AN EVALUATION OF A MODEL OF CARE FOR CHILDREN WITH SERIOUS ILLNESSES AND THEIR FAMILIES IN NEW ZEALAND

Cynthia Ward

RN, BN (WINTEC, Waikato, NZ),

Post Grad Cert Palliative Care; Post Grad Cert Child & Family Health;

MA (Applied) (Victoria University, NZ)

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ACU
AUSTRALIAN CATHOLIC UNIVERSITY

Research Services, Melbourne Campus,

Locked Bag 4115, Fitzroy, VIC 3065

STATEMENT OF AUTHORSHIP

This thesis contains no material extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma.

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All research procedures reported in the thesis received the approval of the Australian Catholic University (ACU) Human Research Ethics Committee (HREC).

This thesis contains two (2) original papers published in international peer-reviewed journals. The ideas, development and writing of all the papers in this thesis were the principal responsibility of me, the candidate, under the supervision of Dr Alicia Evans, Dr Rosemary Ford, and Professor Nel Glass from the School of Nursing, Midwifery and Paramedicine. These papers are attached as Appendices.

The contribution of co-authors to manuscripts is indicated in the declaration accompanying each publication in the thesis, where the specific percentage of student contribution is noted. My contribution to each work is shown in Table 1.

Table 1: Summary of publications

Thesis chapter	Publication title	Publication status	Nature and extent of candidate's contribution
2	Care in the home for seriously ill children with complex care needs: A narrative literature review.	Published 2015. *Journal of Child Health Care, 19(4), 524-531. DOI: 10.1177/136 7493514538 327 231– 237.*	Principal author; solely responsible for overall literature review. First author for creation and revision of manuscript upon feedback from co-authors. Author accepting overall responsibility for the publication.
4	Children living with serious chronic illness: the health professional as care provider.	Published 2015. *Nursing Praxis in New Zealand Journal, 31*(2) 25-34.	Principal author; solely responsible for overall study design, literature review, and preparation of dataset, data analysis and interpretation of results. First author for creation and revision of manuscript upon feedback from co-authors. Author accepting overall responsibility for the publication.

Candidate's name: Cynthia Ward

Candidate's signature: Date: 05/04/2019

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DEDICATION

This thesis is dedicated to my husband, David. His love, care, patience and belief in me have always been the 'wind beneath my wings'. Without him, I could not have walked this journey. He has given me the courage to listen to my own 'child' within, which has set me on a path to advocate for children, to provide an opportunity to listen to their voices and those of their families. This contributed to my motivation to become a change agent for children and their families, hence the importance of this thesis.

Ka nui taku aroha ki a koe
My love for you knows no bounds

ABSTRACT

Background: Due to advances in knowledge and medical technology, many neonates and children survive pre-term birth and serious illness. They are cared for by their families, predominantly their parents, in the family home. While there is a high demand on health services to provide care to the seriously ill child, the highest burden of care falls on the child's family. The impact of the child's complex and highly technical care needs on the family unit is often not understood. Although health service providers can provide high quality care, at times, they do not fully comprehend the issues of importance to the child and the child's family.

A family-centred model of care, with partnership between health clinicians, the child and family, was developed in response to these circumstances. This model of care provided nursing care to children with serious illness and psychological care to the entire family. The child health organisation clinicians worked collaboratively with external health service providers (health professionals) to provide this care. While it has been operational for some time, this model of care had not been fully evaluated.

Aim: The aim of this research was to evaluate this model of care, which is provided by a child health organisation (program) in New Zealand, in terms of its capacity to provide care to the child with serious illness, the child's siblings, their parents, and the child's external health service providers.

Methodology: Pawson and Tilley's realistic evaluation methodology was used in this qualitative study to understand what worked within the model of care, for whom and in what context. It was critical to understand if the model's psychological and nursing care interventions were useful in easing the burden of care on families.

Methods: Twenty-one participants, namely, one child with serious illness, four healthy siblings, four parents and twelve external health service providers participated in the study. The two methods used for data collection were focus groups with the siblings, parents and external providers, and a semi-structured interview with the child with serious illness.

Analysis: A two-step approach was used. The first step, thematic analysis, provided a systematic method to manage the quantity of participants' data. The identified themes were then analysed in the second step of the analysis—realistic evaluation. The themes were analysed in relation to the realistic evaluation formula of context, mechanism and outcome (C + M = O) in order to understand what mechanisms were triggered, and from what context, in order to produce an outcome.

Findings: Five key themes were identified: 'coping under pressure', 'experience and skill eases the burden', 'adjusting to rare health conditions and new circumstances', 'advocacy and flexibility make a difference', and 'the challenge of asking for help'. Four CMO configurations were identified: 'burden in care', 'psychological distress in care', 'a partnership with families' and 'a partnership with service providers'.

The findings clearly depict what the child with serious illness, parent and sibling participants deemed was critical in order for them to cope as a family. Having skilled knowledgeable clinicians delivering the model of care, which provided both specialist nursing and psychological care, while working in collaboration with external health service providers, reduced psychological distress and the burden of care for families. The child health organisation's clinicians, through their collaborative work with external health service providers, reduced isolation and burden for these providers in their care delivery to children with serious illnesses. Participants chose to engage with the program due to the trusting and respectful relationships developed in regard to the competency of the program clinicians. These attributes were significant for the family-centred care and partnership model for it to be useful for the child with serious illness, their siblings, parents and external health service providers.

The model of care fulfils a societal need for skilled nursing and psychological support within health care services for children with complex health conditions. These findings will contribute to the current literature available in this field, provide opportunity for further development of the current model of care with the potential to inform other similar programs internationally, along with influencing child health policy in New Zealand, to relieve the burden of care on families.

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LIST OF ACRONYMS

ACT	Association of Children with Life-Threatening Illnesses
ACU	Australian Catholic University
APA	American Psychological Association
CEO	Chief Executive Officer
CMO	Context, mechanism, outcome
CMOC	Context, mechanism, outcome, configuration
ED	Emergency Department
FTE	Full time equivalent
HREC	Human Research Ethics Committee
ICU	Intensive Care Unit
NICU	Neonatal Intensive Care Unit
NZ	New Zealand
PHAC	Public Health Advisory Committee
RA	Research Assistant
UK	United Kingdom
UNCRC	United Nations Convention of the Rights of the Child
US/USA	United States of America

GLOSSARY OF TERMS

Aotearoa	New Zealand, land of the long white cloud
Hapu	sub-tribe
Iwi	people, tribe
Kaumatua	older people, elders
Mana	standing or authority
Manaakitanga	cultural and social responsibility
Rangatahi	Māori word for young people
Serious illness	complex health conditions, often reliant on technology to live
Taha hinengaro	the domain of mind and behaviour
Taha tinana	the physical domain
Taha wairua	the spiritual domain
Taha whanau	the family or social domain
Tamariki	children; can be used to include young people
Tāngata whenua	indigenous people of New Zealand
Tapu	a state associated with risk and warranting a cautious approach
Te reo Māori	the Māori language
Te Whare Tapa Wha	Māori health and wellbeing care model
Tika	research design
Tikanga	fundamental custom, principles and values guiding acceptable behaviour
Whakapapa	genealogy, the origins of people and their connection with others
Whānau	immediate and extended family
Wharenui	meeting house
Whare Tapa Wha	a health model based on a 'four-sided' house

RESEARCH OUTPUTS, SCHOLARSHIPS, AWARD NOMINATIONS DURING CANDIDATURE

PUBLICATIONS

Ward, C., Glass, N., & Ford, R. (2015). Care in the home for seriously ill children with complex care needs: A narrative literature review. *Journal of Child Health Care, 19*(4), 524-531. doi:10.1177/1367493514538327.

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CHAPTER ONE: INTRODUCING THE RESEARCH

He aha te mea nui o tēnei ao?

Maku e ki atu - He tāngata, he tāngata, he tāngata.

What is the greatest treasure on earth?

It is people, it is people, it is people.[1]

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[1] Maori proverb from Northland Tribe Te Aupouri (Auckland District Health Board, Tikanga recommended best practice policy).

CHAPTER ONE: INTRODUCING THE RESEARCH

INTRODUCTION

Many children with complex and disabling health conditions live with their parents in the family home. Due to improvements in knowledge, clinical practice and technology, neonates now survive into childhood and go on to live with conditions that once would have been fatal (Allen, 2014; Maddox & Pontin, 2013). These children may continue to require care throughout the different stages of their lives, from infancy to adulthood (Benini, Ferrante, Pozza, Trapanotto & Facchin, 2008).

Children with high health care needs and their families require multiple levels of care that bring them into contact with a range of services (Cohen et al., 2011). There is a high demand on health services to provide care to seriously ill children, but the highest burden of care can often fall on the child's family, specifically their parents (Schuster, Chung & Vestal, 2011). The burden of a child's illness impacts on family dynamics, adult dyadic relationships, finances, employment and the emotional well-being of the whole family (Brown, Gallagher, Fowler & Wales, 2010; Donovan, Williams, Stajduhar, Brazil & Marshall, 2011; Giallo, Roberts, Emerson, Wood & Gavidia-Payne, 2014). The impact of the child's complex care needs on the family unit is often not understood. Although health practitioners can provide high quality care, at times they do not comprehend the issues of importance to the child and the child's family (Kou & Houtrow, 2016).

The aim of this research was to evaluate a model of care provided by a child health organisation (the program) for children with a serious illness, the child's healthy siblings and parents. Clinicians from the program also collaborate extensively with the child's external health service providers (health professionals). The terminology of 'external health service providers' was used in this study to clearly differentiate the role of the program clinicians and the external health service providers. The child health organisation (name withheld) was established in a health district in the North Island of New Zealand in 2004. It was founded on a model of care that provided specialist nursing care and psychological support in a partnership of care with the child or young person with a serious illness (0 to 18 years), their family and their external health service providers. Influential to the child health organisation being founded was the work of the Diana community nursing teams in the United Kingdom

(UK) (Davies, 1999) and the Bristol joint working party (ACT/RCP, 1997) for paediatric palliative care. The Diana community nurse-led services were founded to honour the work of the Princess of Wales and funded by the Department of Health in the UK. The nursing teams worked closely with other agencies and multi-professional teams to provide services to children with life-limiting and life-threatening conditions (Davies, 1999).

As a researcher undertaking this qualitative study, I am not separate to the study. I hold multiple roles in the organisation, namely, Founder, Chief Executive Officer, Nurse Specialist and the researcher of this study. I adopted a reflexive approach to the research, being aware of my thought processes throughout each step and conscious of my own assumptions and knowledge that I brought to the research. I remained conscious of my role as both an insider and an outside researcher. As an outside researcher I did not have the experiences of being a child with a serious health condition, or a sibling, or a parent of a child with a health condition. Therefore, the commonality between participants was outside my own experiences. Yet as an insider researcher due to my different roles within the organisation I understood the culture of the organisation, the values and the rationale as to why children with serious illnesses and their families were referred to the organisation. These issues, and the assumptions that I bring to the research, are explained later in the chapter.

In this chapter, I provide the context and background of the study and introduce the child health organisation's model of care, outlining its origin and how I am associated with it. I acknowledge the importance in this study of both the Māori cultural heritage in Aotearoa New Zealand and the New Zealand child health policy environment. Also included in this chapter is a literature overview of current models of care for the child with a serious and chronic illness. The research aim and research questions are identified. Brief outlines of each chapter complete this introductory chapter.

THE CHILD HEALTH ORGANISATION'S MODEL OF CARE

My nursing career has been influenced by early childhood my experiences. Not having my voice heard at critical times within my childhood and the vulnerability this created, resulted in my resolve to have children's voices at the forefront of their treatment and care requirements. This focus extended to the child's family, as they are central to his, or her, care and development. My own childhood experiences have been a motivating factor to raise the

awareness of what is important to children, specifically in their health care as they are often misunderstood or underestimated.

Before the child health organisation being founded and the start of this research, I believed that care for children with serious illnesses and their families in the community was poorly supported and resourced. Services appeared to be fragmented, poorly coordinated and were minimally collaborative. My assumption was that the child with a serious illness and their family required a model of care that was holistic, family-centred and based on a partnership with the child and family. I believed the child and the family required nursing and psychological (counselling) services to support them from the time of the child's diagnosis and throughout their disease trajectory. I identified the need for a health service in New Zealand that would potentially meet the needs of the seriously ill child and their family, with the aim that this proposed model of care would fill the gap within services at the time.

In line with my vision, in 2004 I established a child health organisation in New Zealand. It is an organisation independent of government funding; it is funded by charitable funds, donations, fundraising and sponsorship. It has been in continuous existence since 2004 and has provided care to over 2000 children with serious illnesses and their families. The organisation's service provision covers a geographical area of 25,000 square kilometres within the centre of the North Island. There are 10 territorial local authorities within this geographical region, seven positioned in rural areas. The child health organisation is situated in the centre of the city within that region and at the commencement of this research was supporting 130 children with serious illness and their families.

My previous experience of working within a Hospice facility for many years influenced the shape and scope of the model of care for children and their families. A child-focused Hospice facility provides an array of palliative care services to children who have a life-limiting or life-threatening health condition, along with support to their families. However, there are many children whose health condition did not fit within the remit of Hospice care, for example, respiratory or neurologic complications of preterm birth or syndromes such as Down syndrome. While those children might be very ill at times, they still can live quite full lives and don't necessarily require palliative care. Also noted was the reluctance of parents to have their child referred to a Hospice facility to receive palliative care, as this was deemed to be giving up hope that their child would continue to live. Some physicians were reluctant to refer to a

Hospice organisation as they considered they were abandoning the child and their family (Hawley, 2017). There was a need for a service that provided a holistic approach to care for all children diagnosed with a serious health condition.

The child health organisation (program) aimed to provide a continuum of care for all children with serious illness from the time of diagnosis, whether that was with hope for cure, or through to bereavement if cure is not attained. For example, when a child was diagnosed with cystic fibrosis at birth, the nursing care and counselling support would continue throughout the child's disease trajectory and may be required off and on for many years. At times, referrals were sent to the program to support parents in the shock and the grief they experienced when finding out their baby had Down syndrome that had not been detected in utero. These families often required support for a shorter period of time as they adjusted to their new situation. They were then linked to other appropriate services specifically related to children with Down syndrome. At other times, referrals were sent to the program specifically to support a child at the end stage of her or his life, through their dying process, managing their symptoms, and providing psychological support to the entire family. If the child died at a young age due to the complexities of their disease, bereavement support was offered to the child's family. Bereavement support continued for as long as the family required this care.

Hence, children and their families may be on the organisation's case load for a short period of time, i.e. weeks, before their file was closed, or dependent on the child's health condition and the stage of the child's health trajectory, they could remain on the organisation's case load for a period of months or years. At times if the child stabilised, their file would be closed and then reopened on their next admission to hospital or when the child had a health crisis. Another example of the child's file being reopened was if a sibling required psychological care or the parents required support as individuals or as a couple to manage their child's health care and the impact on them as a family.

The purpose of this support was to enhance the quality of life for children, young people and their families. Care goals aimed to be holistic based on Durie's (1994) Whare Tapa Wha Māori health model. Professor Mason Durie believed a health model represented the four-sided concept of the basic beliefs of life; Te Taha Hinengaro (psychological health), Te Taha Wairua (spiritual health), Te Taha Tinana (physical health), Te Taha Whanau (family health). This concept of health can be applied to any health issue. Within this holistic health model, children

and young people are part of a wider family unit, or whānau, therefore, the sick child's needs are centred within their family's care.

The vision of the program was to establish a foundation of support for children with serious illnesses and their families. The values of the program included seven overarching themes: resiliency, support, education, respect, collaboration, communication and accountability. Resilience incorporated strengthening the family unit during the time of illness, creating opportunity for meaningful engagement with children, their families, and extended community through focused and committed support. Within this support, respectful honouring of the child and family's rights and beliefs were paramount. This respect included care with the highest degree of dignity, equality and trust and a commitment to the Treaty of Waitangi, recognising the status of Māori as the original inhabitants of New Zealand. Strategies and education regarding the child's health condition and care of the wider whānau incorporated connecting families and agencies through collaborative professional relationships. Listening to the voice of the child with open, honest dialogue in partnership with their families, and taking responsibility for best practice in the overall care was a significant value. The value of accountability and responsibility included transparency in service delivery, fundraising and the cost effectiveness of the program. The overall mission of the child health organisation was to support seriously ill children, their whānau and community during their time of need, through counselling, nursing care and education. The child health organisation's strategic plan is included in Appendix E.

The child health organisation's team worked collaboratively with other external hospital and community organisations such as paediatric and neonatal nurse specialists, allied health workers, and paediatricians. There was a Memorandum of Understanding between the child health organisation and external health service providers to work alongside them in their care of children with serious illnesses and their families. This enabled (for example) the nurse specialist or counsellors to work within the local hospital when called in by the child's health team to provide guidance to the team caring for the sick child and/or to provide support to the child and his or her family.

When this study began in 2011 and when the data collection was collected in 2013, the child health organisation (program) was governed by a Board of Trustees. The board was composed of a lawyer, accountant, paediatrician, marketing specialist, parent representative and a

Kaumatua (Māori elder to provide cultural guidance). The program team at this time was made up of a nurse specialist (the student researcher) with the dual role of CEO, a psychotherapist, one counsellor and an administrator. The program was based in a two-storied house in a residential area of the city, close to the local hospital. The house's rooms were used as meeting rooms, play therapy rooms and offices. Previously, these areas were bedrooms, lounges and a double garage. A homely environment rather than a clinical one was intended to enable children and their families to feel comfortable and specifically for children to feel safe in the knowledge they were not going to have any procedure or treatment carried out at the venue. The house was not a respite place, rather, children and their families attended for counselling or play therapy for approximately an hour at a time.

The program team provided a responsive and ongoing blend of symptom management and psychological care to seriously ill children and their families where the child required ongoing treatment and care in the family home. Symptom management was provided by the nurse specialist in a variety of ways. For instance, this included after-hours callouts to the child's home to administer pain relief or anti-seizure medication to the child and emotional support to distressed parents. These children were existing patients receiving care from the program, therefore, case management plans and medication charts overseen by the child's paediatrician were currently in place in the home. In the hospital setting the nurse specialist was at times called in to provide support to distressed parents and to provide information and advice to the child's health team at the end stage of a child's life. In the child health organisation's house, information and guidance on care management was provided.

Psychological support was provided by the psychotherapist and counsellors to the sick child, the child's siblings and their parents. This psychological support was provided in the child's home if the child was too unwell to attend the program house, or there were issues with the family being unable to access or afford transport. When a child is admitted to hospital, it is a stressful time for both the child and their parents. This is particularly so when a baby spends months in a newborn intensive care unit (NICU), therefore the role of the psychotherapist and counsellors, along with the nurse specialist, is to provide psychological support. Counselling support is also provided to clients at the program house. This could be relationship counselling due to the impact of the child's condition on relational dynamics, or grieving parents requiring grief and bereavement care.

Modalities utilised to provide psychological support to children included developmentally age-appropriate therapies such as art, sandtray, and play and music therapy. These therapies are known to be useful to assist children of all ages to articulate their experiences and needs, and are appropriate when counselling children (Wallace et al., 2014) as they enable children to communicate when oral expression of ideas could be difficult to articulate (Arrington, 2007; Wallace et al., 2014). The children who were offered psychological support either had a serious illness or had a sick sibling.

The role of the administrator was varied. It ranged from welcoming families at the door of the program house and providing them with a drink while they waited for their counsellor or taking calls and taking messages when a distressed parent phoned in to talk to one of the program clinical team members. Her role included applying for funding grants, setting up cash flow reports, payments, writing up reports and involvement in fundraising, along with any daily administrative tasks.

An overview of the program has been discussed, however, the overall program logic model is included as Appendix F. This explains the inputs, such as what the organisation invested. For example, staff, technology, such as computers and phones, funding for at least a year in advance for sustainability and resources, such as cars for the clinicians, resources for art supplies and other modalities utilised with the children and families. The outputs are such as what the organisation was responsible for and to whom are explained. For instance, specialist nursing care to provide symptom management, advice and guidance to sick children and their families; counselling care, whether that be individual, relationship or family therapy; bereavement support, advocacy support, mentoring of health providers and education such as workshops and training days. This care was provided to the child with a serious illness and his or her family, inclusive of extended family. Training and mentoring were provided to external health service providers.

The outcomes, or the impact that occurred as a result of the outputs were classified as short, medium or long-term outcomes. Short-term outcomes included the immediacy of children's symptoms being relieved and families gaining the psychological care they required. It included collaborative care with health service providers which incorporated effective care coordination and communication with families and all providers. The medium-term outcomes incorporated the above attributes of effective collaboration, care coordination and

communication that had been adopted into workable partnerships between the child with a serious illness, their families and health service providers. The long-term outcomes related to the program's strategic direction. This included, children and their families receiving the best optimal care to maintain quality of life, to maintain the current model of care (comprehensive specialist services available throughout the region), be at the leading edge of care models for children with serious illness, actively involved nationally in policy development in children's health care, the program's name to be valued in the community and finally, sustainability of reputation, team and funding. The program logic was in alignment with the organisation's mission statement.

Since its inception in 2004, the child health organisation has evaluated the extent to which the service was meeting stakeholders' needs. Surveys were sent to all families in the organisation's case load to receive feedback on how care was perceived and whether changes were needed to the service delivery. External service providers who had referred a child and family to the organisation had the opportunity to attend focus groups to provide input on the program's activities. All data were analysed and were used to direct the development of the program.

While programs are shaped by a vision of change (Pawson & Tilley, 2004), to continue to develop services incorporating partnership, family-centred care, knowledge, skill and experience, it was important to return to the core theory of why the program was implemented and how it was envisaged to work. Pawson and Tilley (2004) argued, according to realistic evaluation, programs are 'theories', with the cornerstone of the realist project being on how intervention may bring about change (p. 3). Therefore, a more structured, rigorous, formal evaluation by way of a post graduate degree has been undertaken.

The core theory of this evaluation is my belief that children with serious illnesses and their families were carrying the burden of care alone. This included my assumption that their care was fragmented with a lack of collaboration and coordination between providers, along with limited access to resources and funding. As shown in Table 2, I believed a model of care that provided nursing and counselling support in partnership with families and their external health providers would provide better outcomes for children with a serious illness. These improved outcomes would be evident in more effective symptom management and families experiencing a greater level of support.

Table 2: Initial assumption and expected outcomes of program

Fragmented services to children with serious illness and their families - lack of collaboration, coordination, resources and funding		
INITIAL ASSUMPTION	**PROPOSED INTERVENTIONS**	**PROPOSED OUTCOMES**
Model of care that is holistic inclusive of nursing and counselling support in partnership with families and external health providers is required.	Nursing care Counselling support Bereavement support Partnership of care with families and external health service providers	Children with serious illness receiving coordinated and effective care to manage symptoms. Families experienced support as they cared for their child at home. Effective partnerships between families, external service providers and program team to provide better outcomes for children with serious illness and their families.

As I embarked on this research journey, I was conscious of the multiple roles I hold in the organisation, namely, founder, Chief Executive Officer (CEO), nurse specialist, and the student researcher in this study. Therefore, I was mindful of my potential to influence this study. This reflexivity, or conscious awareness of my own assumptions and prejudices and continuous self-introspection (Brannick & Coghlan, 2007; Hibbert, Sillince, Diefenbach & Cunliffe, 2014) is a practice that is present throughout the study. Journal excerpts from a reflective journal are entered throughout the thesis to provide evidence of this reflexive process. While the potential of my influence on the study will be discussed further in Chapter Three, it is important to bring it to the reader's attention at this point.

There is longstanding debate in realistic evaluation, the methodology used for this study, about whether the researcher should be an insider or outsider evaluator (Pawson & Tilley, 2004). Pawson and Tilley (1997, 2004), viewed the knowledge of stakeholders as paramount in both understanding the program and making it work, therefore an insider evaluator engages in developing a shared understanding about program improvements. An outsider evaluator views stakeholders as key sources for eliciting data and will use objective methods

to make judgements about the efficacy of the program (Pawson & Tilley, 2004).

My commitment and sense of urgency to create avenues of change for children with serious illnesses and their families, to improve equity of care and social justice, potentially placed this research at risk. A very early excerpt from my reflective journal explained my motivation for the study:

> *I realise there is an urgency within myself to ensure I am hearing from children and families as I continue to develop the model of care. I want to understand what it is in a model of care that supports families to continue to provide the care to their children who are seriously ill. It is important to hold the concept that the seriously ill child is part of a family unit and therefore we need to understand the strengths and skills of both the child and their family and to walk with them through their health care journey.*
>
> *As I consider what is important to the growth and development of the child health service, it is crucial to first investigate whether the organisation is currently meeting the needs of children and their families. If not, it may be necessary to change the way the service operates to ensure the care is person-orientated and not organisationally driven.*

To minimise the risk of influencing this research due to my familiarity with the program, an experienced research assistant, not known to myself, the participants, or the child health organisation, was employed to undertake participant recruitment and data collection. Data transcripts were anonymised before I received them for data analysis. The participants in the study were advised that I would not be able to identify them. This was aimed at providing the best conditions for the participants to speak freely. Regular dialogue with my supervisors and review of my work assisted in identifying hidden prejudices. One assumption spoken about frequently and interrogated was whether the child health organisation was meeting a need and doing good work as, clearly, I would have liked this to be the case. However, I was also aware that the child health organisation could not develop further and do effective work if there were deficits that were not known to the organisation. Robust discussions about my potential bias and my own reflections kept the awareness of my potential influence on study findings at the forefront of my mind.

The above reflection conveys my deep resolve to ensure I carried out this research with a full commitment to understand participants' perspectives on what was important in a model of

care. This will help scope future growth and development of the child health organisation. The findings will guide the organisation's clinicians and managers to develop services that enhance the provision of quality care to children with serious illnesses and their families. The realistic evaluation will also provide evidence to policy makers and funding bodies and will inform future programs, nursing education and research.

NEW ZEALAND CULTURAL HERITAGE: WHAT THIS MEANS FOR HEALTH CARE

MY CULTURAL HERITAGE

This thesis is undertaken in the context of the Aotearoa New Zealand health service. Aotearoa is the Māori name for New Zealand and its meaning is the land of the long white cloud. While this name is significant, for the purposes of this thesis, I will use the word 'New Zealand'. While Māori are the Indigenous people of New Zealand, as a non- Māori person my relationship with the culture and people is important to my own way of being, my values and my connection with others. Each chapter begins with a Māori proverb that epitomises the influence of Tikanga, or traditional values, that I brought to this research. The values of viewing people as our nation's greatest treasure, of goodwill towards others, of being firmly grounded, of being strong and steadfast and of seeking knowledge were integral aspects to this research.

It was important to acknowledge the Treaty of Waitangi. This was New Zealand's founding agreement signed in 1840 between the British Crown and New Zealand's Māori chiefs (Durie, 1994). The Treaty established the relationship between the Crown and Māori as tāngata whenua (people of the land) - this is inclusive of tamariki (children). There was consensus that the Treaty of Waitangi is relevant in contemporary New Zealand (Ministry of Health, 2014). Durie (1994) stated that the Treaty had profound implications in the way that Māori participated as full citizens in education, health and the economy. Therefore, this agreement has dual obligations to both Māori and non-Māori. The Treaty has a key role in shaping the government's activities as a Treaty partner inclusive of its broad responsibilities to all New Zealanders.

The Treaty was of relevance to this research as the child health organisation is in New Zealand. Therefore, it was important to provide the three key principles that guide the treaty relationship between the Crown and Māori, principles that are particularly relevant in relation to health and disability issues. The first principle is 'participation at all levels', as stated in the

agreement between Iwi (Māori tribe) or Hapu (sub-tribe) and the crown. The second principle is 'partnership in service delivery'; and the third principle is 'protection and improvement of Māori health status, ensuring Māori have the same rights and privileges as other New Zealanders' (Ministry of Health, 2014).

Māori health expert Mason Durie developed the Te Whare Tapa Wha model in 1982. Different parts of a wharenui (meeting house) represent each of four key elements of Māori health and wellness, Taha Tinana (physical health), Taha Wairua (spiritual health), Taha Whānau (family health) and Taha Hinengaro (mental health) (Durie, 1994). These four elements are fundamental in all aspects of health care.

CHILD HEALTH CARE PROVISION IN NEW ZEALAND

The New Zealand Public Health Advisory Committee (Ministry of Health, 2010) had a focus to make a positive difference for children, particularly in child health. Some children and young people in New Zealand however, had needs so high and complex that health, education and social services could not cater for them (Ministry of Health, 2005). These children required services that were specific to their health needs.

Research by the Public Health Advisory Committee (PHAC) identified factors in the poor health status of New Zealand children, including: increasing pressures on families (including financial and time pressures); widening socio-economic disparities; comparatively low government investment in early childhood; lack of coordination of services and of information collection and sharing (Ministry of Health, 2010). A former Children's Commissioner of New Zealand, Angus (2011) believed there were barriers to meeting the needs of sick children in New Zealand. He argued children were invisible, resulting from a lack of political focus on their interests.

Currently in New Zealand, while there are many health and disability services in place, the health sector is under pressure due to significant changes to the population and ways of living (Ministry of Health, 2017). Although life expectancy is increasing in NZ, for those with ill-health and disability there is an increased need for funding and resources. To meet this challenge, a collaborative, coordinated approach to improve service delivery was identified (Ministry of Health, 2017). Recommendations put forward focused on new models that would reduce the

demand for hospital-based services and build personal and community resilience in order to maintain and improve health and wellbeing (Ministry of Health, 2017).

Access to healthcare can be challenging in New Zealand, with children being disadvantaged if their parents are unable to obtain the care they require. Difficulty in accessing healthcare for children may include geographical barriers, particularly when families live in isolated rural regions and services are located far away. Long transport times to access care also have financial implications for families (Bidwell, 2013). Craig et al. (2013), noted that children under the age of 15 were hospitalised at a high rate in NZ, due to financial and location barriers as well as reduced access to primary health care services.

The New Zealand Child Health strategy (Ministry of Health, 1998) reported the government's vision was "all children/tamariki to be seen, heard and getting what they need" (p. 17). However, improvements in services nationwide were required for children to gain the appropriate care, therefore, integrated service delivery is critical to meet the needs of vulnerable children (Ministry of Health, 2017). Government initiatives in New Zealand, such as the Whānau Ora (family health) initiative, were driven by Māori cultural values, providing opportunity to support families, with services that were flexible, culturally anchored and inclusive to whānau. This strategy places family at the centre of decision making (Te Puni Kōkiri, 2016-17). Endeavouring to incorporate a holistic approach in a model of care, Mason Durie's (1994) Te Whare Tapa Wha health and wellness model incorporated all health issues and population groups within the health sector. However, as there is diversity in New Zealand's population, awareness, respect, and the valuing of other cultures needs to be central to a model of care for children with complex needs and their family.

Globally, child health care models remain well behind adult service delivery models (Kossarova, Devakumar, & Edwards 2016; Wolfe & Mckee, 2013). While child health care models are emerging, there is still little understanding of how models of care for children and young people might lead to an improvement in quality of care and health outcomes (Kossarova et al., 2016). Doell and Clendon (2018) argued that, "information sharing, coordination of services, holistic approaches and partnerships have potential to identify whether systems and services are upholding the rights of children and their families" (p.155). The Charter of Children's and Young People's Rights in Health Care Services in New Zealand

(2010) reported an integrated and collaborative service delivery with access to resources was required so children with serious illness would have the best possible care.

The New Zealand Child Health Strategy was formulated in 1998 as a beginning document, along with the Strengthening Families Guidelines (1999, updated 2018) to improve health for children and young people throughout the nation. While further strategies specific to different aspects of health and disability have been created, the New Zealand Child Health Strategy (1998) acknowledged children and young people with high health and disability needs required access to assistance from a range of individuals and agencies. To effectively co-ordinate service delivery a model of care with other health disciplines working collaboratively to produce an inter-sectorial approach was essential, so that children and families were offered a seamless care package. The principles within this strategic document continue to be fundamental in caring for children in New Zealand.

SERVICE PROVISION WITHIN A MODEL OF CARE

Caring for a seriously ill child is complex. Many are highly technology-dependent. Much of the care falls to the parents, with care provided at home. Many international authors stress the need for the seriously ill child and their family to receive a model of care that is family- centred, child and family focused and that incorporates a partnership with health service providers (Bellin, Heffernan, Levy, Osteen & Snyder-Vogel, 2011; Carter, Bray, Dickinson, Edwards & Ford, 2014; Cummings, 2011; Curtis, Foster, Mitchell & Van, 2016; Foster, 2015; Hudson et al., 2014; Kenney, Denboba, Strickland & Newacheck, 2011; Smith, Swallow & Coyne, 2015). These concepts are described in various ways, however, the overarching elements are constant, namely, care for the entire family, not just the child (Shields et al., 2012), understanding the family's view of care and treatment (Santos, Tosco, Collett & Reichart, 2016), understanding the child's and family's psychosocial health (Bellin et al., 2011) and provision of support for parents in their role as carer (Arabiat, Whitehead, Foster, Shields & Harris, 2018; Grimheden, Lindqvist, Bylund-Grenklo & Sandgren, 2017; Smith et al., 2015; Whiting, 2013). However, Foster (2015) reported, that despite many years of "ongoing research, education and theory into the development, translation and impact of family-centred care" (p. 4), there continued to be little evidence of the effectiveness of this care for children, parents and providers.

Berry (2015) believed that, as the field of children's complex care moves forward, there was a unique opportunity to determine how to best to provide for them. Berry et al. (2015), identified the need in the community for specialised service providers, with the appropriate skills, to walk alongside these families to meet their care needs. Law, McCann and O'May (2011) acknowledged this level of community care required both generic and specialised knowledge and skills; however, these might not be available, while Carter et al. (2014), reported there is much to understand about how to meet parents' care needs. It is known that parents often feel stressed and overwhelmed with the technological and emotional load that their seriously ill child brought into their lives (Carter et al., 2014).

More recently, Curtis et al. (2016), reported that a model of care that reduced parental anxiety required effective communication and continuity of care between providers across the whole span of care. This would enable parents to build stronger relationships with their clinicians and gain more effective support (Hill et al., 2018). Parents gain confidence in their child's clinicians only if communication is achieved, this confidence is also associated with a belief that the clinicians' care is safe, competent and holistic, and will meet their child's needs (Horridge, 2011; Rushton et al., 2006).

In terms of care for the child with complex health needs, the concept of partnership of care and family-centred care has evolved over the last decade (Jolley & Shields, 2009; Pordes, Gordon, Sanders & Cohen, 2018). Perry et al. (2017), noted that the focus of care has often been on technical aspects rather than on the strategies and support systems that are required to strengthen health care in the community. There is more development required to meet the needs of this population group with partnership models that are more inclusive of parents and adequately resourced and supported (Cohen et al., 2011; Kuo & Houtrow, 2016; Smith, Cheater, Bekker & Chatwin, 2013).

Partnership approaches to care, however, have had little research on how they were implemented across different service settings, and particularly with families who may be vulnerable (Rossiter, Fowler, Hopwood, Lee & Dunston, 2011). Despite literature being available on the ideal models of family-centred care or partnerships in care (Curtis et al., 2016; Fowler et al., 2012; Pordes et al., 2018; Rossiter et al., 2011), evaluations of these models in terms of their effectiveness in everyday practice have not been published. Smith et al. (2015), concept synthesis reviewed 30 studies on family-centred care and partnerships in care to

identify attributes and antecedents of these models. They identified a lack of clarity in roles, entrenched ways of practice of health professionals and a lack of guidance which provided insight into what may have been barriers to evaluations being undertaken on these models of care.

In relation to the current study, and evaluation of the child health organisation's model of care, this understanding of the preferred models of care provision and the difficulty still faced by parents in their search for meaningful support is informative. This will be explored further in the literature review in chapter two.

THE RESEARCH PROBLEM

Child health care for children with serious illnesses in New Zealand can be fragmented, lacking coordination and collaboration (Bidwell, 2013; Cumming, 2011), potentially leaving families unsupported in caring for their child who is seriously ill. Models of care that are family-centred and focused on partnership can potentially reduce this burden and improve service delivery (Gremheden et al., 2017).

The model of care under evaluation in this study has not been formally evaluated. Therefore, there is no evidence that the program is creating 'social betterment' (Pawson & Tilley, 2004, p. 2) for the child and family. For instance, is the child experiencing a better care regime, is the family experiencing less burden, and is there a sense of partnership between parents and clinicians? Currently it is not known if the model of care is useful, and if so, in what ways, for whom and in what contexts.

THE RESEARCH AIM

The aim of this research is to evaluate a model of care provided by a child health organisation (program) in New Zealand in terms of its capacity to provide care to the child with serious illness, the child's siblings and parents, and the child's external health service providers.

RESEARCH QUESTIONS

In order to address the research aim, this study seeks answers to the following questions.

1. How does the program meet the needs, or fail to meet the needs, of the child with

serious illness, the child's siblings and parents, and external health service providers?

2. In what circumstances and through what mechanisms does the program meet the needs, or fail to meet the needs, of the child with serious illness, the child's siblings and parents and external service providers?

SIGNIFICANCE OF THE RESEARCH STUDY

The child health organisation's program is embedded in the social system of child health care in New Zealand. An evaluation of this program was important in order to understand if the program had the capacity to meet the needs of children with serious illnesses, their families and their external service providers. For instance, currently families, specifically parents, have the responsibility to care for their child's complex care needs at home. External service providers must develop strong relationships with the family to ensure that they are accessing the appropriate care and resources and providing safe and effective care in the home. Therefore, it was critical to understand if the program's specialist nursing and psychological care interventions were useful to the child with serious illness and their families, and if external service provider's collaborative relationship with the program was useful in delivering care to the child and their family. The current evaluation of the program will provide evidence that will guide future program developments.

It was appropriate to actively involve all stakeholders to access this information on what worked or did not work, for whom and in what circumstances (Pawson & Tilley, 1997). This evaluation will provide an insight into whether the program's specific interventions of nursing and psychological care have triggered change. This will be located in the reasoning of the participants in response to the opportunities provided by the intervention as to whether they were able to actively engage with the program that led to the outcomes (Pawson & Tilley, 2004). For instance, the program's interventions of psychological and nursing care may be available to families; however, whether the interventions are engaging and hold a potential for change is quite another thing. As the program is within a social system, external factors may also impact on the delivery of the program, such as unanticipated events, organisational imperatives and political change (Pawson & Tilley, 1997, 2004). This will be discussed further in Chapter Three.

An expected outcome is that the findings from this evaluation will be used to inform, policy decisions within New Zealand, education and further research. As such, this research could contribute to change within the wider social system for children with health and disability conditions and their families who provide care at home. Furthermore, the outcomes of this study have the potential to inform other similar programs internationally. Combinations of attributes in place for a program to be effective provide the potential for transferability to other programs on the basis that concepts may link to other program theories. This will be discussed more fully in Chapter Six.

THESIS STYLE AND PRESENTATION

This study has been presented in accordance with the Australian Catholic University's Guidelines on the Preparation and Presentation of a Research Doctoral Thesis for examination (Australian Catholic University, 2018).

While two journal articles from this study were published in peer-reviewed scholarly journals, they are included in the Appendices rather than embedded in the thesis.

THESIS OVERVIEW

This chapter introduced the study and provided an explanation of the context of this research. The background to the study was introduced with the rationale of the implementation of the child health organisation's model of care. The organisation's origin and my association with it were explained. The importance of both the Māori cultural heritage and the child health policy environment in New Zealand was explicated. The research aim and research questions were identified.

In Chapter Two, a literature review of the care of children with serious illnesses, their families and models of care that are deemed beneficial to this population group is presented.

Chapter Three presents the theory driven realistic evaluation methodology and design. The research questions are identified as they are central to the evaluation. The realistic evaluation methodology and sampling, data collection and data analysis methods are explained. Ethical issues are also outlined and addressed before an explanation of the data analysis is provided.

Chapter Four reports on the thematic analysis as the first step of analysis. The first research question of whether the program had the capacity to meet the needs of families and external service providers caring for a child with serious illness is answered.

Chapter Five presents the findings from the Realistic Evaluation analysis. Four linked concepts explain the analysis of participants' perceptions of the program through 'context, mechanism, outcome' configurations.

Chapter Six discusses these findings in relation to the literature. The findings are compared to contemporary evidence within the literature that are relevant to health care for children with serious illness and the support required for those providing the care. The discussion considers the study's findings in relation to the existing knowledge and the contribution the study makes to extend this knowledge.

Chapter Seven concludes the thesis, with an overview and a consideration of whether the study met the research aim and addressed the research questions. I discuss some of the limitations of my study. Implications of my research and whether these findings contribute to further development of the program and policy making in the context of child health care in New Zealand for children with serious illness are discussed. Recommendations for further research conclude this chapter.

THESIS FORMATTING STYLES

The styles used throughout this thesis are consistent with the sixth edition of the Publication Manual of the American Psychological Association (APA) (American Psychological Association, 2010).

The main body of text in this thesis is written in '12 point Calibri' font and text within tables is reduced to '11 point Calibri' for ease of reading. The main header pages for each chapter are written in Heading 1 'CALIBIRI LIGHT 18' with Te Reo Māori proverbs written in 'italic 14 point Calibri' font. The headings throughout the text are written in Heading 2 'CALIBIRI LIGHT 14' with sub-headings Heading 3 in 'CALIBIRI LIGHT 12', and Heading 4 in 'Calibri light 12 italic'.

Excerpts from an earlier reflective journal in this study is written in '*12 point Calibri font*' as are the participant data excerpts in the findings chapters, four and five. The excerpts of participant's data will not always conform to the conventional rules of English grammar, due to my endeavour to retain the original structure and meaning of the participants' voices.

Words such as, whanau, tamariki and wairura from Te Reo, the Māori language, are interspersed throughout the study.

CHAPTER SUMMARY

This first chapter introduced the study and provided explanation of the context of the New Zealand culture for this research. The system of child health, specifically for children with serious illnesses, is fragmented and lacks both coordination and collaboration. Families feel burdened by the care they provide to their sick children in their homes. My initial assumption was that a model of care that was family-centred, was in partnership and provided specialist nursing and psychological care would optimise the care to children with a serious illness and their families. The child health organisation model of care (the program) was implemented to meet this population group's needs. However, since it's commencement in 2004, there has been no formal evaluation process to determine if the program is useful for families and their service providers, or even to ascertain if the nursing and psychological care is detrimental to their care.

Hence, this realistic evaluation undertaken via way of post graduate research provides the rigour and structure required to identify what worked or what didn't work, for whom and why. Participants were clients of the child health organisation, namely, seriously ill children, siblings of seriously ill children, parents and external (to the program) service providers.

Chapter Two reviews the literature on the child's serious illness, parents as care providers and health service provision within the acute setting. This literature review will contribute to realistic evaluation of a model of care that is useful for children with serious illness, their families and the external service providers overseeing their care.

CHAPTER TWO: CURRENT LITERATURE AND APPROACHES TO CARE

He taonga rongonui te aroha ki te tāngata;

Goodwill towards others is a precious treasure [2]

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[2] Maori Proverb - Whakatauki aroha - Massey University

CHAPTER TWO: CURRENT LITERATURE AND APPROACHES TO CARE

INTRODUCTION

Chapter One outlined the study and provided an explanation of pertinent contextual factors. First, parents were required to assume responsibility for the care of their child with serious illness in the family home. Second, the child with serious illness attends a variety of health services throughout the course of their life. Third, the child health model of care that was established in 2004 in New Zealand has had no formal evaluation. The aim of this research is to evaluate the model of care provided by the child health organisation (the program) for the child with a serious illness, the child's siblings and parents, and external health service providers.

This chapter provides a narrative literature review regarding the child with serious illness, parents as providers of care, and service provision within the acute hospital setting. The literature review was initially undertaken in 2013 and included articles published up to 2013 and (See Ward, Glass & Ford, 2015, Appendix D). Due to the time frame of the study (commenced 2011 and completed 2019), a further review of the literature published up until October 2018 is provided.

METHODS FOR LITERATURE SEARCH

The first stage of the search strategy was a search of electronic databases, namely, Academic Search, Cumulative Index of Nursing and Allied Heath Literature (CINAHL) Complete, Health Source: Nursing/Academic Edition, Medline Complete and Psychology and Behavioural Sciences Collection. Inclusion criteria for the search strategy were English language, peer reviewed publications from the years 2007 - October 2018, and seriously ill children up to 18 years of age.

The search history is shown below in Table 3. The key search phrases and terms used in the first search were, "life limiting", "life threatening", "life shortening", chronic, terminal and palliative, along with truncated terms child* and teenage*, and other terms adolescent, youth, boys and girls. Search number two used the phrase "complex health" and search number three used truncated terms parent*, care*, mother*, father* and famil*. Searches one, two and three returned many articles. Search number four used the phrase "technology

dependent" and returned 331 articles, while the term technology dependent returned many more articles for search number five. Combining searches one, two, three and four/five, however, proved unproductive, as only four and 12 articles respectively were returned. Further investigation identified that the term technology dependent had erroneously limited the number of returns, therefore the term was removed for the final search.

