involving the case manager. As with duration, the majority of children were at the lower end of the scale, receiving up to 20 contacts per month.

Figure 13 shows the average monthly contacts and durations, including administration and travel time reported by the case manager. By adding administration and travel time, Figure 13 provides a complete snapshot of the level of case management time provided to each child ($R=0.641$, p=0.000).
As seen above in Figure 13, average month case management involvement ranges from 11 to 1382 minutes per month. By including administration and travel time in the level of case management, involvement almost doubles. The majority of children receive up to 500 minutes of case management involvement per month, a range 200 minutes greater than seen in Figure 12, which considered direct and indirect contact only.

5.2b Medical complexity and case management involvement

As seen in Figure 14 (overleaf), the relationship between the number of case management contacts and the number of medical interventional care needs was explored.
Figure 14

*Average number of case management contacts per month by medical interventional care needs*

Whilst this graph only demonstrates a moderate correlation ($R^2=0.258$, $p=0.000$) between these two variables, it can be noted that those children with one to two medical interventional care needs appear to receive a lower number of case management contacts, with the majority of children and their families receiving an average of 10 or less contact per month. The children with 6 or more medical interventional care needs, receive an average of between 10 to 50 contacts per month. The group of children with this number of interventional care needs was limited; however, the number of interventions they require suggests a high level of ‘intensity’, and potentially ‘vulnerability’. Based on these results, it is possible to suggest that medical complexity may have some impact on the level of case management involvement a child and their family require.
Figure 15 provides similar results when exploring the relationship between medical interventional care needs and the average duration of case management contact (direct and indirect) per month.

![Graph showing average duration of case management involvement per month by medical interventional care needs](image)

**Figure 15**

*Average duration of case management involvement per month by medical interventional care needs*

The group of children with six to seven interventional care needs tended to receive consistently higher levels of case management involvement than the other group, with most receiving over 200 minutes of case management involvement per month. This result supports the possibility of an impact between level of medical complexity and case management involvement.

From a statistical perspective, there was a moderate positive relationship between the number of medical interventions of the child and the level of case management involvement they receive ($R^2= 0.217$, $p=0.000$).
Similar to the findings above, Figure 16 shows the relationship between the total number of medical interventional care needs of the child and the average monthly duration of case management involvement, including administration and travel time.

![Figure 16](image)

**Figure 16**

*Average duration of case management involvement (includes administration and travel) and medical interventional care needs*

As seen in Figure 16, children with fewer medical intervention care needs did tend to have a lower level of case management involvement, which appeared to increase in line with the increase in the number of interventional care needs. When considering the impact on total case management duration, including administration and travel time, there was a weak to moderate positive correlation ($R^2=0.180$, $p=0.000$).
Figure 17 explores the impact of medical ‘vulnerability’ and/or ‘intensity’ on case management involvement, by the average number of total contacts per month.

Children assessed as ‘vulnerable’ received an average of 6 case management contacts per month, ranging from a less than 1 contact on average per month to just under 40. Children assessed as ‘intense’ had a slightly higher average number of contacts at around 10 contacts per month, a similar range to the ‘vulnerable children’. The highest average number of contacts per month was among children assessed as ‘vulnerable and intense’, again possibly suggesting a connection between the medical complexity of the child and the level of case management involvement they receive.
Figure 18 also shows the relationship between case management contact and the medical ‘vulnerability’ and/or ‘intensity’ of the child, and also shows the duration of contacts.

Figure 18

*Average duration of case management involvement per month by medical vulnerability and/or intensity*

The average duration of case management involvement for all children ranged from 6.2 minutes per month to over 600 minutes or 10 hours per month. There was limited impact on the duration of case management involvement by the medical vulnerability or intensity of the child. Interestingly, the children considered ‘both medically vulnerable and intense’ on average received a higher total duration of involvement from their case management. Children considered ‘both medically vulnerable and intense’ received an average duration of approximately 250 minutes or just over 4 hours of case management involvement per month, compared with an average of 100 minutes for those considered medically ‘vulnerable’ and approximately 175 minutes per month for the medically ‘intense’. The children with ‘neither
medical vulnerability nor intensity’ documented had both the lowest range and average total duration of case management involvement per month.

5.2c Psychosocial complexity and case management involvement

The relationship between the number of documented psychosocial stress and the level of case management involvement is shown in Figure 19.

Figure 19

*Number of psychosocial stressors and the average number of case management contacts per month*

As seen above, Figure 19 shows weak positive correlation ($R^2=0.127$, $p=0.004$) between the number of documented psychosocial stressors and the number of contacts with the case manager each month. However, it can be noted that the number of contacts involving the case manager does change at four psychosocial stressors.

Children and families with four or less documented psychosocial stressors had fewer contacts with a case manager, on average each month, in comparison to the rest of the group: children
and families with five or more documented psychosocial had a greater range in average number of case manager contacts. The group of children with five or more documented psychosocial stressors produced a broader spread with the range from 1 contact up to almost 40 contacts per month, almost double that of the group with four or less stressors, suggesting a small relationship between psychosocial complexity and case management involvement.

The relationship between psychosocial stress and case management involvement, this time exploring the duration of contacts, is shown in Figure 20.

Figure 20

*Number of psychosocial stressors and the average duration of case management contacts per month*
Similar to the results above, Figure 20 shows a weak to moderate positive correlation between the duration of case management contacts and the psychosocial stressors documented ($R^2 = 0.174$, $p=0.001$).