The final search covering literature for the period 2007 – October 2018 used searches one, two and three to return 108 articles. It can be seen in Table 3 that 87 duplicates were removed in this final search.

Table 3: Search strategy for the literature review (timeframe2007 – October 2018)

Search	Search terms	Academic search complete	CINAHL complete	Health Source: Nursing/ Academic edition	MEDLINE Complete	Psychology and behavioural sciences collection	Total (inclusive of duplicates)
1	"life limiting" OR "life threatening" OR "life shortening" OR chronic OR terminal OR palliative AND child* OR teenage* OR adolescent OR youth OR boys OR girls	56,101	26,419	12,308	110,440	4,574	209,842
2	"complex health"	919	951	340	1,360	106	3,676
3	parent* OR care* OR mother* OR father* OR famil*	2,446,190	1,038,386	460,629	1,902,045	152,222	5,999,472

Search	Search terms	Academic search complete	CINAHL complete	Health Source: Nursing/ Academic edition	MEDLINE Complete	Psychology and behavioura l sciences collection	Total (inclusive of duplicates)
4	"technology dependent"	114	75	24	110	8	331
5	technology dependent	108,620	1,168	3,393	52,505	1,006	166,692
6	S1 AND S2 AND S3 AND S4	1	0	1	2	0	4
7	S1 AND S2 AND S3 AND S5	3	2	3	4	0	12
8	S1 AND S2 AND S3	54	37	36	54	14	108 (87 duplicates removed)

The PRISMA flowchart below in Figure 1, shows the literature identification and screening process of the articles identified in the literature search above ($n = 108$). Three duplicates were identified and removed during screening of titles and abstracts. Full text articles were reviewed for eligibility, it was found that 27 did not relate to a child's serious illness, and 18 did not relate to care provision. Fifty-seven articles remained for inclusion in the literature review.

Figure 1: Prisma flowchart of literature search (Timeframe: 2007 – October 2018)

Identification

Records identified through Advanced Search, CINAHL Complete, Health Source: Nursing/Academic Edition, MEDLINE Complete, Psychology and Behavioural Sciences Collection
(n = 108 after removal of 87 duplicates)

Screening

Titles & abstracts screened

Removal of duplicates (n = 3)

Full-text articles assessed for eligibility (n = 105)

Removal due to mismatch of study participants and/or definition of serious illness (n = 45)

Eligibility

Full-text articles assessed for inclusion (n = 60)

Removal of book chapters and opinion pieces (n = 3)

Included

Articles included in literature review (n = 57)

The second stage of the search strategy involved a manual search of literature, with the use of snowballing (searching references in reference lists), along with the use of Google Scholar alerts. All cited references of relevant articles were searched, as well as conference abstracts, and unpublished theses. An additional eight articles were included in the literature review. The final total for the literature review (2007 – October 2018) was 65 articles. The literature review identified three key themes, namely, 'children with a serious illness, 'formal service provision within the acute hospital sector' and 'parent as care provider'.

CHILDREN WITH A SERIOUS ILLNESS

Historically, children did not commonly survive serious illness or birth trauma. Over the last three decades, survival rates have improved due to advances in medical knowledge and the development of improved practice and sophisticated technical equipment (Elias & Murphy, 2012; Kuo & Houtrow, 2016; McIntosh & Runciman, 2008; Malatest International, 2016). In contemporary neonatal and paediatric care, although a child now survives the early health challenge, they often experience ongoing problems related to their initial illness and/or their intensive treatment regime (Elias & Murphy, 2012; Kuo & Houtrow, 2016; Pordes et al., 2018; Schuster et al., 2011). The key points raised in the published literature are presented below, namely, children's complex medical conditions and symptom management, and the child's reliance on technology for survival.

CHILDREN'S COMPLEX MEDICAL CONDITIONS AND SYMPTOM MANAGEMENT

The literature portrays serious illness in childhood as 'complex', 'life limiting' or 'life-threatening' illness, all of which require paediatric specialty care in a tertiary centre (Elias & Murphy, 2012; Hain, Heckford & McCulloch, 2012; Kuo & Houtrow, 2016; Tamburro, Shaffer, Hahnlen, Felker & Ceneviva, 2011). A tertiary treatment centre is a specialist health care facility that provides advanced medical procedures and treatments. While serious illness in childhood encompasses many conditions, the literature documented specific diagnoses such as respiratory or neurologic complications of preterm birth, and disorders of congenital, genetic, metabolic, and neurologic origin. Conditions such as mucopolysaccharidoses, Batton disease, leukodystrophy, cystic fibrosis, cerebral palsy and muscular dystrophy, the sequelae

of severe infections and trauma and malignancies were also threaded through the literature (Elias & Murphy, 2012; Malcolm, Forbat, Anderson, Gibson & Hain, 2011; Murphy, Carbone & Council on Children with Disabilities, 2011; Tamburro et al., 2011). While Elias and Murphy's (2012) clinical report addressed home care for the child with complex health issues after transition from hospital, the report also provided an in-depth description of the complexity of a child's health condition, specifically if they were technology dependent. The purpose of this clinical report was to act as a guide and resource for paediatricians responsible for the overall care of these children, when caring for children with complex conditions in the home (Elias & Murphy, 2012).

Over the last decade, diagnostic foetal surveillance has advanced so that now at the 12-20 week scan cardiac and chromosomal conditions, and rare congenital anomalies are detected, for which further testing is available (Farquhar, Arroll, Sadler, Stone & Masson, 2012; McKenchnie, Pridham & Tiluczek, 2015). Marokakis, Kasparian and Kennedy (2016) reported in their systematic review, this period created distress for parents with fear and anxiety prevalent. While parents in this review reported they preferred counselling support as soon as possible after the diagnosis, these authors argued there was further research required to understand the impact of this prenatal counselling on other psychological outcomes (Marokakis et al., 2016).

In some instances, parents will continue the pregnancy knowing that the neonate may have high health needs and an uncertain future (McKenchnie et al., 2015). McKenchnie et al. (2015), interviewed pregnant women (n =37) and male partners of pregnant women (n = 12) following the diagnosis of a foetal anomaly. These authors wanted to understand how parenting develops in the heart and mind of expectant parents in the context of foetal anomaly. Expectant parents in this study reported three specific trajectories, namely, "claiming the child as one's own, delaying the connection to the foetus, and doing the routine of pregnancy" (p. 1196). These authors reported that parents' trajectories could influence the level of resilience that parents bring to the care of their baby. When these babies are born, they spend considerable time in the newborn intensive care unit (the NICU) due to the complexity of their health conditions or premature birth. Once the baby is stable, transfer of care to the parents

is actioned as they transition home to the community. However, due to the prematurity complication of a baby's compromised lungs and at times dependence on oxygen, or a severe neurologic condition, there may be many hospitalisations over the first few years of their lives (Cohen et al., 2011). This is particularly so over the winter months when these medically fragile children are susceptible to childhood illnesses that can be life-threatening.

Overall, serious childhood illnesses were viewed as highly complex (Elias & Murphy, 2012; Kuo & Houtrow, 2016; Pordes et al., 2018), they were often rare, were characterised by a variable trajectory with prognostic uncertainty and possibly the child's early death (Benini et al., 2008; Elias & Murphy, 2012; Whiting, 2014). These children were well known to service providers due to their usually frequent and lengthy hospitalisations with a high resource requirement (Hudson et al., 2014; Kuo & Houtrow, 2016). The vital dependence on technology and others for functioning means these children often referred to as being medically fragile (Kuo & Houtrow, 2016). The medical fragility and technology dependence of these children were components that added to the complexity of care that their parents were expected to provide within the home. As noted by Simon et al. (2010), these children returned home to their parent's care, often before their symptoms were resolved, and their complex care and symptom management were typically the responsibility of their parents. Cohen et al. (2011), reported the complex intensive needs of these medically fragile children were not easily met by current models of care. They recommended sustainable evidence-based models of care to be delivered by health providers who were specifically trained to meet the needs of medically fragile children to provide better outcomes and enhanced quality of life for this population group (Cohen et al., 2011).

Malcolm et al. (2011), surveyed United Kingdom families (n = 16) and health professionals (n = 43) predominantly nurses, regarding symptom management for the seriously ill child. Mucopolysaccharidoses, Batten disease and leukodystrophy, all rare conditions, were found to be commonly reported as requiring complex symptom management. There was a requirement for a high level of clinical evidence to manage symptoms, and a highly unpredictable and changeable nature of symptoms as the conditions progress. Of particular note was the challenge to manage changes in the child's seizure activity during disease

progression. Also noted were changes in cognition, vision and other sensory changes, all of which were challenging to manage. Malcolm et al. (2011), argued that it can also be difficult to access information on symptom management when the disease trajectory differs from child to child. Symptoms for children who have life-limiting conditions may include psychological or existential aspects, this can be difficult to assess if children are unable to articulate their needs verbally. Malcolm et al. (2011), reported these symptoms could be related to the child's condition or from the side effects of the treatment they received. Their qualitative study was the first phase of identifying what rare life-limiting conditions families and health service providers deemed a priority for further investigation, specifically in relation to symptom management. However, these authors cautioned the need to listen to a family's perspective rather than being overshadowed by their health professional's views (Malcolm et al., 2011). There was a delicate balance required in treating a child's condition and managing their symptoms that was not impactful on the child's quality of life and that of their family.

Benini et al. (2008), earlier commentary on paediatric palliative care highlighted the sick child's highly challenging symptom management regimes. These symptoms often had an impact on their general wellbeing and quality of life, with 90% of these children experiencing generalised suffering and more than 70% suffering pain. These authors reported that although there were options available to manage symptoms, the application of daily symptom management was often inadequate. A responsibility of medical teams was to find the best way for children to live with their conditions. They argued that, despite new advances in medicine and technology, the outcome for the child was not necessarily beneficial; some children live with severe conditions that caused them prolonged suffering (Benini et al., 2008). This aligned with Larcher, Craig, Bhogal, Wilkinson and Brierley's (2015) document outlining a framework for ethical decision making when it comes to limiting life-sustaining treatments for children with life-limiting or life-threatening illnesses when the outcome may no longer be in the child's best interest. Despite the key roles of medical teams to alleviate suffering, reinstate health, support life and avert disease, Larcher et al. (2015), argued that all health professionals have a duty of care to abide within a legal framework to do no harm and to put the child's best interest at the forefront of care. Determining what the child's best interest is can be difficult, specifically when a child is unable to speak for themselves. Therefore, discussion

involving all parties was critical to ensure informed decisions were made regarding treatment and symptom management which was beneficial to the child and his or her family (Larcher et al., 2015).

THE CHILD'S RELIANCE ON TECHNOLOGY FOR SURVIVAL

Reliance on technology is common in seriously ill children. This technology compensates for the child's loss of a vital bodily function (Spratling, 2015), such as feeding and breathing and other everyday needs (Hobson & Noyes, 2011). If the technology fails in some way, the child can suffer adverse health consequences and will often require hospitalisation (Elias & Murphy, 2012). Spratling's (2015) integrative review of 26 articles identified the terminology of technology and complex care were utilised in reference to the level of skill and care that nurses and families required in care provision. They deemed this terminology to be critical components in a definition when a child or young person was technology dependent (Spratling, 2015).

Elias and Murphy (2012) reported, children reliant on medical devices such as "pacemakers, ventriculoperitoneal shunts, intravascular catheters, colostomies and other devices" (p. 1001), are at risk of complications related to their devices, and therefore require close monitoring. Technologies commonly utilised for seriously ill children included assisted enteral or parenteral feeding pumps, intravenous pumps, respiratory ventilators, tracheotomy equipment and respiratory suction machines (Elias & Murphy, 2012; Hobson & Noyes 2011; Shuster et al., 2011). Long-term or permanent hospitalisation is no longer an option due to the number of children with high complex needs and the longevity of these children's lives. Therefore, due to limited public resources, this level of care is now provided in the family home (Shuster et al., 2011). Managing these technologies in the home has become the norm in parents' advanced care provision to their seriously ill children. However, parents required specific training to manage these intensive cares. For instance, it was equally important to know how to suction a child's tracheotomy as it was to determine when a child required this suctioning (Elias & Murphy, 2012). While parents became skilled in managing their child's medical technology, this made it challenging for others to help care for the seriously ill child. Other family members were not so skilled and confident; therefore the responsibility of the

care management was on the parent most skilled which created the dichotomy of not only being the child's parent, but also becoming his or her nurse (Whiting, 2014).

While much of the literature on children's serious illness reported the advancement of technology in prolonging, sustaining or maintaining life (Elias & Murphy, 2013), arguably as already stated, it is not always in the child's best interest. Larcher et al. (2015), provided a guiding document on the ethical and legal framework in decision making on life sustaining treatments for those children who have life-limiting or life-threatening illnesses. Their document followed two previous editions produced by the Royal College of Paediatrics and Child Health, originally in 1997 and reviewed again in 2004. The intent of this document was not to be prescriptive in decision making, rather to provide guidance on what might be the best interest of the individual child, recognising the complexity of children's health conditions. Pre-term babies are now surviving from 22 and 23 weeks with reliance on technology for months if not years, this along with the advanced gene therapy and paediatric surgical procedures contributes to the complexity of decision making. Therefore, the use of technology may at times be questioned for those children living with life-limiting or life-threatening conditions. It may be inappropriate for both the child and their family, if the child's pain and suffering are prolonged. Larcher et al. (2015), document provides guidance for healthcare teams regarding parents and family's needs in relation to decision making.

As the child ages, serious illness puts them at risk of a difficult passage through physical, psychosocial and other developmental stages. They require many specialist physician and allied health services, for example, speech, physical and occupational therapies, mental, developmental and behavioural health services (Shuster et al., 2011). It is important to define what a child's developmental concerns are to understand whose responsibility and specific roles are the families, the primary health care teams, the home care agency or specialist service (Elias & Murphy, 2012). Shuster et al. (2011), article described children's health care needs in the United States of America specifically regarding responsibilities of parents, employers, and the existing network of the federal, state and family leave benefits. Due to the complex care needs of children, parents were expected to manage technology that once would have only been available in an inpatient setting. They reported that mothers in

particular often gave up their careers to care for their children and managing technology was an expected aspect of the care. While parents picked up a great share of the health care responsibilities, described as 'shadow care' (Shuster et al., 2011, p. 92), this was largely not acknowledged by health providers or the State. Schuster et al. (2011), found that health providers were reliant on this shadow care, however, to provide the care; parents were reliant on ad hoc employment arrangements and family leave benefits. This placed a strain on parent's energy and finances. Recommendations proposed from Schuster et al. (2011), were to implement a national family leave policy that would protect the interest of not only the parents but also their employers. It is clear that the child with serious illness can experience complex health conditions and distressing symptoms that are disruptive to everyday life, economic security and future plans. Within the New Zealand context, when a child has a disability or serious health condition parents can access the child disability allowance from Work and Income New Zealand. This allowance is not tested on the parent's income. Specific child health disorders may be included in accessing the child disability allowance, such as degenerative neurological conditions, for example, Duchenne Muscular Dystrophy, or different syndromes. However, the diagnosis alone does not warrant this level of support from government and extra financial assistance can be difficult for families to access. The child disability allowance can contribute to prescriptions, power and heating and travel to medical appointments. General practice services are now free for children in New Zealand (except for afterhours) and public hospital care is free. However, New Zealand does not have access to a national Medicare such as Australia or the United States.

FORMAL SERVICE PROVISION: THE ACUTE HOSPITAL SECTOR

Caring for a child with serious illness is complex and the responsibility of care falls primarily to parents, with care provision occurring in the family home. Traditionally, in previous years, if these children did survive their health conditions, they would be hospitalised for weeks or months at a time. In earlier decades, New Zealand nurses had a greater role in providing this care to seriously ill children. Up until the early 1970s, nursing training was provided within the hospital with a senior nurse responsible for supervising students on the ward when working with patients. In the 1970s and 1980s nursing training was moved from hospitals to

universities or polytechnics, hence removing student nurses from being positioned within the hospital wards. This international shift of nursing training moving to tertiary institutions (Curtis et al., 2016) has had an impact on care of children. This paradigm shift, along with the advances in paediatric medicine and surgical aspects of care has had significant impact on what is currently expected of parents in their child's care within the hospital setting. Parents now have a greater role in partnering with their child's health service providers to deliver care to their children who have medically fragile conditions (Kuo & Houtrow, 2016). This has been a shift for both the parents and the health service providers as clarity around what this partnership involved could be misunderstood and difficult to implement (Curtis et al., 2016). It is instructive at this point to review the literature on care provision to the seriously ill child within the formal health service. The highly medicalised care environment is presented below.

The seriously ill child's care environment in the hospital is highly medicalised - the child is often dependent on multiple technologies, their illness and symptom management is complex and they need highly skilled health carers (Berry, Hall, Cohen, O'Neill & Feudtner 2015). However, the conventional health system is neither structured nor resourced to meet these children's needs (Berry, 2015; Berry et al., 2015). There continue to be deficits in health care services where "bureaucratic and system interests have been privileged over the needs of children and young people" (Carter et al., 2014, p. 14), a finding supported by Kuo et al. (2014), who note that children with complex health conditions are susceptible to inequalities in health and health care access. Kuo et al. (2014), secondary analysis of a national survey of children with special health needs (2005-06 and 2009-10) found that children with high medical complexity are less likely to have their needs met, regardless of their ethnicity, or their social situations.

Health providers' care of children with serious illness requires comprehensive assessment of their physical, psychological, and spiritual needs and this necessitates a multi-disciplinary approach incorporating the child and their family (Hewitt-Taylor, 2012; Michelson & Steinhorn, 2007; Smith et al., 2015). Confidence in service providers' knowledge and skills is critical to whether parents experience support in their own home-based care role and are included in a partnership of care (McIntosh & Runciman, 2008). In their qualitative study McIntosh and Runciman (2008) were specifically interested in the role of partnership when

caring for children with special needs in the home. Key questions in the research were the extent to which technical advice and expert guidance were beneficial, and the extent to which the manner of service provision enabled high quality care. Two evaluations of paediatric services in 2001 and 2004 were undertaken in different locations of the Scottish Health Board area to answer these questions. The children in each evaluation group (respite care and complex care) had life-limiting and life-threatening conditions. These authors found that trusting relationships developed between the nurses and families, specifically by "critical listening, respect, sharing of expertise and empathy for parents and children" (McIntosh & Runciman, 2008, p. 723). McIntosh and Runciman identified communication as key within the partnerships, along with choice about care interventions and advocacy by health professionals of parents' needs. Kuo and colleagues (2014) identified that for children with medical complexity to have optimal care, effective coordination across the continuum of care was required, whether this was in a hospital setting, or within the home.

Coyne and Cowely's (2007) early study of parents' participation in hospital care reported the swing from parents being excluded in their child's care to a circumstance that puts them firmly in a lead care role. More recently, Cady and Belew (2017) in their study identified families in fact provided care coordination. However, they often learnt these skills from other parents and figured things out on their own, while also experiencing many unmet needs. Cady and Belew's qualitative study (2017) in Minnesota evaluated a program that was funded to test primary care-specialty care coordination partnerships for children with medical complexity. The program model was established to bridge the gap within primary and specialty care, with medically fragile children receiving care from at least three specialists. Four focus groups were held to gain parent perspectives on the care coordination services. The unpredictable nature of their children's complex medical conditions resulted in only two parent participants at each focus group (n = 8). The eight parents represented seven children, mothers (n = 5), fathers (n = 3). These parents reported the greatest challenge in care coordination was communication gaps with their providers. When this was their experience, they then assumed the responsibility to share information across providers and different settings. This finding supports Shuster et al. (2011), earlier study of parents' care of their child with serious illness. As noted by Shuster et al. (2011), health service providers in acute health services can be

managing the care of many acutely sick children and are therefore reliant on a child's parent being able to stay by the bedside to provide the child's care. Also noted by Shuster et al. (2011), was the lack of appropriate support services in the community which added significant hardship and burden to parents.

Cady and Belew (2017) and Shuster et al. (2011), believed there is at times a rupture in the relationship between families and health providers brought about by misunderstandings and poor communication. The child with serious illness has a care regime that is intensive and highly technical, the poor communication adds to parents' care burden. The literature highlighted the challenge to find a way to gain the support required from health agencies that is beneficial to the sick child and contributes to the child and the parents' quality of life.

PARENT AS CARE PROVIDER

Although the seriously ill child has frequent and sometimes lengthy hospitalisations, the responsibility of care and decision-making falls to the parents in the family home (Cumming, 2011; Grimheden et al., 2017; Hatzmann, Peek, Heymans, Maurice-Stam & Grootenhuis, 2014; Lindahl & Lindblad, 2011; Maddox & Pontin, 2013; Mendes, 2013; Shuster et al., 2011; Smith et al., 2015). The key points raised in the literature are presented below, namely, the parent/sick child dyad, the parent/well sibling dyad, health services support for parents and the need for a partnership of care.

THE PARENT/SICK CHILD DYAD

All children are dependent on their parents or caregivers to provide care, however, when that child has a serious illness, there is a blurring of the normal activities of care with the role of parent also incorporating the role of care provider for their child's health needs (McCann, Bull & Winzenbeurg, 2012; Schuster, et al., 2011). Due to the complexity of their child's health, parents can feel uncertain, powerless, frustrated and panicky; emotions that often influence their decisions regarding care (Hudson et al., 2014). Even normal day-to-day activities, such as washing the child's hair, can cause uncertainty for parents. They can be fearful that any activity has the potential to trigger symptoms and they are hypervigilant about the child's condition (Hudson et al., 2014).

Hudson et al. (2014), undertook a descriptive qualitative study of parents' (*n* = 18) and health providers' (*n* = 24) perspectives of the factors that precipitated admission to hospital of children with complex care needs. These children have frequent admissions to hospital, often in acute situations. Hudson and colleagues were specifically interested in the protective and risk factors that influenced children's admissions to hospital. Their study was guided by Bronfenbrenner's social ecological model (cited in Hudson et al., 2014) in recognition there are many components influencing an individual, such as family, culture and society. These authors explained risk factors as the features of an individual or environment associated with increased likelihood of a specific undesirable outcome, while protective factors were explained as those features associated with a lesser likelihood of an undesirable outcome. Hudson et al. (2014), found that protective factors cushioned the effect of risk factors on outcomes. While health service providers and parents in this study were often in agreement about risk and protective factors, the frustrations of ineffective communication experienced by both parties contributed to risk factors. Health service providers in this study perceived parents did not take their advice or follow through with their recommendations for the sick child. Whereas parents in the study perceived the health service providers did not listen to them, they felt misunderstood and the expertise they had in relation to their child was not acknowledged. This communication breakdown posed a risk factor for the child with serious illness regarding possible admission to hospital; however, both parents and health service providers agreed that effective communication was a protective factor. They acknowledged communication that was open, where both parties felt listened to and understood built stronger rapport within the parent-provider relationship.

Risk factors included the severity of a child's condition and how quickly they deteriorated from a minor illness to being admitted to hospital. Lack of resources, such as transport, finances, dysfunctional communication between health care providers and parents, lack of information and knowledge also contributed to increased risk of hospital admission. Protective factors that reduced hospital admissions included knowledge and information for parents that equipped them to assess their child's requirement for early intervention at home, effective communication with their providers, access to resources and funding, along with strong extended family support and support groups. Parents viewed their children as being

particularly susceptible to minor illnesses leading to hospitalisation, while health providers viewed these children to be at higher risk due to their complex illnesses (Hudson et al., 2014). The highly stressful roles parents have does not diminish the love and care they have for their child, however, reported is the negative impact on the family structure (Koch & Jones, 2018) in terms of sibling welfare (Elias & Murphy, 2012) and marital longevity, with the martial relationship often showing marked deterioration (McCann et al., 2012).

McCann et al.'s (2012) systematic review (from four electronic databases, searched in 2010, that identified 32 articles) explored the patterns of time use for parents of children with complex needs. They found parents to be time-pressured by care requirements of the seriously ill child while also managing their normal, ongoing domestic and other responsibilities. These authors recommended that health service providers remained mindful of the time demands of care for parents who were already burdened by other responsibilities (McCann et al., 2012).

The role of the parent in the care of the seriously ill child is highly demanding. The evidence within the literature highlighted the burden that parents experience (Al-Gamal, 2013; Elias & Murphy, 2012) by a role that is time-consuming, arduous, rigorous, taxing and exhausting (Byrne, Hurley & Cunningham, 2010; McCann et al., 2012) and one that is isolating and shrouded in grief (Al-Gamal, 2013). The uncertainties of the child's health condition, the knowledge their child will live with disability or possibly have a shortened life due to their illness, created the phenomenon of anticipatory grief in parents (Al-Gamal, 2013). Rando (2000) described anticipatory grief as "mourning, coping, interaction, planning and psychological re-organisation that are stimulated and begun in part to response to the impending loss of a loved one and the recognition of associated losses in the past, present and future" (p. 288). While this study is almost 20 years old, the description of anticipatory grief provides an accurate image of parents' experience of loss and uncertainty. Overton and Cottone (2016) in their more recent paper identified the impact anticipatory grief has on the entire family system. They argued a theoretical framework to support the family rather than individuals within the family was a better approach to care.

Most participants in Al-Gamal's (2013) investigation of parents' care of children with cerebral

palsy (*n* = 204) expressed feelings of sadness as a negative experience of caring for their child and felt a high level of sacrifice burden. Al-Gamal (2013) utilised the Marwit-Meuser Caregiver Grief Inventory (MM-CGI Cerebral Palsy) modified from the original version of MM-CGI Childhood Cancer, to measure the physical, emotional and social aspects of a parent's life. These three concepts were framed as personal sacrifice burden, heartfelt sadness and longing and worry and felt isolation. These parents also experienced higher levels of psychological distress and depression and poorer physical and mental health than parents of children without cerebral palsy. Al-Gamal (2013) reported that while advanced medical knowledge and intervention has increased the longevity of children with cerebral palsy, a parents' care role in the family home is also extended. Parents reported reduced quality of life due to ongoing anticipatory grief. Al-Gamal (2013) recommended psychosocial support and family-centred care as vital for these parents. Koch and Jones (2018) in their review of parent caregivers of children with life-limiting illnesses, found a high level of emotional strain in parents when caring for a child who required highly technological care. Parents reported that they were socially isolated in the home and were unable to take their child out of the house due to both the medical paraphernalia and the high infection risk. These authors reported parents' wellbeing has a direct impact on the child with a serious illness and closely linked to the child's needs and suffering. For instance, distress secondary to pressures of caring for their seriously ill child, such as relational, financial and social hardship could affect the child's wellbeing. Koch and Jones (2018) reported, assessment of parental distress was not standard practice, due to inexperience of health professionals and limited resources. They argued psychosocial assessment of the sick child's parents were an equally important aspect of care, with evidence-based interventions of psychological support required to enable them to provide care for their child within the home (Koch & Jones, 2018).

In their controlled study of the effect on parents of having a chronically ill child, Hatzmann et al. (2014), found that parents, specifically mothers, were often disadvantaged in society due to the challenge of combining childcare with work and leisure activities. Study participants included parents of chronically ill children (*n* = 576) in the following 10 disease groups: asthma, diabetes, Down's syndrome, Duchenne muscular dystrophy, end-stage renal disease, metabolic disease, profound multiple handicaps, sickle cell disease, spina bifida and brain

tumour survival. The control group comprised parents of healthy children (*n* = 441). These authors noted the ongoing care requirements of the child created an unrelenting sense of responsibility.

High survival of seriously ill neonates and the use of technology can support the child's survival for extended periods, often from infancy and into adulthood (Ling, 2012). However, the responsibility of providing this high level of care for an extended time can be overwhelming and stressful for parents making their lives highly complicated (Hatzmann et al., 2014). The long periods of uncertainty, particularly if their child was medically unstable or requiring symptom management and frequent hospital appointments, could have direct negative impact on the parents' physical and mental health and their emotional resilience (Benini et al., 2008; Koch & Jones, 2018).

THE PARENT/HEALTHY SIBLING DYAD

In addition to the impact on parents, the literature reported the impact on healthy siblings of care provision in the family home of the seriously ill child. The high-level and constant demands of care for the seriously ill child, together with out-of-home visits to specialists and hospitals, can result in emotionally and physically exhausted parents who have little time and energy to attend to the needs of their other children (Alderfer et al., 2010). In these circumstances, healthy siblings may suffer emotional distress, such as confusion, resentment, guilt, fear, anxiety and depression (Emerson & Giallo, 2014; Knecht, Hellmers & Metzing, 2015). This may be displayed in behaviour that is withdrawn, aggressive, angry, loud and attention seeking (Hartling, et al., 2014; Knecht, et al., 2015). Healthy siblings may experience loss of status and believe they have little importance within the family. It can be difficult to talk to others of their concerns and their fears can be exacerbated when there is limited information about their sick sibling (Alderfer et al., 2010; Nolbris & Ahlström, 2014; Strohm, 2014).

While some studies reported not all healthy siblings struggled with the psychological impact of living with a sick brother or sister (Anderson & Davis, 2011; Havermans, et al., 2010), other studies identified the psychological impact of this period in their lives may result in long term health, emotional and behavioural problems (Besier, Holling, Schlack, West & Goldbeck, 2010;

Strohm, 2014). Strohm (2014) explored risk factors and protective factors that influenced adjustment when siblings had a brother or sister with special needs. Strohm identified siblings as a group at risk of future mental health problems if they did not have access to psychological support; however, they were overlooked by policy makers in preventative mental health programs in Australia. Risk factors for siblings included, not having information or understanding about their brother or sisters' special needs; not being able to communicate to others their thoughts and emotions and experiences of isolation (Strohm, 2014). With parents already burdened with the care of their children with serious illness, siblings were possibly reluctant to add to this burden. Protective factors identified by Strohm (2014) were open communication, strong connections with others and external emotional support through specific programs. While there is more awareness of sibling support in Australia, evaluation measures of what interventions were useful were required and the need for a comprehensive intervention strategy to support healthy siblings psychologically (Strohm, 2014).

Giallo, Roberts, Emerson, Wood and Gavidia-Payne (2014) used data from the 'Growing up in Australia': Longitudinal Study of Australian Children, to evaluate the emotional and behavioural functioning of children living with a sibling with special health needs. Using parent-reported survey data, Gialla and colleagues compared these children (*n* = 106) with a healthy child cohort over four time points, (4 to 5 years, 6 to 7 years, 8 to 9 years and 10 to 11 years). They found that siblings of a special needs child had significantly higher emotional and behavioural difficulties at most time points and displayed little improvement in functioning over time. Children without a special needs sibling improved in behavioural functioning over time. These authors identified the need for psychological support for children living with a sibling with special needs, a recommendation also made by Nolbris and Ahlstrom (2014). Giallo et al. (2014), and Strom (2014) stress the need for evidence regarding the specific risk and protective factors that limit and assist adjustment and resilience in these children.

HEALTH SERVICES SUPPORT FOR PARENTS

Despite the knowledge that children with medical complexity demand more from parents both financially and in time (Cohen et al., 2011), health and community services were often fragmented, and parents left to manage these cares with little support (Shuster et al., 2011).

While parents have become the experts in managing their child's condition, this is often through necessity rather than choice (Malcolm et al., 2011). Parents shoulder much of the responsibility due to the skilled 24-hour care requirements of their child (Kuo & Houtrow, 2016). Kuo and Houtrow's report (2016) reported parents felt abandoned at times by their providers, specifically as they were left to manage their child's complex symptoms and technology in the home. As previously noted by Schuster et al. (2011), health care services were reliant on this parental expertise and input, however they often failed to acknowledge its importance. These authors suggested that without this shadow health care the formal child health care system would be unable to function (Shuster et al., 2011). This terminology defined the situation of what has now become acceptable in care provision at home. Health managers and service providers have expectations that this is not only acceptable, it is the expected norm, despite the plethora of literature reporting parents being burdened with this high level of care. Schuster and colleagues (2011) reported this burden was not only on parents, employers also were burdened if their (parent) employees were away from work for extended periods of time. However, despite this, parents believed that at times their expertise and unique knowledge of their child's condition was not valued (Davies, Contro, Larson & Widger 2010; Hudson et al., 2014). Their experiences of being patronised or dismissed or having their judgement questioned caused some parents to suffer profound and lasting emotional distress (Davies et al., 2010).

Davies et al. (2010), interviewed parents (n = 36) who had experienced the death of a child. These authors were specifically interested in parents' communication experiences during their child's hospitalisation, inclusive of their child's eventual death in hospital. Study participants were Mexican American (n = 26) and Chinese American (n = 10). Parents were found to be frustrated and angry by the deprivation of information regarding their child. They reported a sense of being victimised within the health service and consequently experienced long-term negative effects. Cultural and language barriers were believed to negatively affect health professionals' ability to communicate and parents' ability to understand important information (Davies et al., 2010).

Poor communication between health services providers and parents is also explained by a lack of resources within the family home, such as lack of income, no landline telephone, no credit on cell phones and/or no transportation (Hudson et al., 2014). Other parents lacked education about their child's condition and/or symptoms which left them feeling isolated, alone, fearful and powerless in their struggle to provide care (Hudson et al., 2014). At times there was conflicting communication from multiple providers of care, leaving parents frustrated and confused (Hudson et al., 2014). Families' expectations of being well supported would incorporate their health service providers having continuity and good knowledge of their child's health needs, along with what was important for them as a family to enable best outcomes in care. However, effective care coordination and a broader integration of care systems and seamless communication between providers was critical for this to occur (Kuo & Houtrow, 2016).

THE NEED FOR A PARTNERSHIP OF CARE

Although health professionals relied heavily on the family to provide care to their seriously ill child, at times they neglected to provide opportunities for the parents' and the children's voices in decision-making (Konrad, 2007). In this regard, parents reported that they had to fight and do battle to have their voices heard (Konrad, 2007; Whiting, 2013; Whiting, 2014). Parents also felt that health professionals disliked their vigilance regarding their child's welfare (Hudson et al., 2014; Konrad, 2007). In the absence of respect, sharing and consultation with health professionals, parents felt undervalued and compromised in their role as carer and parent (Davies et al., 2010; Ertmann, Reventlow & Soderstrom, 2011; Hudson et al., 2014; Konrad, 2007), at times losing trust in their health professionals (Whiting, 2013) and without trust for the service providers, parents felt they must step in and pick up more of their child's care (Fereday, Oster & Darbyshire, 2010). Fereday et al. (2010), qualitative needs analysis in South Australia was undertaken for the purpose of developing disability awareness and resources for health professionals that were not specialised in this field. Through the use of focus groups (n = 5) and individual interviews (n = 7), 34 parents in total participated in the analysis, this included three foster parents and three grandparents who were the child's main caregivers. There were three key aspects that these participants deemed significant in a partnership with their providers, these were; the provision of professional health care

services, respect and trust. In alignment with other literature, parents wanted partnerships with their health service providers that were developed with sensitivity and respect. They wanted these providers to have knowledge in what was important for their child, but also in regard to their own needs in the broader aspect of care (Fereday et al., 2010). High quality interactions with health professionals are important to parents, and if interactions are negative the challenges already faced by parents are increased (Dempsey & Keen 2008; Fereday et al., 2010; Keen, 2007). There is a requirement for a care model delivered by health service providers who exhibit a wide range of skills, expertise and personal attributes to perform the care (Hain et al., 2012; Hewitt-Taylor, 2010; McIntosh & Runciman, 2008) with respect and sensitivity to each family's needs (Fereday et al., 2010). The impact of a health provider's support can contribute to a family's quality of life and therefore, not to be underestimated (Davis & Gavidia-Payne, 2009).

Foster (2015) reported the need for a model of care that was centred on both the family and child, one that was a partnership where trust is built between health care providers and family. Parents have first-hand knowledge of their child's individual needs. Given this, it is important to understand from their perspective what they think their children require in care. The child's main care and support comes from parents and family; therefore, service providers should negotiate with parents so that they can provide for the best psychosocial, physical and emotional outcomes for their child (Foster, 2015). Foster reported there continued to be challenges in implementing family-centred care models despite the 50 years of education, research and theory that has contributed to the development of this model of care. Foster (2015) proposed family-centred-care models should be renamed family and child centred care to ensure the family and sick child were visible and equal in health care provision. This author reported that in New Zealand there was an absence of paediatric models of care that included children and their families at the forefront of their care. Foster (2015) argued that health service providers should honour the rights of parents and their children while Horridge (2011) stressed the need for providers to be collaborative, constructive and inclusive in their work with parents.

CONCLUSION

The literature reviewed in this chapter has revealed important evidence of the challenge of caring for children with complex health conditions. The rarity of these health conditions, along with the technology to survive meant symptom management for these children could be problematic, impacting on their overall wellbeing and quality of life. The capricious trajectory and prognosis of these children's illnesses was challenging for their families living with such uncertainty. The impact on the entire family unit was evident with parents predominately responsible for their child's care in the family home. It was clear from the literature that this responsibility has placed a heavy burden on parents which will be summarised below.

The review of the literature on parents of children with serious illnesses has explained the weight carried by parents in their dual parent/carer role. Anticipatory grief of the potential loss of their child, along with the loss of what they knew as their 'normality' previously contributed to what the literature described as emotional strain and a high level of sacrifice burden on parents. The pressure on parent's time, their finances, and the rupture within their relationships with each other and within the family unit was well documented. Parents often held the dual role of not only being the child's parent, they were also their main care providers. While care of the child in the family home was expected by health service providers, aspects of this care were difficult, with parents experiencing abandonment by their providers. This contributed to their experiences of feeling isolated and anxious, powerless and frustrated.

Parents often had little time or energy for their other children after attending to the care needs of the child with serious illness and the many hospital appointments. These healthy siblings at times felt left out and believed they were not as important as their sick brother or sister. Direct changes in behaviour were obvious as they expressed their resentment, frustration and anger. Evident within the literature was the need for psychological support for siblings; this was in recognition of the possible long-term impact on their physical and mental wellbeing. This was deemed to be a protective factor to assist adjustment and resilience for siblings. However, identified within the literature was the need for further evidence of what the risk factors and protective factors were for healthy siblings to minimise stress and to develop their resilience. Parents were often aware they were not able to meet the needs of

their other children which contributed to their sense of powerlessness.

However, a key feature of parent's distress was poor relationships with their health service providers, difficulty accessing services and poorly coordinated health service delivery. Care was often fragmented leaving parents feeling isolated in the care of their child. Poor communication, lack of information and knowledge about their child's condition left parents feeling frustrated and fearful. While parents predominantly cared for their sick child at home, they often felt undervalued and misunderstood by their health service providers. Respect and sensitivity were expected by families from health professionals providing the care, however, this often was not their experience. It was difficult to develop trusting relationships when parents did not feel respected, and instead felt judged by the care they were providing.

The literature determined family-centred care or partnership of care that included the family was the best approach to care of a seriously ill child. Family-centred care was deemed an optimal model providing opportunity to grow trusting relationships between parents and their health service providers overseeing the care. However, there continued to be challenges in implementing this approach. Families and their children with serious illnesses need to be at the forefront of their health care, currently this is lacking. Much of the focus is on the child and not inclusive of the entire family unit. It is paramount to care for the family as a whole when a child has a complex health condition.

There was a lack of evidence of how evaluations of these specific models of care which were deemed as best practice, namely, family and child-focused care and partnership of care, met the needs of the child with serious illness, their siblings and parents and external health service providers. There was a lack of evidence to understand what worked within a model of care, for whom and in what context? The current study will add to the literature, providing an understanding of what is important for children with serious illnesses, their families and their external health service providers. How the program met the needs, or failed to meet the needs, of the child with serious illness, the child's siblings and parents, and external health service providers will provide further understanding of what is deemed important in a family-centred partnership model.

CHAPTER THREE: METHODOLOGY, METHODS AND PROCESSES

He tina ki runga, he tamore ki raro

In order to flourish above, one must be firmly rooted below[3]

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[3] www.maorilanguage.net

CHAPTER THREE: METHODOLOGY, METHODS AND PROCESSES

INTRODUCTION

In Chapter Two, the literature review reported parents' struggles to gain appropriate resources from health agencies to care for their seriously ill child in their home. There were challenges in gaining support that was beneficial to the entire family unit. There were gaps in the literature regarding evaluation of models of care that are child and family focused and in partnership with providers. Little is known about what works well, for whom and in what context for those families who provide care to their children with serious illness in the family home.

This chapter provides the rationale for the research aim and questions. It explains realistic evaluation methodology. Key scholars Pawson and Tilley's seminal work on realistic evaluation, designed to evaluate complex social interventions, is presented along with an explanation for this work's influence on the current study. Following the discussion of the research methodology, I discuss the sampling and recruitment methods, as well as the data collection methods of focus group interviews and semi-structured interviews. The final components of the chapter explain realistic evaluative data analysis and ethical considerations.

RESEARCH AIM

While the research aim and questions were introduced in Chapter One, they are revisited here in the context of developing the research design and to demonstrate their relationship to the chosen methodology.

The aim of this research is to evaluate a model of care provided by a child health organisation in New Zealand in terms of its capacity to provide care to the child with a serious illness, the child's siblings and parents, and the child's external health service providers.

RESEARCH QUESTIONS

The specific research questions generated from the aim were:

1. How does the program meet the needs or fail to meet the needs of the child with a serious illness, the child's siblings and parents and external service providers?

2. In what circumstances and through what mechanisms does the program meet the needs or fail to meet the needs of the child with a serious illness, the child's siblings and parents and external service providers?

The research questions were the foundation of and guide to this study to test the program's theory to determine if the program met or failed to meet the needs of families and their health service providers. The development of the research is illustrated (Figure 2).

Figure 2: Sequential development of the research evaluation

Scope:
The needs of seriously ill children and their families are complex.

Literature review findings:

Seriously ill children live in the community cared for by their families.

Care and responsibility falls to the entire family unit, predominantely parents.

Gaps in evaluating how care models may meet the needs of the child withserious illness, their sibligs, and parents.

Gaps in what circumstances would care models be useful for families providing the care.

A care model needs to be based on what families indicate as useful.

Research focus:
Understand what children and their families deem useful in a care model to scope future service development that meet their needs.

Research aim:
To evaluate the model of care provided by the child health organisation (program) in terms of its capacity to provide care to the child with serious illness, the child's siblings and parents and the child's external health service providers

Research questions:
How does the program meet the needs, or fail to meet the needs of the child with serious illness, the child's siblings, their parents and external health service providers?
In what circumstances and through what mechanisms does the program meet the needs, or fail to meet the needs of the child with serious illness, their siblings and parents and external service providers?

Realistic Evaluation Methodology

METHODOLOGY – REALISTIC EVALUATION

Having defined the aims and the research questions, the realistic evaluation methodology used to address the research question will now be discussed. However, before going into this discussion, it is useful to explain the terminology of *realistic* in this evaluation. The 'real' within philosophy can be a broad and complex concept to understand. This study has been informed closely by Pawson and Tilley's realistic evaluation paradigm which was founded on scientific realist philosophy. This philosophy incorporated the concept that evaluation of programs can help improve their effectiveness by investigating the *real* (Pawson & Tilley, 1997). The *real* was described by Pawson and Tilley (1997) in terms of examples, such as burglars being real, as are the programs that are working to reduce crime and to rehabilitate prisoners, as are the successes and failures of these programs or initiatives. These authors deliberately utilised the compound word of *realistic,* bringing together the three key components of *real*, *realist* and *realistic*. They described *realist* as the methodology that evaluation should follow, with a view to explain the theory or conjecture which has started in the minds of policy makers or practitioners regarding a social issue where interventions are then introduced into social systems to influence change for betterment (Pawson & Tilley, 2004). Finally, they argued, evaluation needs to be *realistic,* meaning that it is conducted in a way that provides information and evidence for policy makers, practitioners, program participants and the public that is easily understood (Pawson & Tilley, 1997, p. xiii). Much of Pawson and Tilley's (1997) focus was on social reform; hence realistic evaluation was centred on investigating the effectiveness of specific social programs directed at specific social change.

Questions central to realist inquiry, focus on what works, for whom, how and in what circumstances (Connolly, 2007; Pawson & Tilley, 1997; Pawson & Tilley, 2004; Roycroft-Malone, Fontenia, Bick, & Seers, 2010). Realistic evaluation provided an account of the nature of the program being evaluated, what is involved, what contributes to the outcomes and what is required to sustain it (Pawson, Greenhalgh, Harvey, & Walsh, 2005). Consequently, realistic evaluation places emphasis on understanding the context within which an intervention takes place (MacArthur, Wilkinson, Gray, & Matthews-Smith, 2017). These contexts existed before the introduction of a program, for example, one such context relevant to the program that

provided care to seriously ill children and their families, is the New Zealand health care system and its fragmented and under-resourced child health policy (Cumming, 2011).

Marchal, van Belle, van Olmen, Hoeree and Kegels (2012) reviewed published empirical studies in the field of health systems research and found that the emergence of the realistic approach fitted well when evaluating the complexity of health care systems. The realistic approach is designed to evaluate complex social interventions (Pawson et al., 2005) as found in the complex layers of care for the child with serious illness and their families provided by the New Zealand health care system. Therefore, realistic evaluation methodology was relevant for this study due to the complex issues within child health when a child has a serious health condition. The realist questions provided a way to directly understand what worked within the model of care, for whom and in what context.

Pawson and Tilley (1997) reported that realistic evaluation was a relatively 'young' discipline that had broad potential for realistic investigations. However, in the 20 years since Pawson and Tilley made this comment, there has been growing interest in their work (see, Adams, Sedalia, McNab & Sarker, 2016; Clark, Whelan, Barbour & MacIntyre, 2005; Connelly, 2007; Hewitt, Sims & Harris, 2012; Roycroft-Malone et al., 2010; Wand, White & Patching, 2010). Realistic evaluation methodology has become more commonly used by nurse researchers (Porter, 2015), as shown in this study's literature search strategy in which Realistic Evaluation AND Nursing (2005 – 2017) returned 115 peer reviewed published papers.

While realistic evaluation has been utilised more recently (see Marchal et al., 2012; Porter, 2015) researchers still grapple with the complexity of the methodology and substantial skill required to implement it (Adams et al., 2016; Bying, Norman & Redfern, 2005; Hewitt, et al., 2012; Linsley, Howard & Owen, 2015; Marchal, Dedzo & Kegals, 2010; Tolson, McIntosh, Loftus & Cormie, 2007). Nursing researchers have found the concept of context, mechanism and outcomes to be challenging to operationalise (Porter, 2015). Porter argued that the confusion was most likely due to the inconsistencies and ambiguities within the realistic evaluation model. He noted the difficulty of the theoretical underpinnings of the methodology

and how misunderstandings have created misinterpretations. He reported that the theory itself has weaknesses and contradictions which may add to the confusion. For the purpose of this study, I have stayed close to the original work of Pawson and Tilley, heavily referencing their work to enable the reader to understand my interpretation of the theory. It is therefore important to trace the origins of realistic evaluation to outline a broader explanation of this work.

Pawson and Tilley, two British sociologists (Hewitt et al., 2012), contended that realistic evaluation is a theory-driven evaluation, with its 'roots' directly related to the influential realist tradition in the philosophy of science and Bhaskar's (1975) and other's previous writing on realism. These authors explained that realism has been positioned as a scientific explanation to avoid the traditional knowledge of positivism versus relativism aspects of evaluation (Pawson & Tilley, 1997). Pawson and Tilley (1997) argued that there were different layers of reality in social explanation which have vital implications for how causation is understood and perceived. These authors noted that the mechanisms which explain regularity were positioned at a different layer of social reality and that it was the generative or produced conception of causality that was important to understand. Social interventions work through the action of mechanisms bringing resources and reasoning together to make sense of a program (Pawson & Tilley, 1997; 2004). Due to the complex role of generative mechanisms within an evaluation study it was important to explain this in more detail.

Hewitt and colleagues (2012), influenced by Pawson and Tilley's work, agreed that the theory driven approach of realistic evaluation could be applied to most areas of human social life in which policies or programs were utilised, for instance, health care provision. These authors agreed that a realistic evaluation theory driven approach strengthened the explanatory power in evidence-based policy and practice. The theory defined in this study is based on Pawson's et al. (2005), concept. They believed the theories were the program founder's hypothesis or assumption that an intervention would generate an expected outcome. It is these program theories that the researcher analyses in realistic evaluation, whether the interventions are successful or not (Hewitt et al., 2012; Pawson et al., 2005).

Realistic evaluation is an approach focused on programs (Pawson & Tilley, 2004). These authors considered social programs to be products of the human imagination, which involved a supposition about social betterment. They contended that programs should be set in place for social betterment, therefore they chart a course whereby wrongs are put to rights, deficiencies of behaviour corrected, and inequalities of conditions alleviated. These authors described programs as work about people who carry a history and inevitably assume a future (Pawson & Tilley, 1997). These authors argued that social programs are an attempt to address an existing social problem or to create some level of social change.

Within complex social systems, the realistic evaluation methodology assists in transcending the limitations of measurement and causation (Wilson & McCormack, 2006). While evaluations often take place within environments that are rapidly changing, the context is as important as the interventions, or mechanisms being evaluated (Pawson & Tilley, 1997; Wilson & McCormack, 2006). Interventions are not deemed to have causal power alone; context and mechanisms are the factors that trigger the causal relationships to provide the outcome of a program (Pederson, Nielson & Kines, 2011). Further explanation of the context, mechanism and outcome configurations will be explained later in the chapter.

Pawson and Tilley (1997) believed that evaluation focused on the core theory of how a program is supposed to work, considering the underlying mechanisms of that program. Therefore, evaluation was useful for examining and explaining what has contributed to the outcomes of a program (Pawson et al., 2005; Pawson & Tilley, 2004).

Hewitt et al. (2012), reminded us that when the realist researcher evaluated complex social interventions, it was important to recognise that all interventions only ever work for certain people in certain circumstance, therefore questions about, "what worked for whom in what circumstances?" are important (p. 251). The key to realistic evaluation is how an intervention can bring about change in a program, however, identification of underlying causal mechanisms that contributed to change are often not seen (Pawson & Tilley, 2004). Pawson and Tilley (1997) provided a metaphor that was useful to understand the meaning of

underlying mechanisms. They explained that we do not necessarily understand how a clock works by just exploring its face and the moving hands. It is not until we examine the clockworks that we gain a fuller understanding of how the clock functions.

It was clear that programs are sophisticated social interactions within a complex social reality (Pawson & Tilley, 2004). Pawson and Tilley (1997) argued that social conditions which confront any population group are not of their own making. They suggested that the basic task of social inquiry was to explain puzzling, socially significant regularities. They proposed that there is too much emphasis on programs and methods that were aimed at meeting pragmatic ends with findings that leaned towards narrow minded concerns (Pawson & Tilley, 2004). Therefore, it was important to take heed of the different layers of social reality which make up and surround programs, for example, economic conditions, organisational positions, culture and relationships (Pawson & Tilley, 2004).

As noted above, Pawson and Tilley (1997) described realistic evaluation as having three key linked concepts for explaining and understanding programs. These are the "context", those features that are relevant to the operation of the program; the "mechanism", those features that bring about any effects; the "outcome", the intended and unintended consequences of programs, resulting from the activation of different conditions (Pawson & Tilley, 1997, p.6). Moreover, Pawson and Tilley (1997) explained the formula thus: "programs work (have successful outcomes) only in so far as they introduce the appropriate ideas and opportunities (mechanisms) to groups in the appropriate social and cultural conditions (contexts)" (p. 57). Therefore, these authors were led to postulate the following fundamental formula for explanation: context (C) + mechanism (M) = outcome (O), or CMO. While social programs attempt to address an existing social problem or create some level of social change, Pawson and Tilley (1997) reported that causal powers don't reside in objects or people, but in the social relations and organisational structures. Therefore, one action leads to another because of their accepted place in the whole. Realistic evaluators in the social context, utilising the above formula of CMO, search for the causal mechanisms that lead to program outcomes (Pawson & Tilley, 1997). The evaluative process involves an iterative cycle of eliciting, testing

and refining programme theory, constructed as Context-Mechanism-Outcome (CMO) configurations (Pawson & Tilley, 1997).

As the realist explanation is based on the suggestion that causal outcomes followed from mechanisms acting in context (Linsley et al., 2015), the proposed CMO formula allows decision makers and evaluators to specify 'what worked' rather than to ask the question 'did it work'? Tilley (2000) argued that the cornerstone of the realistic evaluation approach is on how an intervention may bring about change, and how change then informs policy and practice.

In summary, in this study I was not only interested in evaluating the program to establish if interventions worked as per my initial assumption, I also wanted to understand how the context fired or did not fire the mechanisms to bring about potential change. This then provided evidence of the program's effectiveness, but also an explanation that would help to improve and develop the organisation further and influence the scope of future programs.

CRITIQUE OF REALISTIC EVALUATION

Due to the complexities of the realistic evaluation approach, it has not been without extensive discussion and debate. Porter (2015) reported inconsistencies in Pawson and Tilley's philosophical approach. He believed that, sometimes they took a "realist position, at times an empiricist or even idealist one" (p. 240). Porter and O'Halloran (2012) were concerned that Pawson and Tilley rejected Bhaskar's realism. Bhaskar was a philosopher who was influential in the development of Critical Realism, a philosophy of science based on truths about the nature and knowability of the social world and social phenomena (Frauley & Pearce 2007; McEvoy & Richards, 2006; Schiller, 2015). Bhaskar's development of a systematic realist account of science provided an alternative to the positivism and social constructionism approach (Bhaskar, 1978). Porter and O'Halloran (2012) believed Pawson and Tilley at times replicated the 'technocratic tendencies' inherent in evidence-based practice, such as randomised control trials (RCT). However, these authors also acknowledged that the methodology of realistic evaluation provided a sound contribution to evidence-based practice in complex health interventions.

As health providers develop stronger awareness of best practice for patients, the evidence base for practice grows in importance. Previously, RCTs have been the preferred approach in evaluating health service research, whereas, realistic evaluation, which has an emphasis on understanding how context influences evidence-based practice, is a good fit for investigating practice and impact of evidence-based care (Roycroft-Malone et al., 2010). While Porter and O'Halloran (2012) acknowledged the advantage of utilising realistic evaluation in health research, they viewed the strengths and weaknesses of this methodology as being attributed to its selective adoption of the tenets of critical realism.

Pawson and Tilley (1997) often used complicated terms to explain empiricist and anti-empiricist ontological notions of generative causality. They also insisted that generative mechanisms are not variables, and that causal powers reside not in particular individuals, but rather in social relations and organisational structures. However, Porter (2015) challenged this belief and suggested that if causal powers were exclusively structural, then individuals' actions would be determined by these structures. He disputed this stating, "It cannot be true because of the ability of individuals to form social relations and organisational structures" (p.44). This author noted that Pawson and Tilley utilised single mechanisms and contexts in realistic evaluation, whereas Bhaskar (1998) conveyed the possibility of multiple contexts and multiple generative mechanisms. Porter's (2015) critique of realistic evaluation, particularly the viewpoints of Pawson and Tilley (1997) and Pawson (2013), is worth noting. However, the critique itself is dense and difficult to comprehend.

Other researchers found Pawson and Tilley's (1997) explanation of realistic evaluation to be a useful framework for forming effective evaluation questions in healthcare, making sense of multiple factors, developing explanations and presenting them in a coherent way (see, Clark et al., 2005; Connolly, 2007; Hewitt et al., 2012; Linsley et al., 2015; Roycroft-Malone et al., 2010; Tolson et al., 2007; Wand et al., 2010; Wilson & McCormack, 2006). It is important to acknowledge that realistic evaluation methodology, while challenging to understand, is a methodology that continues to evolve and develop.

To summarise, realistic evaluation gives a distinctive account of the nature of the program being evaluated, how it works, what is involved, what has contributed to the outcomes, and what are the characteristics required to sustain it (Pawson et al., 2005). The context, mechanism, outcome (CMO) formula provides answers to how programs activate mechanisms, amongst whom and in what conditions to bring about change in behaviours or events (Pawson & Tilley, 2004). Realists refer to human action within the context of a wider range of social processes as "the stratified nature of social reality, with even the most mundane actions only making sense because they contain in-built assumptions about a wider set of social rules" (Pawson & Tilley, 1997, p. 64). Therefore, causal powers are not situated objects or individuals. Rather, they are in the social relations and organisational structures which are formed (Pawson & Tilley, 1997).

While qualitative evaluation research is not intended to be generalisable, it is envisioned to be useful to researchers and practitioners, whose own experience may be corroborated by research findings and may position them to go forward with further research and change to current practice (Taylor & Francis, 2013). For this qualitative evaluation study, I was aiming for cumulation rather than replication of the research. Pawson and Tilley (1997), argued cumulation in realistic evaluation is about "producing middle-range theory, abstract enough to underpin the development of a range of programs, yet concrete enough to withstand testing in the details of program implementation" (p. 116). While CMO configurations are a critical aspect of realistic evaluation, there will always be contextual variations in causal mechanisms and how they are triggered, therefore there is an expectation there will be different outcomes for different programs.

RESEARCH METHODS

Realistic evaluation methodology is not prescriptive and there is no preference for either quantitative or qualitative methods - either, or both, are acceptable (Pawson & Tilley, 2004). For this study, a qualitative methodology was chosen to gain deeper understanding of the program. Analysis of interview and focus group data, explained later in this chapter, enabled deep insight into whether the program worked, for whom and in what circumstances. Prior to

presenting the research methods, it was important to acknowledge my prominent position as an insider researcher.

INSIDER RESEARCHER

An insider researcher brings to the research a complexity of unique challenges. Moore (2012) argued, it is not uncommon for the qualitative researcher to be familiar with their research participant group. While there are multiple definitions for an insider researcher, Breen (2007) defined it as "those who choose to study a group to which they belong" (p. 163). Insider researchers generally understand the politics of an organisation, its performance and culture (Unluer, 2012), and there is a risk that they bring unconscious assumptions to their analysis and reporting of study findings (Unluer, 2012).

However, Arthur (2010) argued that a researcher's position can change, dependent on what is happening culturally, socially and politically. For instance, I was a researcher in the organisation being evaluated, but I was not an 'insider' in that I was not a parent of a child with a serious illness, and I did not have the lived experience of other participants in this study. Therefore, my position can be seen as an outsider/insider researcher, or what Milligan (2016) refers to as an 'inbetweener' (p.239). This is a relatively new idea and describes neither an outsider, nor an insider researcher (Milligan, 2016).

McNess, Arthur and Crossley (2015) argued this notion well, specifically in relation to comparative qualitative research methodologies where researchers seek to be more collaborative, participatory, reflective and inclusive in their research. Currently, the concept in regard to insider-outsider positions within research is changing and there is recognition that research identities can be multiple, flexible and changeable (McNess et al., 2015).

In the conduct of this study, I was mindful that my roles of founder, CEO and Nurse Specialist in the organisation were to be managed with caution. My intention was to be transparent with my assumptions to minimise the risk of influencing study findings. Reflexivity was utilised, specifically through journaling, as I endeavoured to remain focused and clear about my

positioning within the research. This excerpt from a journal entry explained my intent to be transparent.

As I reflect on my roles within the organisation, I know they come from a place that has been driven by passion to ensure change happens for the betterment of care for children who can be seen, heard and understood. This in itself has potential to influence the study. What I may perceive as improvement or betterment for children has been driven from my own perspective of what 'betterment' might be. Therefore this study will be under particular scrutiny to ensure my preconceptions do not 'lead' the study.

It is so valuable to have discussion with my supervisors to challenge me on the specific risk area of influence. I want the spotlight shone into all the corners of this study, as the outcome is about improving services to children and their families at a national level, not just for those utilising the services of the program. Therefore, if the study is purely led by my own preconceptions and passion, there is potential for the issues related to child health not to be taken seriously. The credibility and validity of this research is paramount.

The practical steps taken in this endeavour to ensure rigour and credibility included regular meetings with my research supervisors and robust discussion specifically in relation to my influence in the study. I also had monthly meetings with an external (to the organisation) business mentor to discuss the operational aspect of the organisation. I found it useful to have this additional avenue to discuss my role in the study and the different roles within the organisation. As stated previously, a research assistant was employed specifically for participant recruitment, data collection, transcription and de-identification of the transcripts before I viewed them. The research assistant was accessed through the local university on the recommendation of a senior lecturer I knew professionally. The research assistant was not known to me or the child health organisation. She was a self-employed evaluation researcher who did contract and consultancy work for different organisations, both in non-government and government sectors. She had graduated with her doctorate in 2012.

A rigorous process was adhered to before employing the research assistant. Her Curriculum Vitae was sent to me for consideration before I interviewed her. As per the Vulnerable Children's Act a police vetting check and a referee check were performed before she became involved with the research. The Vulnerable Children's Act was implemented in 2014 as a measure to protect and improve the wellbeing of vulnerable children. While the research assistant was well qualified to recruit participants, collect data and de-identify the data, she had not previously worked with children. Hence it was appropriate to have one of the counsellors who worked with children available for data collection. The processes followed by the research assistant will be discussed more fully later in this chapter.

SAMPLING STRATEGY AND SELECTION CRITERIA

Pawson and Tilley (1997, 2004) are silent on the use of sampling, except to acknowledge that it is important for evaluation researchers to gather as much data as possible such as via literature, existing data and interviewing stakeholders (Pawson & Tilley, 2004). For this realistic evaluation research, purposeful sampling was used. Patton (2015) described purposeful sampling as selecting information-rich cases for in-depth study. He explained that information-rich cases are those from which you can learn about issues that are of central importance to the inquiry (Patton, 2015). Oliver (2013) described purposeful sampling as non-probability sampling, utilised when the researcher is interested in specialised knowledge of the research issue. Weiss (1998) explained that sampling should be driven by whether the program succeeds across a spectrum of 'sites' (p. 164). Therefore, in alignment with the inquiry's purpose (Patton, 2015), participants selected were children with serious illnesses, their siblings and parents and external service providers who work with children with complex health conditions who utilised the model of care under investigation.

The intention of this study is to provide an explanation of how mechanisms within certain contexts produced outcomes that may or may not have created change for this population group within child health. Purposeful sampling was a strategy to engage with the research problem to test and refine the initial assumptions or presuppositions (Emmel, 2013). It was imperative to involve stakeholders purposively selected based on my initial assumption, or

theory that had knowledge of the theory being tested (Pawson & Tilley, 1997). For example, participants in this study understood the program was under evaluation. They had first-hand experience of the program, therefore they would have specific ideas on what is within the program that worked (mechanisms) or didn't work, and for whom.

Participants who were classified as the seriously ill child, their parents and siblings were recruited from the 130 families who were care recipients of the program at the time, and whose details were held confidentially on the child health organisation database. All families received an invitation to participate in the research, inclusive of the child with serious illness, the healthy siblings and the parents. Families lived both within a city and/or isolated rural regions, covering an area of 21,220 square kilometres. External service providers (who referred paediatric patients to the child health organisation) were recruited from the local hospital and community agencies. Fifty-eight service providers were invited to participate.

SAMPLE SIZE

As this is a qualitative research project, sample sizes were not expected to be large as I was not looking for statistical comparisons or to create a representative sample (Patton, 2002). However, I wanted a large enough sample to allow the research questions and aims to be thoroughly addressed (Mason, 2002; Mason, 2010). In considering what I would deem an acceptable sample size to ensure I reached the point where no further themes were apparent, I had envisaged five to six children who had serious health conditions to be interviewed; up to six in the siblings and parents' group and up to 12 participants for the health service providers group.

Recommendations regarding sample size for a focus group are varied, with some authors believing 6-10 participants for a focus group is feasible (Morgan, 1992) while others recommend 10-12 participants (McLafferty, 2004). McLafferty (2004) reported the lack of consensus on what is an appropriate sample size for a focus group, noting a range from four-20. Patton (2015) argued there is no set rule for sample size in qualitative data, instead he believed the more important aspect was the usefulness of the sample size. He reported

sample size was what determined the breath or depth of the information shared by the group. The intent of the larger sample size for the external service provider's focus group was to be more representative of the health population. However, the maximum number for focus groups for this study was 12 so as to enable participants to have the opportunity to share their stories, particularly for those who may not be comfortable in sharing within a larger group. While more ideas may be generated within a larger group, I was interested in the depth of participant's perspectives. I was more focused on rich data (quality), rather than a volume of data (quantity), whilst acknowledging that attainment of rich data is the ideal (Fusch & Ness, 2015). Data saturation in qualitative research relates to the depth of the data rather than the quantity of data (Burmeister & Aitkin, 2012).

Following ethics approval from the university's Human Research Ethics Committee (See Appendix C) 21 participants were recruited for the study, namely, children with serious illness ($n = 1$), healthy siblings ($n = 4$), parents ($n = 4$) and service providers ($n = 12$). The purpose of the study was to understand participants' perspectives from those who had first-hand experiences with the program and those who collaboratively worked alongside this group. Therefore, the program team were not involved in this research as participants. I wanted to have a clear understanding of whether the program 'worked or did not work' for the external stakeholders.

RECRUITMENT OF PARTICIPANTS

Participants were recruited via information packs posted to the home addresses of 130 parents on the child health organisation database, as well as to 58 health professionals who worked at the hospital and community agencies that referred paediatric patients to the program. The information packs included a letter of invitation and a participation information letter (Appendix A) and a reply-paid envelope in which a signed consent form could be returned by those interested in the research. Within the information pack was the explanation to participants including information on the aim of the project, their involvement requirements, recording and transcribing of material as well as a clear statement indicating

that they could withdraw from the research at any time. This is explained further in this chapter when the ethical issues in relation to the research are discussed.

CHILD PARTICIPANTS

Children invited to this participate in this research were in the middle-child age group between six and 12 years of age. Developmentally in healthy children, it can be expected that they become competent, independent, self-aware and have cognitive understanding from age six (Eccles, 1999). Waligora, Dranseika and Piasecki (2014) reported there was a lack of clarity in acquiring children's consent and how their capacity was determined. These authors argued for a more personalised approach, however, children were to be at least school-aged to be competent to understand information in relation to research. Children participating in this study were within this age group and would have some understanding of what it meant to assent to and participate in the research and so will more likely be able to determine if they want to be involved or not involved in research (Waligora et al., 2014).

THE CHILD WITH A SERIOUS ILLNESS

Children with serious illness included in the current study were invited to participate in the research via the information pack that was sent to families on the program database. As stated above, inclusion required children to be developmentally competent, over the age of five years, and therefore of an age to understand the information and assent process to participate in the research. The information letter was sent to the children's parents to read and discuss with their child as to whether they would like to participate. Assent was required from the children participating, as well as their parent's consent.

Excluded from this study were children under the age of five years or over the age of 12 years. Very young children (≤ 5 years) may not have the ability to fully understand and engage in a focus group, while older children (≥ 12 years) are cognitively and developmentally different to their younger peers. To gain their perspectives on what is important to them in a care model requires further research.

There was one 12-year-old female child with serious illness who agreed to participate in this research. Her cognitive development was that of a 12 year old, the illness did not affect her cognitive development. It was important that she had understanding of the research she was participating in; she informed the research assistant she was excited to be invited to participate in the research.

The challenge in recruiting children with serious illnesses to participate in research is well documented in the literature (Farrington, Tauschmann, Randell, Trevelyan & Hovorka, 2016; Hudson, Oostendrorp, Candy, Vickerstaff, Jones, Lakhanpaul, Bluebond-Langner & Stone, 2017), with a lack of evidence about parents and children's attitudes towards recruitment. The discrepancies regarding power relationships are a concern when involving children in research. Carter et al. (2014), argued children are vulnerable, particularly when they have been traditionally marginalised in areas such as health care. As children may find it difficult to dissent when wanting to please the adults in their lives, it is paramount they understand and assent with knowledge and understanding (Carter et al., 2014). While there may be a willingness from both parents and children to participate in research, protective barriers in relation to a child's vulnerability may contribute to the complexity of decision making about participation. This will be discussed further in Chapter Seven in relation to the limitations of this study.

HEALTHY SIBLINGS

There were four male siblings of a seriously ill child. These participants were aged eight and nine years of age. As stated in Chapter One, it was important to have the children's perspectives in this study as they are recipients of the program provided by the child health organisation. The healthy siblings were of a similar age (eight and nine years). The children in the study were of an analogous developmental stage where they could participate together in 'play' and articulate their perceptions and experiences of the program. If children have the opportunity to play with peers of a similar developmental age they experience greater control over their situation (White, 2012). This study wanted all child participants to be comfortable. The four healthy siblings who participated in this study were known to each other from previous sibling support groups facilitated by the program. They were comfortable within the

setting as they had all previously visited the program house. While healthy children in the above age group are competent to speak of their own experiences, it was challenging to recruit children to participate in this study. This will be discussed more fully in Chapter Seven, however, for future research, further investigation of what may be helpful for children to engage in the recruitment process and assent to participate is required.

PARENT PARTICIPANTS

Four parents consented to participate in this study, one father and three mothers from separate families attended the focus group. There were another three parents who consented, however, they made contact to explain that their child was unwell or had been hospitalised therefore they were unable to participate. This was a reality for this population group, the vulnerability of their children meant they found it difficult to plan ahead or attend appointments. The decision was made not to reschedule the focus group to include these parents, as this change might impact the availability of those four parents who were already available. Therefore, the focus group went ahead as arranged rather than rescheduling or facilitating a second focus group. The research assistant was employed for a specific time frame for recruitment of participants and data collection. Due to the time allocation and resources set aside for her part in the research, the three parents unable to attend the focus group were not followed up with an interview. This will be explained further in Chapter Seven.

Included in this research were parents who had a child with a serious health condition. Excluded were bereaved parents who were potentially vulnerable in their grief. Ethically this population group would have potentially required a separate focus group to ensure that further trauma and re-evoked grief could be managed. Further research is required to gain understanding of this population group as their perspectives would be valuable to gain insight into what they viewed to be useful or not useful as they cared for their child throughout the child's dying process.

EXTERNAL SERVICE PROVIDER PARTICIPANTS

Twelve service provider participants consented to participate; these service providers were not employed by the program, rather, they worked at the local hospital and community agencies. The group comprised nursing (n = 7), allied health (n = 4), and medicine (n = 1), thus representing the key disciplines and professional expertise involved in the child's care. Included were service providers who had referred a paediatric patient to the program or/and were overseeing care for the child with serious illness and their family. Excluded were those service providers who had not referred a paediatric patient or were not mutually caring for a seriously ill child in unison with the program's clinicians.

SETTING

The setting for data collection via focus groups was carefully considered; the physical environment needed to allow participants to share their perspectives on care and listen to other's perspectives in a 'permissive nonthreatening environment' (Krueger & Casey, 2009, p. 2). A room in the program's house was chosen for focus groups. Most participants had visited the house previously, there was ample car parking and it was situated close to the hospital, a facility known to all participants.

The two-storey house was purchased by a local celebrity specifically for the child health organisation to support children with serious illnesses and their families. The upstairs rooms are used as offices, counselling rooms and meeting spaces. Downstairs, the double garage with three rooms and bathroom attached was converted into therapeutic spaces for art, music, sandtray and play therapies. In developing this space, the local polytechnic fashion design students completed a project to design a child-friendly therapeutic place with the organisation's values and mission at the heart of the work. Therefore, the walls and beams have artwork, murals and quotes with which children and young people could resonate. A smaller room downstairs was also utilised as a counselling room for parents who needed to be close to their child who may have been vulnerable due to their illness, or anxiety.

The house is in a residential area and looks like a family home rather than a clinical setting. This was an intentional decision when looking for a venue at the start of the program, as many of the children spent so much of their time in a hospital setting. It was a deliberate decision that no clinical nursing care would occur at the house, as children and their families were often traumatised by their hospital experiences.

The adult participants (external service providers and parents) met in the upstairs lounge, a large comfortable room. The child participants (siblings and sick child) met in the downstairs art/play therapy rooms, a space known to the children and one designed to minimise stress and encourage play.

The research team took all measures to ensure that each participant's well-being was protected during data collection. Considering the nature of study questions, there was the potential for participants to experience emotional stress. Participants were provided with contact details of psychologists and were informed of debriefing opportunities. Participants were invited to contact the researcher or a Human Research Ethics Committee (HREC) member if required.

DATA COLLECTION METHODS

Focus group and semi-structured interview methods were used in this study. Interview questions focused on apparent program successes and failures, leading to propositions about what worked, for whom, and in what circumstances, and may reveal reasons for crucial choices made by participants (Pawson & Tilley, 2004). These methods are now explained.

FOCUS GROUP METHOD

In health research, focus group interviews have been a common means of data collection since the early 1980s (Liamputtong, 2013). Focus groups are known for their usefulness in being cost effective with the potential to gain more data in a set space of time compared to a one on one participant interview. The interactions within a group of participants who share similar backgrounds enable insight into participants' perspectives (Krueger & Casey, 2009). A key

aspect of focus groups was the interaction within the group; their rhetoric, experiences and ideas shared, this was an integral part of the data (Holloway, 2005; Morgan, 2008). However, there are potential limitations and challenges with the use of focus groups; for example, one or two individuals may dominate the conversation, silencing other participants, or participants may become influenced by other participants (Holloway & Wheeler, 2010). There was potential risk that participants may compromise another participant's confidentiality (Holloway & Wheeler, 2010).

The social interaction amongst group members was important (Hollander, 2004); participants could question, challenge, agree and disagree with each other thus enacting the 'everyday' processes of social interaction. Therefore, this provided an opportunity for more 'naturalistic' conversations with the data revealing the ways the meaning of a topic was negotiated among participants, how the topic was elaborated and justified and how participants came to a collective sense-making (Braun & Clarke, 2013). It was understood that participants who came from similar social and cultural backgrounds were likely to feel comfortable and even empowered to talk openly, therefore enabling a free-flowing discussion (Barbour, 2007; Liamputtong, 2013). This collective sense-making from participants' experiences provided rich and detailed data.

As stated in Chapter One, the views and experiences of some participants in this research could be marginalised within the larger society. Therefore, the focus group method for data collection was appropriate and useful in examining sensitive issues with potentially sensitive and vulnerable participants. The interaction with others who had similar experiences provided an opportunity to be comfortable in sharing those experiences with each other (Liamputtong, 2013). This method allowed participants who possibly felt apprehensive or anxious about communicating to be involved in sharing their perspectives. This population group often has little opportunity to express its opinions regarding experiences within the health sector (Carter et al., 2014). Therefore, focus groups provided a way to share with others in an analogous supportive environment.

The focus groups were moderated by the qualified research assistant. As previously stated, the research assistant was unknown to me and unknown to the child health organisation. She was employed specifically from the local university to recruit participants, collect data and to anonymise the data before giving it to me for analysis. The research assistant was a skilled evaluation researcher whose own PhD research was an evaluation research project. While the research assistant had not previously worked with children, she was skilled at moderating focus groups and conducting interviews. A counsellor skilled in working with children was present in the healthy sibling focus group and when interviewing the child with serious illness to ensure that all of those present were comfortable and that the environment was safe.

The research assistant set a clear agenda for the participants in each of the focus groups, initially recapping what the research was about and reminding participants they could withdraw at any time. Participants were also reminded that they could have further support, such as access to a psychologist or counsellor, if they felt unsafe or were re-traumatised or experienced a reawakening of their grief process. Each group discussion was an hour long after which discussion was drawn to a close. The process was completed within one and a half hours.

The discussion was prompted by key open-ended questions and the research assistant had a clear mandate to allow the discussion to flow. However, in the event that the conversation became chaotic, vague or abstract, she was to gently bring the group back to the point (Stewart & Shamdasani, 2007). The research assistant had awareness of the participant's potential effect on each other and was comfortable in her skill to ensure that all participants had the opportunity to talk. The focus groups provided a means of learning how people from diverse social, geographical and disability backgrounds perceived the model of care.

While the participants had similar backgrounds, there were possible differences in socio-economic status, norms and values. While invitations were sent to all parents on the program database incorporating all ethnic groups, participants represented in this research were all

non-Maori New Zealanders. The absence of Maori New Zealanders is a limitation of the study which is discussed later in the thesis.

The focus group sessions were recorded by the research assistant and transcribed by an external person. The research assistant summarised her notes from the sessions. These notes and transcriptions were anonymised, such as removing any names or identifiable features, before being submitted to me for data analysis. Each of the three focus group components will now be explained. The questions for each group are shown in Tables 4 to 6. These questions were used as prompts to encourage participants to share openly, to expand, reflect and clarify their perceptions.

GROUP 1 – HEALTHY SIBLING FOCUS GROUP

Four male participants of a similar age (8 and 9 years) assented to participate. The research assistant facilitated the group in the play room of the program house. One of the program counsellors was present at the focus group so that immediate action could be taken if sibling participants became anxious or overwhelmed. The presence of the counsellor, who was known to them, enabled them to feel comfortable. While parents were invited to attend the research interviews, given that sensitive material might be evoked, none did so. The sibling participants were asked if they would like their parents present, however, all declined this offer.

The sibling participants were familiar with the play therapy environment at the program house. The modalities of art and play were utilised to enable the child participants to express what they were thinking and how they were feeling. These modalities are developmentally appropriate to use when research involves child participants (Plummer, 2011; Purdy & True, 2012; Wallace et al., 2014) and were used to assist the children to relax and have 'fun', while sharing their perspectives of the model of care.

The child participants' parents were informed that their child could meet with a counsellor or psychologist if they were concerned their child had been distressed by their participation in the group. Contact details were provided to the parents before the interview took place. In

addition to this, the contact details of the researcher and a Human Research Ethics committee member were provided, for possible follow up enquiries or complaints.

Table 4: Questions for healthy sibling focus group

Questions for healthy sibling focus group
- What do you find helpful [with the program]?   - What is it that you don't find helpful? (This question was included to give an opportunity to share negative responses if this was the case.)   - What is important for you as a sister/brother of a sick child?   - Has your family changed since your sister/brother has been sick?   - What is the hardest thing for you in having a sick sister/brother?

GROUP 2 – PARENT FOCUS GROUP

Four parents consented to participate in a single focus group. Originally there were seven participants, however, three parents withdrew due to unanticipated changes in their sick child's health needs. When participants signed up to participate in this research, it was clearly stated they could withdraw at any time during the research.

Table 5: Questions for parent's focus group

Questions for parents' focus group
- What do you find helpful at [the program]?   - What is it that you don't find helpful at [the program]?   - What do you see as the most helpful or important part of the service? Why was it useful?   - Has [the program] met your expectations?   - What is different about [the program] compared to other health providers?   - If [the program] didn't exist, what do you think you would do to gain the assistance you require?   - Where do you perceive there are 'gaps' within [the program], or where would you like more support?

GROUP 3 – EXTERNAL SERVICE PROVIDERS' FOCUS GROUP

Twelve external service providers consented to participate in a single focus group. They were all known to each other as they worked within the same regional hospital board, although in different departments. Their occupations were: Newborn Intensive Care Unit nurses and social worker (n =3), community paediatric clinical nurse specialists (n =3), play specialist (n =1), dietician (n =1), paediatrician (n =1), nurses from the paediatric department (n =2) and a physio (n =1). Most in this group were nurses.

Table 6: Questions for external service provider's focus group

Questions for external service provider's focus group
• What do you see as the purpose of [the program]?
• Do you know of other health professionals that may not be aware of the purpose of [the program]?
• How did you find the referral process?
• How did you find the communication between [the program's clinicians] and yourselves as health professionals, and their communication with families?
• What are the differences you see for families once they have engaged with [the program]?
• Is there anything [the program] could do differently or more effectively?

To conclude this section on the focus group method, my intent was to illuminate the participant's perceptions and understanding of the program. I wanted the participants to be encouraged to generate and explore their own perspectives through open conversations with each other, developing their own analysis of common experiences and therefore minimising the feelings of isolation and aloneness.

SEMI-STRUCTURED INTERVIEWS

Semi-structured interviews are the most common and familiar qualitative methods of data collection, recognised by both researchers and participants alike (Barbour, 2007; Braun & Clarke, 2013; Kvale, 2007). These interviews may be known as 'professional conversations' (Kvale, 2007), or 'special conversations' (Holstein & Gubrium, 2003).

A crucial aspect of this research was to gather rich and detailed data about how the child with a serious illness perceived the program. The intent was to capture the language and concepts of how she experienced her health condition and how she felt about the program. The strength of using the semi-structured interview method was the use of open-ended questions creating a balance of flexibility and structure. It provided an opportunity for the participant's own words to be captured when describing her perceptions from an 'insider' perspective (Taylor, 2005, p. 39). This method could capture information when other data collection methods, such as focus groups, were not possible due to the child's physical and emotional vulnerability. There was the opportunity for the participant to raise issues of importance to her (Braun & Clarke, 2013).

INTERVIEW MODERATION

Because of my role as 'insider' researcher, data collection was the responsibility of the research assistant. Therefore, the research assistant interviewed the child participant (n = 1) who responded (through their consenting parent) to the research invitation. A program counsellor known to the child was present during the interview to oversee the welfare of the child. The child's parents were invited to attend the interview; however, they did not attend. The participant assented to continue in the absence of the parent.

The research assistant introduced the research and informed the participant that she could withdraw at any time throughout the interview session. The participant understood she could talk with the counsellor if she experienced anxiety or distress and/or if she did not want to continue. The participant's parents were informed that their child could meet with a counsellor or psychologist if they were concerned their child had been distressed by her participation in the research. Contact details were provided to the parents before the interview took place. In addition, contact details of the researchers and a Human Research Ethics committee member were provided, for possible follow up enquiries, doubts, or any complaints.

Play therapy was used throughout the interview. Play therapy in the play room had been undertaken by the participant on many occasions during therapeutic sessions and is a developmentally appropriate modality when undertaking research with children (Plummer, 2011; Purdy & True, 2012; Wallace et al., 2014). The research assistant introduced the open-ended questions into the play therapy with the intent to gain a broad understanding of what the participant's experiences and perceptions were of the program. She was encouraged to talk freely regarding the guided questions put to her (Polit & Beck, 2006). To build trust and rapport with the child participant the research assistant joined in the play, weaving the questions into the play session. The research assistant assured the participant that there were no right or wrong answers. At times she used prompts and follow up questions to either bring the participant back on track (when caught up in her play) or to delve deeper for understanding and clarification. The questions are provided in Table 7.

Table 7: Semi-structured interview questions for a child with serious illness

Semi-structured interview questions for child with serious illness
• What do you find helpful at [the program]? What is the most important thing they can help you with?
• What is it that you don't find helpful at [the program?] Is there anything they could do better?
• How do you think they have helped your family?
• What is the hardest thing about being sick for you?
• What has been the biggest change for your family since you have been sick?
• What is really important for you as someone who has an illness?

This next section explains the ethical process for the research. These values and principles were central to ensure participants were fully informed, participation was of their free will and they understood the processes of the research and potential risks of participating in this study.

ETHICAL RESEARCH PROCESSES

Earlier in this chapter, I explained the context of myself as an insider researcher undertaking research within the organisation I founded and in which I am currently employed. The Australian Catholic University (ACU) confirmation panel and ethics committee highly recommended that an external research assistant be used for the participant recruitment, data collection and de-identification of data transcriptions aspects of this study. The ethical concerns related to the insider researcher and the potential for bias in data analysis and reporting. The contribution of the research assistant will be explained later in the chapter when discussing the ethical component of the research.

Throughout the research, ethical conduct has been assured. Concern for the rights and wellbeing of the participants has been at the heart of this study, particularly for those who may be perceived as vulnerable, in this instance, children with serious illness and their families (Holloway, 2005). I have been mindful of not doing harm, instead being focused on doing good; for example, to improve services for children with serious illnesses and their families. I have been guided by the ethical principles of; respect for autonomy, therefore respecting the decision making of the participants; non-maleficence, avoiding harm; beneficence, providing benefits and balancing these against risks and justice, distributing benefits and risks fairly (Holloway, 2005).

When considering what was essential to ensure this research was culturally sensitive, I endeavoured to be clear, honest and transparent in the information pack provided to participants about the purpose of the research. I explained that there is no direct benefit to participants, except perhaps for some benefit in sharing their experiences with others. Future clients of the program, namely, children, families and services providers, will benefit from this research.

Ethics is about values, and ethical behaviour reflects the values held by specific population groups. For Māori, ethics is about 'tikanga'- their values, beliefs and the way they view their world (Te Puni Kokiri, 1994). An ethics framework in research for Māori incorporated four

tikanga based principles; whakapapa (relationships), tika (research design), manaakitanga (cultural and social responsibility), and mana (justice and equity) as the primary ethical principles (Ministry of Health, 2006). These principles aligned with the Treaty of Waitangi principles of partnership, participation and protection. While this research is not specific to Māori; it is inclusive of Māori, and all ethnic groups who were clients of the child health organisation. The above principles have been integrated into all aspects of the research. This qualitative evaluation is 'value laden' (Patton, 2015) with the focus on hearing if the participants deemed the program useful in caring for a child with serious illness.

INFORMED CONSENT

The process of informed consent within this research was located within the principle of respect for autonomy. This principle demanded that participation was voluntary, and the participants were aware of the personal and individual risks involved (Holloway & Wheeler, 2010). For instance, the information packs sent out initially to recruit participants outlined clearly what the evaluation research process entailed. Prospective participants were aware that in the case of emotional stress being evoked due to the content shared in the focus groups or semi-structured interviews, or by sharing their experiences, they could access a counsellor or psychologist to support them. Potential participants were aware that participation was voluntary. They were aware that they could withdraw from the study at any stage. There were no Māori participants, and only a low number of child participants in this study. These limitations will be discussed later in this thesis. Consent was essential in undertaking this health research, particularly regarding the vulnerability of children who had health and disability conditions and for those who cared for them (Carter et al., 2014).

NO HARM

In considering the design and methodology for this research, I was conscious of not doing harm to the participants. Being mindful of the potential vulnerability of the group, the research assistant appointed was subject to background check with her referees. This included a police vetting check to ensure she would be suitable as part of the research team and to fulfil the requirement of the Vulnerable Children's Act. I was mindful of guarding against misconduct and impropriety that would not only cause harm for the participants but would

also have a negative impact on the research and indeed on the organisation being evaluated. The research assistant was chosen for the role for her competency, qualifications and her interpersonal and relational skills. As previously stated, the research assistant had completed her own doctorate and was self-employed as an evaluator researcher contracted at times through the local university.

The participants' privacy and confidentiality were of utmost importance. Information was collected anonymously. The research assistant recruited the participants, was responsible for data collection and anonymising the data before I received it for analysis. The use of pseudonyms prevented identification of the participants. Transcribed data was kept in a locked filing cabinet at the program's premises as per ACU HREC requirements for data storage. Data will be kept until the completion of the research project.

As a registered nurse practicing in a health care setting, I abided by the profession's professional code of ethics. As a researcher at ACU, I had ethics approval from HREC to undertake this research (see Appendix C). This research involved collecting data from people about their experiences and perspectives of the program they were involved with. Therefore, I was mindful of the risk of adding further stress or further marginalising the individuals participating. My intent was to enable the participants to feel empowered by sharing their experiences with others. Also, the shared experiences may have the outcome of enhancing resiliency and reducing a feeling of isolation regarding their unique individual experiences. I had the dual role of researcher and health professional and while I was committed to the research I was also committed to the care of the participants, particularly those participants who (children and parents) were clients of the program.

I have endeavoured to promote integrity in the way the research was undertaken. I have been conscious of clearly stating my position as a researcher, and disclosing the potential bias from my personal, cultural and historical contexts (Creswell, 2009). As previously stated, due to the dual roles I had at the program, the ACU confirmation panel and ethics committee recommended I use an external research assistant to recruit participants, collect data and

anonymise the data before I received it for analysis. This process would then minimise the risk of implicit or subtle coercion and pressure. Even though the participants were assured that their participation was voluntary, they may have felt obliged to take part because they knew me as not only the researcher, but also the professional they were, to a certain extent, dependent on (Butler, 2003). While the risk was potentially present due to the participants' awareness that I was undertaking the research, an external research assistant provided an opportunity for them to share their honest perspectives of the program. This may have been different if they were concerned about the future care of their child or their relationship with me as the researcher, nurse and CEO at the child health organisation.

When analysing the data, I chose to undertake manual coding rather than use a software program. I felt this kept me closer to, or more intimate (Holloway & Wheeler, 2010), with the heart and essence of the data. This was particularly relevant as I was not able to check the transcripts against the original audio recordings for accuracy due to the risk of recognising the participants' voices.

In health services, there are often complex social interventions to contend with which act on complex social systems, therefore program outcomes are dependent on context and implementation (Pawson et al., 2005). Consequently, it is important to explain (in the following section) the relationship between context in which the intervention was applied, the mechanism by which it worked and the outcomes which were produced.

DATA ANALYSIS

Realistic evaluation does not stipulate, recommend or provide guidance on data analysis (Tolson et al., 2005); rather Pawson and Tilley (2004) argued that realistic evaluation is about testing and refinement of the initial assumption or program theory. These authors stated that there is no single analytic method suitable for understanding the outcomes of a program, rather they suggested that the context, mechanism, and outcome configurations explained how the program worked, for whom and in what conditions (Pawson & Tilley, 2004). Therefore, mechanisms were contingent upon contexts to determine outcomes within a

program. The CMO configuration needs to be refined to explain the associations of cause for change (Pawson & Tilley, 2004). To summarise, the refined CMO configuration is the finding of an evaluation (Pawson & Tilley, 1997).

Data analysis for this study was conducted in a two-staged approach. Due to the many of pages of data from the different sub-groups (child with serious illness, healthy siblings, parents and external service providers), thematic analysis was a useful initial step to systematically organise and gain an understanding of the interview data. The first step involved immersion in the data to establish familiarisation. This involved recursive reading of the data, noting initial codes. These codes were identified by highlighting datasets that related specifically to the research questions. These highlighted datasets were coded and collated to facilitate inductive analysis and identify themes (Braun & Clarke, 2006).

The second stage of data analysis involved an examination of the themes to identify outcome patterns, which included the intended or unintended effect of the program due to activation of the mechanism in different contexts (Pawson & Tilley, 2004). While Pawson and Tilley (2004) argued there is no single analytic method suitable for this purpose, they reported that the realist's primary expectation is that there will be outcome patterns of successes and failures within and across interventions provided by the program.