However, for children and families with up to four documented psychosocial stressors the duration of contact is at the lower end of the results overall. Within this group duration of contact ranged up to an average of 400 minutes per month. Again, the majority of children in this group were at the lower end of case management involvement per month, receiving an average duration of up to 200 minutes.

In comparison, for children and families with five or more documented psychosocial stressors, the range in duration of case management involvement received was greater, ranging up to 647 minutes. Despite the extended range in durations of contact in this group, the majority of children sat in the lower end of duration, around 200 minutes per month.

In adding the time taken for administrative tasks and travel time, Figure 21 (overleaf) shows the relationship between the total duration of case management involvement and the documented psychosocial stressors experienced by the family.

The results shown in Figure 21 again suggest a weak to moderate positive relationship between psychosocial complexity and the level of case management involvement ($R^2=0.161$, $p=0.001$). As with the previous results, those with four or less psychosocial stressors are generally represented at the lower end of case management involvement.

Similar to the results above, children with five or more psychosocial stressors had the greatest range in duration of case management contacts. This group required between 6 and 600 minutes of case management involvement per month; this result increased three fold due to the including of administration and travel time.
This result suggests that whilst the psychosocial complexity of a family appears to be linked to the level of case management they require; the greatest impact of increased psychosocial complexity is on the number of administrative tasks required by the case manager. In considering the potential administrative tasks that a case manager may be required to complete, it is not surprising to find a relationship between psychosocial stressors and overall case management involvement. Many case managers will assist families with applications for additional funding, disability and housing supports, referral to other support systems including services to support the mental health of parents and sibling. Whilst these tasks may not require direct or indirect contacts, they still require the involvement from the case manager and would be captured in the administration time, as shown in Figure 21.

Figure 21
Average duration of case management contacts (including administration and travel) by number of psychosocial stressors
5.2d Respite allocation and case management involvement

The relationship between the amount of respite received each week and the level of case management involvement provided per month is presented in Figure 22.

![Diagram showing the relationship between hours of respite and average monthly total duration.](image)

**Figure 22**

*Respite received by duration of case management involvement (includes administration and travel)*

Coordination of respite is a key task for all case managers. As seen in Figure 22 the level of case management involvement required across the groups of respite hours varies. Firstly, those not receiving respite have the lowest level of case management involvement across the group, ranging up to 427 minutes and with an average of only 100 minutes. The two exceptions to this are at the higher end of average monthly case management duration; this may suggest that these children are not receiving respite due to difficulties in carer recruitment and are therefore requiring high levels of case management involvement to assist with this.
The greatest level of case management involvement can be seen for the children receiving six hours of respite per week or more, with each of the respite received categories having an average of between 400 and 600 minutes of case management involvement per month.

Children who were not receiving respite had the lowest levels of case management involvement. This group showed the greatest variation in the results, perhaps suggesting that level of case management involvement is related to whether or not respite is received, rather than the amount of respite received each week.

5.3 The impact of medical and psychosocial complexity on service provision

As discussed in Chapter Three, the final stage of data analysis was to consider the impact of the variables on service provision within the FCP.

As mentioned earlier, the results indicated a strong correlation between the total average number of case management contacts per month and the total average duration of case management contacts per month. Given this, case management involvement based on the duration of case management contacts only was examined.

5.3a Impact of medical complexity, psychosocial complexity and age on the provision of respite

ANOVA was completed to compare the impact of medical complexity (number of interventional care needs and medically ‘vulnerable’ and/or ‘intense’), psychosocial complexity and the age of the child and the level of respite received per week, as shown in Table 12 (overleaf).

The previous analyses have explored the relationship between each individual variable; however, this table provides a deeper understanding giving findings from the ANOVA. Table 12 shows that there was not one statistically significant variable to predict the hours of respite received. This result will be explored further in the discussion in Chapter Six.
Table 12

*Test between subjects: Comparing the impact of medical and psychosocial complexity and age of the child on the respite received*

<table>
<thead>
<tr>
<th>Source</th>
<th>Type III Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
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<tr>
<td>Total Number of Psychosocial Stressors</td>
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<td>6.12</td>
<td>1.036</td>
<td>.313</td>
</tr>
<tr>
<td>Medical ‘Vulnerability’ and/or ‘Intensity’</td>
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<td>11.01</td>
<td>1.864</td>
<td>.146</td>
</tr>
<tr>
<td>Total Number of Medical Interventional Care Needs</td>
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<td>.420</td>
</tr>
<tr>
<td>Age of the Child</td>
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<td>1</td>
<td>.07</td>
<td>.011</td>
<td>.917</td>
</tr>
<tr>
<td>Error</td>
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<td>58</td>
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</tr>
<tr>
<td>Corrected Total</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

**5.3b Impact of medical complexity, psychosocial complexity and respite on duration of case management**

The findings from the ANOVA comparing the impact of age of the child, medical complexity, psychosocial complexity and whether respite was or was not allocated on the average duration of case management contact are shown in Table 13.