The process of identifying patterns from these themes was iterative as I searched for the mechanisms from the various contexts to answer what it was that worked for whom, in what context and why specific outcomes were produced (Pawson & Tilley, 1997). The CMO configurations identified from these patterns were then compared with each other. Comparison of the CMO configurations was undertaken to understand the links between the program and the outcomes. These refined CMO configurations explained the 'complex signature of outcomes left behind by an intervention' (Pawson & Tilley, 2004, p. 11). Specifically, the purpose of the realistic analysis was to test the CMO configurations with the initial program theory. I wanted to understand if the initial program theory was supported or refuted by the analysis. The stages of data analysis are outlined below (Table 8).

Table 8: Stages of data analysis

Stage 1: Thematic Analysis (based on Braun and Clarke, 2006)
Immersion in the data
Familiarisation
Recursive reading
Generation of codes and themes
Systematic coding of interesting aspects of data
Searching for themes, collating codes into identified themes
Reviewing of themes, checking the themes in relation to the coded extracts of data
Stage 2: Realistic Evaluation Analysis (based on Pawson and Tilley, 1997; 2004)
Outcome patterns identified from the themes (from thematic analysis)
Identified the mechanisms that were fired from specific context to produce the outcome patterns, CMO configurations
Comparison of the configurations, identifying what worked for whom (child with serious illness, their healthy siblings, parents and external service providers) and why, in what environment?
Testing of the program theory, (how do the CMO configurations fit with the initial assumption or program theory)
Refinement of the program theory –is there a CMO configuration that explains the 'footprint' of outcomes left by the program (Pawson & Tilley, 2004, p. 11)
Final assessment of the program theory; has it been supported or refuted by the analysis

CHAPTER SUMMARY

This chapter has elucidated the methodology of realist evaluation. The congruence of the methodological approach with the research questions was highlighted. Realistic Evaluation methodology was used as the means by which questions regarding the program were addressed, namely, what worked, or was useful within the program, for whom and in what context. Research processes, such as the ethical stance within this study have been highlighted; as transparency of these processes provide rigour and credibility. The data analysis process that generated the realistic themes from the participants' perspectives has been explained. Chapter Four will present the thematic analysis findings answering the first research question, namely, is the program useful for clients and service providers.

CHAPTER FOUR: RESEARCH FINDINGS – STEP 1 – THEMATIC ANALYSIS

Kia kaha, kia maia, kia manawanui

Be strong, be brave, be steadfast [4]

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[4] (Biggs, 1969)

CHAPTER FOUR: RESEARCH FINDINGS - STEP 1 –THEMATIC ANALYSIS

INTRODUCTION

As discussed in Chapter Three, thematic analysis was a useful initial step to systematically organise and gain an understanding of the interview data. In the thematic analysis of the four participant groups' data, 14 themes were identified. Data were collected from the parents of the children with serious illness (n = 4), the siblings of children with serious illness (n = 4), the external hospital and agency service providers (n = 12) and the child with serious illness (n = 1). These themes were reported separately with an aggregated summary. The aggregated data reported overall key themes from all participants combined and identified the synergies and differences between participant groups. These synergies are analysed further in Chapter Five.

The research questions that guided the data analysis were:

1. How does the program meet the needs or fail to meet the needs of the child with a serious illness, the child's siblings, the parents and external service providers?

2. In what circumstances and through what mechanisms does the program meet the needs or fail to meet the needs of the child with a serious illness, the child's siblings and parents and external service providers?

PARTICIPANT GROUP 1

PARENTS OF CHILDREN WITH SERIOUS ILLNESS

Participants (*n* = 4) readily shared their perspectives of the program, specifically reporting that the program clinicians (nurse specialist and counsellors) assisted them with issues of importance in family functioning on a day-to-day basis. The support provided to the whole family was highly valued. Pseudonyms were used to protect participant privacy and confidentiality. Five key themes were identified in this participant group. These themes were; families coping under pressure, experience and skill eases the burden, adjusting to rare health conditions and new circumstances, advocacy and flexibility make a difference, the challenge of asking for help.

Families coping under pressure

Parent participants reported that the demands of caring for a child with serious illness had an impact on all aspects of their family life. Due to the high health needs of their child, parents were often exhausted and caught up with just 'surviving' each day. The many hospitalisations and being away from home and the rest of the family put families under pressure. At times, this pressure put stress on relationships and finances. These participants stated:

> *The parent who stays with them the most, works more at the front of the war so to speak, so they are the more exhausted. (Ben, parent)*

> *You get so caught up in it all, and think hang on, we need to manage this and carry on with everyday life, and then something else happens. We have to juggle being at the hospital and then home, then hospital, then home… and the bills don't get paid, and you get caught up in just surviving, that you close off any needs of your own, so I think you don't even realise you have needs. (Christine, parent)*

At times, children had long hospital stays and many clinic appointments leaving participants often feeling 'bombarded' or overwhelmed. Participants valued the counselling and nursing support from the program team, which was provided to them in their home, on the program premises and importantly, in the hospital during periods of their child's acute illness. This support empowered them as individuals, which helped them to cope as a family. Participants reported that the care was vital to their survival, explaining that they felt 'someone else carried the load for a bit' and enabled them to breathe. This participant stated:

> *When at the hospital you are just bombarded and overwhelmed… Once here [program house], they [program team] are just like, let me take it from you and they control, not in a controlling, 'I'm going to tell you what to do', it's let me take the load for a while and they let me just breathe, sit there and have a cup of tea and breathe. (Christine, parent)*

Participants readily spoke of the impact on the wider family unit and discussed what the program support meant for them in relation to coping as a family. They reported that their healthy children (siblings of their sick child) often missed out on their attention due to the ongoing health demands of the sick child and time limitations. At times these children

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displayed negative attention-seeking behaviours at home and school. School teachers contacted parents about behavioural issues witnessed in the classroom and playground. Participants acknowledged there were limited resources within schools, particularly primary schools, with no access to counsellors or nurses provided. This participant stated:

> *[Healthy sibling] had issues, when he first started at school, he ended up in the principal's office within the first few weeks of starting school, he was really acting out, had attention seeking behaviour. (Suzie, parent)*

Participants reported the difference in their healthy children when they had one-on-one counselling with the program counsellors. Participants noted an improvement in their child's behaviour, both within the home, and at school as they became more settled. They acknowledged the impact of a child's health condition on the siblings. This participant stated:

> *It's been vital for him … being able to care for the siblings [has] actually been hugely beneficial for our family to be able to cope… he has had one-on-one [counselling] which has made a big difference for him. I think my family probably uses the whole package [program] and it's been amazing... they support the whole family, so it is not limited to the child with the condition or just to the child and the parents. Even the siblings pay a price, when they are in a family with a child with extra needs... having a service for the whole family and the flexibility of it… covers what our needs are. (Suzie, parent)*

All participants were acutely aware of their healthy children's needs, and their own lack of capacity to meet these needs. They reported not knowing how to access help and assistance for these particular concerns contributed to the helplessness and powerlessness they were already experiencing. Participants agreed the level of psychological support provided to their healthy children by the program counsellors reduced those feelings of helplessness. Participants acknowledged siblings who attended groups and had one-on-one support were made to feel "special".

> *My middle child has the neediness thing as well, because she doesn't get much time with me, my oldest one and my youngest needing my time, so she just acts out. So coming here [program house] and seeing [program counsellor] makes her feel special… but just the situation that we have been pulled into [medical*

condition and treatment plans] she feels so left out so coming here she enjoys. (Krystal, parent)

However, when asked by the research assistant what would happen 'if the program did not provide these services to children with serious illnesses and their families', participants voiced their strong concern, as they were not sure where they would access support for themselves or their family. They reported there were limited options for their children to gain the support required, with this participant stating:

I don't know where else I would go... I would be lost [without program], I would still carry on with everything in life, I would just plant a smile on my face and carry on, but it is still the fact that I have got them to lean on a bit every now and then. (Christine, parent)

While this question appeared to unsettle the participants, the research assistant reassured the focus group the program was not planning on changing its service delivery and this was not the intent of the question.

Experience and skill eases the burden

Participants reported how much they valued the expertise and skill of the program clinicians that included nursing and psychological care. They valued the clinician's long-term experience of caring for children with chronic health conditions, in relation to counselling and nursing care. This skill incorporated the clinician's sensitivity, in knowing when to share information and when to hold this knowledge until participants were ready to gain further understanding of their child's condition. They conveyed how the program clinician's experience supporting other families in similar situations was useful to their own situations. These participants stated:

It's just their experience with a whole lot of families, and how they are the common ones... [Counsellor] will just come up with these little gems... it is those little gems from [counsellor's] observations of seeing more people and obviously they have a wealth of experience themselves... I guess maybe their experience is like gold. (Ben, parent)

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I sometimes hear myself saying to [nurse specialist];'you know from all of your experience, what can we expect?' And I think, please don't tell me because I don't want to know, but if I do want to know some specific thing about in five years' time, then she can give me that information, but she is sensitive enough not to just bombard me with it. (Suzie, parent)

While participants have the responsibility of care for their child, they reported they did not know what help and support they initially needed when they first met the program clinicians. Often, they were exhausted and were providing care to their child to the best of their ability. They expressed their relief at receiving support from a service that was not demanding and instead was flexible enough to meet their individual needs. While they acknowledged it was hard enough being a parent, to have a child with a serious illness made this role even harder. Therefore, participants appreciated the program's clinician's skill and expertise in knowing when to step in and out of families' lives, so as not to overload them further. This care was valued, allowing participants to feel well supported and helped them to relax knowing the program clinicians were there when needed. This participant stated:

I am very much feeling as though [program] is something that is there when you need it, which is why it is so beneficial. It's not something that is demanding anything from me, it is just something that is provided for support and there are not many things like that. Even the hospital has a lot of demands on you, they are providing support, but are constantly demanding as well. (Christine, parent)

The long-term experience of the clinicians in supporting other families in similar circumstances was appreciated by the parent participants. They valued a service that did not demand anything further from them as they were constantly managing the demands from their children's medical complexity.

Adjusting to rare health conditions and new circumstances
Participants reported that the counselling and psychological care provided by the program team assisted them to adjust to changes within their lives and gave them a different perspective on their situation. They recounted they were better equipped to not only deal with their child's health condition, but also to accept their circumstances with more equanimity. This participant stated:

[Program counsellors] said, the journey you go on now is going to be completely different to the journey you would have gone on, or were expecting to go on, it will be a different journey, a harder journey, but it will also in some way be a better journey. You will meet people that you wouldn't have met and it will change your views on things and that was a very valuable thing to say. Because for me, that has been true and it has completely changed my life, but I don't think in a bad way. Certainly not in every way a better way, there are some things I would obviously change back if I could, but to not struggle against it I guess has helped me and my husband to accept having a child with a terminal condition and to be able to live with it and have a good happy family and two happy children who also… struggle to accept it, so do we sometimes, but generally speaking I would describe us as a happy family, far happier than a lot of people that aren't living with that kind of issue in fact. (Suzie, parent)

Participants explained that before they had access to the program, information and knowledge regarding their child's condition was difficult to access. They spoke of the rarity of their child's condition, which at times caused the health professionals to struggle for answers. They considered they were 'outside' of things and their child did not 'fit' into any particular criteria. Participants felt alone, anxious and did not know where to seek information, or what to do regarding their child's care. Participants often resorted to the internet. One participant reported being told by a medical consultant to "Google" their child's rare condition. Other participants in the group were shocked by this advice, noting that information gained this way could be overwhelming. These participants shared:

I still feel outside of it because [of] my daughter's rare condition … I didn't know what I was doing for my daughter. (Krystal, parent)

I think what brought us here [program] was just that timing, before the referrals appear and I think we had just got our results back, some bloods had to be sent to California, the only place in the world that could do these things [testing for specific diseases], it was that rare. [Medical team] said don't worry about it, it is that rare it is like winning lotto, so yes, that is what brought us here… to manage it, you spend the first six months, twelve months and maybe your whole life just accepting it. (Christine, parent)

The participants reported that the nurse specialist on the program team provided advice on their children's health conditions and linked them to the appropriate services and resources

in a timely fashion. The nurse specialist explained information the medical team had provided about their children's condition in a language understood by families. The one-on- one support offered by the program clinicians provided strategies and skills that parents could use to support themselves. One participant reported:

> *That is what makes the [program] so valuable I think, the fact they have that 'medical' expertise as well as the counselling… They can interpret some of the things that you get told that can be difficult to understand… actually we shouldn't have to be our child's medical professional… One on one counselling from the [program clinicians] has provided amazing support over the years and turned the situation from a nightmare into something great… I was enduring life, not enjoying it. [Program clinicians] didn't fix it for me, but gave me the skills to fix it for myself… That was really empowering and helpful. (Suzie, parent)*

Participants valued being accepted and respected by the program clinicians. They were used to the rigid and inflexible nature of hospital systems, where, at times, they felt judged. They reported that some hospital teams made assumptions regarding the quality of care they, as parents, provided. Therefore, they valued the flexibility within the program, as they felt they did not 'fit' into the hospital system or the hospital demands of clinical appointments and admissions, where they often felt bombarded and overwhelmed. This participant shared:

> *We were constantly judged. They were constantly making assumptions of us or of him and some of them, pretty bluntly to his face. Whereas when we brought [the program counsellor] in, he just accepted it, he didn't query what was going on, he didn't make judgements on how we had handled it or what we were doing to deal with it or anything like that… You filter information to people, because the more information you give them, the more they judge you, or the more they say you are nuts. (Ben, parent)*

Although strongly approving of a referral to the program, participants reported that these referrals were not timely, and would have preferred an earlier referral. They felt they had suffered a great deal of stress trying to manage on their own and were in 'desperate' need for the service long before their referring physician took action. Other participants spoke of the frustration of their child's ineligibility for some services because of their rare conditions. They

felt they had struggled with little support because their child did not fit into a neat 'box'. These participants stated:

> *I think for us, we only were referred here a few months ago, I think if somebody had picked us up two and a half years back and said, 'this is the way you should be going', I think we would have had a much easier ride on that journey, but nobody identified and we didn't know [program] were here... I think it would have been good for us and a huge benefit to [our child]. (Ben, parent)*

> *I think I would have coped a lot better. I think it would have helped the two younger [healthy siblings] boys... because they definitely got abandoned in the first year while we were juggling, literally it felt like fireballs in the air. It would have been good for them to have somewhere to come, but somewhere that we could all come to... because [names sibling] was scared, he didn't know what was going on, so yeah, I think it would have made life easier having their support. (Christine, parent)*

Participants valued the availability of the afterhours advice and symptom management care provided. They described this as a 'safety net' and even if they did not call after hours, it was reassuring to know they could if their child required symptom management or they needed advice. This participant shared:

> *You just know that if something happens you can call someone at 3.00am if you had to and they wouldn't say, look we are not open until 8.00am buddy, just all those little things that you know that you are going to need, if you need them, they are there. (Christine, parent)*

Participants valued the interface of nursing and counselling which provided a platform to access information about their child's rare health conditions along with supporting them to adjust to their situations. Parents felt empowered to care for their child and more readily able to accept their child's condition.

Advocacy and flexibility make a difference

Participants acknowledged the varied needs they had outside of caring for their sick child that limited their ability and capacity to do things, causing them added stress. Participants appreciated being linked to appropriate services; they appreciated the support in meeting

other service providers, as they did not necessarily know where to access services, whether that was health or external services.

> *The [nurse specialist] has advocated for me at the hospital, we have had various issues with different things at the hospital that she has been able to advise me on, as well as get in touch with doctors up there if I would like her to… The practical things actually being at the hospital and being able to liaise with the hospital and providing practical solutions… It is really dependent on what your needs are and the level [of support required]. You can come in every week, or once a year, it really is completely guided by yourself and I think that is really valuable. (Suzie, parent)*

Participants valued the care provided by the program as they felt 'burdened' emotionally and unable to ascertain clearly what was required for their child's health needs.

They appreciated advocacy not only in the health sector, but also in their child's schooling. The program clinicians could meet with the child's teacher and advocate on behalf of the child and parents on what may be required to meet their needs at school. This was seen as a valuable aspect of the program as participants acknowledged how challenging it was to articulate their child's needs in a way that was easily understood. These participants explained:

> *It's hard for me to explain things when I am not a medical type, even though I do everything for my daughter. I think you are so tied into the situation emotionally it does shadow how you are able to express yourself. (Christine, parent)*

> *[Counsellors] helped him to deal with his anxiety…his teacher really needed to know how to support him…They were saying, 'we can teach him and we can support him with is education, but at the moment he is too emotional'… They met with the teacher and one of the management team. It is really helpful because I have a lot of trouble with the school understanding. It's difficult for people to understand and when they don't understand, they can make some wrong decisions… It's hard work advocating constantly. (Suzie, parent)*

Participants reported that the flexibility of the program met their needs. The advocacy at the hospital and at school supported participants in their management and coping strategies, particularly as they were the main caregivers.

The challenge of asking for help

When asked if there were any 'gaps' in the model of care provided by the program, participants mentioned that they sometimes got so busy, they forgot to contact the program clinicians. They identified more regular contact would be useful, particularly as they were not used to asking for help. This participant stated:

> *I forget they are here sometimes, so the regular contact would be good…and I am not bringing them down, it's just I don't have regular contact with them or anything so I am constantly busy with other organisations that people are working with me because of other issues and I would like them to contact me every now and then. (Krystal, parent)*

However, other participants identified it would be more useful to have the option of regular contact, as each family's needs were different. For instance, one participant felt well supported and did not perceive there were gaps within the service.

> *So maybe the option of regular contact, because I wouldn't want them [to contact me], they have left me to call them. We all want such different things, so maybe, 'would you like us to give you a call as an option, something like that would be good. (Ben, parent)*

Aggregated summary of parent's data

Parent participants reported caring for their children with serious illnesses left them feeling exhausted, at times financially stressed, and overwhelmed. They were concerned about their healthy children due to the frequent hospital admissions and appointments and were acutely aware they had limited time for their other children. They reported their healthy children's behaviour was attention seeking, both at home and at school.

Participants valued the program clinicians' support of the whole family. They experienced an easing of their loads and reported being empowered to find strategies to support themselves as they cared for their children. Knowing the support from the program clinicians was available afterhours reduced anxiety and was perceived as a safety net once they left hospital care. They found the program to be important in helping them to cope as a family.

PARTICIPANT GROUP 2

SIBLINGS OF CHILDREN WITH A SERIOUS ILLNESS

The perspectives of the four siblings are reported here. The participants shared their perspectives on how they viewed the program. Four key themes were identified; being understood in uncertainty; adjusting to changing circumstances; the importance of distraction; and support for their sick sibling.

Being understood in uncertainty

All participants expressed how they experienced uncertainty when their sibling was seriously ill, particularly when they were hospitalised and at least one parent was at the hospital. They felt uncertain about the future, separated from what was happening, and missed their parent/s along with the usual home routines. When asked by the research assistant, what was the hardest thing about having a sibling that was not well, this participant responded:

> *When your brother or sister is in hospital you don't know what is going on… It's the thought when they go to hospital; what's going to happen and wondering if they're going to make it back or anything. (Liam, sibling)*

Often when a participant spoke, the other participants nodded their heads in agreement (information provided by research assistant). The lack of information about their sibling, or not knowing what to expect, was difficult and challenging for them all. The participants understood when they experienced uncertainty, they could talk to the program counsellor who would assist them to talk through what they were experiencing, providing strategies to view their situations from different perspectives. This participant stated:

They [counsellors] help you think about the good stuff about your family and help you forget about the bad stuff…. Cos they like, talk about the good stuff and only a tiny bit of the bad stuff. (James, sibling)

Adjusting to changing circumstances

Participants identified the continual compromises and adaptions that they had to make to their ever-changing circumstances. Arrangements for their care outside the home were made when their siblings were in hospital, the clinic or seriously unwell at home. 'After school care' was seen by all as 'boring', otherwise they reported an acceptance and resignation to unexpected changes in their own care routines. This participant stated:

We had to go to an after-school program at my old school when she had an operation… It's boring… when my sister's in hospital, I have to travel up to the hospital a lot, and it takes about half an hour. (Sebastian, sibling)

Participants reported how their sick sibling's behaviour changed when they were experiencing pain or feeling unwell, often becoming angry. This had an impact on them physically and emotionally and was unexpected as they were engaging with their brother or sister.

It's hard because she [my sister] gives me a headache…. When she's not well, she's angry… and she's bossy. (James, sibling)

Sometimes she gets mad and isn't very nice to me, when I walk into her room and try to tell her stuff she yells, "Get out of my room". That's what gives me a headache as well. (Zayden, sibling)

When participants were asked if their families had changed since their brother or sister was born, or had become sick, they considered their lives hadn't changed. However, in discussion it was revealed they were either the younger sibling, therefore it was all they had known, or others were too young to remember their sibling being born, it was apparent this was their 'normality'. Nevertheless, they clearly articulated they 'missed out' on things by having a seriously ill sibling. This participant stated:

You can't do stuff cos there are things you can't do…. Like sometimes you can't be together and do special stuff together. (Sebastian, sibling)

Participants identified not doing special things together as a family was directly related to having an ill sibling. They were aware their brother or sister did not have the capacity to join in some family activities, however, because of this, they too missed out on these special times or travel. While participants may not have had the insight that their families were different to others when asked that directly, they eloquently spoke of their losses, whether that was special occasions or the everyday things that siblings rely on each other for such as help with homework:

Sometimes there are just some things you cannot do… sometimes there are special things you cannot do together… sometimes you just have to do it with a friend rather than your brother or sister….Like you can't go to your brother for help with your maths homework. (Liam, sibling)

The importance of distraction

All participants identified the need for fun and distraction from the sadness and intensity of emotions they sometimes experienced. When asked by the research assistant what was important to them, participants responded they wanted to have fun. Participants recognised the time spent with a counsellor at the program's house created light-hearted relief from the challenges they often faced. Play therapy and the connection of being with the counsellor are evident with this participant comments:

They [counsellors] help you to have fun… like when you're really sad or something. The sad feelings just go away. (Liam, sibling)

Participants also reported what they liked about coming to the program house, not only meeting with the counsellors, but also meeting with the other siblings within the groups. This participant stated:

I get to see [names program counsellor] and meeting nice people [then named the other participants in the focus group that he knew from previous sibling groups]. (Liam, sibling)

It was important for the participants to remember the positive aspects of their family life along with the difficulties they experienced. Meeting with the counsellors for play therapy gave them an opportunity to have fun. This distraction assisted them to have a shift in emotion and move away from the intensity of the experiences of living with their sibling with serious illness. All participants had insight and awareness that it was the role of the program clinicians to help them because they had a sibling was seriously unwell. When participants were asked if there was anything else the program team could do to 'help more', although there was careful consideration, participants reported they did not have an answer to that question.

Support for the sick sibling

Participants shared their experiences of how the program counsellors 'helped' their siblings. They identified and understood that their sick brother or sister became angry at times due to pain or their illness. It was evident the participants valued the role of the program clinicians as they witnessed the benefit to their sibling when able to talk through their concerns. This had a positive impact on the wider family. This participant shared:

Like with my sister, she had a little bit of an anger issue, so [the counsellor] came over and worked with her, and made her quieter and she's like stopped it now… She made it much quieter, instead of a screaming sister. (James, sibling)

All participants agreed the behaviour of their ill siblings was unpredictable and unexpected at times as they had outbursts of anger, shouting and bossiness. The participants expressed insight that the program clinician's role was valuable in helping their brother or sister through these times.

Aggregated summary for sibling participants

Sibling participants identified the program as being beneficial for themselves and for their whole family. They appreciated the counselling support provided through play therapy which reduced anxiety and sadness and enabled them to have fun and be distracted from the

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uncertainty of living with a sibling who had serious illness. While healthy siblings often experienced being left out, and not knowing what the future held, they appreciated meeting with other children in similar circumstances. Having the opportunity to talk with a program counsellor was significant, knowing they could talk about their concerns, alongside the lighter aspect of fun and distraction.

These key aspects of care and support provided by the program counsellor to relieve anxiety and fear, along with the 'lightness' of fun and distraction via play therapy was also identified by the child with serious illness. Meeting with the program counsellor created a sense of 'normality'. The overall experiences of the child participants were analogous.

PARTICIPANT GROUP 3

EXTERNAL SERVICE HEALTH PROVIDERS

The external service health providers willingly shared their perspectives of the program. Aspects of these findings have been published (Ward, Evans, Ford & Glass, 2015) and are attached as Appendix D. However, the findings are detailed in greater depth here. There were six key themes identified; program vital aspect of care delivery, collaborative care builds strong partnerships, the interface of effective communication and expert skill essential in complexity of care needs, supportive collegial relationships reduce the burden of care, flexibility an aspect of care that supports families and access to afterhours care reduces anxiety.

Program vital aspect of care delivery

Participants viewed the program as both positive and a vital aspect of care delivery and had a good understanding of what the program provided for families. They perceived the program team provided care for children who were chronically ill which meant the care regime may be for long periods of time. The program included support to the whole family. This participant stated:

They work with families who have chronically ill children, or children who have got chronic illnesses that impact on the whole family. They work not only with that child, but working with the whole family… I see them as being in it for the long journey and they do that more extensive work. (Stella, service provider)

Participants valued the attributes of the program in providing care to children and their families, while also acknowledging that they valued their relationships with the organisation.

Collaborative care builds strong partnerships

Participants in this study reported that the program complemented the care they provided. The program team members worked with parents and families to provide emotional support. This was seen as a very important aspect of care. The external service providers reflected that before the establishment of the program they had endeavoured to respond appropriately to emotional disclosures. They now believed their responses did not necessarily result in the best outcomes for families. They reported there were 'gaping' holes within services, therefore they had previously worked outside of what they were comfortable to do. Since the implementation of the program, participants identified there were clear role definitions and boundaries between the program team and general health providers which resulted in greater efficacy in the provision of care. These external service providers now felt they were free to work within their own scope of skill, knowledge and expertise. This participant stated:

The program kind of complements our service. Prior to [the program], families would disclose something to you and so we would try and deal with it possibly not in the best way… It was very much up left up to us and I think there were some great gaping holes. I find now that I go in and do my job, which is to check medical interventions, and knowing that 'that' [emotional support] is taken care of… parents do not need to talk to me about it. [The program] is more appropriate, so it complements, and they know that they are there for the emotional support and they are very good with boundaries on what their role is and what our role is. (Raewyn, service provider)

Participants reported the program team worked in partnership with other services, acknowledging they were well known to child health services and known for their professionalism. The partnership was particularly appreciated in the hospital wards and neonatal intensive care (NICU). They saw the program team working alongside their teams at

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the hospital, and this combination provided the best care for families. The program team had defined roles to provide emotional support, encouraging parents to be parents and advocating when needed in a way that was supportive to families and external service providers. This participant stated:

> *It links back to patient advocacy, so when you have a family who have a long term hospitalisation and there are difficulties for parents to know what their role is, and when they don't agree with the consultant or some of the medical decisions, they [program team] have worked alongside us really well and alongside the family really well in order to provide the best care for the baby and family…[The nurse specialist] allowed a mother to parent and validating that she needed to parent, which is easily lost in our environment. So, it is about patient advocacy, but it is also about standing up and walking with us in a way that is definitely not medical or nursing". (Shelley, service provider)*

Interface of effective communication and expert skill essential in complex care needs

Communication with the program clinicians was strongly valued by external service provider participants. They reported that the program clinicians had effective communication, which incorporated key interpersonal skills, listening with discernment to hear what families and health providers conveyed. They viewed these communications skills as essential when multi-agencies were involved with a child's care. This transparent or open communication facilitated the attainment of child/family carers' goals. Participants were highly appreciative of the role of program clinicians as a mouthpiece for the child/family. They thus received important information about responses to care and were able to appropriately vary the care. Participants reported that this transparent communication supported their professional relationships with families. This then enabled further very useful conversations regarding the care of the child. This participant stated:

> *I often talk [with the program nurse specialist after she has had] a meeting with a family… and she will say, I have spoken with mother and gained her permission, and there is always that, mum is aware that this is what I am going to tell you…. If she feels that there is something that I need to know to help me give better care, and better support, then she has no hesitation in asking their permission, and seeking me out and telling me and that has worked really well*

you know, time and time again. So, it's a very transparent process. (Raewyn, service provider)

These participants noted the important communication role provided by program clinicians. The clinicians had a depth of skill and expertise that was required when caring for children with complex health needs, and their families. Their understanding of the health and hospital systems was beneficial in communicating with both health providers and the families. This was particularly evident when a child was hospitalised. Parents were often unsure how to relinquish their care role and allow health professionals to take the lead. An admission to an acute care facility provided parents with a period of respite. During this time, they were encouraged by program clinicians to be fully 'in' their role as parent. Participants described the program clinician as being committed to finding workable solutions for families and working hard to ensure the voices/needs of the child, parent and family were heard. This participant stated:

In patient meetings, [inclusive of parents, the program clinicians] are very skilled at saying… 'Now what I am hearing is'… there is a lot of validation so that everybody that is sitting around that table is very clear about what is being said, and what is being reflected. There is always a plan at the end of it, I think they are very skilled at that….and they have the knowledge and the skill to bring people back and settle them down… communication wise they have got it. (Shelley, service provider)

Participants acknowledged that medical/nursing knowledge and medical technology has enabled children to survive what were previously fatal conditions. As a result, greater skill was now required from service providers. They were also very aware of their need to continually learn and adapt their clinical practice in a rapidly changing care environment. Participants acknowledged that program clinicians demonstrated advanced skills in symptom management, end-of-life care, and family communication strategies in the care of the child, and at times with bereaved families. Participants expressed that program clinicians were not afraid of having 'real' conversations with families that often were hard for service providers to manage. This sharing of expertise, guidance and mentoring was an aspect of the program

that was highly valued by participants. This contributed to their knowledge and skill base. These participants stated:

> *[In relation to the program nurse specialist] … Because of [her] level of knowledge in terms of symptom management and pain management, and all that stuff, she gives a lot of advice to nursing and medical staff about medications and the right path to take…. [This has resulted in] up skilling all of us in our end of life care. (Debra, service provider)*

> *I forget that when families come into hospital, they tell me later, what they are facing straight away. They are waiting for the doctor to come and give them bad news, and they are right back at the place where, my child is going to die again. I think having [program clinicians] there to remind us of that stuff, that this is actually really stressful for families and we forget that, because it is constantly like this all the time…They remind us that these are parents with children that they need to parent their children and have goals and make decisions about what they want for their son or daughter… They help bring the anxiety down. (Penny, service providers)*

Participants appreciated the program clinicians providing the broadened context for children and their families when admitted into the acute care setting. They acknowledged when providing care at the times of acute illness, they did not necessarily appreciate or have the greater context of what was happening with these families. They were only seeing a small part of their lives and, at times, appeared to be desensitised to families' situations. This participant reported:

> *I think too with over the years with our NICU babies, the survival rate is now so much greater and the complexities that a lot of these children now have, you have got a greater need than was ever before. The need was always there, but when you are asking parents to care for children in chronic situations, you know, a long, long time, you know there are children out there now that would never have left hospital and I think that is where their services have evolved. It is not just about palliative care… mums in particular, they are on those journeys that are challenging, and they are challenging every day. These parents with 90% outside in the world, we only see them with an acute illness and I think that is something that [program counsellor and nurse specialist] come in, they are walking alongside these families and that is where the trust has been built as well, they are there for the families. (Charlene, service provider)*

Participants reported how the program clinician's skills incorporated being able to walk alongside families throughout the challenges of acute illness and adaption to home life after hospitalisation. At times this care incorporated bereavement support. Participants acknowledged, due to working within acute care settings, they themselves did not necessarily have the time, or capacity to provide ongoing support for families. However, they reported this is what the program clinicians did well, which helped ease the fear for families. The skills of the program clinicians and the provision of long-term care was appreciated by external service providers. They knew families were gaining the skilled support they required, therefore, they could leave this aspect of care to the program clinicians. These participants stated:

> *I think they remove a lot of the fear and the sense that some of the families are very apprehensive, particularly every time coming back into hospital often means your child if they are ill, it means that they are never quite as well again. You know I often use the example, that they drop and then they plateau until they drop again, and I think they [program team] are very, very good at helping the families come to terms with that event each time and of course, they walk the journey home with those families. That helps families normalise that little bit. I think the other great thing they do in that respect, is… We are such an acute area and often will have the child extremely unwell and often if they were to pass away with us as well, but the next child is knocking on our door so it doesn't mean we are not sad and we are not involved, but the next child is waiting for our care. [Program clinicians] follow the family history, that journey so much more than we do, so much of our contact is related to when they have the child and they are coming to us. They [program clinicians] are there for those families beyond and I think that the families sense that and it helps the relationship with the bonding that they have. (Penny, service provider)*

Supportive collegial relationships reduce burden of care

Participants reported that program clinicians provided emotional and practical support to children and their families. In addition, much-needed support was extended to themselves as service providers. Participants reported the care of children is more complex, particularly as babies in NICU are now surviving. They were conscious of the heavy burden they experienced at times within the emotionally confronting nature of their care role with children with serious complex illnesses. The collegial support from the program clinicians was very welcome at such

times; it enhanced their care delivery and made them feel less isolated and lonely in their clinical work. These participants stated:

> *When I first began in NICU and in my second week and we had a crisis in the ward, I just freaked you know…. The program team invited me back to talk, and really, it was a complete debrief… They seem to know when we need them… they just seem to know when you are going through rough times. (Shelley, service provider)*

> *We all have one [use by date] and when we work at this real high pace, people burn out and I just think we all suffer in our own jobs as well as the families… us as practitioners suffer too. (Charlene, service provider)*

Participants highlighted the skill the program clinicians had in providing support to different health providers who may all be experiencing different emotions from an intense care situation. This participant stated:

> *… Just going back to staff support, we had a couple of years back some quite difficult situations where [program counsellor and nurse specialist] were invited in to help staff in a semi-debriefing process… they were incredibly skilful, because they were adult people who had really strong feelings about how things had been handled and how things were done, and they were amazing… they just have the knowledge and skill to bring people back and settle them down. (Shelley, service provider)*

FLEXIBILITY AN ASPECT OF CARE THAT SUPPORTS FAMILIES

Participants perceived the program as being more flexible, with more time available, therefore having greater capacity than they had to care for families. This flexibility included care of the whole family, for longer periods of time, and when the families required support. Participants noted the program was set up for children's and family's needs rather than having them try to fit within the health system that was busy and less flexible.

> *…One thing I really like… within 24 hours they [program clinicians] have tried to make contact [with a family after receiving referral]… At the same time, if they have rung and the parents have changed their mind, and said, actually, I don't*

need the service, they always feed back to us and let you know, and at any time
they are happy to be reconnected. (Mary, service provider)

These participants acknowledged the change they had seen in some families due to the flexibility of the program, with the program clinicians having time to listen. They also perceived, not being employed by the hospital was a strength and added to the program clinician's connection with families. This participant stated:

I have seen their presence in a couple of families that we have had, have actually
been really empowering for the family. The fact that they are like a conduit
really between the medical complexity, the yucky stuff that is going on and they
can unravel that stuff for them and give the families the power to feel confident
to say what they want for their child or what they think is best… of course they
[program clinicians] have time to listen. (Hazel, service provider)

Access to afterhours care reduced anxiety

Participants recognised afterhours support provided by program clinicians as an important component of care for the parent/family. This is particularly in relation to minimising anxiety when the child's condition deteriorated. The participants highlighted the benefit and assurance this provides to families.

And the afterhours stuff is huge; I think whether it's for a health crisis or an
emotional crisis. The family knows that they can call and get [a program
clinician] to talk them through whatever is going on and advise them what to
do… when it is happening, at the time. (Jenny, service provider)

….When they [the parents] take their baby home from us, they are really scared
about what is out there, and to know that they have the home care nurses [in
the day] and they have [program clinicians] who have that 'in the middle of the
night stuff', that phone call to ask that question,… it's just so important and
brings their anxiety down. (Susan, service provider)

While there was strong approval for the 24 hour on-call service provided by program clinicians, the health professionals' conveyed anxiety over the vulnerability of the service. Participants were concerned for the welfare of program clinicians in terms of the heavy load that could

occur during the overnight call service. They were also concerned about the sustainability of the program and the need for ongoing funding.

> *That is a weakness that I know they are aware of. I have spoken to the [program clinicians] many times and it is potentially a big issue, that they provide 24-hour service. (Tina, service provider)*

> *I have tried really hard to get [District Health Board] funding… it is a problem because they have a huge proportion of the clients. I just definitely worry about that afterhours stuff, it is a big problem and I know that the [program team members] are aware of it. (Raewyn, service provider)*

When asked by the research assistant if there was anything the program could do differently or more effectively, participants responded, there was a need to 'multiply' recognising the growing demands of families with complex children and the burden on the organisation and on its team members. One participant stated:

> *They need to multiply… it means cloning because you could add more people; it is the dynamics that make it unique. It is about the fact that they are on call 24 hours a day. You see them exhausted and they have worked all weekend, they have worked all night and they are still turning up… you know they are giving you 100% again, but you also know that actually they might not get sleep tonight either and I think that is, there are so many more families out there, that really they are only probably scratching the surface, but it would have to be cloning of them. (Raewyn, service provider)*

However, while participants were concerned about the ongoing sustainability of the program, due to the pressures of a growing population group, they acknowledged this service was vital not only to the families, but also to themselves.

Aggregated summary for external service providers

External service health provider participants viewed the program to be a vital aspect of care delivery and complementary to their care as health providers. The collaborative partnerships, effective communication and the multi-layered skill base provided by the program clinicians provided a greater depth of care for families. The long-term psychological care for families that the program incorporated was valued by external service providers, as they were often

limited by time constraints in the busyness of acute hospital settings. This support reduced anxiety for families, while also reducing the sense of isolation for themselves in the intensity of the care. Working alongside the program team enabled external service providers to work within their own scope of practice, knowing families also received care from the program. The flexibility of the program and the afterhours care provided to families was deemed a significant aspect of care delivery. However, this was perceived as placing the program clinicians at risk of burnout due to the demand for services therefore, further funding and more staff were essential in maintaining and sustaining a program that was deemed vital for children with serious illness and their families.

PARTICIPANT GROUP 4

CHILD WITH A SERIOUS ILLNESS

The perspective of the child with a serious illness is reported here. While play therapy was utilised within the semi-structured interview, data were heavily intertwined into the details of her play as this became her focus. Two themes were identified; being different due to a health condition and being valued and supported when living with a health condition.

Being different due to a health condition

This participant articulated her perspectives of what was important for her in a model of care via her play which included creating food and carrying out medical procedures that related to her health condition. The participant acknowledged the pain she experienced which led to an inability to sleep well. She was unable to eat orally as she was fed via a gastroscopy tube. The following excerpts identified the difference she felt due to her health condition and what was helpful:

> [It is hard being sick] because you are not being able to be normal and do what other kids can do, and not eating as much. (Heart Rose, sick child)

> [The counsellor] helps me get through my pain and helps me work out strategies… When I don't eat, [he] helps me with a strategy because I don't eat dinner, so [he] helps me choose like a strategy and it's doing something at the

dinner table… I like to make mummy and daddy some dinner instead. (Heart Rose, sick child)

The participant's play was heavily involved with shopping for food, creating meals for others and directing the research assistant and counsellor to eat those meals. There was a strong focus on this play. This excerpt identified an aspect of her play:

But tonight you have to eat fruit and veges at dinner and your sister and everyone else can have what they are having and you have to have fruit and veges, even if they are not eating… and you can have wedges and they also have got vitamins in it, but you don't know that. (Heart Rose, sick child)

While the participant did not articulate her thoughts about being unable to eat, her play was focused on food as she got others to 'eat' what she created for them in her play. This led into play of medical procedures as depicted by the following excerpt:

I need to check you first, just check your ears, tongue out…where did I put that injection… we are testing if you have got diabetes… I am going to put some cream on it and that stings even more… you disobey, you do not give yourself injections and so you get really sick and you eat coke and stuff and say I will buy something good from the school vendor but you don't. (Heart Rose, sick child).

Being valued and supported while living with a health condition

The participant identified having solutions and strategies to help her with symptoms of her health condition was helpful to her overall wellbeing. This is depicted in the following excerpt:

They [program counsellors] help me with solutions, they help me, and they talk about it [health condition] and make me feel normal. (Heart Rose, sick child)

The participant valued the strategies that enabled her to know what to say to explain to others why her health condition made her different.

[It is important] that people understand why, if they laugh at me, I know what to say… [The program] has helped me through being sick. (Heart Rose, sick child)

The participant's play was strongly present in the data, often the cues of the research assistant's questioning was missed as her focus was intensely on her play. However, she reported what was beneficial for her as she lived with her health condition, specifically when this helped her to feel 'normal' and supported.

CONCLUSION

Thematic analyses of data were useful as an initial step in systematically organising the data. In the first instance, the four participant groups were analysed separately, and their unique context and needs were explained. There was a strong synergy between the different sub-groups.

It was evident the hardship of a child's health condition and the impact of the complexity of children's often rare health conditions on families and external service providers was in the level of responsibility and burden of care identified by participants. Overwhelmed family relational dynamics, and service providers being stretched within their skill base in providing care were contributing factors to this burden. The introduction of the program provided opportunities for participants to gain skills and strategies assisting them to cope with the ongoing demand of care, helping to shape their resiliency. Strong relationships and partnerships were formed with transparency of effective communication, collaboration and established clarity and maintenance of specific roles. The flexibility and availability of the program, particularly afterhours care was viewed as a safety net for families, reducing anxiety when caring for a child with serious illness.

However, participants identified that this availability put the program's sustainability at risk due to limited resources and funds. As the program was deemed a vital service, if it was not able to be sustained, it would leave an enormous gap within care for this population group. Therefore, in answer to the first question of whether the program provided benefit for clients, there was strong evidence the model of care does provide benefits and is seen as vital to all participants. The key themes ascertained from the thematic analysis lead to the second part

of the data analysis in Chapter Five. The next chapter identifies the CMO configurations, and addresses research question number two about the overall effectiveness of the program.

CHAPTER FIVE: RESEARCH FINDINGS – STEP 2 – CMO CONFIGURATION ANALYSIS

Ki te whei ao

Ki te ao mārama

Tiheiwa mauri ora!

To the glimmer of dawn, to the bright light of the day, there is life[5]

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[5]Mai te Whei ao ki te ao Mārama: Māori Module (Auckland University, 2016)

CHAPTER FIVE: RESEARCH FINDINGS – STEP 2 – CMO CONFIGURATION ANALYSIS

INTRODUCTION

The previous chapter presented the findings from the first step of data analysis, thematic analysis. This was a useful first step in which an understanding of each participant group emerged. The analysis addressed the first research question, 'to what extent does the model of care provided by the child health organisation prove useful to each of the client groups (the child with a serious illness, the child's siblings, the parents and external service providers)?' The aggregation of data then allowed broader patterns and themes to emerge. Chapter Four concluded with four key synthesised themes found across the complete aggregated data. These key themes were the foundation for the second step of data analysis, presented here, the CMO analysis.

CMO CONFIGURATIONS

In this evaluation of the child health organisation's model of care (the program), the chief concern was the outcome experienced by users of the program, that is, what was it about the program that made it work for them. The context, mechanism, outcome (C + M = O formula) provided answers to how programs activate mechanisms, amongst whom and in what conditions that brought about change in behaviours (Pawson & Tilley, 2004). Analysed findings are presented below in the 'context-mechanism- outcome' (CMO) configurations discussed previously. As noted by Pawson and Tilley (1997) it was important to explicate the mechanisms under which the outcome was achieved, and the unique context within which it took place. Importantly, we know that 'outcomes follow from mechanisms acting in context' (p. 58). In the configurations presented below the context as seen through participants' eyes is presented first, followed by mechanism and finally outcomes. Four CMO configurations were presented: burden in care; psychological distress in care; a partnership with families; and a partnership with service providers.

CMO CONFIGURATION 1 – BURDEN IN CARE

It was reported in the literature review that survival rates for sick and/or premature infants were higher than in previous years (Elias & Murphy, 2012; Kuo & Houtrow, 2016; McIntosh & Runciman, 2008; Malatest International, 2016). It is known that many of these infants grow into childhood and their complex and chronic illnesses are managed by their parents in the family home. The 'burden in care' configuration is presented below.

CONTEXT

The context of 'burden in care' for the family of the child with a serious illness is explained below. The perceptions and experiences of parents, healthy siblings and external service providers are stipulated.

In the excerpts below, this study participant (external service provider) noted both the higher survival rate of neonates in her neonatal intensive care unit, and the long-term burden for parents as primary care providers.

> *I think too with our [neonatal intensive care unit] NICU babies, the survival rate is now so much greater and the complexities that many of these children now have, you have a greater need [for the program] than was ever before. The need was always there, but when you are asking parents to care for children in chronic situations, you know, for a long, long time. You know, there are children out there now that would never have left hospital. (Charlene, service provider)*

The intensity of care required was burdensome, and the impact on parents far reaching in terms of their physical, financial and emotional wellbeing. One mother explained below her struggle to manage her sick child's condition, her domestic responsibilities, and her emotional wellbeing. Her words suggested that she gained little understanding/support from health professionals at the hospital. In the second excerpt, a father used the term 'war' to describe the enormity of the responsibility he faced at home with his sick child.

> *You get so caught up in it all and think, hang on, we need to manage this and carry on with everyday life, and then something else happens. We have to juggle being at the hospital and then home, then hospital, then home. The bills are not paid and you just are caught up in just surviving. …you close off any needs of*

*your own, so I think you do not even realise you have needs. …At the hospital,
you are just bombarded and overwhelmed. (Christine, parent)*

*The parent who stays with them [sick child] the most, works more at the front of
the war so to speak, so they are the more exhausted. (Ben, parent)*

The entire family experienced the burden of care. Of note was the impact on the healthy siblings of the child with serious illness. In the excerpts below, children spoke about living with unpredictability in family processes, and their lack of knowledge and even fear about what was happening regarding their sick sibling. In the third excerpt a mother explained the negative consequences for her well child's schooling.

*We had to go to an after school programme at my old school when she had an
operation. It's boring when my sister is in hospital. I have to travel up to the
hospital a lot and it takes about half an hour. (Sebastian, sibling)*

*When your brother or sister is in hospital, you don't know what is going on… It's
the thought, when they go into hospital; what's going to happen, and wondering
if they're going to make it back or anything. (Liam, sibling)*

*He [sibling] had issues, when he first started at school he ended up in the
principal's office within the first few weeks of starting school, he was really
acting out, had attention seeking behaviour. (Suzie, parent)*

In addition to the burden experienced by the entire family outlined above, was the worry and confusion related to the child's rare disease. This made families feel different, including the child living with the health condition, they experienced being on the 'outside' of social normalcy. In the following excerpts, two parents explained their experiences.

*I still feel outside of it because of my daughter's rare condition… I didn't have
[communication] with the physio, the OT, or speech therapist… I didn't know
what I was doing for my daughter. (Krystal, parent)*

*It's just the rare thing though, you get the diagnosis and you think what the hell
do you do now…What I am trying to say, you just have this bubble, where you
have these rare things, and I am sure you guys agree, but you always just seem
to be just outside of it. (Ben, parent)*

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The rarity of their child's condition, and the lack of answers from medical providers regarding diagnosis, prognosis and care regimes, resulted in the need for parents to develop expertise in their child's unique care needs. This parent below explained that he teamed up with parents of children who had 'conditions he has parallels with'.

> *You get the diagnosis [of rare condition]... and the worse thing is, we got told by our initial paediatrician to google it, which was the worst thing to do…We were told, "just google it" … sure thing buddy. Yeah, so I guess we would just team up with people that we know. Or if not similar things there are, some of the conditions he has parallels with [such as] cystic fibrosis. (Ben, parent)*

This lack of understanding also extended to the education sector. Below, a mother explains how her sick child's school teachers did not understand the child's special circumstances and health needs.

> *I have a lot of trouble with the school understanding. It is difficult for people to understand and when they do not understand, they can make the wrong decision, its hard work advocating constantly [for child with serious illness]. (Suzie, parent)*

Study participants described the context within which care was provided to the sick child. Parents experienced burden associated with responsibility for care, while well siblings experienced burden associated with lack of predictability in family processes and lack of understanding. The mechanisms fired within this context are now explained.

MECHANISM

The child health organisation's model of care (the program) was introduced in recognition of the societal expectation on families to take over responsibility for their sick child's care and provide this care in the family home. The mechanisms, according to Pawson and Tilley (1997), identify the macro and micro processes within the program that prompted a response, either positive or negative, from program participants. The mechanisms 'explained how things worked by going beneath their surface appearance and delving into their inner workings' (p. 65). This mechanism presents the perceptions and experiences of parents and service

providers regarding the program processes that reduced, or failed to reduce, the burden of care experienced by families.

The program provided both macro and micro processes. In terms of macro processes, the program's facility itself was found by participants to be amenable. Families were exposed to a large and rigid healthcare system, and the experience of care was often impersonal and frightening. Two parents explained their response to the program facility, particularly related to its non-clinical appearance and feeling.

> *It's non-threatening, it's comforting, it's embracing and it's warm. [It's quite key the fact that] It's a house and not an office or doesn't feel like a doctor's room or a hospital. It doesn't have that clinical feel and the last thing they [sick child and sibling/s] want to do is to go to another [clinical space]. (Ben, parent)*

Micro processes, in this case the specialist nursing and counselling services, were highly valued by all participants. One mother explains a positive outcome for her sick son on meeting the program's nurse specialist.

> *[Child with serious illness] came in recently and saw [nurse specialist] himself and I know that benefited him hugely. Because he had had a really rough time at school and he was getting bullied, he was really down on himself. Coming in and seeing [nurse specialist] just really transformed him… He is probably feeling a lot more confident about coming in and talking about it now. (Suzie, parent)*

In the excerpt below, a parent's words attested to the program clinician's understanding of her care burden, and expertise in their approach to that burden. She explained her interaction with the program team, as 'they were just like …let me take it from you'.

> *When at the hospital you are just bombarded and overwhelmed… Once here [program house], they [program team] are just like 'let me take it from you'. It's 'let me take the load for a while' and they let me just breathe, sit there and have a cup of tea and breathe. (Christine, parent)*

Another participant, a service provider, reported that the support provided by the nurse specialist and counsellor enabled families to gain some 'normality' when engaged in communication.

> *I think they [program team] have skill and sensitivity in listening to families and siblings, who can be very young children [about end of life care and issues]. They really engage in a positive way with them as well and can normalise it in a good way for some of those families. (Stella, service provider)*

The child's serious illness and the need for complex care provision in the family home caused the family, namely, parents and well siblings, to experience burden in care. Within this context, the macro aspect of the program mechanism was the program house with its purposely non-clinical aesthetic. The micro aspect of the program mechanism was the program team's knowledgeable and skilled approach to lessening parents' burden. The outcomes presented below follow from these mechanisms acting in the context of the burden in caring for the child with serious illness.

OUTCOME

In this study, most families of the sick child reported being burdened by their child's complex and constant care needs. In the excerpt below, a mother who appreciated the program 'house' contributing to her sense of comfort and wellbeing explained the macro aspect of the mechanism.

> *I [initially] thought, this is just another support group, but you walk in and it's, wow, this is amazing… this warm home… It's non-threatening, it's a friendly environment, it's comforting, it's embracing and it's warm. (Christine, parent)*

> *That is what makes the [program] so valuable I think, the fact they have that medical [nursing] expertise as well as the counselling… They can interpret some of the things that you get told that can be difficult to understand… one on one counselling from [program team] has provided amazing support over the years and turned the situation from a nightmare into something great… I was enduring life, not enjoying it… They didn't fix it for me, but gave me the skills to fix it for myself… that was really empowering and helpful (Suzie, parent)*

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I would be lost [without the program]… It is the fact that I have got them to lean on a bit every now and then. (Christine, parent)

When [sick child] was going through middle school, [specialist nurse] helped him to deal with his anxiety… His teacher really needed to know how to support him… The teacher wanted to know if the [nurse specialist] could meet with them, and she was happy to do so. She met with the teacher and one of the management team. It is really helpful because I have a lot of trouble with the school understanding. (Suzie, parent)

Engaging with the counselling support empowered families to cope. In the excerpt below, the presence of the program's counsellor prompted this father to sigh in relief.

… So when you come in and hear the things said [by counsellor] it's just a sigh of relief (Ben, parent)

Study participants reported many beneficial outcomes regarding the specialist nursing and counselling services provided by the program. However, many expressed their concern that they, and other parents, were left alone to manage by themselves for too long before they were referred to the program. In the excerpt below, a father reported that an earlier referral would have made things easier for him and his family, while another participant was left to juggle 'fireballs in the air' before achieving a referral to the program.

We were only referred here [the program] a few months ago, I think if somebody had picked us up two and a half years back and said, 'this is the way you should be going', I think we would have had a much easier ride on that journey. But nobody identified [our need] and we did not know [the program] was here… I think it would have been good for us and a huge benefit to [our child]. (Ben, parent)

I think we would have coped a lot better. I think it would have helped the two younger boys [healthy siblings]… Because they definitely got abandoned in the first year while we were juggling, literally, it felt like fireballs in the air. It would have been good for them to have somewhere to come, but somewhere that we could all come to… Because [sick son] was scared, he did not know what was going on, so yeah, I think it would have made life easier having their support. (Christine, parent)

The context of 'burden in care' was experienced by the sick child's parents and healthy siblings and it negatively impacted their day to day lives. The program clinician's knowledgeable and skilled approach to lessening parents' burden was appreciated by parents. The relief from burden was explained by parents as enabling them to cope better, to feel a new sense of empowerment in adversity and to experience a sense of relief. They experienced a break from their daily burden which allowed them to gain a sense of self as an individual in the care role.

Parents criticised the delay they experienced in gaining a much-needed referral to the program. Before referral they and their children struggled with the care burden. Parents viewed this as a failure in the system, rather than a failure of the program itself. Even so, they expressed clearly the need for families to be referred to the program immediately on taking over the care of their sick child.

CMO CONFIGURATION 2 – PSYCHOLOGICAL DISTRESS IN CARE

When a child with a serious illness and complex care needs was cared for in the family home, the family experienced the burden of care. As noted in the literature review, the burden of responsibility for care of their sick child resulted in psychological distress.

CONTEXT

The context of 'psychological distress in care' of the family of the sick child is explained below. The perceptions and experiences of parents, healthy siblings and external health service providers are presented. Excerpts from parents attesting to their own and their well children's psychological distress are provided. Healthy siblings of the sick child give voice to their distressing experiences. External health service provider's voices are also heard in this configuration, as they attest to the psychological distress they witnessed in families.

When parents took their child home from hospital at the very beginning of their care journey, they were fearful regarding their responsibilities. One service provider described this in the following excerpt.

> *When they [parents] take their baby home from us [hospital], they are really*
> *scared about what is out there. (Susan, service provider)*

Parents experienced ongoing fear and anxiety regarding their sick child's future and their own capacity to keep their child well. A mother's fear and anxiety were clear below in her quest to gain information about what to expect in the future, while at the same time, being too fearful to listen to the answer.

> *I sometimes hear myself saying to [the program's nurse specialist] 'you know*
> *from all of your experiences, what can we expect?' And I think, please don't tell*
> *me because I don't want to know. …If I do want to know some specific thing*
> *about in five years' time, then she can give me that information, but she is*
> *sensitive enough not to just bombard me with it. (Suzie, parent)*

The same desire to gain information about the sick child is reported below. In this case, the father described the tension he felt having gained information about his son's condition but wanting to shield his partner from the news.

> *There were lots of things I found out that I never told my partner. … I thought*
> *you don't want to know this, so I hid some things from her. (Ben, parent)*

Frequent and multi-professional medical appointments caused stress to parents and their well children. In the excerpt below, a mother explained that she was completely 'tied into' her situation of managing all of her daughter's care at home, but in the presence of medical personnel she could not find the words to use.

> *It's hard for me to explain things when I am not a medical type, even though I do*
> *everything for my daughter. I think you are so tied into the situation emotionally*
> *it does shadow how you are able to express yourself. (Christine, parent)*

When the sick child is re-admitted to hospital, their parents' sense of fear and loss of control caused psychological distress. One service provider explained in the following excerpt the impact on parents when their child had an acute exacerbation of their illness.

*…When families come into hospital, they tell me later what they are facing…
They are waiting for the doctor to come and give them bad news; they are right
back at the place where 'my child is going to die'. I think having the [program
team] there to remind us of that stuff, that this is actually really stressful for
families and we forget that [they face this] all the time. They are waiting for that
bad news 'tell me about it, something is worse again'. (Penny, service provider)*

*Some of the families are very apprehensive, particularly every time coming back
into hospital. It often means your child if they are ill, it means that they are
never quite as well again. You know, I often use the example, that they drop and
then they plateau until they drop again. (Penny, service provider)*

This apprehension was a constant presence for some parents. At times parents found it
challenging to allow their sick child to engage with 'normal' day-to-day activities without being
overly protective. The mother's words below showed her underlying psychological distress as
she endeavoured to push through her own fears to parent her sick daughter.

*I am always on the edge. My daughter is just a happy-go-lucky child; she will just
go and do whatever she wants… I [try not to] care if she goes and gets dirty, I
am trying to treat her like a normal child. … I put her into kindy [even though]
she could have been kept home in a bubble. … I am always on edge [and] I think
that maybe it filters down to her. (Krystal, parent)*

Psychological distress was also apparent in well siblings. While parents were acutely aware of
their well child's needs, they were time limited due to the care needs of their sick child. Two
mothers attested to their well children's psychological distress, using terms such as 'acting
out' and 'neediness'. These mothers acknowledged the impact of the sick child's extra needs
on their families, particularly their well children.

*He was really acting out and had attention seeking behaviour and clearly
needed some support. (Suzie, parent)*

*My middle child has the neediness thing as well, because she doesn't get much
time with me, my oldest one and my youngest needing my time, so she just acts
out… But just the situation that we have been pulled into [health condition and
treatment plans] she just feels so left out, so coming here [program house] she
enjoys. (Krystal, parent)*

These children, the siblings of the sick child, explained their distress in terms of a 'headache'. Two healthy siblings in the excerpts below explained their experiences when their brother or sister was not well.

> *Sometimes she [sick sister] gets mad and isn't very nice to me, when I walk into her room and try to tell her stuff, she yells, "Get out of my room". That's what gives me a headache as well. (Zayden, sibling)*

> *It's hard because she [sick sister] gives me a headache… When she's not well, she's angry… and she's bossy. (James, sibling)*

The impact of not being able to do things as a family added another aspect of psychological distress to healthy siblings. Family activities, whether going out as a family or simply doing homework with the sick brother, were missed because of the sick sibling's health. The sick child's illness had far-reaching effects on family functioning.

> *Sometimes there are just some things you cannot do… Sometimes there are special things that you cannot do together… Sometimes you just have to do it with a friend rather than your brother or sister… Like you can't go to your brother for help with your maths homework. (Liam, sibling)*

> *You can't do stuff cos there are things you can't do… Like sometimes, you can't be together and do special stuff together. (Sebastian, sibling)*

Another two healthy siblings showed their unhappiness regarding missed family opportunities for overseas travel and special holidays together.

> *I was going to go [overseas] but then I didn't, cos [my sister] went to hospital the day we were leaving. (James, sibling)*

> *We can't go on as many holidays… cos [my sister] can't go on a plane, so I have never been overseas. (Zayden, sibling)*

Study participants described the context within which they provided care to their sick child. All family members experienced psychological distress associated with care provision, with

the unpredictability and uncertainty of the illness causing fear, anxiety (parents) and confusion and unhappiness (healthy siblings). It was made clear that psychological distress in care experienced by all family members caused the family to feel powerless, to struggle through and only endure their lives. The mechanisms fired within this context are now explained.

MECHANISM

In recognition of the possible negative impacts on family processes and relationships, the program provided care and support to the entire family. The mechanisms presented below identified the macro and micro processes within the program that prompted a response, either positive or negative, from program participants regarding their 'psychological distress in care'.

The excerpt presented below shows that one participant understood that the program operated at a macro level with a broad-based aim to improve the family's quality of life. This mother noted that there is 'no service' that she could go to, in the event that the current program ceased to function.

> *[The program] has a wider scope of people they can accept, so there is no*
> *service that I am aware of that I could go to and it's something I don't really like*
> *to think about the idea [if program no longer existed] because as I say I think*
> *they have been pretty vital to our family's survival. (Suzie, parent)*

The program operated at a micro level through the program team. The program focus was on nursing (nurse specialist) and psychological care (counsellor) for the sick child and family. In the excerpt below one mother explained the counselling support her well son received from the counsellor.

> *Being able to care for the siblings [has] actually been hugely beneficial for our*
> *family to be able to cope… He [well son] has had one on one [counselling], which*
> *has made a big difference for him… Even the siblings pay a price, when they are*
> *in a family with a child with extra needs. (Suzie, parent)*

The healthy siblings of the sick child valued time with the program counsellors. In the excerpts below it can be seen, through the healthy siblings' words, that the counsellor provided distraction from their sadness and worry about family. It was clear in these young children's words that a relationship of trust is in place between themselves and the counsellors.

> *They [counsellors] help you think about the good stuff about your family and help you forget about the bad stuff… Cos they like, talk about the good stuff and only a tiny bit of the bad stuff. (James, sibling)*

The depth of trust between the counsellor and the sick child was evident as she reflected on what meeting with the counsellor meant for her. She was able to articulate how important it was to her to be valued as a person despite having a serious health condition. This enabled her to trust that she could share anything and not feel strange about what she wanted to express either in her play, singing of talking.

> *The thing I appreciate the most when I am playing and singing with [counsellor] I don't feel odd and can share anything… he makes me feel like even though I have medical issues I am still [Heart Rose] and I am valued as a person. (Heart Rose, child with serious illness)*

The program counsellors also contributed to sharing information and knowledge regarding what a child's serious illness might mean for families. This participant explained how she and her husband had counselling sessions during which the counsellor provided information and an explanation of the health journey they had ahead of them with their sick son. The ongoing counselling and the development of a trusting relationship were clear in this mother's words.

> *When our son was diagnosed… my husband and I used to come together to see the [program counsellor]. The [counsellor] said the journey you go on now is going to be completely different to the journey you would have gone on or were expecting to go on. It will be a different journey, a harder journey, but it will also in some ways be a better journey. You will meet people that you wouldn't have met, and it will change your views on things. (Suzie, parent)*

Another aspect of psychological distress for parents occurred when their child was in hospital or attending clinic appointments. One parent explained the assistance she gained from the nurse specialist's advocacy and liaison on her behalf. The nurse specialist's interventions were beneficial particularly in this case where communication with the hospital staff had broken down.

> *The [nurse specialist] has advocated for me at the hospital, we have had various issues with different things at the hospital that she has been able to advise me on, as well as get in touch with doctors … Also, [she assisted with] the practical things, actually being at the hospital and being able to liaise with the hospital and providing practical solutions. (Suzie, parent)*

The child's serious illness and the need for complex care in the family home caused the family, namely, parents and well siblings, to experience psychological distress in care. Within this context, the macro mechanism was the program's unique broad-based concern for the quality of life of the sick child and family. Also, within this context, the program operated at a micro level through the program team. This program team had the necessary knowledge and skill to facilitate the development and endurance of a long-term, trusting, therapeutic relationship with the sick child and family members. This was not explicitly stated by the family members but was heard through their various comments. This relationship was established through psychological support (parents, sick child and well siblings) and play therapies (sick child and well siblings). The outcomes presented below follow from these mechanisms. What it is about the program that lifted, or failed to lift, the family's psychological distress in care is explained.

OUTCOME

The participants in the current study identified various aspects of psychological distress. The outcomes presented here were triggered by macro and micro program mechanisms that worked to establish a trusting, therapeutic relationship between the program team and the sick child and family. This parent explained in the following excerpt how her whole family benefited from the programme.

> *I think my family probably uses the whole package [program] and it's been amazing… They support the whole family, so it's not limited to the child with the*

condition or just to the child and the parents… Having a service for the whole
family and the flexibility of it… covers what our needs are. (Suzie, parent)

One father explained in the following excerpt how the skill and experience of the program clinicians helped make a positive difference.

It's just their experience with a whole lot of families… [Counsellor] will come up
with these little gems… It is those little gems from [counsellor's] observations of
seeing more people and obviously, they have a wealth of experience
themselves…it is the small things [that make a difference] I guess their
experience is like gold. (Ben, parent)

The program clinicians often had a long-term therapeutic relationship with families due to the chronicity of the child's health condition. These ongoing relationships with families can create strong bonds. Service providers in the following excerpts explained how they saw the program team lift the family's psychological distress.

[The program clinicians] are very very good at helping the families come to
terms with that event [acute admission] each time, and of course they walk that
journey with those families. That helps families normalise that little bit. I think
the other great thing they do in that respect is that they follow the family
journey so much more than we do… They are there for those families beyond
[into the future] and I think that the families sense that and it helps the
relationship with the bonding that they have. (Penny, service provider)

They work with families who have chronically ill children, or children who have
got chronic illnesses that impact on the whole family. They work not only with
that child, but working with the whole family… I see them as being in it for the
long journey and they do that more extensive work. (Stella, service provider)

I see the purpose of [the program] as being mainly to provide emotional support
for families, not just in the end of life phase, when a child is imminently dying…
but through the long haul of months and years of chronic illness, where often
the child will peak and fall and emotions all go like that as well. (Charlene,
service provider)

This emotional support provided during 'the long haul' of months and years of chronic illness is described below by the sick child, who noted;

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*Even though I have a medical condition, he [counsellor] never treats me
differently… one of the hardest things is being different…. He does play with me
that help my problems to become smaller. (Heart-Rose, sick child)*

The psychological support from her counsellor enabled the child to feel accepted and valued for who she was *with* her medical condition as she noted being different was one of the hardest aspects of having her health condition.

This emotional support is evident also in the healthy sibling's excerpt below when he explained how his sadness goes away when the [the program's] counsellor supported him in having fun.

*They [counsellors] help you to have fun… like when you're really sad or
something. The sad feelings just go away. (Liam, sibling)*

To reduce psychological distress, trusting therapeutic relationships with those providing care to seriously ill children are required. This participant (external health service provider) explained how trust was built between the program clinicians and families, rather than with the sick child alone.

*Mums in particular, are on these journeys that are challenging, they are
challenging every day, and I think they really get tremendous benefit from [the
program]…. These parents [and the sick child are] are 90% outside in the world,
we only see them [during] an acute illness. [The specialist nurse and counsellor]
are walking alongside these families and that is where the trust has been built;
they are there for the families. (Charlene, service provider)*

A mother expressed the benefit she and her husband have gained through ongoing counselling. She reported earlier how the counsellor had told them that their life would be different from what they expected. She explains how counselling and support has provided the means by which she stopped the 'struggle against' and how the family could live a happy life even during the time of their sick child's terminal illness.

[The child's illness]… has completely changed my life, but I don't think in a bad way. Certainly not in every way a better way, there are somethings I would obviously change back if I could, but to not struggle against it. I guess has helped me and my husband to accept having a child with a terminal condition, to be able to live with it and have a good happy family and two happy children… so we do [accept it] sometimes. …Generally speaking, I would describe us as a happy family, far happier than a lot of people that aren't living with that kind of issue in fact. (Suzie parent)

Psychological distress in care experienced by parents and well siblings of the sick child caused the family to feel powerless, to struggle through and only endure their lives. The child with a serious illness also identified her own distress in being 'different' to others. The program clinicians were strongly focused on building and maintaining a trusting, therapeutic and long-term relationship through psychological support (parents, sick child and well siblings) and play therapies (sick child and well siblings). Parents' and well siblings' psychological distress was minimised through their relationships with experienced clinicians who were there for the whole family and for the entire journey.

CMO CONFIGURATION 3 – PARTNERSHIP OF CARE WITH THE FAMILY

In the two CMO configurations already analysed, it was seen that study participants faced burden and psychological distress as a result of being the primary care provider for their sick child. The 'partnership of care with the family' configuration is presented below.

CONTEXT

The context of 'partnership of care with the family' for the family of the sick child is explained below. The perceptions and experiences of parents, healthy siblings and service providers are provided. As previously stated, when participants made their first visit to the program facility (program house), many families were surprised by its informal, but warm and welcoming ambience. The program clinician's acceptance of the family unit, coupled with their warm understanding and tolerance, was different and in stark contrast to the family's experience with other health services.

It was clear from one participant's words that the inflexibility of healthcare provision caused him frustration. It is seen that communication with health professionals in the acute ward was judgemental, even to the extent that the sick child was targeted. Unsurprisingly, this parent withheld information in order to avoid the sanction of health professionals.

> *We were constantly judged. They [health professionals] were constantly making assumptions of us or of him [sick son], and some of them, pretty bluntly to his face…. You filter information to people, because the more information you give them, the more they judge you, or the more they say you are nuts. (Ben, parent)*

A mother reported that demands from hospital personnel were frequently directed at her. She acknowledged that the hospital team did provide support, but the team was also demanding.

> *The hospital has a lot of demands on you, they are providing support, but they are constantly demanding as well. (Suzie, parent)*

In the excerpt below, a parent described her exposure to the suffering of other parents and children during her time in the oncology unit with her sick daughter. It was clear that witnessing other family's distress and loss was hard to bear.

> *…I'm in the oncology area [with my child]. I see lots worse [than my child]… my mate lost his 2 year-old after 22 operations, 2 of them were open-heart surgeries. …I always count my blessings that my daughter is not as bad as what some kids are out there. (Krystal, parent)*

One parent took a wry approach to explaining that the doctor had no answers for him regarding his son's complex health condition. He felt dismissed because it was all too hard for the health care team. He noted below, that he was expected to just sit quietly and hope that someone turned up with an answer.

> *You get a doctor who says look I don't know much about this mate. [It feels like he is saying] "Put this hat on, sit over there and if someone turns up from the UK who has seen it before, [well] they might deal with you". (Ben, parent)*

The context of 'partnership of care with the family' was parents' experiences of the structured and sometimes rigid confines of the health care system. Some parents felt judged and disrespected, others felt overwhelmed by the sadness and loss occurring within the health service, while others reported that they got no answers from the medical team because their child's health condition was rare. The mechanisms fired within this context are now explained.

MECHANISM

The mechanisms presented below identified the macro and micro processes within the program that prompted a response from parents, either positive or negative, regarding the program's development of a 'partnership of care with the family'. In terms of macro processes, the program facility itself was located within two kilometres of the main children's specialty hospital in the North Island of New Zealand. Families knew that the program team was close by if their presence was needed by their sick child's bedside.

The program was initiated in recognition that sick children and their families required a service that worked with them in partnership. Micro processes were the program clinicians, specifically the specialist nursing and counselling services. Participant excerpts presented below 'go beneath' (Pawson & Tilley, 1997) to explain how the program worked to ensure, or failed to ensure, that a partnership was provided.

Parents had no expectations when introduced to the program. The following excerpt conveyed one mother's experience: she started with a 'blank page' however, appeared to understand that everything was there in the program for her and her children. There was a sense of her comfort of knowing she and her children would have their needs met in partnership.

> *I had no expectations… it's just a whole blank page for me anyway. So if it [care] needs to go in a certain direction I feel that everything is here and all the resources for them [children] are here and they are good to go with it. (Christine, parent)*

Participants found the program clinicians respected their need to manage their child's condition in their own way. This contrasted with feeling as though the health care service did not respect their experience with or views on treating their sick child. In the following excerpt a parent explained how the program team met her needs and continued to do so 'in whatever shape or form was helpful to us'.

> *… They [program team] will provide you with support but they won't lift the carpet under your feet about anything you don't want the carpet lifted on. …A lovely way to put it. I didn't feel it was useful to talk about what happened [in the past] it was really about the journey I was on now and our family. I remember the first time we saw them [program team] they said they were just there on the journey with us in whatever shape or form was helpful for us. (Suzie, parent).*

The father below also spoke of his introduction to the program and his expectation that he would utilise the program more as his sick child grew older. He had been encouraged to use the program and establish a beginning partnership. In the meantime, however, finding some normalcy and managing by themselves, was important to him and his family.

> *[I was encouraged to] see them before you need them, get to know them and then go from there, which is what we have done, and yeah we see the services [program] and we have a good understanding. …We do come in here from time to time just to keep in touch, but we don't keep it too regular because I think maybe we like to just normalise it at home and not always [use] a service. To just have a normal life again, just to keep an eye on things and chug away. (Ben, parent)*

Further to this comment, the father explained his appreciation of the flexibility of the program to meet his sick son's and his family's changing needs. In the following excerpt, this father described a typical informal chat with the program clinicians. He explained the value of this partnership with the program clinicians and their flexibility to meet changing needs; he explained that the team provided a 'safety net' when his family required further help and support.

What often happens… you will see them and all they might just say is 'hey, we haven't seen you for a while'. And you know we might say 'thanks for what you have done' and they are 'we haven't done anything' and we say, 'yes you have, you are there and a great safety net for when and if we fall'. So they do help us… Yeah, it is comforting. (Ben, parent)

The program included an after-hour service in recognition that parents' responsibility for care continues on a 24 hours basis during which time the sick child's circumstances can dramatically change. Parents could require advice, guidance, reassurance, a specialist nurse visit, or to have their child admitted to the hospital. This mother described how the partnership of care operated even in the middle of the night. There was respect and concern for her, despite the hour.

You can call someone at 3am if you have to and they [program team] wouldn't say 'look we are not open until 8am buddy'. Just all those little things that you know you are going to need. (Christine, parent)

A service provider explained how important the after-hour service was for families.

And the afterhours stuff is huge; I think whether it's for a health crisis or an emotional crisis. The family knows that they can call and get [program member] to talk them through whatever is going on and advise them what to do… when it's happening at the time. They are very very accessible for afterhours… so that is great. (Jenny, service provider)

The burden and psychological distress in care, coupled with the often impersonal and inflexible care provided by acute health services, was the context within which the program mechanism of partnership of care was explained. Parents' and external health service providers' voices painted a picture of a program team that entered a partnership of care with the family. The program clinicians entered into a respectful and reliable partnership with the family. The clinicians respected parents, allowed them to decide for themselves how they would engage with the program throughout the duration of the care journey, and were always available to them, regardless of the hour. The program team also engaged with the family with respect and empathy for their unique circumstances. Importantly, the program team remained flexible to the family's changing needs over the long term. The outcomes presented

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below follow from these mechanisms acting in context and show what it was about the program mechanisms that built and maintained, or failed to build and maintain, a partnership of care with the family.

OUTCOME

As described above, in this study, most parents of the sick child reported being burdened by their sick child's needs and also the impersonal and inflexible nature of health services (context). The outcomes were triggered by the mechanism of respectful care that allowed the family to decide for itself how it would engage with the program during the duration of the care journey. It can be seen in the excerpts below that the program team enters into a partnership of care with the family and the various ways in which this partnership benefited them.

A parent reported on the longevity of her partnership of care with the program, and noted that the program 'certainly met and exceeded' her needs. In the early days of the partnership, she did not know what she needed, but as she notes 'they knew what we needed'.

> *I didn't have any expectations; it was something I did [commencing with the program] because people told me I should. So I came along. Nearly nine years later I am still coming. So it certainly met and exceeded any needs that I would have identified as being valuable to support us through the journey. …I think if someone had asked me to say what things would be helpful for me; I wouldn't have been able to tell them. So that was probably what was so helpful about [program team] is that they knew what we needed … because I certainly didn't. (Suzie, parent)*

Knowing that someone was always available to talk to was a valuable aspect of the partnership. The trust in the relationship, as previously stated, meant the parents in this study felt comfortable to ask for help when it was needed. A parent explains how important the phone connection was to her.

> *I certainly wouldn't know what to request …apart from someone on the end of that phone. Like I said before, someone on that phone, if you need it it's there, and I feel it's there so I am comfortable with that. (Christine, parent)*

The flexibility of the program was appreciated by all parents, particularly the knowledge that they could contact the program clinicians whenever they needed, even if this contact continued long into the future. In the amusing excerpt below, a mother explained how her 12-year-old son, involved in partnership of care since he was only two years old, suddenly realised that he didn't understand the intricacies of the program. It appears that the program team had just been part of the normal background to his life.

> *I think the service is very valuable and they actually morph to what you need and at that [particular] time. …The [program clinicians] has always been very perceptive about our changing needs for [sick child]. When we first started in the service, my [sick child] didn't need counselling as he was two. But now that he is twelve, it's been really vital for him. All of a sudden he said to me "what, how do we know them, do they live there?" You know he kind of visits a house and 'why are we going to see these people and talk about our feelings exactly?' (Suzie, parent)*

The flexibility in the partnership of care was highly valued by parents, particularly considering the chronic and often cumulatively deteriorating nature of their child's health condition. Families' particular circumstances were taken into account with the program clinicians remaining empathetic to their particular needs. Families were more used to the rigidity of clinic appointments and hospitalisations, where they were expected to fit into large systems. The following parents explained that flexible care was important to them.

> *I would have to agree with you its flexibility and I think that is a huge thing…
> (Ben, parent)*

> *… However, you would like to put it [helpful aspect of the program] it is having that service for the whole family and the flexibility of it, and the way that it just covers what our needs are. (Suzie, parent)*

There were often limitations in what services could provide for sick children in way of specialist nursing and counselling. The mother below voiced her concern that if the program was not available, she would be disadvantaged as the program was vital to her family's survival.

There is no service that I am aware of that I could go to [that supports whole family] and it's something I don't really like to think about. …Because as I say, I think they have been pretty vital to our family's survival. (Suzie, parent)

This service provider explained how she perceived the program to work in partnership with the family to 'unravel' the complexity and 'yucky stuff'. Empowerment was a strong focus of this service provider's perception.

I have seen their presence in a couple of families that we have had. [They] have actually been really empowering for the family. …They are a conduit really between the medical complexity, the yucky stuff that is going on, and they can unravel that stuff for them. They give the families the power to feel confident to say what they want for their child or what they think is best. (Hazel, service providers)

Parents experienced burden and psychological distress in their caring role for their sick child. At the same time, in their frequent visits to health services they could also encounter lack of respect for their position as carer and even negative judgement about the performance of that care (context). It was seen here that the program clinicians entered into a respectful and collaborative partnership of care with the family, within which the parents' expertise in the care of their sick child was recognised (mechanism). The outcome was that families experienced great comfort in the partnership. They knew that they could rely on the program, with the program house and program clinicians being geographically close by and available to them at any hour. This safety net supported parents in moving forward with a higher degree of confidence in both their care journey and their own life journey. Of concern for parents, however, was their reliance on the program and their uncertainty about the program being maintained over time. They expressed fear about what the future would hold for them without the program as their partner in care.

CMO CONFIGURATION 4 – PARTNERSHIP WITH SERVICE PROVIDERS

It has been explained in previous configurations that the sick child's care journey is difficult, often requiring complex care regimes, multiple hospital admissions and consultant clinic visits. External health service providers and families were involved in a complicated dynamic around

the sick child, a dynamic that also involved the program team. This configuration gave voice to service providers' perceptions of, and experiences with, the program team during their own hospital-based care provision to the sick child and family. The 'partnership with service providers' configuration is presented below.

CONTEXT

In the following excerpt a service provider recognises the 'gaping holes' in care that resulted in the complex and time intensive nature of the care for the sick child in the acute hospital setting. In this case, the participant admitted that she responded to care needs but 'possibly not in the best way'.

> *…Families would disclose something to you and so you would try and deal with it, possibly not in the best way… It is very much left up to us and I think there are some great gaping holes. (Raewyn, service provider)*

While parents were totally responsible for the care of their sick child in the home, during a child's hospitalisation, the shared decision making with the child's medical team could be challenging. This external health service provider described the dyadic relationship in the following excerpt.

> *…So you have a family who have long term hospitalisations [for their sick child] and there are difficulties for parents to know what their role is when they don't agree with the consultant or some of the medical decisions. (Shelley, service provider)*

The delicacy of this relationship is shown in the following excerpt in which the service provider explained her difficulty in speaking to parents about their child's terminal condition.

> *…The fact that she [baby] was not going to live, the fact that we were planning to [undertake]… the steps, the talking about the stuff that sometimes is hard. …It is that next step. (Susan, service provider)*

External health service providers often experienced the stress of caring for a child with complex needs who was seriously ill. The following excerpt summed up how one service provider perceived their daily clinical workloads.

I think for us, a lot of us are juggling a lot of balls, and I think many balls in many ways. (Debra, service provider)

Study participants described a context within which multiple demands were made on them in their care responsibility to the sick child and family. The high care demand in their daily clinical workload was deemed to feel like juggling a lot of balls in a service delivery with gaping holes. The mechanisms fired within this context are now explained.

MECHANISM

There were multiple providers involved when a child had a serious health condition. The chronicity of the illnesses brought a level of complexity that could be challenging to manage (context). A multidisciplinary approach was deemed an effective way to provide best care to meet the needs of the child and family. The mechanisms presented below identified the macro and micro processes within the program that prompted a response from external health service providers regarding the program development of a partnership of care with service providers. Participant excerpts 'go beneath' (Pawson & Tilley, 1997) to explain how the program worked to ensure, or failed to ensure, that a true partnership with service providers was achieved.

In terms of macro processes, again the geographical location of the program facility was a benefit to service providers, they knew that the program team were close by if their presence was needed. Although not explicitly reported by participants, this proximity reinforced the concept of partnership between themselves and the program.

The micro processes referred to the complementary way that the program clinicians worked side-by-side in partnership with service providers. These service providers explained how important this was to them as they worked with sick children and their parents.

My job is to go in and work with the child, who is acutely unwell, and a lot of the time, I will be in the room with a child who is extremely unwell and [program clinician] will come and sometimes take the parents from the room, or sit with the parent in the room. It actually allows me to focus on just the child, which is, as far as I am concerned, really my main job… [It is good] knowing that the family have that support, the [program clinicians] is there at the same time as me as I am providing more of the medical care for the child. (Penny, service provider)

One of the roles they [program team] have fulfilled very well within NICU, I am not sure if it is their purpose, but it links back to patient advocacy… They have worked alongside us really well and alongside the family really well in order to provide the best care for the baby and family… [The specialist nurse] allowed a mother to parent [she] validated that she needed to parent, which is easily lost in our environment. So it is about patient advocacy, but it is also about standing up and walking with us… (Shelley, service provider)

An important aspect of partnership was effective communication with the multiple professionals involved in the sick child's care. Open communication ensured important information was shared in relation to the child's care and also supported professional relationships with families. The following excerpt depicted the relationship between the program nurse specialist and external health service provider to ensure the best care was given to the sick child and their family, working in unison in a partnership of care.

I often talk with [the program specialist nurse] after she has had a meeting with a family… and she will say 'I have spoken with mother and gained her permission'. … If she feels that there is something that I need to know to help me give better care, and better support, then she has no hesitation in asking their permission and seeking me out and telling me. That has worked really well you know, time and time again. So it's a very transparent process. (Raewyn, service provider)

Collaborative care ensured all providers shared information that was important for the care of the sick child and family. Multi-disciplinary meetings were an aspect of communication that was effective in ensuring all providers found workable solutions for families. This external health service provider explained that program clinicians provided enormous benefit in facilitating these meetings.

In patient meetings, [inclusive of parents] the [program clinicians] are very skilled at saying, 'Now what I am hearing is'… There is a lot of validation so that everybody sitting around that table is very clear about what is being said, and what is being reflected. There is always a plan at the end of it. I think they are very skilled at that… and they have the knowledge and the skill to bring people back and settle them down… communication wise they have got it. (Shelley, service provider)

The program clinicians and external health service providers worked in unison in a partnership of care to ensure the best care for sick children and their families. Health service provision to children with serious and ongoing illness was known to be complex and involved multiple disciplines. This is the context within which the macro and micro program mechanisms of partnership in care with service providers were explained (context). Within this context, the macro mechanism related to the geographical location of the program facility which proved very convenient when the program clinical team was needed by service providers. The micro program mechanism of the program clinicians' focus on the family, while also communicating and collaborating within the multidisciplinary team to build strong professional relationships was enacted. The outcomes will now be discussed in relation to what it was about the program that built and maintained a partnership of care with service providers.

OUTCOME

As described above, the participants in this study identified multiple demands on themselves as service providers when caring for children with complex health needs (context). The outcomes were triggered by the mechanism of partnership of care with the program team. An important aspect of partnership was effective communication and collaboration, which assisted in building strong professional relationships (mechanism).

Participants in this study reported that the program team provided emotional support to them at their workplace. This seemed to be particularly needed in relation to neonates and young babies who had highly complex needs. The collegial support was appreciated by these service providers who explained the support, and 'debrief', provided to them by the program team.

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*They support the staff and that is really tremendous… they bring continuity…
and I think their commitment is such an example to all of us, because they never
seem to lose their professionalism, even in the most trying circumstances.
(Debra, service provider)*

*Yeah… you are able to talk about some of your feelings about some things
because quite often in my position, I get a lot of the queries from the staff and
you try and balance everything out… and do the right thing for everybody. I
personally find them really good at times. … [They] get things into perspective,
so that I can do the right thing… It is like supervision really. (Stella, service
participant)*

*I first began in NICU, my second week and we had a crisis in the ward, I just
freaked out you know… The [program clinicians] invited me back to talk, and
really, it was a complete debrief… They seemed to know when we need them…
they just seem to know when you are going through tough times. (Shelley,
service provider)*

The clinical workload of caring for children with serious illness had an impact on those
providing the care. Partnership of care between providers delivering services was beneficial
not only for the sick children and families, it was also supportive and useful for the health
team providing the care. The following excerpt highlighted the value the participants in this
study placed on this partnership.

*I think the wonderful thing about the conception of this service [the program],
was being able to do all of the things that we cannot do, to take that time to be
with families and be with the children. Not only a sick child, the whole family…
Having time is part of their role, you know, and they do it so very well. It has just
become an absolute essential part of our service that we can all provide. (Debra,
service provider)*

Another external health service provider explained how she perceived the relationship with
the program clinicians and what this meant for the families within their care.

*The [program] kind of complements our service… I find that now that I go in and
do my job, which is to check medical interventions, and [I know] that [emotional
support] is taken care of and parents do not need to talk to me. The [program] is
more appropriate, so it complements, and they [parents] know that they are*

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*there for the emotional support and they are very good with boundaries on what
their role is and what our role is. (Raewyn, service provider)*

Parents experienced high anxiety when their sick child was acutely admitted to hospital following health deterioration. The hospital team's focus was the sick child; however, they also recognised that the parents needed psychological support and care. The service provider below explained her relief at being able to work in unison with the program clinicians, thus enabling her to continue with her clinical duties in the knowledge that the program team was there to support parents.

> *So instead of just sitting and watching all this stuff happening to their child, they
> [parents] have got the ability to talk things through [with the program team]. …
> There is going to be another [sick child] that I am going off to see in half an
> hours' time… but there is still support there as you leave to go and do your next
> job. That is kind of how we work [in acute care] we are just going from one [child
> patient] to the other, but [with the program clinician's involvement] I know there
> is support left behind for the family. (Stella, service provider)*

A practical aspect of the partnership in care with external health service providers was the program clinician's capacity to manage behaviours in the acute care environment. A service provider described the program team's knowledge and skill in dealing with distressed and angry parents.

> *… We had some quite difficult situations and [specialist nurse and counsellor]
> were invited in to help staff in a semi-debriefing process… They were incredibly
> skilful … They [specialist nurse and counsellor] just have the knowledge and skill
> to bring [the parents] back and settle them down. (Shelley, service provider)*

External service providers faced multiple demands during their clinical care role with the sick child and family. The impact of this demand in their daily clinical workload was deemed to feel like juggling a lot of balls in a service delivery with gaping holes (context). It was seen that the program clinicians entered into a partnership of care with the external health service providers. As the program house was near to the hospital, external health service providers knew they could call on the program clinicians when needed. They focused on the family, while also communicating and collaborating within the multidisciplinary team to build strong

professional relationships (mechanism). The outcome was a continuity of care - the external health service providers felt supported in the treatment they provided and comforted in the knowledge that gaps that occur in their own care provision were met by the program team.

CONCLUSION

A key finding of the evaluation was that families of seriously ill children experienced a burden of care in their day to day functioning. The rarity of the child's condition, the intensity and complexity of the care required along with the uncertainty of the future had a negative impact on the parents and healthy siblings. The program clinician's knowledge and skill to provide emotional support, was seen to equip parents and healthy siblings to cope better as a family. The result of this emotional support meant they felt empowered and relieved, allowing them a sense of self as individuals in the care role, easing the burden of care.

Throughout the child's serious illness, parents and healthy siblings experienced psychological distress. Anxiety, confusion, powerlessness and being unhappy due to the long-term unpredictability and the nature of the illness were aspects of this distress. The child with a serious illness experienced her own distress of being different and valued the therapeutic relationship with her counsellor. These therapeutic, trusting relationships were developed due to the knowledge and skill of the program clinicians. Skilled psychological support provided to parents and play therapies to the sick child and healthy siblings, minimised distress, with families gaining the benefit for the entire journey.

The rigid inflexible confines of the healthcare system placed extra demands on families. They experienced being judged and misunderstood by their health teams at times. The respectful engagement with the program clinicians, who were reliable and flexible in meeting the family's needs, resulted in a productive partnership of care. The availability of support, regardless of the hour, resulted in parents feeling more empowered and confident in their care role. The partnership with program clinicians resulted in families feeling they had a safety net of care regardless of the hour.

There were multiple demands on the external health service providers caring for the child with complex health issues. There were gaping holes in the care provision due to these providers 'juggling a number of balls' and not having the capacity to meet the need. Working in unison with the program clinician's, focusing on the family, with effective communication and collaboration had resulted in strong professional relationships being developed. This partnership has ensured continuity of care for the child and family, and external health service providers experiencing support. Partnership of care with the program clinicians meant external health service providers felt supported and gaps within care were being met by the program.

The complexity of a child's serious illness had multiple demands on the family and the external health service providers overseeing the care. The program fulfils a societal need of removing the gap within health care services by providing skilled psychological support which relieved the burden of care for parents and service providers.