Table 13

*Test between subjects: Comparing the impact of medical and psychosocial complexity, age of the child, and presence of respite on the total monthly duration of case management contacts*

<table>
<thead>
<tr>
<th>Source</th>
<th>Type III Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of the Child</td>
<td>8908.1</td>
<td>1</td>
<td>8908.1</td>
<td>.663</td>
<td>.419</td>
</tr>
<tr>
<td>Medical ‘Vulnerability’ and/or ‘Intensity’</td>
<td>21952.0</td>
<td>3</td>
<td>7317.3</td>
<td>.545</td>
<td>.654</td>
</tr>
<tr>
<td>Respite Allocated</td>
<td>45373.2</td>
<td>1</td>
<td>45373.2</td>
<td>3.378</td>
<td>.071</td>
</tr>
<tr>
<td>Total Number of Medical Interventional Care Needs</td>
<td>162613.2</td>
<td>1</td>
<td>162613.2</td>
<td>12.106</td>
<td>.001</td>
</tr>
<tr>
<td>Total Number of Psychosocial Stressors</td>
<td>66906.1</td>
<td>1</td>
<td>66906.1</td>
<td>4.981</td>
<td>.030</td>
</tr>
<tr>
<td>Error</td>
<td>765625.0</td>
<td>57</td>
<td>13432.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corrected Total</td>
<td>1271039.8</td>
<td>64</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The findings in Table 13 showed that the total number of medical interventional care needs (F=12.106, p=0.001) and the total number of documented psychosocial stressors (F=4.981,
predicted the duration of case management contacts. Respite allocated (F=3.378, p=0.071) was relatively close to significance and therefore considered important for further statistical analysis. However, the age of the child (F=0.663, p=0.419) and the description of ‘vulnerable’ and/or ‘intense’ (F=0.545, p=0.654) did not provide significant results and are not considered strong predictors of the level of case management involvement in this thesis.

Table 14 adds to the finding above by considering the variables which were significant or close to significant only, being whether respite was allocated, the total number of medical interventional care needs and the number of psychosocial stressors.

Table 14

<table>
<thead>
<tr>
<th>Source</th>
<th>Type III Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite Allocated</td>
<td>63687.0</td>
<td>1</td>
<td>63687.047</td>
<td>4.875</td>
<td>.031</td>
</tr>
<tr>
<td>Total Number of Medical Interventional Care Needs</td>
<td>172025.3</td>
<td>1</td>
<td>172025.301</td>
<td>13.169</td>
<td>.001</td>
</tr>
<tr>
<td>Total Number of Psychosocial Stressors</td>
<td>89911.2</td>
<td>1</td>
<td>89911.174</td>
<td>6.883</td>
<td>.011</td>
</tr>
<tr>
<td>Error</td>
<td>796832.9</td>
<td>61</td>
<td>13062.834</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corrected Total</td>
<td>1271039.8</td>
<td>64</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

When including the significant variables only, the findings of the ANOVA show greater statistical significance: case management contacts was predicted by the respite allocated (F=4.875, p=0.031), the total number of interventional care needs (F=13.169, p=0.001) and the total number of documented psychosocial stressors (F=6.883, p=0.011).

In considering what this means for the duration of case management contacts per month, the allocation of respite adds an additional 74 minutes of case management involvement per month (95% CI: 7.0, 140.6), compared to those without respite allocated. The number of medical interventional care needs, appeared to have the greatest impact on case management duration, with an additional 35 minutes per documented interventional care need (95% CI: 15.8, 54.6). Finally, each psychosocial stressor documented was analysed to result in an additional 16 minutes of case management involvement per month (95% CI: 3.8, 28.2).
The same variables were used in the next ANOVA, however administration and travel time were incorporated into the total duration of case management involvement, as shown in Table 15.

Table 15

*Test between subjects: Comparing the impact of the presence of respite, number of medical interventional care needs and number of psychosocial stressors on the total monthly duration of case management contacts (including administration and travel time)*

<table>
<thead>
<tr>
<th>Source</th>
<th>Type III Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite Allocated</td>
<td>350725.7</td>
<td>1</td>
<td>350725.7</td>
<td>5.834</td>
<td>.019</td>
</tr>
<tr>
<td>Total Number of Psychosocial Stressors</td>
<td>357867.0</td>
<td>1</td>
<td>357867.0</td>
<td>5.952</td>
<td>.018</td>
</tr>
<tr>
<td>Total Number of Medical Interventional Care Needs</td>
<td>599516.4</td>
<td>1</td>
<td>599516.4</td>
<td>9.972</td>
<td>.002</td>
</tr>
<tr>
<td>Error</td>
<td>3667445.2</td>
<td>61</td>
<td>60122.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corrected Total</td>
<td>5595004.8</td>
<td>64</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In doing this, the significance of the allocation of respite increased, however the statistical significance of the total number of medical intervention and total psychosocial stressors reduced slightly. Whilst, a minor change to the statistical significance, it can be understood that the presence of respite increased administration and travel time to the workload of the case manager.

Again, in considering the impact of each variable for children with respite allocated, this increased by an average of 173 minutes of case management involvement per month (F=5.834, p=0.019, 95% CI: 29.8, 316.4). Each medical interventional care need documented added 66 minutes to the case managers average monthly involvement (F=9.972, p=0.002, 95% CI: 24.1, 107.2), and finally, each documented psychosocial stressor added 32 minutes (F=5.952, p=0.018, 95% CI: 5.8, 58.1)).

**Chapter overview**

This chapter has examined service provision, focusing specifically on respite and case management involvement. Respite provision was considered in relation to the number of hours allocated and the number of hours received each week. Drawing on the findings in Chapter
Four, this chapter explored the relationship between medical and psychosocial complexity and respite provision within the FCP.

The chapter also explored case management involvement within the program. Case management involvement considered both the number and duration of case management contacts, including both direct and indirect contact with families as well as exploring the addition of administration and travel time. Again, drawing on the findings from Chapter Four, this chapter considered the relationship between medical and psychosocial complexity and the predictors of respite provision and case management involvement.
Chapter Six – Discussion

This thesis provided an exploratory review of medical and psychosocial complexity for children and their families within the Family Choice Program (FCP) and how these two factors impact on service delivery. As discussed in Chapter Two, literature on children with complex medical care needs is limited and what is available often raises the challenges of describing such a diverse and specialised group. This thesis aimed to add to this literature and to encourage further discussion about these children and their families from a program-based approach. It examined the question: what is the relationship between medical and psychosocial complexity and the provision of case management and respite services for children and families accessing the FCP? In examining this question, the following key areas were explored:

1. the documented medical complexity of children accessing the FCP
2. the documented psychosocial stress experienced by the families of children with complex medical care needs
3. the documented respite provision and its relationship to medical and psychosocial complexity
4. the documented frequency and duration of case management contact within the FCP, and, the relationship between this and medical complexity, psychosocial complexity and the provision of respite.

This chapter reviews each of these areas providing an interpretation of the key findings and the relevance of these to the current literature, finishing with a review of the limitations and strengths of the study, and the implications for practice.

6.1 Understanding medical complexity

As discussed in Chapter Two, the literature around defining medical complexity varies between the different medical home models in practice internationally. As this thesis provided a program-based approach as distinct from a medical one, it was important the study focussed on the definition of medical complexity within the program.
This study provided an understanding of medical eligibility categories for the FCP. As discussed in Chapter Two, medical eligibility within the FCP is based on the terms ‘vulnerability’ and/or ‘intensity’. Whilst these concepts are similar to several definitions of children with complex medical care needs in the literature (Farmer et al., 2005; Nageswaran et al., 2012; Farasat and Hewitt-Taylor, 2007; Olsen and Maslin-Prothero, 2001), the use of these specific terms appears to be unique to the program. The study then used these terms to understand what medical complexity means within the FCP. The study found that most children accessing the FCP were considered medically ‘vulnerable’. This result extends the current literature about children with complex medical care needs, who are usually discussed in terms of the level of care they require or demand on the service system (Kuo et al., 2014 and Bramlett et al., 2009), suggesting a more ‘intense’ nature to their conditions.

The study also found a relatively high number of children (16.9%) were not documented as either ‘vulnerable’ or ‘intense’. Given the use of these terms was an expected component of assessing eligibility, this result was interesting. However, on closer review it appeared that these children included the entire group of children on Total Parenteral Nutrition (TPN). Whilst TPN represents a small number of children, it was interesting to find no child on TPN was considered ‘vulnerable’ or ‘intense’. This result suggests some confusion about the eligibility criteria and the use of these terms. This also highlights the challenges of working with a group of children whose care needs are rapidly evolving, making the program’s structure for determining eligibility in need of constant review to avoid it becoming out of date.

The study also explored the number and type of medical interventional care needs the child requires. The study found fourteen medical interventional care needs documented within the children’s files and that many children had multiple care need types. Considering children in this individualised way is well supported by the literature (Cohen et al., 2008; Stille & Antonelli, 2004); however, developed lists of medical care need types or the frequency of these care needs has not been documented in the literature to date.

Whilst the findings presented in this thesis provide an understanding of the type of medical interventional care needs that may result in children being defined as medically complex, the
thesis does not provide an understanding of the intensity of each medical intervention or care need, i.e. the frequency of suctioning each day. This could not be explored in the scope of this thesis. However, it is important to understand that one medical interventional care need, i.e. suctioning, may be a vital need for one child however infrequently used for another. In some cases, the presence of just one interventional care need may be sufficient for eligibility for the program due to the high frequency it is required, that is the ‘intensity’ of the intervention.

Given the relationship between the number of medical interventional care needs and the level of case management involvement demonstrated in this thesis, further review of the relationship with medical input should be considered for future studies. Anecdotally, in social work, we often discount the importance of medical complexity on the psychosocial work we do, instead focussing on the impact of psychosocial factors on medical care. However, this result challenges this and gives further insight into the challenges faced by case managers working with children with such complex medical needs.

This descriptive review of medical complexity in the program begins to provide an overview and understanding of the children on the FCP. Whilst not providing weighting toward specific medical interventions or the frequency of these interventions, the results do provide opportunities for further discussion about how we define this group of children. As discussed in Chapter Two, many definitions of medical complexity in the literature relate to the number of health conditions the child has, the number of organ systems involved or the frequency of contact with health care professionals (Cohen et al., 2005; Farmer et al., 2005). The FCP’s approach provides a different outlook, one based on the care needs of the child, the number of interventions the child will need and how quickly they may deteriorate. This approach allows for greater diversity of medical diagnoses and a more individualised approach. This understanding of medical complexity within the program adds to the conversation and assists in guiding literature around defining this group of children.
6.2 Documented psychosocial complexity

This thesis explored and described the number of psychosocial stressors documented by case managers in the child’s psychosocial assessment. The results describe the commonly documented psychosocial stressors for children on the FCP and their families. The high number of stressors documented suggests a high level of psychosocial complexity within the program, further, the breadth of stressors represents the diversity of this group of children.

Supporting a child with complex medical care needs is accepted in both practice and literature as a challenge. Many families with children with complex medical care needs also have complex psychosocial needs (Kelly et al., 2008). Understanding the psychosocial complexity experienced by families accessing the program was a key component to this thesis.