In this evaluation of the program, four 'context-mechanism-outcome' configurations (Pawson & Tilley, 1997) were used to develop an argument about the program's worth in terms of meeting the needs of the sick child and family of the sick child. Overall, the outcomes experienced by the users of the program were beneficial, with participants clearly articulating what it was about the program that made it work for them.

CHAPTER SIX: DISCUSSION

Titiro Whakamuri

Kokiri Whakamua

Look back and reflect

So that you can look forward

CHAPTER SIX: DISCUSSION

INTRODUCTION

The previous chapter presented the overall findings of the realistic evaluation, i.e. the refined Context-Mechanism-Outcome (CMO) configurations. The overall macro context was families, predominantly parents, caring for their child with a serious illness in the family home. The program team clinicians provided the micro interventions of specialist nursing and counselling that enabled the service users, namely, the child with serious illness, the child's siblings and parents, and the external health service providers to engage with mechanisms of skilled knowledge.

The specific mechanism fired in the context of burden of care experienced by families and service providers, was the program clinician's knowledge and experience shared within a respectful and trusting relationship. Study participants reported that their engagement with the program produced outcomes of empowerment regarding confidence in caring for their sick child, and empowerment to seek support for themselves and to share the burden of care. Participants reported that effective communication and collaboration, and partnership of care with the program team reduced their experience of burden in care.

The purpose of this chapter is to discuss these findings in relation to the international literature reviewed in Chapter Two and other relevant literature. The focus is specifically on recommended partnership and family-centred models of care for children with serious illnesses and their families. The findings from this study will be considered in relation to what this evaluation adds to the existing literature.

The findings of the thematic analysis are first explored in relation to the literature. The findings are grouped under main headings; parents of children with serious illness, siblings of children with serious illness, and external service health providers. Within each section sub-headings are used to provide greater understanding of what worked in the program, and for whom it worked. The realist CMO findings are then explained in relation to the contemporary literature

on partnership and family-centred care models. Main headings include burden in care, psychological distress in care, partnership with family and partnership with service providers. Finally, program theories are discussed in relation to new knowledge regarding child health care and future policy direction. Throughout, to distinguish my study findings, I refer to 'the current study' and 'participants in the current study'.

DISCUSSION OF THEMATIC ANALYSIS

PARENTS OF CHILDREN WITH SERIOUS ILLNESS

Families coping under pressure

It was evident in this current study that when a child has a serious illness, the impact on the entire family was far reaching, with the family often trying to cope under enormous pressure. When a child with complex health issues was cared for at home, everyone within the family unit was affected in some way. This finding supported Schuster et al. (2011), research in which they found that parents reported enormous burden due to the complex care provision in the home, often with the child reliant on technology. Care in the home has become the accepted option rather than long-term hospitalisation (Elias & Murphy, 2012), however children were sent home from hospital with complex symptoms still unresolved to parents under-prepared to care from them (Elias & Murphy, 2012). Anderson and Davis (2011) in their critical literature review of families with chronically ill children identified a plethora of risks, stressors and needs of these families; however, they reported a scarceness of evidence-based interventions to enable families to cope. Furthermore, Cohen and colleagues (2011) reported children's complex high health needs were not easily met by current models of care.

When providing care to their child with serious illness, parent participants in the current study often felt overwhelmed and exhausted with their child's high health care demands. At times, they were unaware of their own needs as they were focused on the care of their child, the many hospitalisations or clinic appointments, along with the needs of their healthy children. They often felt they were just 'surviving' in their day to day activities due to being 'bombarded' with the intensive demands of caring for their sick child. Furthermore, although these

participants managed complex care regimens for their children with a health condition, it dominated daily routines, restricted normal family activity and often resulted in social isolation. These findings supported Alderfer et al. (2010), systematic review of the psychosocial adjustment of siblings of children with cancer. They reported that all family members were involved in the chores and adjustments created by the child's illness. Healthy children were found to experience concern for their sick brother or sister's wellbeing, particularly in relation to hospital admissions and the possibility that they might die (Alderfer et al., 2010). Activities outside the home for well siblings were curtailed and there were changes to normal family roles and activities, thus also increasing anxiety, depression and stress in parents (Alderfer et al., 2010). Other studies (Ling, 2012; Looman et al., 2013; McArthur & Faragher, 2014; Miller, Nugent & Russell, 2015) also reported these issues for parents and the added burden of the responsibility for the family's welfare. In her literature review of respite services for children with life-limiting conditions and their parents Ling (2012), reported that parents often exhausted their physical, emotional and practical resources.

Furthermore, the constant juggling or balancing of their sick child's needs along with the demand of family life meant parent participants in the current study were not available for their healthy children. Other studies (Alderfer et al., 2010; Besier et al., 2010) reported similar challenges for families when parents were not able to meet the needs of their healthy children. In the current study, participants noted that parent/healthy sibling dyad was negatively impacted as parents had limited capacity to meet everyone's' needs within the family unit. These findings supported Emerson and Giallo's (2014) study where healthy sibling's wellbeing was impacted; at times they suffered emotional distress, resentment, anger, fear and anxiety. The parent participants in the current study identified some of these behaviours as attention seeking and while they were time poor and had limited capacity, they were concerned for their healthy children's wellbeing.

These demanding responsibilities added to the psychosocial, financial and physical stressors for parents, which negatively affected their ability to cope, or to attend to their own needs.

This finding supported Tong, Lowe, Sainsbury and Craig's (2010) earlier findings from the in-depth interview study on parental perspectives of caring for their children with chronic kidney diseases. In Tong et al. (2010), parents (n = 20) of children with rare kidney conditions were interviewed to better understand their experiences of caring for their children. These authors found the parental role to be negatively affected by the additional role of care provider for their sick child. The major focus of the parents' attention was directed to the sick child thus leaving limited time to focus on the family unit. The findings in the current study supported what was known in the literature about families under pressure when caring for their sick child at home.

However, new findings in the current study extended and explicated what parent participants deemed as vital for them to cope as a family unit. The program therapeutic support groups for healthy siblings and the one-to-one counselling with a healthy child supported not just these siblings, it helped ease the parents' guilt, anxiety and concern they had for their children. Parent participants noted the improvement in negative behaviours of their healthy children that they had previously described as attention seeking. Family relational dynamics improved because of this family-centred support. This level of support was significant in that it enabled their entire family to 'cope'.

The child health organisation's program was introduced to provide not only specialist nursing care, but also psychological support for families in recognition of the limited support they have in providing care to their children in their family homes. Participants in the current study reported being empowered through their engagement with the program and the strategies provided by the program clinicians empowered them to protect, or support, themselves and the whole family throughout their caring journey. Parents in the current study reported that the program interventions of specialist nursing and counselling support positively affected the ability of each family member to live their life and to deal with the impact on themselves as individuals when caring for the child with serious illness. This level of support enabled them to function better as a family in their day-to-day living.

Experience and skill eased the burden

In the current study parent participants in the program valued the expertise and skill of the program team clinicians, as competence instilled confidence and trust. This included the program clinician's interpersonal and clinical aspects of care to the sick child and their wider family. Parents had often felt misunderstood by their external health service providers. These findings supported those of Rossiter et al. (2011), in their qualitative study of working in partnership with vulnerable families. These authors spoke of the delicate balance of knowledge and power. They reported the unintended consequence of misunderstanding between parents and health professionals (Rossiter, Fowler, Hopwood, Lee & Dunston, 2011) when parents were exhausted and already feeling overwhelmed with the responsibility of care. It was clear therefore, that an essential requirement was for health service providers to be skilled in discerning a situation and to communicate in a way that avoided further anxiety.

Rossiter et al. (2011), reported it was only recently that health providers and government agencies are moving towards partnership models for effective care for children and their families. These authors identified the lack of investigation of partnership models across services and the experiences of vulnerable families in what the partnership model contributed (Rossiter et al., 2011). Their qualitative study reported on a research project to gain knowledge on how partnerships were experienced by these families they deemed vulnerable. They described vulnerable families as those who were disadvantaged by socioeconomic inequalities that impacted on health and development resulting in insecure parental/child relationships. Rossiter et al. (2011), interviewed 25 health professionals, predominately nurses (n = 22) who had been trained in one partnership approach of the 'Family Partnership Model' in Australia. Their focus was specifically on how the family partnership model addressed engagement of families to improve outcomes. While a family partnership model was seen as having potential for those deemed as vulnerable, a limitation of Rossiter et al.'s (2011), study was the families experiences were described from the perspectives of the health service providers and not from the families themselves. The authors identified that health providers often held the power of whether they chose to engage with families and thus influenced whether these families engaged with the health system or whether they experienced alienation. Their

findings identified that it was crucial for health providers to be willing to engage with parents, with specific skill and knowledge required for partnerships with families to be effective (Rossiter et al., 2011).

McIntosh and Runciman (2008) reported that there could be frequent shifts of power between parents being the expert and the nurse being seen as the expert when engaged in information sharing. The way this shift in power was managed affected the success of the partnership between the parents and the health service providers. For instance, when parents were exhausted and too emotionally invested to make quick decisions about their child's care, a health service provider was more likely to make a decision, and this was accepted (McIntosh & Runciman, 2008). However, at other times parents were clear they were the ones to make decisions on their child's care and treatment. These authors argued that the development of good relationships between professionals and parents required insight into parents needs in terms of their capacity to care for their child (McIntosh & Runciman, 2008). However, this could be challenging to discern. For instance, at times parents, such as the participants in the current study, while having the overall responsibility of caring for their child, did not know what they needed to know, or where to turn for help and support. It required an experienced health service provider with the appropriate skill to perceive what may be needed to support not only the child, but the wider family unit, for a family to feel comfortable with care provision.

The current study's findings supported and extended McIntosh and Runciman (2008) and Rossiter et al. (2011), findings. The perspective of what families experienced was a crucial aspect of understanding what was important for them in a partnership. Therefore, their inclusion in the study was paramount. The family participants reported that the skill and knowledge of the program clinicians enabled them to engage with the specialist nursing and counselling interventions of the program. Entering into this partnership reduced the feelings of isolation and alienation they had previously experienced as reported by Rossiter et al. (2011).

A key finding in this current study was the report from participants that the program clinical team assisted them without placing extra demands and expectations on them. The sensitivity of the program clinicians' discernment and skill to 'step in and step out' without intruding into a family's personal space was valued by parent participants. Trusting relationships with the program clinicians who had experience with other families in similar situations and the skill that incorporated both symptom management and interpersonal relationships eased their burden of care, a burden they previously carried alone.

Adjusting to rare health conditions and new circumstances

While parents often become the experts in managing their child's health condition, Malcolm et al. (2011), argued that their expertise is often developed through necessity rather than choice. This is particularly so when those health conditions are rare, as found in the current study. Parent participants identified that gaining support and access to information about their child's rare condition was challenging. Anderson, Elliot and Zurynski (2013) developed a self-administered survey for Australian parents caring for children with a rare disease. The survey used pre-validated tools to evaluate parents' (n = 30) experiences of diagnosis, health services, peer support, and financial support. These authors identified there was little evidence on experiences of families who had a child with a rare health condition. This Australian study, while small in sample size, provided significant findings, for example, that medical professionals require better education regarding diagnosis and treatment of rare diseases. Their study identified there was little psychosocial support offered to families through the time of diagnosis, access to information, and treatment. These authors identified the need for routine psychosocial support and information from time of diagnosis (Anderson et al., 2013). The current study supported Anderson et al. (2013), findings that families received little attention from health agencies and that, although families benefited from a specialised multidisciplinary team, better coordination of care was required (Anderson et al., 2013).

In relation to the current study, parent participants were often left to seek information from the internet. Anderson and colleagues (2013) reported, while there is much information to be gained from the internet, it was difficult to discern its quality and trustworthiness. Participants

in the current study were often overwhelmed, and the lack of information added to their experiences of being 'outside' or in a 'bubble' from others in society. Parents with a sick child often felt different to other parents, participants reported feeling alone, anxious and not knowing where to access help. These findings supported Litzkendorf et al. (2016), findings from their qualitative study of the information needs of patients living with a rare health condition. These authors highlighted the psychological burden on patients and their families when living with the uncertainty and fear a chronic incurable disease brought into their lives. They identified how patients and their families coped better once they had gained access to information and knowledge post diagnosis of their child's disease (Litzkendorf, et al., 2016). These authors found that parents desired an experienced professional who could provide them with the appropriate information and support them to understand that information. Parents' need for information continues to be poorly dealt with by health service providers, specifically in relation to Litzkendorf et al.'s (2016) participant group (n = 69) who were affected by children's rare conditions. While these authors contributed to the literature on informational needs for families who have children with rare health conditions, they did not explain how families could process this information in regards to their own unique situations, or to make sense and meaning of the knowledge gained.

The current study's findings identified counselling and the psychological care provided by the program clinicians not only provided information on the rare diseases, but enabled participants to process what this meant for them and helped them to adjust to changes their child's rare condition brought into their lives. This psychological support empowered them to shift their perspectives of their situations so they could view their circumstances with some acceptance. However, participants in the current study reported they would have preferred an earlier referral to the program as they deemed this level of support would have benefited their entire family, yet they did not know of the service.

Advocacy and flexibility make a difference
Participants in the current study reported the advocacy of the program clinicians supported them in both the health and education sector. This finding supported Whiting's (2013) study in which it was found that the help and support to parents from their health service providers

made a positive difference to their own capacity to care for their child with serious illness. Parents often had the role as advocate for their child (Koch & Jones, 2018), and felt they had to go into battle with their health service providers and health agencies to access resources, equipment or symptom management (Whiting, 2013). In the current study, participants valued the program clinical team when the clinicians advocated on their behalf at hospital clinic appointments and with their external health service providers. This support extended to a child's school, whether this was advocating for a sick child's education needs or for the sibling of the sick child. Participants reported the lack of understanding from the education sector which appeared to be under resourced and did not have the capacity to understand what a child with serious illness and their healthy siblings may require in a school setting. At times families feel too emotionally close to their child's situation to be able to articulate clearly their child's needs, or their own.

While there is literature available on the need for flexibility within the work place when a parent is caring for their child with serious illness and time allocation off for specific appointments (Shuster et al., 2011), there was no published evidence regarding the value families put on flexible care or afterhours availability. Whiting's (2013) qualitative study explored the experiences of parents of 34 children with complex health needs (n = 33 families) in relation to the support they received when caring for their children. Parents identified the lack of afterhours support was a significant issue (Whiting, 2013). Wolfe and McKee (2013) identified that child health overall required systems that were more responsive to evolving child health needs. These authors identified emerging aspects of paediatric care in Western Europe, namely, flexible first contact models, availability of afterhours care and professional training would provide effective expertise and outcomes for children and their families; however, this required a whole systems approach to improve health (Wolfe & McKee, 2013).

A key finding in the current study was the value families placed on afterhours support and availability. Participants reported reduced anxiety and fear when they knew they could contact the program clinicians for advice, guidance or symptom management for the sick

child. The flexibility and availability of the program that included afterhours care was deemed a safety net by participants in this study.

The flexibility of working in partnership with families regarding timing of appointments was absent from the published literature. Families in the current study were expected to work around hospital time frames, rather than appointments made in partnership that might suit a family's specific situation. For example, an early morning appointment for a family who had to travel long distances from a rural region, added pressure to the entire family. The program team's flexibility in making appointments around the child's condition and care, along with the parent's other roles and responsibilities were highly valued by participants in this study.

The challenge of asking for help

Parent participants in the current study reported that it was difficult to ask for help when they themselves often did not know what they needed. Parents also did not want to be negatively judged for the care they were already providing to their child. The findings supported Whiting's (2013) findings regarding the experiences of parents caring for their children with health and disability needs. Whiting (2013) found the health service providers limited understanding of a family's situation and their misconceptions, first in relation to the families experience of living with a disabled child and second, the capability of that child, created a barrier within the relationship. Whiting (2013) reported, parents at times felt misunderstood in the care of their sick children. In support of this, Davies et al. (2010), reported that parents felt at times that their expertise and unique knowledge of their child's condition was not valued. The experiences of being patronised or dismissed or having their judgement questioned caused some parents to suffer profound and lasting emotional distress (Davies et al., 2010). These authors reported that families were frustrated and angry due to deprivation of information regarding their child and they felt victimised (Davies et al., 2010).

Parent participants in the current study would have preferred an earlier referral to the program. They believed having access to the program's interventions from the time of the child's diagnosis would have helped them to cope as a family. This finding may be relevant for

parents of seriously ill children in other jurisdictions as well. Due to the feeling of grief at their child's diagnosis, trying to access information and knowledge while caring for their child often meant there was a fracture in relational family dynamics. This current study's finding supported Al-Gamal's (2013) study of parent's grief regarding their child's uncertain disease trajectory and Muscara et al. (2015), prospective, longitudinal design study reporting on parent's distress when their child was diagnosed with a serious illness. They reported the anxiety and stress initially experienced at diagnosis could have long-term consequences for parent's mental health. For instance, they may suffer post-traumatic stress disorder (PTSD) symptoms for some time; and in the long-term of their child's illness, they may continue to suffer clinically significant levels of distress. While Muscara et al. (2015), highlighted the implication that this had for paediatric health services and the need for greater understanding of parents' mental health. Their study did not provide the interventions required to minimise these effects as they did not conduct an evaluation study. Parent participants in the current study reported that making sense of their child's diagnosis was challenging and they valued the program clinical team's knowledgeable skilled support. They received, and highly valued, the information and guidance on care for their child and the strategies provided within counselling sessions that empowered them to find ways to self-support.

The findings of this study supported the evidence within the literature regarding the burden on parents providing care to their healthy children, along with the high needs of their sick children. However, there was little evidence on specific interventions of how parents could sustain themselves when caring for a child with serious illness. While the findings in the thematic analysis provided evidence the program was beneficial to families, and many aspects of this had been previously reported in the literature, further discussion is required in relation to the realist evaluation findings and the literature.

SIBLINGS OF CHILDREN WITH SERIOUS ILLNESS

Being understood in uncertainty

In the current study, healthy sibling participants expressed how hard it was to have a sick brother or sister. The challenge to gain information on what was happening, the uncertainty

of what the future held, and the constant hospitalisations distressed these children, particularly when they were separated from their parents. These findings supported Besier et al. (2010), evaluation study of healthy siblings' elevated behavioural and emotional problems when living with a sibling who had a chronic illness. These authors reported that there were many challenges to the healthy sibling's emotional wellbeing when their sick sibling was in pain or was hospitalised (Besier et al., 2010). The negative impact on healthy siblings, when living with a sick brother or sister, was well documented in the literature (Alderfer et al., 2010; Anderson & Davis, 2011; Bellin & Kovacs, 2006; Canter et al., 2015; Prchal & Landolt, 2012).

Sibling participants in the current study reported the value of talking through their concerns with the program counsellor. These findings supported those of Besier et al. (2010), who found that the implementation of a family-oriented inpatient rehabilitation program had the potential to improve the mental health of children with a chronically ill sibling. However, these authors also argued the need for more intervention studies for children with a chronically ill sibling to gain evidence of the effectiveness of specific interventions.

Adjusting to changing circumstances

Sibling participants in the current study reported that their sick brother or sister was often in hospital and during these times family circumstances changed. They reported that they were not able to go away on holiday or to do special things as a family. Sometimes holiday plans were cancelled when their brother or sister needed to be hospitalised. The unpredictability and uncertainty of their sick sibling's health condition and their hospital visits added to the siblings' anxiety and frustration. These findings supported those of Prchal and Landolt (2012) regarding forced changes in the family when a child was diagnosed with a serious illness and this included changed routines of daily living for healthy siblings. These siblings learned how to adjust and compromise their lives to fit around the sick child's needs. These authors also highlighted the adjustments made by the healthy siblings concerning their holidays and social activities. Prchal and Landolt's (2012) qualitative study aimed to understand paediatric cancer patient sibling's experiences (n = 7) in the first six months post diagnosis. These siblings reported having to get used to a hospital setting along with their brother or sister's illness dominating conversations. They experienced being alone and disliked the empty feel in their

homes when at least one parent was mostly at the hospital with the sick child. These children reported that going back to school was difficult and that it was difficult to get back into school regimes. While there were emotional and behavioural shifts for health siblings, such as jealousy, worry, fear, sadness, helplessness, anger, guilt and anxiety, the seven siblings also identified a family cohesiveness and strengthened bonds when they had experienced acute illness as a family (Prchal & Landolt, 2012).

Furthermore, sibling participants in the current study expressed their concern when their sick sibling was admitted into hospital as to whether they were going to come home or not. This finding supported a number of study findings (Alderfer et al., 2010; Prchal & Landolt, 2012; Yang, Mu, Sheng, Chen & Hung, 2016). Yang and colleagues (2016) systematic review of the experiences of siblings of children with cancer found that healthy siblings experienced vulnerability and insecurity due to the changing nature of their brother or sister's health condition. Nolbris and Ahlstrom's (2014) qualitative study supported these findings as the healthy siblings reported the loss of family life as they knew it.

The importance of distraction

The sibling participants in the current study valued having distraction with the program counsellors, rather than always focusing on their sick brother or sister and the intensity of things at home. Play and art therapies were useful in creating this distraction. While Carroll's (2002) study is now dated, it continues to be relevant. This author found that study participants (aged 9 -14 years) enjoyed the fun of play therapy and the relationship with the therapist. This author believed having fun in the creativity was in itself a healing and therapeutic process (Carroll, 2002). Purdy and True's (2012) later study also found art to be an effective and fun intervention that was useful when working with children. When children are able to engage with the therapeutic modality of art and play to express themselves, it enables them to articulate their own thought processes and to enact what may be worrying them. So, while it may be a good distraction, it is a useful therapeutic tool in working with children, in this case, the healthy siblings in the current study.

Support for their sick sibling

Sibling participants in the current study reported that their sick brother's or sister's behaviour, namely, their anger, sometimes caused them to experience a headache. They were not sure what mood their sick sibling was going to be in at any one time. Prchal and Landolt's (2012) study reported behaviour changes in the sick child were also a relevant experience for most healthy siblings. These authors stated that healthy siblings noticed their sister or brother becoming more aggressive or moody (Prchal & Landolt, 2012).

The current study findings supported other literature on the emotional impact on healthy siblings when they have a sick brother or sister. The unpredictability of the sick child's mood was something that the sibling participants in this study found challenging to manage, however the sibling participants appreciated the program clinicians supporting their sick sibling as they all expressed concern for their brother or sister. Discussion on the realist findings in relation to the literature will highlight the evidence of how the program benefited the healthy siblings.

EXTERNAL HEALTH SERVICE PROVIDERS

Collaborative care builds strong partnerships

When caring for children with complex health conditions, the needs are multi-layered. External health service provider participants in the current study recognised the challenge of providing the depth of care required and recognised the gaps in service delivery. They were aware of how the complexity of a child's illness meant that care was resource-intensive and required a skilled multi-professional approach. This supported Carter and Thomas's (2011) study as they reported that while there is a plethora of agencies and professionals required to provide the level of care required, there is rarely a single service that has the capacity to provide the depth of care required. The complexity of a child's health and disability needs required a wide range of health service providers to meet the child's and family's needs. Other studies (Hain et al., 2012; Hewitt-Taylor, 2010; McIntosh & Runciman, 2008) reported the necessity of health service providers having a range of skills, expertise and personal attributes to perform the care role. While Law et al. (2011), acknowledged the requirement for both

generic and specialised knowledge and skills, they reported that the right skills in the right place were not always obtainable. The current study supported the Law et al. (2011), report on needing the appropriate skill in working with children with serious illness and their families. These authors reported inconsistencies in service delivery to seriously ill children, with concerns of inequity of care. While they reported there is much known about children with complex health issues, more understanding was required to improve services in the UK. Law et al. (2011), argued that an evaluation of existing services was required initially to understand the quality, cost and value of the different models.

Participants in the current study identified that before working with the program clinical team, they had worked outside of their comfort level of skill and experience, doing the best they could to provide emotional support when they were unsure themselves of what to say or do in those circumstances. The psychological support the program clinicians provided was highly valued by the external health service providers which enabled them to do the care they were skilled to do with children with serious illness, knowing the family had psychological support.

External health service provider participants in the current study valued the collaborative relationship with the program clinicians; in addition, they valued the way in which the program team worked alongside them. They reported that the input of the program clinicians facilitated better care provision for children with serious illnesses and their families. The program was seen as complementary to the services provided by the external health service providers who worked within hospital and community funded health services. Reported in the literature, was the need for teams to work in collaboration, to be constructive and demonstrate inclusivity with effective care coordination when caring for children with complex health needs in the community (Horridge, 2011; Simkiss, 2011). External health service providers in the current study reported that effective collaboration built stronger partnerships between program clinicians and families.

Effective communication and expert skill

External health service provider participants in the current study valued the open and transparent communication with the program clinicians. They reported effective

communication was important in care delivery when there were clear role definitions and boundaries between providers. These findings supported earlier research findings by Simkiss (2011) who found that the role of inter-agency communication and collaboration was important to improve care in the community. Hewitt-Taylor (2012) also reported good communication and collaboration by health service providers was important in gaining a common understanding within the care delivery. This author reported that while parents are the main providers of their child's care, there is a role for health service providers, particularly nurses, to oversee the care in the home and provide resources where needed (Hewitt-Taylor, 2012).

A key finding identified by external health service providers was that the effective transparent communication with the program clinicians assisted them in their relationships with families and provided better outcomes in their care.

Supportive collegial relationships

While medical knowledge and technology have enabled children to survive even though they have serious illnesses, the findings in the current study highlighted the cost on families and their service providers to deliver this care. External health service provider participants reported that they too felt the burden of, and responsibility for, the child's complex care needs. Collaboration between the program clinicians and external health service providers has already been touched on previously, however, a key finding of the current study is that collegiality and support from the program clinicians reduced external health service providers' burden in care. The current study findings supported the study of Carnevale, Alexander, Davis, Rennick and Troini's (2006) study, as they reported the moral dilemma of parents caring for children with high technological needs at home, carrying most of the burden of care and responsibility. The external health service provider participants identified concern for parents being totally responsible for the care of their child in the home after the child had spent a lengthy time in hospital. The participants reported that while medical technology may have enabled a child to survive, the complexity of the care in the home was high and would be required for years. They were aware of the long-term impact on parents providing most of the care, recognising the anxiety and fear that was evoked as well as the impact on them.

Participants identified the collegial support from the program clinicians enhanced care delivery. They reported a positive change in families once they had engaged with the interventions of nursing and counselling support provided by the program clinicians.

Participants identified when working collaboratively with the program clinicians there were clear roles and boundaries which produced efficiency in the provision of care. The knowledge and skill of the program clinical team, specifically in relation to end of life care, was shared with external health service providers who felt this enhanced their practice.

Flexibility in care model

External health service provider participants in the current study often felt time pressured by the busyness of their clinical workloads, the lack of flexibility of work regimes and the complexity of the care for the child with serious illnesses and their families. They acknowledged that they could attend to the sick child's needs which were medically or clinically focused, however, due to being rushed and needing to go from one child patient to another, there was no time to attend to a family's psychological needs even though they were aware of them. While Rempel's study (2004) is now dated, the findings are still relevant. Rempel (2004) highlighted the challenges nurses faced when they were under time and work pressures and the negative impact this pressure on their work life and home life. Rempel (2004) reported that health professionals often felt they did not have the time to develop in-depth relationships with parents. Therefore, parental beliefs, values and practices may have been overlooked with parents left feeling undervalued or not understood. Service providers felt restricted by time and did not have the capacity to meet the family's needs. The findings in the current study supported Rempel's (2004) study.

The current study findings of flexible care being highly valued supported the study of Wolfe et al. (2013), as they reported the need for flexible models in which child health professionals working closely together could provide a way to balance the need to deliver expertise to sick children and their families.

Afterhours access

In the current study, external health service provider participants identified the need for an afterhours service as this was important to families' sense of feeling supported during home care of their child with serious illness. However, they were not resourced to provide this care themselves. There was a gap within the literature on acute afterhour's services when caring for a child with serious illness within the home. Emergency departments at hospitals featured in much of the literature on afterhours care. There was evidence of telephone triage as an aspect of out of hour's service provision (Car, Koshy, Bell & Sheikh, 2008; Huibers, Smits, Renaud & Giesen, 2011). Huibers et al. (2011), systematic review on the safety of telephone triage for patients phoning out-of-hours reported this was not always safe for patients. Due to the cost of afterhours care for organisations, telephone triage was seen to be an effective strategy to provide this support required. Huibers, Giesen, Wensing and Grol's (2009) review of afterhours care in Western countries identified there were nine models that were predominantly based in accident and emergency departments, general practices and primary care centres (Huibers et al., 2009). These authors identified most of these models were doctor operated and while these had their strengths, particularly in the family doctor and primary care settings, continuity of care was lacking overall. This review identified the need for change regarding afterhours support, however due to the resources required to operate these services, there continued to be gaps within this area. A plan to integrate services and to provide telephone triage was identified as necessary to improve services for patients in the future (Huibers et al., 2009).

While all participants in the current study identified the need and valued the afterhours service, the external health service providers had concern for the program clinicians providing this service. They reported, to ensure sustainability of this service; further resources and funding were required. This finding supported the evidence within the literature that while afterhours care was seen as beneficial to reduce anxiety for families caring for children with serious illness, there was the need for resources and funding to ensure this was sustainable. The lack of resource and funding continues to be a problem not only in child health, but across all health sectors. In New Zealand for those regions outside of the area the program operates

from, if a child is unwell afterhours, they are usually expected to go to the nearest primary health accident and emergency department or hospital emergency department. At times the local hospices are involved with a child who is at the end stage of their life, however, this care remains ad hoc throughout different regions in New Zealand.

CHILD WITH A SERIOUS ILLNESS

Being different due to a health condition

Children who live with a health condition often have complex symptoms to manage. There is a plethora of literature providing evidence of this (Elias & Murphy; 2012; Hobson & Noyes, 2011; Shuster et al., 2011). However, the impact of this on the child living with the complex medical condition is less evident. In the current study, the child with a serious illness identified aspects of her condition that made her different to others, for example, unable to eat and experiences of pain. These findings supported Knowles, Tadic, Hogan, Bull, Rahi and Dezateux's (2016) UK collaborative study of congenital heart defects. Children aged between 10 years – 14 years (n = 436) who participated in the study aspired to be the same as their peers. They wanted to be treated as 'normal' rather than being seen as a child with a cardiac condition. Being accepted by, and keeping up with their peers, was of significant importance to these children (Knowles et al., 2016). In the current study the child participant valued the program counsellors supporting her in knowing what to say to her peers, to be understood. She appreciated the acceptance of the program counsellors which enabled her to 'feel normal'.

Being valued and supported while living with a health condition

While much of the literature focuses on the complexity of a child's health condition and what the impact is on the wider family, there is little evidence on the impact of a child's health condition on their mental health and overall wellbeing. Carter et al. (2014), argued, to know how a child makes meaning of their illness and the impact on their world, the child needs to be at the centre of the health professional's care. In the current study, the child participant with a health condition felt she was listened to and understood by her counsellor. Her

understanding of her illness was conveyed in her play acknowledging it was helpful to talk things through with her counsellor as she made sense of her situation. The findings in this study supported Carter et al. (2017), qualitative participatory research where they utilised autodriven photoelicitation interviews with children (n = 45) between 6- 12 years of age. Their study aimed to investigate children's perceptions and understandings of how their lives were influenced (or not) by their chronic health conditions. The results of their study, while reflecting the level of understanding the children had of their health condition and things important to them, they also wanted to fit in, rather than their illness defining them. The child participant in the current study, shared her experiences with the program's counsellor enabling her to 'feel normal', therefore, not defined by her illness.

In summary, the thematic analysis findings supported the evidence within the literature of what families and their health service providers deemed to be challenging when caring for a child with serious illness. These findings supported and contributed to the literature regarding the burden on both families and their health service providers regarding the intensive care needs and symptom management the sick child required. However, there was little reported in the literature about what was useful for families to support them in the care of their seriously ill children to ease the burden and responsibility.

The findings from this study have produced new knowledge in this area, specifically in relation to what eased the burden of care for this population group. Program interventions of skilled specialist nursing and counselling care instil confidence and trust to be developed in the care of the sick child. These interventions that include advocacy and counselling support enabled families to be empowered to cope with and adjust to the changes brought about by their child's serious illness. Psychological support that incorporated care of the healthy siblings utilising modalities such as art and play therapies can provide distraction and reduce fear and anxiety. Care that is collaborative with families and health service providers can improve outcomes for the child with serious illness and their families and reduce the burden of care. The psychological support of the child with serious illness reduced the experience of being different and enabled a sense of 'normality'.

The next discussion turns to the realist CMO findings. These are explained in relation to the contemporary literature on partnership and family-centred care models. The main headings include burden in care, psychological distress in care, partnership with family and partnership with service providers.

DISCUSSION OF FINDINGS FROM REALIST EVALUATION

The thematic analysis answered this study's first research question and found that the program met the needs of the child with a serious illness, their siblings and their parents. In addition, external health service providers found the program to be beneficial and complementary to their delivery of care. This study's second research question is now addressed, that is, in what circumstances and through what mechanisms did the program meet the needs or fail to meet the needs of the child with serious illness, their siblings, parents and external health service providers?

The CMO configuration findings will now be discussed with realist explanatory principles applied. It is acknowledged that study participants (the child with a serious illness, their siblings and parents) were embedded into the social reality of living with, or caring for children with, serious illness, while external service providers were providing care to children with serious illnesses. This social reality has influenced how the interventions of the program were implemented and how study participants responded.

BURDEN IN CARE

Within the context of caring for a child with serious illness, all family members experienced aspects of burden. Parent participants were experiencing the responsibility, aloneness and burden of care, while healthy siblings were experiencing the impact of uncertainty and the unavailability of their parents who were taken up with the sick sibling's cares. This finding supported McCann et al. (2012), systematic review examining the daily patterns of time use by parents caring for children with complex health needs. These authors reported parents, specifically mothers, carrying a significant caregiving burden that extended far beyond what parents of healthy children carried. The unpredictability of their child's complex condition, the

high use and management of technology and symptom management such as suctioning and oxygen requirement in a medical crisis demanded their time and energy. Three key themes emerged in the McCann et al. (2012), review; they identified that parents had significant burden that didn't reduce as a child got older, vigilance of their child was relentless, and along with the child's high care needs placed great demand on the parent's time. These authors cautioned health professionals to be mindful of adding to this caregiving burden by making assumptions that they carry out these roles of health care (McCann et al., 2012).

In the current study, participants interacted with the program clinicians through the mechanism of specialist nursing care and counselling. It was the program team's specific knowledge and skill in providing care that was most beneficial to participants. Participants were willing to engage with the program in partnership with the program clinicians who had insight to and understanding of their needs. This produced the outcome of lessening the burden of care, thereby enabling families to better manage the care. Parents reported that they learned new strategies for both managing the child's care and the care of others in the family unit. They also gained a sense of self as an individual in a care role and they felt a sense of empowerment in their adversity.

While there was evidence in the literature regarding family burden in care and the need for partnership of care, there was limited evidence about what would provide ongoing support for families to sustain themselves in their care role. Piran, Khademi, Taylor and Mansour (2017) reported that the burden of care on caregivers, predominantly mothers, impacted on the quality of life for their children with serious illness. These authors identified holistic and family-centred interventions that could reduce caregiver burden, however, Piran et al. (2017), provided recommendations regarding burden of care, but none regarding how to implement a model of care (Piran et al., 2017). Curtis et al. (2016), in their integrative review of the literature on models of care for families with critically ill children reported that family-centred care principles could improve outcomes for families. They too identified the requirement for a model which provided continuity across the span of care. Al-Gamal and Long (2013) recommended an individual family focus to ensure each family received the support they

required, and they argued for the need to understand the psychosocial impact on parents before support could be provided. The findings of the current study support Al-Gamal and Long's (2013) findings. Participants in the current study reported that the program clinicians displayed knowledge and skill gleaned from previous experience in care provision to families. This knowledgeable and skilled care was appreciated by families and created the means by which a trusting relational partnership was formed.

The current study identified program care strategies that made a difference to the well-being of the child with serious illness, their siblings and parents, thus supporting them to manage the care and their lives within the family unit. These findings contribute to the literature explicating the aspects important to families in a model of care. However, participants in this study identified that a delay in referral to the program added to their burden. They perceived that they would have coped better as a family, therefore experiencing less burden, if they had received earlier specialist nursing and counselling support. In alignment with Al-Gamal and Long's study (2013), understanding the psychological impact on families is crucial to ensure the balance between providing enough support and not intruding on families. This was for the program clinicians to discern. Some participants in the current study identified the 'different than expected' life journey that their child's illness had created for them, and the uncertainty this brought. This supported Al-Gamal's (2013) study investigating quality of life and anticipatory grieving among parents living with a child with cerebral palsy. These authors reported how most parents caring for their child required more emotional energy and determination than they expected. They also found that when parents experienced anticipatory grief, they had poorer quality of life (Al-Gamal, 2013).

The findings of the current study regarding the burden of care on well siblings and parents supported the published literature. However, there was no published evidence regarding specific interventions and strategies underpinning a model of care that worked for the benefit of well siblings and parents. This lack of evidence was recognised by Whittingham, Wee and Boyd (2011) in their systematic review of the efficacy of parenting interventions for children

with cerebral palsy. They found that there was a paucity of literature on interventions that assisted in adaptive behaviours.

Pawson and Tilley (2004) stated that it was important to understand the mechanisms that described what it was about the program or interventions that brought about effect, in this case the easing of the burden of care. Participants in the current study were open to engaging with the program due to the knowledge and skill of the program team that enabled trusting relationships to be developed.

PSYCHOLOGICAL DISTRESS IN CARE

In the context of families providing complex care in the family home, they experienced psychological distress, particularly in relation to quality of life for their sick child and the family unit. Parents experienced powerlessness, with some explaining that they felt overwhelmed and only endured their life. The interventions and mechanisms of the program, particularly the clinicians' skill and knowledge, resulted in the building of a trusting, therapeutic relationship that equipped participants to grow their own resiliency with strategies that would ensure they were doing more than just enduring life. This finding supports Carnevale and colleagues (2006) findings on families living with ventilator-assisted children at home. These authors reported the huge responsibility on parents whom they described as stressed and at times overwhelmed. This responsibility created significant emotional strain and impact on family relationships. The deep isolation experienced by those parents in the Carnevale et al. (2006), study is supported by the findings of the current study by way of parents experiencing being 'outside 'of things and not being understood.

Al-Gamal (2013) reported that parents with a high level of intensity of anticipatory grief had a lower quality of life. Psychological distress when caring for a child with serious illness created powerlessness and hopelessness in the uncertainty of what the future held. Carter (2014) described parents' lives as being totally disrupted due to overwhelming psychological distress. Al-Galmal and Long's (2013) study investigated psychological distress among Jordanian parents who had children with cerebral palsy and their perceived support. These authors reported while there was much attention on children with cerebral palsy and their treatment

needs, there was little attention paid to their families. An approach of care that was not only focused on the child, but the individuals within the family unit is essential to reduce psychological distress. However, in the first instance, health service providers must understand the psychological impact on the family to promote adjustment to living with their situation (Al-Gamal & Long, 2013). Gupta and Singhai (2004) reported that positive perceptions promoted coping and that effective coping strategies in turn enhanced positive perceptions in their study of parents who had children with a disability.

In alignment with this literature, Carter (2014) argued that health professionals had a role to play in assisting parents to grow their self-efficacy, to develop confidence and feel empowered as parents. Hill and colleagues (2018) found that a parent's hope for their seriously ill child can change over time and that the most common issues regarding hope related to their child's quality of life, physical health, future wellbeing and medical care. They believed that if professionals could reassure parents and address their hopes, this would assist in building stronger relationships with parents and provide more effective support to enable parents to cope.

The literature clearly depicted the disruption a child's serious illness brought into families' lives, and the need for psychosocial and emotional support that ensured parents were sustained to have confidence, competence and skills so they could focus on care, while also being the child's parent (Carter, 2014; Whiting, 2013). However, Cohen and colleagues (2011) reported that there were few existing care models that met the needs of both children with complex health conditions *and* their families. More recently, Pordes et al. (2018), review of current models of care for children with medical complexity found a lack of support for family and caregivers of medically fragile children. These authors identified the need for services that provided psychological care; however, they provided no evidence regarding the interventions and strategies needed within a model of care (Pordes et al., 2018).

Eccleston, Fisher, Law, Bartlett and Palermo's (2015) systematic review found evidence of benefit to parents who engaged with psychological therapy when they cared for a child with

a chronic illness. Specifically, problem solving therapy was associated with improved parent adaptive behaviour and improved mental health. However, Emmerson and Bogels (2017) stated that there was little focus on parental stress; rather any psychological support was for the child with the illness with behavioural and emotional support to assist in adapting to their illness. These authors believed a combined healthcare approach that focused on the child while acknowledging parents' distress could lead to better child outcomes in care. For instance, they argued, mindfulness parenting groups would assist in managing parents' suffering and isolation and be supportive in the care of their children with chronic health conditions.

While there is much evidence in the literature about psychological distress for families, specifically concerning parents providing care to their child with serious illness, there was less evidence on interventions that would assist in reducing psychological distress. Cousino and Hazen (2013), in their systematic review of parenting stress among caregivers of children with chronic illness, highlighted the importance of future intervention efforts aimed at preventing or reducing parenting stress. However, they too identified there were few interventions designed to meet this need. The findings from the current study will contribute to the literature regarding the counselling interventions and strategies that successfully support the sick child, and their well siblings and parents and contribute to the alleviation of their psychological distress.

PARTNERSHIP WITH FAMILY

In the context of partnership with family, participants in the current study often felt restricted by the rigid, inflexible health system. At times they felt negatively judged or misunderstood by their external health service providers, and due to the rarity of their child's condition, they often could not access appropriate information about the condition, the prognosis or care interventions. The interventions and mechanisms of the program enabled respectful partnerships to be developed. Families decided what aspect of the program care they required and when that care was needed. For instance, the afterhours aspect of the program was seen as a safety net for families, with the outcome being that they felt less alone and more supported.

The collaborative, empathetic, respectful partnerships with families, along with the flexibility of that care were beneficial. Families valued the program's strategies in the partnership that empowered them to build their own skill and resiliency to sustain them in providing care to their children with serious illnesses. The program reduced their anxiety and isolation. Once engaged with the program, participants connected strongly with it. They reported that their reliance on the program was high, and they did not know how they would cope if they could no longer access the program. Being understood and accepted in their specific situations produced the outcome of being less alone. This study finding supported the Smith et al. (2015), study in which it was found that the attributes of family-centred care and partnership in care was seen by parents as valuing their expertise and knowledge regarding their child's care. This included building trusting relationships with the sick child and family.

Shields, Pratt, Davis and Hunter (2007) reported that care to the whole family, or family-centred care, included partnerships that were built on trust, respect and the establishment of a therapeutic relationship. However, Foster (2015) stated that while much education and research had gone into the development of family-centred care and the likely impact of this care, there continued to be issues in implementing this model. Foster, Whitehead and Maybe (2010) and Coyne, Murphy, Costello, O'Neill and Donnellan (2013) noted the difficulty in implementing family-centred care, stating that while partnerships in care are reliant on trusting, respectful relationships that enable families to cope and better outcomes for children, there was little evidence of partnerships working well. Much of the literature recommended the instigation of family-centred care partnerships. However, there was little evidence regarding how such a model would be implemented (Coyne, 2008; Foster, 2015).

PARTNERSHIP WITH EXTERNAL SERVICE PROVIDERS

In the context of caring for children with serious illnesses, service providers have multiple demands due to the complexity of the illnesses and the technology required for these children to survive. The program clinicians with skills in effective communication and collaboration were valued by these external health service providers who viewed the program as complementary to their own service and a vital aspect of care delivery in caring for children with serious illnesses and their families. External service providers viewed the program's

psychological care interventions as vital for the long-term wellbeing of families, noting also that providing this care themselves was not possible within their own busy and complex care provision to the sick child. The value of working alongside the program team meant that they could focus on the nursing and medical care, knowing that the psychological support that families required would be provided by the program team.

The outcome of working in collaboration with the program clinicians reduced the responsibility and burden of care identified by many external service provider participants. External health service providers reported that they had neither the time nor the expertise to manage the child's and parents' emotional and psychological needs. The collaboration with the program team reduced the pressure and responsibility of their work and reduced their isolation. In addition, the collaboration meant that the sick child and family received better care. These findings support Cohen et al. (2011), who found that traditional models of care established in many health institutions often did not meet the needs of the sick child and the family. These authors believed children with high health needs and their families required models of care in which service providers had the appropriate skill required to enhance the quality of life and outcomes of seriously ill children (Cohen et al., 2011).

CONCLUSION

The findings of the current study added to the body of literature on what was useful for families in providing care at home for their children with serious illnesses. Within the context of families, predominately parents, who provided care to their child with serious illness, engagement with a model of care was reliant on how confident parents were in those providing the care. Critical to reducing the burden of care on families were clinicians who were both highly knowledgeable and skilled in providing the interventions of nursing and psychological care in a model that was family-centred and in partnership with all those involved in the care.