In reviewing the documented psychosocial complexity of families accessing the FCP this study found a total of twenty-seven stressors, which were compiled into ten key themes including; adjustment reaction, supports, family structure/dynamics, parental health, siblings, accommodation, financial/employment, legal/child at risk, access to services and other. Limited research in this area meant there was not an appropriate validated tool to conduct the thematic analysis of the file. Instead, the analysis focussed on key terms and themes throughout the 65 files, developing a database of results in the process which potentially explains the large number of stressor types collected. Not being able to apply a validated tool to the thesis means it is not possible to compare the results to other populations; therefore, the results do not aim to explain the psychosocial stress experienced by families of children with medical complex needs internationally. Rather, the results provided an exploratory review of the type and frequency of stressors documented in the psychosocial assessments of the families accessing the FCP.

The study found the most frequently represented stressors related to adjustment to diagnosis, documented in 66.2% of files. As explored in Chapter Two, literature often referenced the practical impact rather than the emotional or psychological impact for families. Given the complex diagnoses of many of the children accessing the FCP, it is not surprising to see this as
one of the most frequently represented stressors, however it raises questions about why this is. Many case managers in the program would discuss the provision of emotional support around adjustment to diagnosis as a key component of their role. It is possible that the highly medical focus of the program encourages case managers to focus on the child’s diagnosis, and the family adjustment to this, over other psychosocial stressors. With this in mind, it is possible to suggest that this stressor is more frequently considered by case managers when working with families, therefore they are more likely to document this as a cause of stress when completing the psychosocial assessment.

Interestingly, adjustment to care needs was not as highly represented in the group at 26.2%. In completing the audit of psychosocial assessments many case managers had listed adjustment to care needs and diagnosis as separate causes of stress, therefore it was importance to keep them separate in the thesis. As discussed previously, one of the main components of the FCP is the provision of in home respite. Based on this it is possible to hypothesise that the inclusion of respite and other practical supports from the FCP reduces the stress around adjustment to care needs, a point that has also been suggested in the literature (Olsen & Maslin-Prothero, 2001).

As discussed in Chapter Two, many families of children with complex medical care needs have additional social stressors including inadequate housing, limited transportation options, single care givers, financial burden and higher rates of unemployment and underemployment (Kelly et al., 2008; Kuo et al., 2011; Hewitt-Taylor, 2008). Each of these stressors was also identified in the thesis, with financial stress and employment being amongst the top five documented stressors. Practice wisdom and experience in working with the families of children with complex medical needs highlighted the significant impact the care needs of the children has on the parent’s ability to maintain previous levels of employment. Employment in the context of this thesis referred to stress around unemployment, underemployment and concerns about how parents felt they would be perceived in current employment, especially due to high levels of carers leave they may require.
Some literature has suggested links to the exhaustion and anxiety experienced by families (Woodson et al., 2015); however, few have commented specifically on parental mental health, which was highly represented in the sample at 41.5%. In completing the analysis of the psychosocial assessment, many case managers commented on stress caused by current or previous mental health issues, mostly in relation to anxiety and depression. The high representation of parental mental health amongst the sample is concerning and further research into this area should be considered.

Whilst many of the identified psychosocial stressors can be seen to directly relate to the role as carer of a child with complex medical care needs, the results did not observe a link between the two. The number of medical interventional care needs did not appear to impact on the psychosocial stressors documented. With only minor variations seen when exploring the number of psychosocial stressors under each category of ‘vulnerable’, ‘intense’, ‘both’ and ‘neither’; the children described as ‘both vulnerable and intense’ appeared to have a slightly higher average number of documented psychosocial stressors at six per child, compared with five for the other three categories.

Whilst the key areas of psychosocial stress were not surprising based on practice knowledge and the supporting literature, the number of documented stressors was surprising and concerning in some cases. As Social Workers, we often only see those with the higher level of psychosocial stress, which means there is sometimes a risk of becoming ‘desensitised’ or perhaps minimising the level of stress many of the families we work with face. Articulating psychosocial stress is also difficult, especially in a medical model like that of the FCP. This was definitely true of the FCP group, whilst many of the case managers would acknowledge that the families they work with had high levels of psychosocial stress trying to describe this made defining medical complexity look easy or ‘black and white’. The results of this thesis provide a description of the stressors and further understanding of the psychosocial stress faced by these families, who are already managing the daily care of children with complex medical care needs.
6.3 Service provision – respite

Working with these children and families I have noted that respite is often seen as the saving grace by families and other professionals. Respite, as seen in the FCP, provides appropriate medical care to the children, whilst supporting the psychosocial needs of families (Olsen & Maslin-Prothero, 2001). Provision of respite within a medical home model is supported by the literature; however, there is no literature available on how respite services are delivered within medical home models.

The study found that the majority of children had respite allocated through the program, with only a small group not using all allocated hours. The hours of respite allocated to children varied with children receiving between six hours to over forty hours per week. Around one third (32.3%) of children were not receiving any respite at the time of the study, respite may not be allocated due to the child’s care needs and is determined at the point of assessing eligibility for the program. For those with respite allocated but not being utilised, this could be for a variety of reasons. This may be at the request of the family; some families will decide to call upon available informal supports rather than utilising the allocated respite hours. Other issues may be due to the care needs of the child being considered too unpredictable for a carer to be trained in their care needs, or may relate to difficulties recruiting appropriate support workers. Understanding how respite is used within a program such as the FCP adds greatly to the literature, providing further understanding of options to support these families as well as knowledge about the delivery of services to children with complex medical care needs.

The study also reviewed the relationship between the medical complexity of the child and the level of respite they receive. During the intake phase, staff within the FCP determine the level of respite allocated to a family based on the medical care needs of the child. Over time, this can shift, as can the psychosocial complexity of the family. Interestingly the study found limited links between medical complexity of the child and the level of respite they received. The assessment of medical ‘vulnerability’ and/or ‘intensity’ found minor variations between the group, with the highest levels of respite being provided to those considered ‘intense’ or both medical ‘vulnerable and intense’. In considering the number of medical interventional care needs of the child and the respite they received, the variation was again relatively
insignificant, with only some suggestion of a small relationship between the two. This result may be partially due to the way medical complexity was described for this thesis.

The findings on psychosocial complexity and respite received provided interesting results, especially when considering the group that did not receive any respite. This includes those with respite allocated but not accessed and those who do not have respite allocated through the program. The study found that whilst the children receiving zero hours of respite per week had the greatest range of psychosocial stressors, the average for this group was the lowest at four documented stressors. This range perhaps explains the number of reasons a child may not be receiving respite, that is: care needs too complex, recruitment challenges or parents request. Those with care needs considered too medically complex for carers may be likely to have increased psychosocial stress, especially around domains such as adjustment reactions, parental health, sibling, financial/employment and others. Similarly, those experiencing difficulty in carer recruitment would also be expected to have higher levels of psychosocial stress for the same reasons as the previous group as well as access to services. However, perhaps those who decline respite do so because they have lower levels of psychosocial stress. In practice, these are the families who have extensive informal support available to them as well as limited financial stress. As discussed above, the literature around respite provision is limited and its link to psychosocial stress for families of children with complex medical care needs is nonexistant.

Understanding respite for this thesis involved understanding the current allocations and how respite was impacted by medical and psychosocial complexity. This exploratory review of respite, especially the finding around the relationship between lower average psychosocial stress for those not receiving respite, provide an interesting area for further review. As discussed, respite through the FCP has always been seen as a vital component of care for these families; however the variation in psychosocial stress may indicate a need for further review and perhaps options to explore a training model of informal supports such as friends and family.
6.4 Service provision – case management

The provision of case management services was the final stage of this thesis and provided an overview of the four key areas of the study. In first understanding the provision of case management within the FCP, it was important to consider the frequency and duration of contact, and then to consider what impacted this. Literature around case management involvement in medical home models was almost non-existent. The existing literature about case management more generally referenced the importance of this approach within the healthcare system (Jones & May, 1992); however, they did not provide an indication about what this involves or what impacts of the provision of case management services.

Reviewing the frequency and duration of case management contact was completed in retrospect over a six month period; results were averaged for the month and then averaged again across the six month period. The study found frequency and duration of case management contact across the group varied significantly. In considering the reasons for this variation, there are a number of factors. The data for this thesis were collected from nine case managers, each with their individual styles and approaches. Some case managers prefer short and frequent contacts, whereas others prefer less frequent but longer contacts with their families. Interesting the correlation between frequency and duration was strong. The accuracy of the data collected on case management involvement was only as accurate as the documentation itself. Given the data collection were done in retrospect, case managers were not advised to focus on documentation any more than usual. It is possible to expect some variation in the results based on documentation standards as well as potential human errors around staff documentation entry.

In reviewing case management involvement, medical complexity, psychosocial complexity and respite provision were considered. Firstly, in exploring the impact of medical complexity the results did not show a direct correlation with case management involvement. However, those with fewer medical interventional care needs did have a lower level of case management involvement generally. At the other end of the scale, those receiving the highest levels of case management involvement also had the greatest number of medical interventional care needs generally. This theme continued when considering the medical ‘vulnerability’ and/or ‘intensity’ of the child; with children defined as ‘both medically vulnerable and intense’
receiving a higher level of case management involvement on average. This result was unexpected, whilst case managers working with children with complex medical care needs would see this work as more intensive than other groups, the separation based on medical complexity was interesting. At the point of case allocation, case managers often consider the level of respite allocation and the psychosocial stressors as an indicator for workload, however this result suggests the need to consider the medical complexity of the child as well.

Secondly, the relationship between psychosocial complexity and case management involvement was considered. Similarly to the medical complexity results, the review of case management involvement and psychosocial complexity did not show a direct relationship. However, in breaking the sample down further patterns seem to emerge. Families with four or less documented psychosocial stressors received a lower level of case management involvement on average compared to those with five or more stressors documented. Unlike medical complexity, this result was expected. The case management role within the FCP is designed to support the psychosocial needs of family, therefore it would be expected that this would increase according to the number of stressors the family have. Whilst understood on a practice level, the impact of a family’s psychosocial stress on workload has not been quantified in the literature. Understanding that case management involvement shifts at around five psychosocial stressors provides an opportunity to predict the impact on the case manager’s workload.

The third area considered in reviewing case management involvement with the allocation of respite. Respite in the thesis explored whether respite was allocated or not and the amount of hours of respite the family was receiving each week. As discussed in Chapter Two, not all children on the FCP are allocated respite a decision which is generally based on the medical needs of the child. The development of respite allocations within the program has been based on the practice wisdom of staff and takes in to consideration operational factors, such as budget constraints. Whilst the importance of respite has been documented (Olsen & Maslin-Prothero, 2001), the literature does not discuss how this is allocated or how this is managed. Within the FCP, the coordination of respite is one of the key roles of the case manager and many would suggest that the greater the number of respite hours the child has the greater the level of case management involvement required. However, a review of the results did not suggest a clear
link between the hours of respite allocated and the level of case management involvement. Instead, the results provided a clearer distinction of case management involvement based on whether respite was or was not allocated.