There was strong evidence in the international literature that families who were caring for a child with a complex health condition were burdened by their care role. While evidence

highlighted the need for a model of care that was family-centred and enacted in partnership with all concerned in the care, much of the literature identified that parents remained non-trusting of their current health providers' care. While the literature addressed the 'who' might benefit from these models and 'what' may be useful, there was a lack of evidence in what worked for whom in what circumstances and how for children with serious illnesses, their families and health service providers.

The findings from the current evaluative study will contribute to the international literature, providing evidence that it was possible to provide the care families required within the context of caring for seriously ill children. Key findings extended what is known currently, as it was clear that a program that addressed the entire family's needs when caring for a child with serious illness fulfilled a societal need to reduce the burden of care, aloneness and isolation. Specialist nursing care for the sick child and skilled psychological care to the family unit reduced burden, aloneness and isolation. Collaborative care, with all health service providers, working in unison with a focus on the family resulted in strong partnerships of care. This study drew on the experiences of the child with serious illness, their siblings, parents and their external service providers.

The following chapter concludes the thesis with a reflection on the research process, followed by an explanation of the implications of the research in relation to what children with serious illness and their families require for care provision within the family home. The strengths and limitations of this study are discussed and the final section comprises a summary of the thesis.

CHAPTER SEVEN – CONCLUSION

Ehara taku toa I te toaI

Takitahi engari he toa Takimano

My strength is not that of an individual

but that of the collective

CHAPTER SEVEN – CONCLUSION

INTRODUCTION

Previous chapters have the motivation for the research and its significance in the context of care for seriously ill children in New Zealand. It is known that neonates and children survive serious illness and traumas and require highly technical and complex care regimes into later stages of their lives. It is also known in New Zealand, Australia and internationally that this care is predominantly provided by parents in the family home. Unfortunately, care for seriously ill children continues to be fragmented – lacking collaboration and coordination between health service providers and between these providers and parents. Many experts in the field have recommended, and many have adopted, a 'family-centred' or 'partnership' model of care. However, at the time of completing this research there was no published evidence of the effectiveness of these models of care in meeting the needs of the child with serious illness, their siblings and parents, and their health service providers

The program under evaluation in this study was a family-centred, partnership model of care based on Mason Durie's (1994) Te Whare Tapa Wha Māori health model of wellbeing. Its aim was to engender social change for the betterment of those burdened by the care of children with serious illnesses. Recipients of the specialist nursing and psychological care provided by the program clinicians were the child with serious illness, their siblings and parents, and their external health service providers. Realistic evaluation was the methodology chosen for the research. Realist methodology examined the core theory of how the program was intended to work and questions it to understand if it was plausible, sound and valid and meeting its purpose (Pawson & Tilley, 2004). The methodology and the methods of semi-structured interview and focus groups were explained fully in Chapter Three. The findings of what worked and did not work in easing the burden of care for families were presented in Chapters Four and Five.

Encapsulated in this chapter are my reflections on the research process and the translation of knowledge that was actioned while the study was being undertaken. The implications of the

findings and the limitations of the study are explained along with recommendations for education, policy and practice in the field of caring for the child with serious illness, their siblings, parents and external health service providers. There is a need for future research. The chapter ends with a summary of the thesis and the key contributions made to knowledge in this field. This chapter begins with a review of the research aims and questions, as it is important to reflect on the purpose of the research and how this was addressed.

REVIEW OF THE RESEARCH AIM AND QUESTIONS

The aim of this research was to evaluate the model of care provided by a child health organisation in New Zealand (the program) in terms of its capacity to provide care to the child with a serious illness, the child's siblings and parents, and the child's external health service providers.

The program evaluation was focused on what it was about the program that made it work for families and external health service providers and to understand whether the program had capacity to meet needs. Therefore, it is important to return to the initial reasoning and purpose for the program being founded in 2004. Fragmentation of services, lack of coordination and collaboration between providers, negatively impacted parents' ability to access appropriate services and resources to care for their children with serious illnesses in the home. In my role as nurse specialist I foresaw a need for a model of care that could improve outcomes for this population group. As the program became embedded into the social system of child health in New Zealand, my initial assumption was that the program would fulfil the societal gap identified, with the program's interventions of specialist nursing and psychological support significant to this improved care. However, I understood that it could only be through the involvement of entire systems of social relationships within the child health sector that change could occur (Pawson & Tilley, 2004; Wolfe et al., 2013). To understand whether the program was meeting this assumed need, it was appropriate to ask the following questions. 'How did the program meet the needs, or fail to meet the needs of children with serious illnesses, their families and external health service providers?' and 'In what circumstances and through what mechanisms did the program meet the needs or fail to

meet the needs of children with serious illnesses, their families and external health service providers?'

The findings of this research addressed the aim that the program did indeed have capacity to meet the needs of children with serious illnesses, their siblings, parents and external health service providers. In answer to the above questions, it was found that first, the program interventions eased the burden of care for all participants in this study, and second, that the program eased the psychological distress for families when caring for a child with serious illness at home. Of particular interest were the choices that participants made when they engaged with the interventions of the program as it would be these choices which could possibly lead to regular patterns of social behaviour which in the long term could bring about change for this population group (Pawson & Tilley, 1997).

Two important findings emerged from the study data. Firstly, participants reported that they had confidence in the skill and knowledge of the program's clinicians, leading them to feel better equipped to continue their care for their child. Secondly, participants experienced trusting and respectful interactions with the program's clinicians, leading to higher levels of engagement with the program, thus again, enabling them to continue to care for their child. These attributes had been identified within the literature as being important factors for family-centred care partnership models to be successful in child health. It was these mechanisms of confidence, trusting and respectful interactions with the program interventions fired within the context of participants caring for seriously ill children that produced the outcomes of reduced burden of care and reduced psychological distress. Once participants made the choice to engage with the program, partnerships were developed, and it was this engagement that was significant in this realistic evaluation. The interventions of specialist nursing care and counselling strategies equipped and empowered all participants to sustain themselves, specifically those who provided care to the seriously ill child. The skill and knowledge of the program team enabled participants to grow in confidence and strong partnerships developed with the focus on family-centred care. My reflections and revelations are now discussed in view of the significance of the findings.

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REFLECTION AND SIGNIFICANCE OF THE FINDINGS

While I had assumed a model of care was required to meet the specific needs of children with serious illnesses and their families, I had underestimated the depth of what was experienced by families in this study and the direct impact this had on their sick child's care needs. The four significant aspects of the findings in this study that were a revelation to me were; the depth of the aloneness and isolation experienced by participants; the relevance of trusting relationships between parents and their health service providers; appropriate skilled and knowledgeable clinicians are pivotal as to whether parents develop trusting partnered relationships; and finally, the flexibility of a care model that reduced the burden of care. These revelations are now further detailed and the significance of the findings is explained.

THE DEPTH OF ALONENESS AND ISOLATION

The depth of aloneness and isolation families experienced when their child was diagnosed with a rare health condition, along with the complexity of the care these children required made them feel outside of 'normal'. While this experience of being outside of 'normality' was felt by all in this study, it was specifically significant for parents providing the care. This aloneness became accentuated by health service provider's judgements regarding the care of their child. Within the literature, these aspects of families' experiences were well documented However, after deeper realist analysis and going 'beneath' the words of what the participants shared, the revelation was that families experienced not 'fitting' into society and often felt misunderstood. This had an effect on the confidence and belief they had in themselves as individuals and as a family. Once a parent's confidence was knocked, it flowed on into the care of their child, particularly if they felt as one participant in the current study described, 'being tied into their situations emotionally which shadowed how they would normally express themselves'.

These findings revealed aspects of marginalisation, families feeling 'separate' from the rest of society. Therefore, engagement with the program interventions of specialist nursing care, counselling support, advocacy, after hours care, advice and guidance was significant as aloneness and isolation previously experienced was reduced. These interventions empowered participants to grow their own confidence and self-support. This parent participant's

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comment epitomised the significance of empowerment, 'I was enduring life, not enjoying it. The program clinician didn't fix it for me, but gave me the skills to fix it for myself, that was really empowering and helpful'.

THE RELEVANCE OF TRUSTING RELATIONSHIPS BETWEEN PARENTS AND THEIR HEALTH SERVICE PROVIDERS

As already documented, families experiencing being 'different' were sensitive to others' judgements, particularly those of their health service providers. Therefore, establishing trusting relationships was problematic. Parents carried the responsibility of care for their child whose rare conditions were complex and required intensive time, skill and energy. This was well documented within the literature and the current findings supported this evidence. Parents quickly became the experts in their child's care once they gained the appropriate knowledge and information about their child's specific needs. However, they often 'battled' to gain this information and skill and felt let down by their health service providers. Trusting relationships can only be formed if parents experience the respect, acceptance and empathetic understanding of others regarding their circumstances.

Participants in the current study engaged with the program interventions once they experienced acceptance and empathetic care from the program team. The respectful approach of mentoring, guiding and counselling care by the program clinicians enabled participants to develop trust and engage with the interventions of specialist nursing and psychological care.

APPROPRIATE SKILLED AND KNOWLEDGEABLE CLINICIANS PIVOTAL TO TRUSTING PARTNERSHIPS

Following on from the concept of parents being the experts in their child's often rare health conditions and the specific care required, parents wanted to experience confidence in the competency and capability of their child's health service providers. Respect for each other's competency, skill and knowledge was critical for partnerships to be developed. While these attributes were mentioned throughout the literature expressing their significance in

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developing partnerships, the evidence also showed that ruptures in relationships between health providers and families made it difficult to establish partnerships.

Interventions that incorporated skilled nursing care, specifically regarding children's complex health needs, were pivotal in gaining parents confidence and trust to engage in a partnership with the program. Psychological care, skilled in interpersonal and therapeutic modalities incorporating strategies to provide empowerment, enabled participants to develop respectful partnerships in the care of children with serious illness.

FLEXIBILITY IN EASING THE BURDEN OF CARE

Within the intensity of the care children required, the rigidity of hospital appointments and working within a large institutional system was challenging for families to navigate. While understanding that hospital systems do not have the flexibility to work around each family's needs, it was something participants in the current study found difficult to work within. This lack of flexibility added to the pressure when families already felt burdened with their child's health care needs. A further aspect of burden and vulnerability for families was the 24-hour responsibility for their child's care. In particular, if their child had spent weeks or months in a hospital setting the transition home from hospital created anxiety as parents had been used to ongoing help and assistance in the hospital. Their community external health service providers did not offer a 24-hour on call service which evoked anxiety about managing their child's care alone.

Therefore, the flexibility of the program where parents could meet at the program house for counselling appointments and have the nurse specialist attend hospital appointments to advocate and liaise with the child's medical team enabled participants to feel supported and less alone in the care of their child. The afterhours availability, where advice and guidance on symptom management was provided was seen as a 'safety net' for families. This flexibility of the afterhours service provision of telephone support, home visit assessments and symptom management or triaging to hospital was deemed significant by families and external health service providers and eased the burden of care and responsibility for families.

In summary, the psychological distress experienced by parents and families in regard to the care of their sick child was likely to be underestimated by their health service providers. If families' experiences were not being heard or understood, it is challenging for trust to develop or partnerships to be formed. Partnerships with families, namely, children with serious illness, their siblings and parents and health service providers are only likely to be effective if there is trust and respect with these providers and confidence in their skill and knowledge. These revelations directly support what was identified in the literature (Cady & Belew, 2017; McIntosh & Runciman, 2008; Schuster et al., 2011; Smith et al., 2015).

Therefore, a program that provided skilled nursing specialist care and psychological support with interventions of symptom management, advice, mentoring, advocacy, guidance, counselling and the use of therapeutic modalities, enabled engagement with the participants in this study. Effective communication and collaboration between the child with serious illness, their family and the providers delivering care enabled strong trusting, respectful relationships and partnerships to be developed. Flexible packages of care that worked for families regarding hospital appointments and afterhours support provided a sense of safety and care that was family-centred rather than institutionally or organisationally focused.

The findings from this study confirmed that family-centred care and partnerships with providers was indeed the preferred model. While the findings in this evaluation study will contribute to current evidence within this field of child health, more importantly, they may contribute to change within this sector for the betterment of care for children with serious illness and their families. Realistic evaluation provided the 'real' in this study of what participants deemed vital in caring for a child with serious illness in the community. The findings from this study will inform educators, policy makers, practitioners, program participants and the public. These implications will now be discussed.

IMPLICATIONS OF FINDINGS

The key to change is the mechanisms that operate at middle range, a level between big policy ideas and the day to day realities of implementation. This is where there is greater opportunity for transference of the findings (Pawson & Tilley, 2004). While there have been improved changes in child health in New Zealand, the literature provided evidence of care remaining fragmented and inconsistent in some regions in New Zealand. There continues to be inequalities, specifically between rural and urban sectors, Māori and non-Māori. While the current study is not specifically focused on these aspects, the key findings of skilled and knowledgeable care, and trusting relationships that enable partnerships to develop can be transferred to other areas of health. For example, Māori health, mental health services and reduction of child poverty are currently key areas of focus for the New Zealand government. The key findings from this current study of interventions that supported trusted and respected partnerships are directly transferrable to these areas of health care. As previously discussed, these findings will add new information and knowledge to the current literature on aspects of care that families found useful in easing the burden of responsibility and psychological distress experienced when caring for children with serious illnesses at home.

A dominant discourse in society is that the wellbeing of a child is the responsibility of their parents and their family. However, the care of a child requires government, institutions and organisations to work together to ensure the wellbeing of the child. It is timely that the New Zealand government is for the first time implementing a child and youth wellbeing strategy to be launched in 2019. The findings in this study represent the voices of children with serious illnesses, specifically those with complex health issues, and their families. Therefore, it is critical to ensure they are heard, particularly in view of the risk of marginalisation. If as suspected, the needs of seriously ill children and their families are underestimated as previously discussed, the challenge is to ensure policy makers get the appropriate information to ensure change for the future is moving in the right direction for this population group. The findings from this study have contributed to the child and youth wellbeing strategy. For example, findings from the current study was influential in a written submission to the New Zealand government at the end of 2018 to ensure children with complex medical conditions

and who were technology dependent were also considered. While children with disability had been included in the preliminary documentation of the planning for this strategy, children who were medically fragile, technology dependent or had complex health conditions were not mentioned.

Social health behaviour changes take time; therefore, the challenge is in raising the awareness of what families require to care for their children with complex health needs at home. Finding the appropriate language is critical for policy makers to understand so there is not such a disconnect between those providing the care at the 'coal face' for children with serious illness and those who hold the power in decision making that provides the outcomes for these children. As already stated, the gaps within the current literature were the details of what worked for whom and in what circumstances within a family-centred model of care. Therefore, to reduce the disparity in child health and to ensure policy makers and decision makers have the appropriate information, the findings from this study need to be disseminated through different avenues, for instance, publications in appropriate child health journals, such as, nursing, allied health and medical journals. Another avenue is to present these findings at national and international child health conferences and seminars as well as taking every opportunity to attend appropriate child health forums in New Zealand to ensure these findings contribute to policy and strategies for children.

There are disparities in funding services and specific population groups. Health care for an aging population group is currently the focus for governments in New Zealand, Australia and internationally in regard to allocation of funding and resources. Therefore, further implications of this study are to address the growing population group of neonates and children now surviving their prematurity and illnesses. Due to their compromised health and complex care needs, funded care packages and resources are required to ensure they can remain at home with their families. However, for this to be sustainable for families, these children will require respite care either in the home, hospices or residential care. Put bluntly, if the medical sector is saving babies, the government and health agencies have an obligation to care for them, particularly as they grow older and their care needs require additional

resources and equipment, such as hoists to ensure they are cared for safely. There will be a higher demand on services to enable them to remain in the community. Raising awareness and providing the relevant information from the research findings to those making decisions within the region is key to influencing the allocation of funding and resources.

Currently there are gaps within knowledge on what skill and care children who are medically complex require. In alignment with this, there is a deficit within education regarding the clinical and interpersonal aspects of the knowledge and skill the nurses and medical teams require to care for families with seriously ill children. Ideally, the findings from this study could be implemented into educational training facilities such as universities and polytechnics to ensure long term change in the care for this population group. Presentations at these venues are important to raise the awareness of what is required in the child health curriculum. Change is paramount and ideally there will be long term changes in care for these children. An outcome of the current study has been a change in translation to practice. This will now be explained.

TRANSLATION IN PRACTICE

Realistic evaluation research is envisioned to lead to more improved and effective programs (Pawson & Tilley, 2004). These authors argued there may be variances in explanations for why, when and how a program works, however, there only so many ways that a program might be improved (Pawson & Tilley, 2004). The translation of the findings from this study into the program's practice was intentional, particularly if key findings related to a safety aspect for children and their families, or could immediately benefit families. The current research findings had a direct impact on the program and its development. Changes have been made to the program as a direct outcome of the findings, namely; safety of the program, growth of the program and sustainability of the program.

SAFETY OF THE PROGRAM

The importance and relevance of the program for children with serious illness and their families was evident when these participants reported they would be 'lost without the program', as there were limited options for them to access this level of support. This was particularly so for those children with rare conditions that did not necessarily 'fit' within other agencies' referral criteria. However, external health service providers were concerned at the heavy workload on the program clinicians, particularly when this involved afterhours care which predominately fell to the nurse specialist who had the dual role of CEO. This was a vulnerability of the program, with external health service provider participants concerned for the wellbeing of the program clinicians and the potential for 'burnout' due to physical, mental and emotional stress and exhaustion. All participants had reported the program as a 'vital' service meeting a specific need for children with serious illness, their families and the external health service providers.

These findings were disseminated in the CEO's (student researcher) monthly report to the board of trustees of the child health organisation. As a direct result of the findings, and the natural growth of the program, the team has expanded. At the beginning of this study in 2011, the program team had one counsellor, one psychotherapist, one nurse specialist with the dual role of CEO (student researcher) and one administrator. Currently, in 2019, the team has expanded to two nurse specialists, with the CEO role still incorporated into one nurse specialist's role, two counsellors, one psychotherapist, one contracted clinical psychologist and one contracted counsellor. The administration role now includes marketing and communication. In 2011, the nurse specialist/CEO (student researcher) was responsible for most of the end of life care in the community, which included afterhours care. The program currently works more collaboratively with the local hospice to provide the end of life care to children with palliative care illnesses, with the call outs to families shared. These findings directly translated into practice with more clinicians now involved in the program. Working more closely with the hospice provider has ensured the program is more robust and contributes to safe practice.

GROWTH OF THE PROGRAM

The main aim of the organisation in 2011 to provide specialist nursing and psychological care to children with serious illnesses and their families has remained the focus. However, an area of growth since the program was founded has been the psychological support for women and parents in the perinatal phase where an anomaly has been revealed via the scans while a baby is in utero. While this was not directly related to the findings in this research, it was a natural growth trend from the psychological care to parents in the new born intensive care unit and is supported by evidence in the literature (Marokakis et al., 2016) that psychological support reduced anxiety for parents in the prenatal period once an anomaly was detected. This growth within the program included bereavement support if a baby dies in utero, or in the event of early miscarriage or stillbirth. This support continues for as long as it is required by families.

The findings revealed that external health service providers valued the guidance and mentoring of the nurse specialist, specifically at the end stage of a child's life. Translating these findings into practice, further growth has been extended to incorporate education and training as a key strategic direction of the program. The nurse specialist/CEO (student researcher) and psychotherapist provide workshops and training days to hospital departments such as the emergency department, intensive care units, neonatal intensive care units, as well as other community organisations, for example, Heart Kids NZ; Child Cancer Foundation and Paediatric Palliative Care education forums. Presentations at the local polytechnic to nursing and midwife students and to allied health students are also undertaken. The workshops and training days incorporate care of the child with a complex health condition and their families; and the impact of grief and loss on the individual and the family unit.

SUSTAINABILITY OF THE PROGRAM

The findings revealed concern for the sustainability of the program; this was specifically in relation to the wellbeing of the program team as already discussed. However, as the program remains unfunded by government, the funding avenues such as trusts, sponsorship and fundraising continue to be the main source of funds. These funding trusts and sponsorship from businesses within the community have ensured the program continued to grow and

develop. The findings identified the external health service providers in the current study had approached planning and funding managers at the local hospital to access funding for the program. They recognised the program had a huge proportion of the clients; therefore there was concern for the sustainability of the organisation if further resourcing and funding were not accessed.

The child health organisation has rebranded since the findings were revealed to ensure greater understanding of what the program provides to families. Funding trusts continue to provide funds consistently to the program and fundraising policy and procedures are robust with currently over one year operating costs in advance. However, the organisation continues without government funding, therefore sustainability of the organisation remains at risk.

In summary, translation of findings into practice has improved safety aspects, growth and development and ensured more robust processes for the sustainability of the program. Collaborative care with other health service providers and agencies has been developed more strongly. This, along with recruitment of extra skilled clinicians into the program, has provided a greater 'safety net' for families providing complex cares to their children with serious illnesses.

As previously discussed, the multiple roles I have within the organisation as the student researcher, founder, CEO and nurse specialist, had the potential for my assumptions to obscure data analysis and the findings. However, an advantage of being the CEO while undertaking the current study meant changes to the program for betterment for families could be implemented on the evidence of the findings from the study. Robust conversations with my supervisors on the research process, and evidence of the findings were discussed with the board of trustees of the child health organisation with regard to translation of these findings into practice. Limitations of this study will now be explained.

LIMITATIONS OF THE STUDY

While realistic evaluation was not necessarily a limitation of the research, it was a challenging methodology to comprehend. The little guidance on how to undertake the evaluation and the time required to identify the context, mechanisms, outcome patterns it is worth noting here. These challenges were noted by other researchers (Byng et al., 2005; Hewitt et al., 2012; Marchal et al., 2012; Tolson et al., 2007) as this methodology is relatively new in health research. Marchal and colleagues (2012) reported there was variance in the way authors interpreted these principles. As previously stated, this study closely followed Pawson and Tilley's (1997) original work to ensure transparency of how I interpreted the principles of realistic evaluation and applied it in this research. However, as it is designed to evaluate complex social interventions (Pawson & Tilley, 2004), it is becoming more popular in health research and was an appropriate methodology for this research.

As stated in Chapter One, to have children's voices at the forefront of their treatment and care was important to me. Therefore, having their participation in this study was significant to hear what they deemed helpful, either as they lived with their health condition, or their experience as a healthy sibling. Ironically, a limitation of this study was that only five children participated, one of whom had a serious health condition. While their perspectives provided valuable insight into what they found helpful, and what they didn't find helpful from the program, the data was limited. The ethical issues of having informed consent and assent were required, specifically when working with a potentially vulnerable group of children who were deemed not old enough to understand what is being asked of them. However, this could at times create barriers to children participating in research. The challenge was how to ensure children had understood what was asked of them when there was possibly an aspect of gatekeeping from adults trying to protect them (Powell, 2011). In the current study, the consent/assent forms were not illustrated for children. On reflection, I have considered if this had been included in the information pack initially sent out to families whether there may have been a better response.

As I reflected on the lack of children's participation in this research, it was important to consider the merits of having an external research assistant for participant recruitment and data collection. To minimise the risk of my different positions within the organisation on influencing the research, it had been highly recommended by the ACU Higher Degree Research (HDR) confirmation panel that I consider the utilisation of an external research assistant. While this had the advantage of minimising the risk of bringing possible unconscious assumptions to the analysis of the study, the disadvantage was the possible lack of engagement from children with the research recruitment process.

My concern was the institutional ethical practice which aimed to protect children from harm may have created barriers to children having their voices heard in this study. While there may be a number of reasons for children's lack of engagement with this study, I was mindful of the sick child participant's views on 'feeling normal' when meeting with her counsellor. One possible reason of lack of engagement, may be that children do not want to focus on their illness, particularly if this meant speaking to a person who they did not know. One parent participant reported she had wanted her son to participate, however, he had intimated he did not want to talk about his health condition; he would rather focus on something else and not the fact that he had a life-limiting condition. This reasoning may have possibly related to other potential child participants as well.

A further limitation of the study was the absence of Māori participants, although at the time of recruitment, 17% of the program's caseload was Māori families. Therefore, this study does not depict what this population group find useful in a model of care supporting a child with serious illness in the community. Previous to undertaking this research, I had a discussion with the child health organisation's Kaumatua (Māori elder) to inform him of the intent of the research, specifically in relation to Māori families invited to participate. While the Kaumatua agreed with the research intent and was supportive, he did not provide specific guidance on the best approach to engage with Māori to participate. At the time, I did not consult with Māori health advisors. Since undertaking this research, I now understand that consultation and conversations with Māori groups before putting the research proposal together would

have been important (Health Research Council of New Zealand, 2010). This would have been significant for Māori, to inform them of the research, to provide opportunity for meaningful engagement and to give them a voice. This level of engagement would have provided greater understanding of whether the program was beneficial for families who identified as Māori. This is a deficit in the research, therefore, for the future when undertaking research projects that are inclusive of Māori, the Health Research Council of New Zealand (2010) guidelines will be followed.

While there were only four parent participants in this study their insights of how they viewed the program in the care of their sick child was rich in explanation. The dilemma of having a child who is seriously ill and the uncertainty from one day to another made it challenging for parents to commit to participating in the research. Three parents put in their apologies informing the research assistant they could not participate due to being in hospital with their child, or their child's health had deteriorated the day of the interviews. The literature provided evidence this was a reality for parents in their everyday life, it was challenging to participate in activities outside of their child's care (Alderfer et al., 2010; Cady & Belew, 2018). As appropriate, the child's needs came first for parents. The evidence within the literature reported parents experienced low energy levels and exhaustion when caring for their sick child (Al-Gamal, 2013). The findings of the current study supported this evidence and that may also have had impact on the level of participation in this research.

There have been limitations to this study. These have been discussed and the knowledge gained from this study's deficits will shape and influence any further research I undertake. It is only by carrying out the current study that this knowledge has been gained. Further to this, there are key recommendations from the findings in this study that are now explained along with the recommendations for further research.

RECOMMENDATIONS FOR PRACTICE

Realistic evaluation has been useful to understand if the program had capacity to meet the needs of the child with a serious illness, the child's siblings and parents and the child's external health service providers. As discussed previously, realistic evaluation has scope for transferability that is critical in moving from one program to another. The findings from this study may resonate with others across other health sectors as there are crucial aspects in care that will ensure strong partnerships are developed between patients, whether that is a child or an adult, their families or their health service providers. While there will be different contexts into which programs or models of care are introduced, it is the mechanisms that describe what it is within the program and interventions that create outcomes and possibility of change. Therefore, realistic evaluation can be utilised across policy, practice and organisational boundaries to promote social betterment (Pawson & Tilley, 2004).

The literature highly recommended a model of care that was family-centred and in partnership with children with serious illnesses, their families and health service providers. However, as stated previously, the literature lacked the evidence of how to implement these models, in fact it was well documented that these models were challenging to implement. Foster (2015) reported there was no framework or tool that currently existed to measure the family-centred care approach when working with children with complex health needs. Realistic evaluation provided a robust framework to evaluate the family-centred program for this study.

The findings in this study clearly depict what is critical to develop strong partnerships between families and their health service providers. These will be listed here as these are the key interventions that enabled participants to engage with the program and can be deemed recommendations going forward when caring for children with serious illness and their families.

- Nurses are to be appropriately trained to a level where they have the knowledge and skill to assess the child who has a health condition that may be rare, complex and the

child technology dependent. These health providers require skills to provide symptom management, advice, empathetic care and support. These skills incorporate clinical, relational and interpersonal aspects of care. This includes effective communication skills and knowledge of determining when to listen, provide advice, guidance and strategies, or knowing when to pass on appropriate information to other colleagues. This is equally important for other health service providers such as counsellors, social workers and other allied health providers when it is essential to be skilled in their own areas of expertise.

- Skilled psychological support that incorporates relationship, individual and family therapeutic and empathetic care is important for families to experience being seen, heard and understood. This care includes acceptance of the child with a serious illness and their family with a flexibility of care that where appropriate is focused on individual's needs rather than having to 'fit' within the rigid confines of the organisation or institution. Care that includes advocacy, counselling, provision of strategies of empowerment enable families to grow their resilience in caring for their children.

- Afterhours support is deemed a safety net that reduces parental anxiety when caring for a child with complex health needs. This is deemed an important element of care by families and by health service providers and offers best practice for families.

Within the context of families and external health service providers being burdened in care provision when caring for children with serious illnesses, the above interventions enabled participants to make the choice to engage with the program. Trust and respect were the mechanisms fired to create outcomes of strong collaborative partnerships to be formed and the care to be family-centred.

The findings from this study supported the literature with respect to the psychological distress and burden families carried when caring for a child with serious illness. A sense of powerlessness and hopelessness was created, which I deemed a brokenness of spirit. The findings from this study extended what was currently in the literature, as evidence was

provided on how critical it was for health service providers caring for these families to have the appropriate skills and knowledge. The findings clearly depicted, for families to engage with a partnership model of care, they need to have confidence in the competency of their clinicians. It was important that families did not feel judged in the care they provided to their seriously ill children and to experience emphatic care from their health care teams. These elements fostered trust and respect. It is only when these attributes were in place that a model of care met the needs of children with serious illness, their families and their health service providers.

RECOMMENDATIONS FOR FUTURE RESEARCH

This study was focused on children between five and 12 years of age. Therefore, further research that incorporated what adolescents deemed helpful in a model of care to enable them to cope with their health condition or their sibling's health condition would strengthen this research.

Bereaved parents were not included in this study. However, their views on what was important in a program during the care of their child at the end stage of their lives and in their dying process and post the death would be hugely significant. These two research projects would follow on naturally from the current study. As previously discussed, the need for understanding what Māori deem to be important when caring for a child with serious illness is required. Currently there is a gap within the literature for this population group. However, as stated, to undertake research that involved Māori families specifically, ideally it would be important to have a researcher who is Māori as part of the research team. It is important to have Māori research and evaluation undertaken with Māori and for Māori. If this was not possible, the guidelines from the Health Research Council of New Zealand (2010) reported, it is important to meet with Māori before the research proposal is considered to ensure there is opportunity for understanding and engagement to participate in research.

While the scope of the current study was not specifically exploring the impact of marginalisation on families who have a child with a rare health condition, this became evident

in what some of the participants expressed. These findings have extended another aspect that has impacted on the care of children with serious illness, therefore, further research in this area could incorporate the child's voice more strongly along with his or her family's perspectives on this issue.

THESIS CONCLUSION

This New Zealand qualitative realistic evaluation study presented the challenge of caring for a child with serious illness. Due to advances in knowledge and medical technology, many neonates and children survive pre-term birth and serious illness. However, child health policies and care models need to reflect this development. The findings of this study supported the existing literature on what is known about children with serious illness and their family's complex needs. The findings have extended what is already known in relation to how to incorporate psychological care of the family to be more integrated into care for children who have serious illness. These findings will inform policy in regard to what this population group requires to implement change for their wellbeing as a family unit.

Children who are medically fragile, who are often technology dependent with high health needs, is a population group that is growing worldwide. The macro context of the child's intensive care demand in the home was predominantly provided by the child's parents and the wider family. The social system of child health expects that parents will care for their child at home and manage their symptoms along with the technology that their child is reliant on to survive. This is alongside the care for their other children and the day-to--day family functioning. These children required multiple levels of care with the impact of their illness affecting every aspect of their own and their family's lives. There is pressure and stress on relationships and the entire family unit.

There was a plethora of literature on an optimal model of care for children with serious illness and their families, one that was family-centred and in partnership with their health service providers. However, there was little evidence on how to implement these models that enabled families to engage to gain the support they required on their health journeys. There was a gap

within the literature on evaluations of care models for children with complex health conditions and their families, to understand what worked in a model of care, how, why and for whom. This realistic evaluation of the model of care (program) for the current study has highlighted new findings that extended what is known in the existing literature in this field and provided evidence of what families and their health service providers reported as vital in a model of care. The realistic evaluation principles utilised in this study may also be transferred to other areas of evaluation in practice. Realistic evaluation, while a confusing methodology to understand, has been appropriate to investigate what worked within the program for children with serious illnesses, their families and their health service providers and in what circumstances.

The findings within this study extended the literature of families burdened with the responsibility of care for their child. They highlighted and illustrated in detail how parent's psychological distress and grief in caring for their child made it challenging for them to cope with their other children's needs while not knowing what their own needs were.

It was evident from this study that a family-centred partnership model is effective in the care of the child with a serious illness. Significant findings from this study identified that families require confidence in their health service provider's skill, knowledge and competence before they engage with health service providers. Both clinical and interpersonal skills are equally important and were deemed essential when there were multi-layered complexities in a child's health condition and its impact on family dynamics. Empathetic understanding of a family's situation, advice, guidance and advocacy were attributes that were deemed important to grow trusting and respectful relationships. Flexible care where appropriate that incorporated afterhours support reduced anxiety and fear for families. Collaborative care that included effective communication and care coordination provided strong partnerships with better outcomes for children with serious illness and their families. While these attributes are evident within the literature, the findings in the current study illustrated what this meant in practice.

In summary, the micro interventions of the program incorporating specialist nursing care and psychological care met the needs of children with serious illness, their families and their external health service providers. The specialist skill, knowledge and empathy of the clinicians reduced the burden and psychological distress for families enabling them to cope better as a family. External health service providers viewed the program as complementary to their service delivery, this unison of working together provided a strong partnership model that was centred on the child and their family for the betterment of their care.

The cornerstone of this realistic evaluation was to investigate whether the program interventions could bring about change for children with a serious illness, their siblings, their parents and their external health service providers. The findings have supported the initial assumption; a model of care incorporating both nursing and psychological care and in partnership with the families and their health providers would improve care in practice for the child with serious illness.

However, the findings that were unexpected were that families would have appreciated an earlier referral to the program. Once having received support from the program clinicians, they felt this would have been helpful for their family from the time of their child's diagnosis. These findings will be incorporated into publications and presentations to ensure families are referred at the optimal time.

There was concern for the sustainability of the program. The program has developed further since this evaluation commenced and is now more robust. However, this finding will be incorporated into reports to policy makers, funders and management to ensure the critical need of access to funds and resources is met.

An effective model of care is one that is family-centred, and in partnership with all of the child's health team. Working in unison for the optimal outcome for the child with a serious illness requires empathetic care, appropriate skill and knowledge specifically in the field of

caring for children with a serious illness and their families. These attributes are essential for families to engage with the program and develop trust and respect with their providers.

Hapaitia te ara tika umau ai te rangatiratanga mo nga uri whakatipu

Foster the pathway of knowledge to strength, independence and growth for future generations

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APPENDICES

APPENDIX A: INFORMATION LETTERS

INFORMATION LETTER TO PARTICIPANTS (HEALTH PROFESSIONALS)

What is important for children and families who receive care from █████████?

Project title: An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families

Principal Investigator: Professor Nel Glass

Associate Researcher: Dr Rosemary Ford

Student Researcher: Cynthia Ward

Dear Participant,

You are invited to participate in a research project being conducted at ████████████. The focus group will be 1.5 hour duration and conducted with 8 – 10 health professionals.

What is the project about?

█████████ provides nursing and counselling support to children who have serious illnesses and their families. It is helpful to know whether this care and support is meeting the needs of the sick child and their family from your perspective. The █████████ Team works closely with many health professionals

from different disciplines. The information that you contribute is highly valued and will assist ▓▓ ▓▓ to continue to make changes and to develop a service that directly meets children's and their family's needs.

Who is undertaking the project?

The research is being conducted by a team headed by Professor Nel Glass from the Australian Catholic University, and includes PhD student researcher, Cynthia Ward.

Are there any risks associated with participating in this project?

We understand that in sharing your experiences regarding the care of children with serious illnesses you may experience some emotional distress. The research team will take the following steps to allay your distress.

1.   In the event that you become emotionally distressed, you will be supported by the research assistant facilitating the group. This person is competent in facilitating groups.

2.   In the event that you may need ongoing support, you will have the opportunity to meet with ▓▓▓▓▓▓▓▓ (Psychotherapist at ▓▓▓▓▓▓) or ▓▓▓▓▓▓▓ (Clinical Psychologist). Their contact numbers are: ▓▓▓▓▓▓▓ – ▓▓▓▓▓ or Dr ▓▓▓▓▓ ▓▓▓▓▓. You are not required to pay for this consultation.

What will you be asked to do?

You will be invited to attend a focus group that will be conducted by a research assistant chosen by the research team. The focus group will be of approximately 1.5 hours in duration and will be audio-taped to assist researchers with accuracy during transcription. You will be invited to contribute to the discussion with other health professionals on issues such as the services offered by ▓▓▓▓▓, areas of need

that are not met at ███████ and areas for improvement at ███████. There is opportunity to also discuss how ███████ works with other health professionals in care provision to the child with a serious illness and their family. The focus group will be held at the ███████ House.

How much time will the project take?

The focus group will take 1.5 hours of your time, and will be conducted in the evening from 7.00 pm to 8.30 pm.

What are the benefits of the research project to me?

There are no specific benefits to you as a participant in this research, although you may gain a helpful perspective as you have the opportunity to express your views along with hearing from others.

More general benefits of the study include

The research will add to the body of knowledge in the care of children and their families who access care and support from the ███████ organisation and other such organisations.

Can I withdraw from the study?

Participation in this study is completely voluntary. You are not under any obligation to participate. If you consent to participate, you can withdraw your consent at any time without adverse consequences. However, once you have participated in the focus group, you cannot withdraw your information as your information is not identifiable. Non-participation or withdrawal will not affect your relationship with members of the research team, or the ███████ team.

Will anyone else know the results of the project?

The researchers aim to publish the results of this study in peer-reviewed nursing and health journals. Group data only will be used in any reports or publications from the research, no individual participant will be identified. Your identity will be known only to the research assistant and other health professionals in the focus group. We will protect the confidentiality of your information in the following way. Audiotapes and written transcriptions of focus group discussions will be kept in a locked filing cabinet in Cynthia Ward's office and on a password protected computer. During transcription of the tapes, your name will not be used. Once transcription is complete, all tapes will be erased or destroyed. Neither Cynthia Ward nor other members of ██████████ House will listen to the audiotapes, the information you share in the focus group will only be seen once it is in written form and all identifiers removed.

The researchers aim to publish the results of this study in peer-reviewed nursing and health journals. Group data only will be used in any reports or publications from the research, no individual participant will be identified.

Will I be able to find out the results of the project?

A brief report of the results is expected to be available at the end of the research. The researchers will make this available to all involved in the focus group. Approximately 6 months after the study is completed the research team will begin publishing results in academic journals and at conferences. If you would like to be informed about these publications, please send us your email address (provide this information on the space provided on the consent form).

Who do I contact if I have questions about the project?

Any questions regarding this project should be directed to the Principal Supervisor Professor Nel Glass.

Professor Nel Glass, School of Nursing, Midwifery & Paramedicine Australian Catholic University Melbourne Campus, Locked Bag 4115, Fitzroy VIC 3065. Ph: +61 3 9953 3478, Nel.Glass@acu.edu.au

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at Australian Catholic University (approval number 2013 17321). If you have any complaints or concerns about the conduct of the project, you may write to the Chair of the Human Research Ethics Committee care of the Office of the Deputy Vice Chancellor (Research).

Chair, HREC Office of the Deputy Vice Chancellor (Research) Australian Catholic University Melbourne Campus, Locked Bag 4115, FITZROY, VIC, 3065. Ph: +61 3 9953 3150 Fax: +61 3 9953 3315 Email: res.ethics@acu.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

How do I sign up?

Please read the consent form provided with this letter. If you wish to participate in the research please sign the consent form. Please sign and date both copies of the consent form. One copy is for you to keep. Place one signed copy of the form in the stamped addressed envelope provided.

Yours sincerely,

Professor Nel Glass Principal Investigator

INFORMATION LETTER TO PARTICIPANTS (PARENT)

What is important for children and families who receive care from █████████?

Project title: An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families

Principal Investigator: Professor Nel Glass

Associate Researcher: Dr Rosemary Ford

Student Researcher: Cynthia Ward

Dear Participant,

You are invited to participate in a research project being conducted at █████████ House. The focus group will be 1.5 hours in duration and will be conducted with 8 – 10 parents who have a child with a serious illness.

What is the project about?

█████████ provides nursing and counselling support to children who have serious illnesses and their families. It is helpful to know whether this care and support is meeting the needs of the sick child and their family from your perspective. The information that you contribute is highly valued and will assist █████████ to continue to make changes and to develop a service that directly meets children's and their family's needs.

Who is undertaking the project?

The research is being conducted by a team headed by Professor Nel Glass from the Australian Catholic University, and includes PhD student researcher, Cynthia Ward.

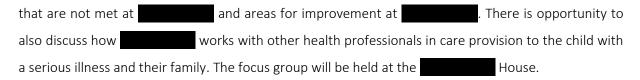*Are there any risks associated with participating in this project?*

Yes, we understand that in discussions regarding the care of your child who has a serious illness, you may experience some emotional distress while sharing your experiences with other participants. The research team will take the following steps to allay your distress.

1. During the focus group if you are unwilling to speak, or unwilling to continue your participation your wishes will be respected without question.

2. In the event that you become emotionally distressed, you will be supported by the research assistant facilitating the group. This person is competent in facilitating groups.

3. In the event that you may need ongoing support, you will have the opportunity to meet with ▮▮▮▮ ▮▮▮▮ (Psychotherapist at ▮▮▮▮▮▮▮) or Dr ▮▮▮▮▮▮ (Clinical Psychologist). Their contact numbers are: ▮▮▮▮▮▮▮▮▮▮▮▮ or Dr ▮▮▮▮▮▮▮▮▮▮▮. You are not required to pay for this consultation.

What will you be asked to do?

You will be invited to attend a focus group (discussion group) that will be conducted by a research assistant chosen by the research team. The focus group will be of approximately 1.5 hours in duration and will be audio-taped to assist researchers with accuracy during transcription. You will be invited to

contribute to the discussion with other parents on issues such as the service offered to you by ▮▮ ▮▮▮▮ the service offered to your child with a serious illness and / or your child who is a sibling of your sick child, areas of need that are not met at ▮▮▮▮▮▮ and areas for improvement at ▮▮▮▮▮▮

How much time will the project take?

The focus group will take 1.5 hours of your time, in the evening from 7.00 pm to 8.30 pm.

What are the benefits of the research project to me?

There are no specific benefits to you as a participant in this research, although you may gain a helpful perspective as you have the opportunity to express your views along with hearing from others.

More general benefits of the study include

The research will add to the body of knowledge in the care of children and their families who access care and support from the ▮▮▮▮▮▮ organisation and other such organisations.

Can I withdraw from the study?

Participation in this study is completely voluntary. You are not under any obligation to participate. If you consent to participate in the study, you can withdraw your consent at any time without adverse consequences. However, once you have participated in the focus group, you cannot withdraw your information as your information is not identifiable. Non-participation or withdrawal will not affect your relationship with members of the research team, or the ▮▮▮▮▮▮ team.

Will anyone else know the results of the project?

The researchers aim to publish the results of this study in peer-reviewed nursing and health journals. Group data only will be used in any reports or publications from the research, no individual participant will be identified. Your identity will be known to the research assistant and other parents in the focus group. We will protect the confidentiality of your information in the following way. Audiotapes of focus group discussions will be kept in a locked filing cabinet in the Cynthia Ward's office. During transcription of the tapes, your name will not be used. Once transcription is complete, all tapes will be erased or destroyed. Focus group transcriptions will be kept locked in Cynthia Ward's office on password-protected computers. Neither Cynthia Ward nor other members of ███████ House will listen to the audiotapes, the information you share in the focus group will only be seen once it is in written form and all identifiers removed.

Will I be able to find out the results of the project?

A brief report of the results is expected to be available at the end of the research. The researchers will make this available to all involved in the focus group. Approximately 6 months after the study is completed the research team will begin publishing results in academic journals and at conferences. If you would like to be informed about these publications, please send us your email address (provide this information on the space provided on the consent form).

Who do I contact if I have questions about the project?

Any questions regarding this project should be directed to the Principal Supervisor Professor Nel Glass.

Professor Nel Glass, School of Nursing, Midwifery & Paramedicine Australian Catholic University Melbourne Campus, Locked Bag 4115, Fitzroy VIC 3065. Ph: +61 3 9953 3478, Nel.Glass@acu.edu.au

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at Australian Catholic University (approval number 2013 17321). If you have any complaints or concerns about the conduct of the project, you may write to the Chair of the Human Research Ethics Committee care of the Office of the Deputy Vice Chancellor (Research).

Chair, HREC Office of the Deputy Vice Chancellor (Research) Australian Catholic University Melbourne Campus, Locked Bag 4115, FITZROY, VIC, 3065. Ph: +61 3 9953 3150, Fax: +61 3 9953 3315, Email: res.ethics@acu.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

How do I sign up?

Please read the consent form provided with this letter. If you wish to participate in the research please sign the consent form. Please sign and date both copies of the consent form. One copy is for you to keep. Place one signed copy of the form in the stamped addressed envelope provided.

Yours sincerely,

Professor Nel Glass Principal Investigator

INFORMATION LETTER TO PARTICIPANTS (PARENT OF THE CHILD WITH A SERIOUS ILLNESS)

What is important for children and families who receive care from ▮▮▮▮▮▮?