This surprising link is most likely a representation of the practice involved in the coordination of respite. Setting up respite through the FCP involves interviews with the family, facilitated by the case manager. It is then also the role of the case manager to develop a respite roster, in consultation with the family. This work in the initial phase of setting up respite is extensive and may explain the feelings of increased work when a child has a larger number of hours allocated, requiring the recruitment of multiple support workers. However, once respite support workers are selected and the roster has been developed the role of the case manager changes to the ongoing coordination of shifts. In considering the practice approach to managing respite, it is possible to understand why there is such a marked distinction in case management involvement between those that do and do not have respite allocated.

Also, as discussed previously, respite is initially based on the medical care needs of the child and then later the psychosocial needs of the family are also considered. Given both medical complexity and psychosocial complexity were clear predictors of case management involvement, a link between respite and case management involvement would also be expected. These results lead to the next section of the study, which, as discussed in Chapter Five, involved completion of an ANOVA of these three main themes on case management involvement to answer the final research question: what is the relationship between medical and psychosocial complexity and the provision of case management and respite services for children and families accessing the FCP.

This component of the thesis provided the most remarkable results, and suggested potential links between medical complexity, psychosocial complexity, respite allocation and case management involvement. Whilst respite was not clearly affected by these variables, the allocation of respite does appear to be a predictor of case management involvement. Basically, this means the results provide an opportunity to predict the level of case management involvement based on the medical complexity of the child, the psychosocial complexity of the
family and whether or not respite has been allocated. For the FCP and for medical homes internationally this result which has not been explored in the literature to date, is exciting.

As discussed in Chapter Five, the results provide a breakdown of the additional duration of case management involvement based on the total number of medical interventional care needs of the child, the total number of psychosocial stressors and finally whether or not respite has been allocated. In practice, these three areas could be known at the point of acceptance onto the FCP, and by doing so, it would be possible to predict the impact each case would have on the workload of the case manager, allowing for improved equity of case allocation across the team.

This research will benefit the case management team in increasing the knowledge of their involvement in the program and the importance of this role on service delivery and coordination and will also improve practice by ensuring consistency in approach. At the time of the study, case management allocation was based on the number of active cases held by the case manager and the anticipated level of case management involvement required. This research will assist in the development of a framework to guide the allocation of cases based on the assessed level of complexity and indicated level of required case management involvement. This knowledge and proposed framework aims to ensure equitable access to services.

### 6.5 Method issues

As with all studies, the methodology of the thesis provided both strengths and limitations. Both are discussed below.

**The strengths of the method:**

Overall, the research method of this study was successful as it provided understanding of the key aspects of the FCP and answered the question about the impact on the provision of service within the program. Obtaining data from various sources in this study, including the Family...
Choice Program Plan (FCPP), the psychosocial assessment and documentation system The Care Manager (TCM) provided a more thorough review of the documentation and provided a richer understanding of the FCP.

Importantly, using a data mining approach provided an unbiased collection of data and was not intrusive for the participants. This also eliminated the need for consent processes as all audited information was routinely collected and stored.

Being a member of the FCP team and completing this practice based research project, brought about challenges at times, especially as the analysis related directly to my role as a case manager within this team. However, the understanding of the FCP and the role of a case manager allowed for a deeper analysis of the results as they I could draw upon my practice wisdom when interpreting the data.

The limitations of the method:

In reflecting on the method, there are a number of limitations which could be reviewed for future studies. Firstly, a major component of the thesis was to explore the medical complexity of the children accessing the program. At the point of method design, this was considered to be for exploratory and descriptive purposes only, and with this in mind, the data collected on medical complexity was simplified to include the number of medical interventions and the use of the terms ‘vulnerability’ and/or ‘intensity’. However, on reviewing the results, medical complexity became one of the key predictors of case management involvement therefore it’s inclusion in the study was vital. Whilst the data collected was sufficient for this study, it would be interesting to provide a deeper review of the interventional care needs of the child with a medical lens to understand whether the intensity of the care need or intervention, the child’s diagnosis or illness trajectory further impact of the level of case management involvement.

Secondly, data relating to the psychosocial complexity of the family was collected from psychosocial assessments completed by allocated case managers. Whilst this data mining
approach was selected due to the decreased impact on the family, it does leave the results open to a greater risk of misinterpretation. As discussed in Chapter Three, there were no appropriate validated tools available to assist in a thematic analysis of the psychosocial assessment. Instead, the researcher self-developed a spreadsheet (see Appendix Three) to collect the key themes of each psychosocial assessment. This was undertaken by only one researcher, therefore limiting the risk of varying interpretations, the psychosocial assessments audited across the sample were completed by nine case managers which may result in different documentation styles and variations in language used.

As all the data were collected via a data mining approach, the results can only be as good as the documentation itself, creating the third limitation. This relates especially to the level of case management involvement, as it is possible that the documentation of time spent on each case may not be accurate due to missed or absent documentation, human error in data entry and individual variations in how time is documented.

Finally, whilst the results of this thesis provided exciting opportunities to predict the level of case management involvement based on the medical complexity of the child, the psychosocial complexity of the family and whether or not respite was allocated, the statistical results show great variation. Whilst the high level of statistical significance makes it tempting to use the results as a formula for determine case management caseloads, the large variance of the results makes this a dangerous and likely inaccurate approach. Instead, the results should be used as a guide for developing a process for case allocation, perhaps a 3-tiered (high, medium, low) approach to case management allocation.

6.6 Implications

This thesis provides a number of implication for case management and social work, as well as for the FCP and the management of children with complex medical care needs more broadly, as discussed below.
1. This research highlights the level of medical complexity of the children accessing the FCP. The importance of medical complexity in this thesis demonstrates the importance of having a greater understanding of how medical complexity is defined by the program. This thesis has begun to define the group of children accessing the FCP and could be used to assist in discussions internationally about how to better define children with complex medical care needs.

2. Whilst we know that these children are medically complex, our understanding of the psychosocial complexity of families is limited and further research is required. This thesis provided beginning information to commence further discussion about the complex psychosocial situations many of these families experience.

3. Further consideration needs to be given to the high numbers of families reporting current or preexisting mental health issues, in addition to other psychosocial stressors. Whilst the case management team are predominately social work trained, consideration of further mental health training should be considered to ensure staff are skilled to meet the needs of the children and families accessing the FCP.

4. Case managers and social workers need to think beyond the impact of psychosocial complexity of their workload. Whilst it is important to recognize how psychosocial complexity impacts on the work of the case manager or social worker, this thesis demonstrates the link between the medical complexity and workload, something which is often not regarded when considering case allocations. This will become more important overtime as the advancements in medical care and technology improve, making it a vital area of consideration of psychosocial professionals.

5. Within the FCP specifically, this program-based research provides the understanding to develop a clearer model for case allocation. Whilst it is not possible to apply the results as a formula to predict case management time, it should be adapted to provide a framework to determine the level of case management involvement a family will require, therefore providing a more equitable approach to case allocation.
6.7 Conclusion

This research is a program-based review of the impact of medical and psychosocial complexity on the provision of service, within the Royal Children’s Hospital, Family Choice Program (FCP). The thesis has provided an exploratory review of the medical complexity of children and the psychosocial complexity of families accessing the program, as well as an overview of the key aspects of service delivery, respite and case management. In considering these key areas, the thesis has also considered how they relate to each other and how they impact of the provision of service within the program.

The exploratory approach of this study provides the FCP and RCH with great benefits. This study has provided knowledge and understanding of the medical complexity of children, the psychosocial complexity of families and the impact of service provision within the program. Prior to the completion of this study, this knowledge was based on practice wisdom only; completing of this study has provided greater evidence to assist in guiding practice. This study also adds to the knowledge and understanding of children with complex medical care needs internationally, it provides greater insight into medical home models and will add to the conversation on how services can best support these children and their families.

The results of the thesis provided evidence to explain how case management involvement varies based on the number of medical interventional care needs of the child, the number of documented psychosocial stressors of the family and whether or not respite is allocated. Using an exploratory approach with a quantitative data set, the thesis also provides an understanding of how medical complexity is defined within the FCP, adding to the conversation internationally about how to define children with complex medical care needs. Further, the knowledge of the psychosocial stressors experienced by the families accessing the FCP encourages further discussion and research about the individualised needs of these children and their families. Finally, this thesis offers the first documented understanding of what impacts on service provision within a medical home model and the level of impact these key factors make.

The results of this thesis suggest a need for case managers and social workers to think beyond the impact of psychosocial stress and to recognise the impact of increased medical complexity
on their workload. At a program level, the results provide opportunity to review the process of case allocation to case managers and to develop frameworks to ensure a more equitable share of work across the team. Finally, at a systems level, this thesis adds to the conversation about this growing group of children, providing a better understanding of not only children with complex medical care needs, but their families and the impact on how we meet their needs.
References


RCH HUMAN RESEARCH ETHICS
COMMITTEE APPROVAL 34065A
HREC REF. No:
PROJECT TITLE: The impact of medical and psychosocial complexity on the provision of service within the FCP
APPROVED DOCUMENTS:
- PLS v4 dated 27 Jun 2014
- Focus Group Email Invitation dated 3 Jun 2014
- Protocol v3 dated 4 Jun 2014
APPROVED PROTOCOL:
PRINCIPAL INVESTIGATOR:
Katherine Maughan
DATE OF ORIGINAL APPROVAL: 07 July 2014
DURATION: 24 Months
DATE OF APPROVAL EXPIRY: 07 July 2016
SIGNED: 7 July 2014
COMMITTEE REPRESENTATIVE

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 Development & Ethics 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 Development & Ethics. Investigators undertaking projects without current HREC approval risk their indemnity, funding and publication rights.

CLINICAL TRIALS
Appendix Two

Example of medical complexity data collection spreadsheet

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<th>Child code no.</th>
<th>Tracheostomy</th>
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<th>AIRVO</th>
<th>BIPAP/CPAP</th>
<th>Oximetry monitoring</th>
<th>Oxygen</th>
<th>TPN</th>
<th>Prostacyclin</th>
<th>Seizure management</th>
<th>EB Care</th>
<th>PEG/PEJ/NG/NJ</th>
<th>Peritoneal Dialysis</th>
<th>Other</th>
<th>Total number of medical interventions</th>
<th>Vulnerable</th>
<th>Intense</th>
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### Appendix Three

**Example of psychosocial complexity data collection spreadsheet**

#### Psychosocial Complexity – Appendix 3

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### Example of respite allocation data collection spreadsheet

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Example of case management involvement data collection spreadsheet

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<th>Month1Dur Indirect</th>
<th>Month1Dur Total</th>
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Author/s:
Maughan, Katherine

Title:
Complexity and service provision in the Royal Children's Hospital's Family Choice Program

Date:
2017

Persistent Link:
http://hdl.handle.net/11343/213487

File Description:
Complete thesis

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