Project title: An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families

Principal Investigator: Professor Nel Glass

Associate Researcher: Dr Rosemary Ford

Student Researcher: Cynthia Ward

Dear Participant,

You are invited to consider allowing your child to participate in a research project being conducted at ▮▮▮▮▮▮ House. Your child will be interviewed by Cynthia Ward (PhD student researcher) regarding the care and support they receive from ▮▮▮▮▮ and what is helpful to them.

What is the project about?

▮▮▮▮▮▮ provides nursing and counselling support to children who have serious illnesses and their families. It is helpful to know whether this care and support is meeting the needs of the sick child and their family. The information that your child contributes is highly valued and will assist ▮▮▮▮▮ to continue to make changes and to develop a service that directly meets your child's and your needs.
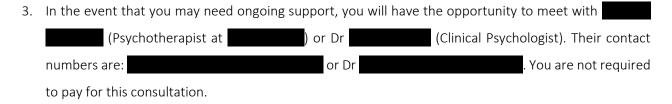
222

Who is undertaking the project?

The research is being conducted by a team headed by Professor Nel Glass from the Australian Catholic University, and including PhD student researcher Cynthia Ward.

Are there any risks associated with participating in this project?

Yes, we understand that your child with a serious illness may experience emotional distress while talking about their health condition and the care that they receive.

The research team will take the following steps to allay your child's distress.

1. Your child will have given assent to participate in the interview (see consent form).

2. At the commencement of the interview, your child will be asked to explain their understanding of the research and the purpose of the interview.

3. At the commencement of the interview, your child will be asked again to indicate that he/she consents to participate. He/she will be provided with age-appropriate methods to express their consent (for example, verbal consent or written consent 'yes' 'ok I want to talk to you').

4. During the interview your child can inform Cynthia Ward (student researcher) if they are unwilling to speak, or unwilling to continue their participation. Their wishes will be respected without question. In preparation for this event, a number of methods for indicating their discomfort with the discussion will be decided prior to the discussion commencing. For example, your child may choose to have a red button within reach that they can touch to indicate their decision to remain silent. Your child may request that the particular topic under discussion that is causing them distress be stopped completely.

5.   In the event that your child becomes emotionally distressed, she/he will be supported by Cynthia Ward, the student researcher. Cynthia is a Nurse Specialist and well used to providing emotional support to a child with a serious illness.

6.   Your child may request that you be present during the interview, or you may choose to be present during the interview.

7.   In the event that your child needs ongoing support, they will have the opportunity to meet with ███████████ (Psychotherapist at ██████████) or Dr ██████████ (Clinical Psychologist). Their contact numbers are: ███████████ – ██████████ or Dr ██████████████████. You are not required to pay for this consultation.

Your child may also display some physical symptoms related to their illness throughout the time of the interview. Cynthia Ward who is a Nurse Specialist, and likely to be involved in your child's care already, will assess this situation and attend to your child's care needs, for example, your child might need to rest or stop the interview.

What will your child be asked to do?

Your child will be invited to attend ██████████ House. The interview will occur during normal activities at ██████████ House, such as art or play therapy, these activities are normally scheduled for 1 hour duration, thus the interview will be no longer than an hour. The interview will be audio-taped to assist the researchers with accuracy during transcription. Cynthia Ward will ask your child the following prompt questions about their experience of ██████████:

What do you find helpful at ██████████? What is it that you don't find helpful? What is important for you as a child who has a serious illness? Has your family changed since you have been sick? What is the hardest thing for you about having an illness?

How much time will the project take?

The semi-structured interview will take one hour of your child's time, this will occur at a time that is suitable to you and your child. Your child will be given a drink on arrival as they normally would when attending the ███████ House for an appointment.

What are the benefits of the research project to my child?

There are no specific benefits to your child as a participant in this research, although they may gain a helpful perspective as they share their experiences of living with their illness.

More general benefits of the study include

The research will add to the body of knowledge in the care of children and their families who access care and support from the ███████ organisation, and other such organisations.

Can my child withdraw from the study?

Participation in this study is completely voluntary. Your child is not under any obligation to participate. If you give you consent for your child to participate, you can withdraw your consent at any time without adverse consequences for yourself or your child. Non-participation or withdrawal will not affect your or your child's relationship with members of the research team, or the ███████ team. Non-participation in the research will not exclude you or your child in any way from the support and care you receive from the ███████ team.

Will anyone else know the results of the project?

The researchers aim to publish the results of this study in peer-reviewed nursing and health journals. Group data only will be used in reports or publications from the research, no individual participant will be identified. Your child's identity will be known only to Cynthia Ward the student researcher. We will protect the confidentiality of your child's information in the following way. Audiotapes of the semi-structured interviews will be kept in a locked filing cabinet in Cynthia Ward's office. During transcription of the tapes, your child's name will not be used. Once transcription is complete, all tapes will be erased or destroyed. Interview transcriptions will be kept locked in Cynthia Ward's office on password-protected computers.

Will I be able to find out the results of the project?

A brief report of the results is expected to be available at the end of the research. The researchers will make this available to you. Approximately 6 months after the study is completed the research team will publish study findings in academic journals and at conferences. If you would like to be informed about these publications, please send us your email address (provide this information on the space provided on the consent form).

Who do I contact if I have questions about the project?

Any questions regarding this project should be directed to the Principal Investigator Professor Nel Glass.

Professor Nel Glass School of Nursing, Midwifery & Paramedicine Australian Catholic University Melbourne Campus, Locked Bag 4115, Fitzroy VIC 3065. Ph: +61 3 9953 3478 Nel.Glass@acu.edu.au

What if I have a complaint or any concerns? The study has been approved by the Human Research Ethics Committee at Australian Catholic University (approval number 2013 17321). If you have any complaints or concerns about the conduct of the project, you may write to the Chair of the Human Research Ethics Committee care of the Office of the Deputy Vice Chancellor (Research).

Chair, HREC Office of the Deputy Vice Chancellor (Research) Australian Catholic University Melbourne Campus, Locked Bag 4115, FITZROY, VIC, 3065. Ph: +61 3 9953 3150 Fax: +61 3 9953 3315 Email: res.ethics@acu.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

I want my child to participate! How do I sign up?

Please read the consent form provided with this letter. If you wish your child to participate in the research, please take some time to explain the research to your child and ask them to consider whether they want to participate or not. If they want to participate, please ask them to sign their assent on the consent form. Please sign and date both copies of the consent and assent form. One copy is for you to keep. Place one signed copy of the form in the stamped addressed envelope provided.

Yours Sincerely

Professor Nel Glass Principal Investigator

INFORMATION LETTER TO PARTICIPANTS (PARENT OF THE SIBLING OF A CHILD WITH A SERIOUS ILLNESS)

What is important for children and families who receive care from █████████?

Project title: An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families

Principal Investigator: Professor Nel Glass

Associate Researcher: Dr Rosemary Ford

Student Researcher: Cynthia Ward

Dear Participant,

You are invited to consider allowing your child (as a sibling of your child who has a serious illness) to participate in a research project being conducted at █████████ House. Your child will join with 6 to 8 other siblings (age range 5 to 12 years) in a discussion group (duration 1.5 hours).

What is the project about?

█████████ provides nursing and counselling support to children who have serious illnesses and their families. It is helpful to know whether this care and support is meeting the needs of the sick child and their family. The information that your child (the sibling of your child with a serious illness) contributes is highly valued and will assist █████████ to continue to make changes and to develop a service that directly meets your child's and your family's needs.

Who is undertaking the project?

The research is being conducted by a team headed by Professor Nel Glass from Australian Catholic University, and includes PhD student researcher, Cynthia Ward.

Are there any risks associated with participating in this project?

Yes, we understand that your child, as a sibling to a child with a serious illness, may experience emotional distress while joining with other children to discuss issues surrounding their sibling and their family life. The research team will take the following steps to allay your child's distress.

1. Your child will have given assent to participate in the focus group (see consent form).
2. At the commencement of the focus group, your child will be asked to explain their understanding of the research and the purpose of the focus group.
3. At the commencement of the focus group, your child will be asked again to indicate that they consent to participate. They will be provided with age-appropriate methods to express their consent (for example, verbal consent or written consent 'yes' 'okay, I want to talk to you').
4. During the focus group your child can inform the research team if they are unwilling to speak, or unwilling to continue their participation. Their wishes will be respected without question. In preparation for this event, a number of methods for indicating their discomfort with the discussion will be decided with the group of children prior to the discussion commencing. For example, a child may choose to have a red button within reach that they can touch to indicate their decision to remain silent or they may choose to remove themselves from the circle of children for a time. Your child may request that the particular topic under discussion that is causing them distress be stopped completely.

5. In the event that your child becomes emotionally distressed, she/he will be supported by Cynthia Ward, the student researcher. Cynthia is a Nurse Specialist and well used to supporting siblings of a child with a serious illness.

6. In the event that your child needs ongoing support, they will have the opportunity to meet with ███████████ (Psychotherapist at ██████████) or Dr ████████████ (Clinical Psychologist). Their contact numbers are: █████████████████████████ or Dr ██████ █████████████. You are not required to pay for this consultation.

What will your child be asked to do?

Your child will be invited to attend a focus group (discussion group). The discussion group will occur during normal group activities at ██████████ House, these activities are normally scheduled for 1.5 hours duration, thus the discussion group will extend up to but no longer than 1.5 hours. The focus group will be audio-taped to assist the researchers with accuracy during transcription. Your child will be asked the following prompt questions about their experience of ██████████ House:

What do you find helpful at ██████████? What is it that you don't find helpful? What is important for you as a sister /brother of a sick child? Has your family changed since your sister / brother has been sick? What is the hardest thing for you in having a sick sister / brother?

How much time will the project take?

The focus group will take 1.5 hours of your child's time, this will occur after school hours. Your child will be given afternoon tea on arrival at ██████████ House. This will include a drink of juice or water and a biscuit as they normally would when attending sibling groups.

What are the benefits of the research project to my child?

There are no specific benefits to your child as a participant in this research, although they may gain a helpful perspective as they hear the stories of other siblings.

More general benefits of the study include

The research will add to the body of knowledge in the care of children and their families who access care and support from the ▮▮▮▮▮▮▮ organisation and other such organisations.

Can my child withdraw from the study?

Participation in this study is completely voluntary. Your child is not under any obligation to participate. If you give consent for your child to participate, you can withdraw your consent at any time without adverse consequences for yourself or your child. Non-participation or withdrawal will not affect your or your child's relationship with members of the research team, or the ▮▮▮▮▮▮▮ team. Non-participation in the research will not exclude you or your child in any way from the support and care you receive from the ▮▮▮▮▮▮ team.

Will anyone else know the results of the project?

The researchers aim to publish the results of this study in peer-reviewed nursing and health journals. Group data only will be used in reports or publications from the research, no individual participant will be identified. Only Cynthia Ward, the student researcher will know your child's identity. We will protect the confidentiality of your child's information in the following way. Audiotapes of the semi-structured interviews will be kept in a locked filing cabinet in Cynthia Ward's office. During transcription of the tapes, your

child's name will not be used. Once transcription is complete, all tapes will be erased or destroyed. Interview transcriptions will be kept locked in Cynthia Ward's office on password-protected computers.

Will I be able to find out the results of the project?

A brief report of the results is expected to be available at the end of the research. The researchers will make this available to all involved in the focus group. Approximately 6 months after the study is completed the Principal Investigator will begin publishing results in academic journals and at conferences. If you would like to be informed about these publications, please send us your email address (provide this information on the space provided on the consent form).

Who do I contact if I have questions about the project?

Any questions regarding this project should be directed to the Principal Investigator Professor Nel Glass.

Professor Nel Glass, School of Nursing, Midwifery & Paramedicine Australian Catholic University, Melbourne Campus, Locked Bag 4115, Fitzroy VIC 3065. Ph: +61 3 9953 3478, Nel.Glass@acu.edu.au

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at Australian Catholic University (approval number 2013 17321). If you have any complaints or concerns about the conduct of the project, you may write to the Chair of the Human Research Ethics Committee care of the Office of the Deputy Vice Chancellor (Research).

Chair, HREC, Office of the Deputy Vice Chancellor (Research) Australian Catholic University, Melbourne Campus, Locked Bag 4115, FITZROY, VIC, 3065. Ph: +61 3 9953 3150, Fax: +61 3 9953 3315, Email: res.ethics@acu.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

I want my child to participate! How do I sign up?

Please read the consent form provided with this letter. If you wish your child to participate in the research, please take some time to explain the research to your child and ask them to consider whether they want to participate or not. If they want to participate, please ask them to sign their assent on the consent form. Please sign and date both copies of the consent and assent form. One copy is for you to keep. Place one signed copy of the form in the stamped addressed envelope provided.

Yours Sincerely

Professor Nel Glass Principal Investigator

APPENDIX B: Consent forms

CONSENT FORM GROUP 3 (HEALTH PROFESSIONALS FOCUS GROUP)

What is important for children and families who receive care from ██████████?

TITLE OF PROJECT: An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families

PRINCIPAL INVESTIGATOR: Professor Nel Glass (Australian Catholic University (ACU)

ASSOCIATE INVESTIGATOR: Dr Rosemary Ford (ACU)

RESEARCH STUDENT: Cynthia Ward (ACU)

I ....have read and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction. I agree to participate in this research and to engage in the data collection methods as listed below, realising that I can withdraw my consent at any time without adverse consequences to my study program. Once I have participated in the focus group, I understand that my contribution to the discussion cannot be withdrawn. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in any way.

I agree to engage in a focus group at the commencement of the research period.
☐ Yes   ☐ No

I   agree   to   the   use   of   audio   tape   during   the   focus   groups.
☐ Yes   ☐ No

I would like to have publications from this research emailed to me at my email address below.

_____@_____

NAME OF PARTICIPANT: ....

SIGNATURE ....   DATE ....

SIGNATURE OF PRINCIPAL INVESTIGATOR: .... DATE:………………………

CONSENT FORM GROUP 3 (Health Professionals Focus Group)

What is important for children and families who receive care from ███████████?

TITLE OF PROJECT: An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families

PRINCIPAL INVESTIGATOR: Professor Nel Glass (Australian Catholic University (ACU)

ASSOCIATE INVESTIGATOR: Dr Rosemary Ford (ACU)

RESEARCH STUDENT: Cynthia Ward (ACU)

I ....have read and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction. I agree to participate in this research and to engage in the data collection methods as listed below, realising that I can withdraw my consent at any time without adverse consequences to my study program. Once I have participated in the focus group, I understand that my contribution to the discussion cannot be withdrawn. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in any way.

I agree to engage in a focus group at the commencement of the research period.
☐ Yes   ☐ No

I   agree   to   the   use   of   audio   tape   during   the   focus   groups.
☐ Yes   ☐ No

I would like to have publications from this research emailed to me at my email address below.

@

NAME OF PARTICIPANT: ....

SIGNATURE ....   DATE ....

SIGNATURE OF PRINCIPAL INVESTIGATOR: .... DATE:………………………

CONSENT FORM GROUP 2 (PARENT FOCUS GROUP)

What is important for children and families who receive care from ██████████?

TITLE OF PROJECT: An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families

PRINCIPAL INVESTIGATOR: Professor Nel Glass (Australian Catholic University (ACU)

ASSOCIATE INVESTIGATOR: Dr Rosemary Ford (ACU)

STUDENT RESEARCHER: Cynthia Ward (ACU)

I ....have read and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction. I agree to participate in a 1.5 hour focus group for this research and to engage in the data collection methods as listed below, realising that I can withdraw my consent at any time without adverse consequences to my support. Once I have participated in the focus group, I understand that my contribution to the discussion cannot be withdrawn. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in any way.

I agree to engage in a focus group at the conclusion of the research period (end May 2013).
☐ Yes   ☐ No

I   agree   to   the   use   of   audio   tape   during   the   focus   groups.
☐ Yes   ☐ No

I would like to have publications from this research emailed to me at my email address below.

_____ @ _____

NAME OF PARTICIPANT: ....

SIGNATURE ....   DATE
....

SIGNATURE OF PRINCIPAL INVESTIGATOR: .... DATE:………………………..

CONSENT FORM GROUP 2 (Parent's Focus Group)

What is important for children and families who receive care from ███████?

TITLE OF PROJECT: An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families

PRINCIPAL INVESTIGATOR: Professor Nel Glass (Australian Catholic University (ACU)

ASSOCIATE INVESTIGATOR: Dr Rosemary Ford (ACU)

STUDENT RESEARCHER: Cynthia Ward (ACU)

I ....have read and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction. I agree to participate in this research and to engage in the data collection methods as listed below, realising that I can withdraw my consent at any time without adverse consequences to my study program. Once I have participated in the focus group, I understand that my contribution to the discussion cannot be withdrawn. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in any way.

I agree to engage in a focus group at the commencement of the research period.
☐ Yes   ☐ No

I agree to the use of audio tape during the focus groups.
☐ Yes   ☐ No

I would like to have publications from this research emailed to me at my email address below.

_____@_____

NAME OF PARTICIPANT: ....

SIGNATURE ....   DATE ....

SIGNATURE OF PRINCIPAL INVESTIGATOR: .... DATE:………………………..

CONSENT FORM GROUP 1 (SIBLINGS FOCUS GROUP)

What is important for children and families who receive care from ████████?

TITLE OF PROJECT: An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families

PRINCIPAL INVESTIGATOR: Professor Nel Glass (Australian Catholic University (ACU)
ASSOCIATE INVESTIGATOR: Dr Rosemary Ford (ACU)

RESEARCH STUDENT: Cynthia Ward (ACU)

I ....have read and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction. I agree to my child participating in a 1.5 hour focus group for this research and to engage in the data collection methods as listed below, realising that he/she can withdraw consent at any time without adverse consequences to their support. Once they have participated in the focus group, I understand that their contribution to the discussion cannot be withdrawn. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify my child in any way.

I agree for my child to engage in a focus group at the conclusion of the research period (end May 2013).
☐ Yes   ☐ No

I   agree   to   the   use   of   audio   tape   during   the   focus   groups.
☐ Yes   ☐ No

I…………………………………… assent to being involved in this research.

I would like to have publications from this research emailed to me at my email address below.

_____@_____

NAME OF PARTICIPANT: ....

SIGNATURE ....   DATE
....

SIGNATURE OF PRINCIPAL INVESTIGATOR:... DATE:………………………..

CONSENT FORM GROUP 1 (Sibling Focus Group)

What is important for children and families who receive care from █████████?

TITLE OF PROJECT: An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families

PRINCIPAL INVESTIGATOR: Professor Nel Glass (Australian Catholic University (ACU)

ASSOCIATE INVESTIGATOR: Dr Rosemary Ford (ACU)

RESEARCH PHD STUDENT: Cynthia Ward (ACU)

I ....have read and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction. I agree to my child participating in this research and to engage in the data collection methods as listed below, realising that he/she can withdraw consent at any time without adverse consequences to their support. Once they have participated in the focus group, I understand that their contribution to the discussion cannot be withdrawn. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify them in any way.

I agree for my child to engage in a focus group at the commencement of the research period.
☐ Yes   ☐ No

I   agree   to   the   use   of   audio   tape   during   the   focus   groups.
☐ Yes   ☐ No

I……………………………….assent to being involved in this research.

I would like to have publications from this research emailed to me at my email address below.

_____@_____

NAME OF PARTICIPANT: ....

SIGNATURE...

DATE................................

SIGNATURE OF PRINCIPAL INVESTIGATOR:... DATE:………………………..

CONSENT FORM GROUP 4 (INTERVIEW WITH A CHILD WITH A SERIOUS ILLNESS)

What is important for children and families who receive care from ▓▓▓▓▓▓▓?

TITLE OF PROJECT: An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families

PRINCIPAL INVESTIGATOR: Professor Nel Glass (Australian Catholic University (ACU)

ASSOCIATE INVESTIGATOR: Dr Rosemary Ford (ACU)

RESEARCH STUDENT: Cynthia Ward (ACU)

I ....have read and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction. I agree for my child to participate in this research and to engage in the data collection methods as listed below, realising that he/she can withdraw their consent at any time without adverse consequences to their care and support. Once they have participated in the semi-structured interview, I understand that their contribution to the discussion cannot be withdrawn. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify my child in any way.

I agree for my child to be involved in an interview at the commencement of the research period.
☐ Yes   ☐ No

I agree to the use of audio tape during the interview.
☐ Yes   ☐ No

I…………………………..assent to participating in this research.

I would like to have publications from this research emailed to me at my email address below.

_____@_____

NAME OF PARTICIPANT: ....

SIGNATURE ....   DATE………………

SIGNATURE OF PRINCIPAL INVESTIGATOR:.. DATE:………………………

CONSENT FORM GROUP 4 (Interview with a child with a serious illness)

What is important for children and families who receive care from ███████?

TITLE OF PROJECT: An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families

PRINCIPAL INVESTIGATOR: Professor Nel Glass (Australian Catholic University (ACU)

ASSOCIATE INVESTIGATOR: Dr Rosemary Ford (ACU)

RESEARCH STUDENT: Cynthia Ward (ACU)

I ....have read and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction. I agree for my child to participate in this research and to engage in the data collection methods as listed below, realising that he/she can withdraw their consent at any time without adverse consequences to their care and support. Once they have participated in the semi-structured interview, I understand that their contribution to the discussion cannot be withdrawn. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify my child in any way.

I agree for my child to be involved in an interview at the commencement of the research period.
☐ Yes   ☐ No

I   agree   to   the   use   of   audio   tape   during   the   interview.
☐ Yes   ☐ No

I………………………..assent to participating in this research.

I would like to have publications from this research emailed to me at my email address below.

_____@_____

NAME OF PARTICIPANT: ....

SIGNATURE ....   DATE………………

SIGNATURE OF PRINCIPAL INVESTIGATOR:.. DATE:……………………….

APPENDIX C: ETHICS FORM

Cynthia

From:	Kylie Pashley <Kylie.Pashley@acu.edu.au> on behalf of Res Ethics <Res.Ethics@acu.edu.au>
Sent:	Monday, 29 September 2014 6:02 p.m.
To:	'crward001@myacu.edu.au'; Cynthia
Cc:	Res Ethics
Subject:	2013 27V Ethics application approved!

Dear Applicant,

Principal Investigator: Prof Nel Glass
Student Investigator: Ms Cynthia Ward (HDR student) Ethics Register Number: 2014 256V Project Title: An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families in New Zealand.
Risk Level: Low Risk
Date Approved: 23/03/2013
Ethics Clearance End Date: 31/12/2013

This email is to advise that your application has been reviewed by the Australian Catholic University's Human Research Ethics Committee and confirmed as meeting the requirements of the National Statement on Ethical Conduct in Human Research.

This project has been awarded ethical clearance until 31/12/2013. In order to comply with the National Statement on Ethical Conduct in Human Research, progress reports are to be submitted on an annual basis. If an extension of time is required researchers must submit a progress report.

Whilst the data collection of your project has received ethical clearance, the decision and authority to commence may be dependent on factors beyond the remit of the ethics review process. The Chief Investigator is responsible for ensuring that appropriate permission letters are obtained, if relevant, and a copy forwarded to ACU HREC before any data collection can occur at the specified organisation. Failure to provide permission letters to ACU HREC before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research. Further, this approval is only valid as long as approved procedures are followed.

If you require a formal approval certificate, please respond via reply email and one will be issued.

Decisions related to low risk ethical review are subject to ratification at the next available Committee meeting. You will be contacted should the Committee raises any additional questions or concerns.

Researchers who fail to submit a progress report may have their ethical clearance revoked and/or the ethical clearances of other projects suspended. When your project has been completed please complete and submit a progress/final report form and advise us by email at your earliest convenience. The information researchers provide on the security of records, compliance with approval consent procedures and documentation and responses to special conditions is reported to the NHMRC on an annual basis. In accordance with NHMRC the ACU HREC may undertake annual audits of any projects considered to be of more than low risk.

It is the Principal Investigators / Supervisors responsibility to ensure that:
1. All serious and unexpected adverse events should be reported to the HREC with 72 hours.
2. Any changes to the protocol must be approved by the HREC by submitting a Modification Form prior to the research commencing or continuing.
3. All research participants are to be provided with a Participant Information Letter and consent form, unless otherwise agreed by the Committee.

For progress and/or final reports, please complete and submit a Progress / Final Report form:

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APPENDIX D: PERMISSIONS AND PUBLICATIONS

PERMISSION TO REPRODUCE PUBLICATION 1

From:	Bernie Carter <jchcoffice@gmail.com>
Sent:	Thursday, 21 January 2016 6:24 a.m.
To:	Cynthia
Subject:	Re: Permission to include article into PhD thesis

Dear Cynthia

Thank you for your email. I am very happy to give you permission to use the article in the way outlined in your email. I wish you the very best of luck with your PhD. It is an important area of work.

All best wishes

Bernie

On Wed, Jan 13, 2016 at 8:50 PM, Cynthia <cynthia@truecolours.org.nz> wrote:

Dear Professor Bernie Carter,

I hope you enjoyed your holiday.

I am writing to gain permission to include an article published by your journal in my PhD thesis. I am undertaking a PhD by publication through the Australian Catholic University. It is titled - "Listening to the Voice of the Child":

An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families in New Zealand

The article of relevance is; **Ward, C., Glass, N., & Ford, R. (2015). Care in the home for seriously ill children with complex needs: A narrative literature review.** *Journal of Child Health Care,* **19(4), 524–531. DOI: 10.1177/1367493514538327**

I look forward to hearing from you.

Thank you.

Warm Regards

Cynthia Ward

1

Care in the home for seriously ill children with complex needs: A narrative literature review

Cynthia Ward, Nel Glass and Rosemary Ford
Australian Catholic University, Australia

Abstract

This article reviews contemporary literature on home care of the seriously ill child with complex care needs and the sick child/parent dyad. The literature search revealed three major themes, namely the increasing acuity of child illness, the evolving role of the parent as care provider, and the health professional as care provider. While there is much known about the complexity of care of children and the role of family in that care, little is known about what families require in terms of support and sustenance during the long years of care provision.

Keywords

Children, family, qualitative, serious complex illness

Introduction

This literature review was undertaken as a component of a research study investigating home care of seriously ill children with complex care needs. The study had the overall objective of evaluating care that enables seriously ill children to remain at home in their communities. Globally, the overall responsibility for ongoing and complex care for children with serious illness rests with the family, predominately with the child's parents. To care for their child at home, parents must develop specialized skills and knowledge to manage not only the child's condition but also the technology that keeps their child ventilated, fed, and hydrated.

Aim

The aim of the narrative review was to explore the contemporary literature on home care of the seriously ill child with complex care needs and the sick child/parent dyad.

Corresponding author:
Cynthia Ward, True Colours Children's Health Trust, PO Box 9458, Hamilton 3240, New Zealand.
Email: cynthia@truecolours.org.nz

Methods

The literature for this review was searched electronically and manually. The search strategy (Table 1) identifies inclusion and exclusion criteria and the electronic databases. Relevant journal articles were also accessed manually from university and hospital libraries using keywords.

Within the palliative care literature, a number of descriptors of serious illness are used, for example, life-limiting, life-threatening, life-shortening, chronic, terminal, and palliative. The term 'serious illness' is deliberately identified for this study as it covers the above spectrum along with complications of premature birth and children with complex care needs and technology dependence. In the United Kingdom, these children are included in category 4, according to life-limited criteria (The UK Association for Children's Palliative Care Royal College of Paediatrics and Child Health, 2009). The search yielded many articles (Table 2), and this number was reduced once exclusion criteria were used. Thirty-seven articles were included in this narrative literature review.

Table 1. Search strategy.

Inclusion criteria	Exclusion criteria	Databases searched
Peer reviewed publications	Children >18 years	CINAHL PLUS
Publication date 2003–2013	Publications >10 years	Sage
Children with complex and serious health conditions	Publications that were unrelated to children's complex health conditions	Wiley
Language—English		PubMed
		Science Direct

Table 2. Database and search results.

Database	Time period	Seriously ill children	Complex health needs in children	Complex health needs and children	Family and children with serious illness	Models of care and children
CINAHL PLUS	2003–2013	53	5		5	17
Sage	2003–2013	42	0	175	4	381
Wiley	2003–2013	16,110	108,022		28,486	245,550
PubMed	2003–2013	2922	26,992		11,107	61,191
Science Direct	2003–2013	242	3464		790	6068

Literature results

The 37 articles identified for this narrative literature review were predominantly qualitative with pediatric palliative care—the strongly emergent field. The literature revealed evidence of the challenge of caring for a seriously ill child with complex health conditions (Al-Gamal, 2013; Donovan et al., 2011; Elias ER and Murphy NA, 2012; Hain et al., 2012; Ling, 2012; Schuster et al., 2011; Whiting, 2013). A child's illness was found to have a profound impact on every dimension of family life, and parents, as carers, were found to be challenged on many levels (Elias and Murphy, 2012; Kenney et al., 2011; McCann et al., 2012; Schuster et al., 2011; Whiting, 2012).

While much is known about the complexity of care for the child, little is known about what parents need to support and sustain them, particularly during the extended years of care provision. Parents find many impediments in their way as they navigate through health and other services for their child. For example, if their child lacks a definitive diagnosis, they may fall outside service eligibility criteria, and there can be duplication, gaps, and poor coordination in services, also poor communication and conflicting information between services (Dybwik et al., 2011; Looman et al., 2013; McIntosh and Runciman, 2008; Robinson, 2010; Whiting, 2012).

Specifically, the literature addressed the increasing acuity of child illness, the evolving role of parent as care provider, and the health professional as care provider.

The increasing acuity of child illness

Increasingly, over the last two decades, survival has been made possible through advances in medical knowledge and the development of sophisticated technical equipment (Elias et al., 2012; Maddox and Pontin, 2013; McCann et al., 2012). In contemporary neonatal and pediatric care, although a child survives the early assault on his/her health, the child may experience ongoing problems related to the child's initial illness and/or the child's intensive treatment regime (McCann et al., 2012; Schuster et al., 2011).

The literature portrayed serious illness in childhood in a number of ways. Illnesses were described as complex medical conditions, life-limiting or life-threatening, all requiring pediatric specialty care in a tertiary center and specialist health care facilities that provide advanced medical procedures and treatments (Elias and Murphy, 2012; Hain et al., 2012; Tamburro et al., 2011). These illnesses were often characterized by a variable trajectory with prognostic uncertainty. Serious illness included conditions such as respiratory or neurologic complications of preterm birth, congenital, genetic, metabolic, and neurologic disorders. Conditions such as cystic fibrosis, cerebral palsy and muscular dystrophy, the sequelae of severe infections and trauma and malignancies were also threaded through the literature (Association for Children's Palliative Care, 2009; Elias and Murphy, 2012; Hain, et al., 2013; Tamburro et al., 2011).

Children with serious illness commonly experience feeding and respiratory problems and are dependent on technology for their everyday needs (Feudtner et al., 2011; Hobson and Noyes, 2011; Maddox and Pontin, 2013). Many of these children are initially cared for in a hospital setting with the goal to be transitioned home to be cared for by their families (Hewitt-Taylor, 2012). In contemporary models of care, therefore, the primary caregiver is the parent(s) and the care setting is the family home. Hobson and Noyes's (2011) study of fathers' care provision to their sick child in the home identified high acuity care such as tracheotomy care, long-term ventilation, enteral and parenteral feeding, and the use of intravenous drugs.

Serious illnesses commonly cause children to have a difficult passage through normal physical and developmental stages and their care requirements impact heavily on daily family functioning (Elias and Murphy, 2012; McCann et al., 2012; Whiting, 2012). For parents, the intensity of care for the child can be unrelenting, leaving them with little personal time and subject to physical and emotional exhaustion (Ling, 2012; Whiting, 2012).

The evolving role of parent as care provider

There is a broad consensus in the developed world that the number of children with serious illness being cared for at home is increasing. The care requirement is commonly seen to extend over

longer time periods, usually from infancy and through to adulthood (Benini et al., 2008; Hollander and Prince, 2008; McIntosh and Runciman, 2008; Ling, 2012). This has a direct negative impact on the parents' physical and mental health and their emotional resilience. The family structure is impacted in terms of sibling welfare and marital longevity, with the marital relationship often showing marked deterioration (Carnevale et al., 2006; Dybwik et al., 2011; Elias et al., 2012; Steele and Davies, 2006).

Parents as care providers for their seriously ill child often experience their role as demanding, with most reporting that it impacts considerably on family life. While many families acknowledge the positive, deep, and enriching experiences (Carnevale et al., 2006; Dybwik et al., 2011; Whiting, 2012), the predominant finding in the literature is that parents are burdened by a role that is time-consuming, arduous, rigorous, taxing, exhausting, and one that is isolating and shrouded in grief (Al-Gamal, 2013; Carnevale et al., 2006; Elias and Murphy, 2012; Whiting, 2012). Parents experience altered roles, financial burden, and marital strain, and in comparison with parents of a healthy child, may experience higher levels of psychological distress (Carnevale et al., 2006; Schuster et al., 2011; Ling, 2012; Whiting, 2012).

Parents have become the experts in managing their child's condition, even though their expertise is often developed through necessity rather than choice (Malcolm et al., 2011). In Schuster et al.'s (2011) recent research on children's needs and parent's responsibilities, it was found that health care services are reliant on parental input to the point where the role of parents was seen as a 'shadow health care system'. They noted a distinct feature of health care for children was the expectation that parents would provide care at home and perform almost all support and care roles. (Schuster et al., 2011) suggested that without this shadow care, the formal child health care system would be unable to function.

Even though parents shoulder the burden for ongoing care at home, at times they believe their expertise and unique knowledge of their child's condition to be unvalued (Ertmann et al., 2011). The experiences of being patronized or dismissed or having their judgment questioned caused some parents to suffer profound and lasting emotional distress (Davies et al., 2010; Whiting, 2012). These authors also found some families to be frustrated and angry about being victimized, ignored, and deprived of information about their child.

Health professionals rely heavily on the family, yet at times, they neglect to provide opportunities for the parents' and the child's voices in decision making (Konrad, 2007). In this regard, parents reported that they battled to have their voices heard (Konrad, 2007; Whiting, 2012). One study revealed the importance that parents placed on the 'battle' with health professionals and organizations caring for their child living with a complex serious illness (Whiting, 2012). Their experiences of care for their child, described as a 'battleground', emerged from exploring parent's views on impact, need for help, support, and sense making when caring for their sick child. In addition, parents in Konrad's study felt their vigilance on behalf of their child to be viewed negatively by health professionals (Konrad, 2007). Without respect, sharing, and consultation from health professionals, parents felt undervalued and compromised in their role as carer and parent (Ertmann et al., 2011; Konrad, 2007; Whiting, 2012). Another challenge for parents was the necessity for them to navigate their way through numerous medical specialist and allied health consultations (Denboba et al., 2006; Whiting, 2012) which, according to parents, put them under time pressure and stress often for what they deemed to be unnecessary appointments (McNeilly et al., 2006; Whiting, 2012).

The parent of a seriously ill child gains important insights into their child's individual needs and wants regarding 'quality of life'. However, the issue of what constitutes the quality of life often

caused conflict and misunderstanding between the child/parent dyad and health professionals (Janse et al., 2005), thus emerging as another problematic area for the parent and a potential restriction on quality care for the child. Health professionals can hold strongly to their own understanding of what makes a quality life, without regard for the feelings of the child and family who face life struggles and unmet dreams everyday.

The challenge for parents is to gain the support from health agencies that is beneficial to the sick child and will contribute to the child's quality of life. This challenge needs to be addressed, first, for the benefit of the child and, second, for the benefit of the entire family.

Parents require care teams that work in collaboration, are constructive, and demonstrate inclusivity (Horridge, 2011). A partnership of care is required, in which the child, parent, and family are engaged in decisions about care and believe their unique needs and circumstances are respected. Denboba et al. (2006) found variation in the level of inclusion of families in care decisions. For instance, some families were included as members of the team, while other families were not. Exclusion was particularly evident for families who experienced poverty and had cumulative sociodemographic risk factors. These authors concluded that further work is needed to facilitate partnerships. This requires that health professionals acknowledge the burden carried by parents and families, willingly engage with the family, and confidently explore care model options that meet the needs of the child and family.

The health professional as care provider

Caring for a child with serious illness is a specialization, with health professionals requiring a wide range of skills, expertise, and personal attributes to perform the care role (McIntosh and Runciman, 2008; Hain et al., 2012; Hewitt-Taylor, 2012). Health professionals at times experience insecurity over perceived lack of training and competence, particularly in symptom management but also in the ability to communicate with the child and parents. Many health professionals believe their care is not optimal when supporting children at the end of life (Law et al., 2011; Rushton et al., 2006), with their lack of confidence affecting the quality of their care and their relationships with child and parent. Law et al. (2011) acknowledged the need for both generic and specialized knowledge and skills and importantly the maturity to manage the care relationship.

The dynamics of caring for a child in their home environment is different to hospital settings, and careful negotiation is required between families and health professionals to establish roles and responsibility regarding administration of medications, care, and technological support (Hewitt-Taylor, 2012). Parents acquire a high level of knowledge, skill, and competence in relation to their child's illness, treatments, and care. They may have specific training regarding technology cares for their child during episodes of hospitalization and will also develop idiosyncratic practices once in their own homes (Maddox and Pontin, 2013). This difference in practice has the potential to create a dynamic of tension between the health professional and the parent regarding role performance particularly in relation to technology management (Maddox and Pontin, 2013). Tension will also occur if parents do not have confidence or trust in the health professional (Whiting, 2012) and may find fault with their skill and knowledge adequacy and their level of confidence and self-assurance.

Confidence in the health professional team's knowledge and skills is critical to whether the parents feel supported in their own home-based care role and included in a partnership of care (McIntosh and Runciman, 2008). Rushton et al. (2006) found the provision of education and support not only increased skill and knowledge, but it also improved confidence in care provision. It is strongly evident that parents desire care that is safe, competent, and holistic (Horridge, 2011).

Discussion

The aim of the narrative review was to explore the contemporary literature on home care of the seriously ill child with complex care needs and the sick child/parent dyad. Home care for children maximizes their time in the familiar, safe environment of the home; however, although viewed as a positive experience by some, many parents report being burdened by the complexity and constancy of their caring role. The responsibility for managing care impacts every aspect of parents' lives, with the normal family structure and dynamic significantly altered. Some parents were found to experience distress and frustration in their dealings with health professionals, with exclusion from decision making and lack of respect and valuing of their knowledge to be major factors. Although parents are viewed as a vital link in the chain of care, their status as an authoritative voice for their child can be compromised. Parents also report frustration over lack of skill and self-assurance in some health professionals, thus causing parents to lose trust and confidence in care provision, and lowering their own confidence in home care to their child. Parents report high levels of frustration and stress related to their interaction with health services.

Although not universally enacted, many practitioners recommend a model of care in which the child and parent are engaged in decisions about care, and where their unique needs and circumstances are respected. This partnership of care is described variously as 'integrated care' (Ouwens et al., 2009), 'family-centered care' and 'family–professional partnership' (Denboba et al., 2006), and 'family–provider partnership' (Kenney et al., 2011). These contemporary models of care are holistic, multidisciplinary, individualized in approach, and centered on the unique needs of the child/parent dyad throughout the illness trajectory (Price and McNeilly, 2009), inclusive of such needs as cultural and linguistic competence (Denboba et al., 2006). Optimal collaboration and coordination between all members are important qualities of the team (Ouwens et al., 2009).

Kenney et al. (2011) called for investigation of the entire health care experience, particularly to increase satisfaction rates for the child/parent dyad and reduce disparities between groups. For families to acquire sustenance during the long years of care provision, dedicated time for complex cross-agency coordination, negotiation with the family, and time to work alongside them on their difficult paths are required (Bromley, 2008).

The child with a serious illness may require care for many years as she/he transitions between hospital and home. To date, there is limited published evaluative research into integrated models of care for children who are cared for in their homes. In order to inform the discourse on optimum care for the child/parent dyad, and what is required to enhance sustenance in the care, targeted evaluative research needs to be conducted.

Conclusions and recommendations

When a child is seriously ill, health care is provided in most cases at home by the parent(s). There is a critical need to focus on what parents require in terms of support and sustenance during the long years of care provision. It is important that the burden of care interventions is eased for parents and that grief, exhaustion, and isolation are effectively and sensitively managed. Further research is needed to investigate models of care and their efficacy in delivering quality outcomes for seriously ill children and their parents.

Funding

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Cynthia

From: Gilmour, Jean <J.A.Gilmour@massey.ac.nz>
Sent: Monday, 18 January 2016 12:40 p.m.
To: Cynthia
Cc: admin@nursingpraxis.org
Subject: RE: Permission to include article in PhD thesis

Dear Cynthia

You have permission to include your article "Ward, C., Evans, A., Ford, R., & Glass, N. (2015). Health Professionals Perspectives of Care for Seriously Ill Children Living at Home. Nursing Praxis in New Zealand, 31(2), 25-34" in your PhD thesis being completed by publication through the Australian Catholic University titled - "Listening to the Voice of the Child":
An Evaluation of an Integrated Model of Care for Children with Serious Illness and their Families in New Zealand.

I hope your study is progressing well.

Jean Gilmour, RN, PhD.
Co-Chief Editor
Nursing Praxis in New Zealand
Journal of Professional Nursing

From: Nursing Praxis Administration [mailto:admin@nursingpraxis.org]
Sent: Monday, 18 January 2016 9:52 a.m.
To: 'Cynthia'
Cc: Gilmour, Jean
Subject: RE: Permission to include article in PhD thesis

Thank you for your request Cynthia. We will process the request and get back with you as soon as possible. Please note that Jean Gilmour and Jill Wilkinson are now the Editors in Chief. Denise Wilson has stepped down due to work and family demands.

Kind regards

Shannon Lamballe
Administrator

Nursing Praxis in New Zealand
Journal of Professional Nursing
PO Box 1984
Palmerston North 4440
New Zealand
DDI: +64 6 358 6000
admin@nursingpraxis.org
www.nursingpraxis.org

From: Cynthia [mailto:cynthia@truecolours.org.nz]
Sent: Thursday, 14 January 2016 10:05 a.m.

1

Nursing Praxis in New Zealand

HEALTH PROFESSIONALS PERSPECTIVES OF CARE FOR SERIOUSLY ILL CHILDREN LIVING AT HOME

Cynthia Ward, MA (Applied), BN, Chief Executive Officer, True Colours Children's Health Trust, Hamilton, NZ

Alicia Evans, PhD, MBA, BN, Senior Lecturer, Australian Catholic University, Melbourne, Australia

Rosemary Ford, PhD, MN, B Hth Mgt., Deputy Head of School, Australian Catholic University, Ballarat, Australia

Nel Glass, RN; Dip Neuro Nurs, BA, MHPEd, PhD, FACN, Honorary Professor, Australian Catholic University, Melbourne, Australia

Abstract

The aim of this article is to report the findings on health professional's perceptions of beneficial care for seriously ill children and their families. This paper represents one component of a PhD qualitative evaluation study investigating care provided by a child health Trust in New Zealand. The Trust provides an integrated care model of nursing and psychological support to children with complex health needs and their families who live at home. The research methodology was informed by critical realism. The research method chosen was a focus group. There were twelve health professional participants who worked in collaboration with the Trust team to provide care to seriously ill children. Data were analysed using a realist analysis to identify initial key aspects and subsequent themes. Five themes were identified: collaboration between health providers; effective communication; expert skills; support for colleagues and, after-hours care availability. Participants perceived the Trust model of care to be integral for children with serious illness, and their families in the community. This study extends our current understanding of models of care for children with complex health needs. It has relevance to health providers who are first 'on call' for children with serious illness and their families as well as those involved with continuity of care.

Keywords

Seriously ill children; health professionals; model of care; complex health needs

Introduction

Global advances in medical knowledge and technology have resulted in increased survival of neonates with complex illnesses. Many of these neonates now live into childhood, however their care requirements have become more complex (Elias & Murphy, 2012; Maddox & Pontin, 2013; Schuster, Chung, & Vestal, 2011). Previously these children remained in a hospital setting, however the contemporary care setting is the family home with parents the primary carers and providers of their child's technical and personal cares (Dybwik, Tollali, Nielson, & Brinchmann, 2011; Elias & Murphy, 2012; Hewitt-Taylor, 2012; Maddox & Pontin,

2013; McCann, Bull, & Winzenburg, 2012). Parents/families are now required to learn how to safely and effectively deliver technical interventions, following instruction from community nurses. Some examples of these interventions are: oxygen and ventilation therapy, tracheotomy care, suctioning, feeding-tube care, intravenous nutrition and intravenous drug regimens (Eilas & Murphy, 2012; Maddox & Pontin, 2013; Shuster et al., 2011; Whiting, 2013).

Shuster and colleagues (2011) described care provided by parents/families as a 'shadow health care' (p. 91) system upon which health care services rely. Publically funded child health care systems would be unable

to function without this level of parental support (Shuster et al., 2011). Buhler-Wilkerson (2007) argued home care could be the cornerstone of a system to meet the needs of the chronically ill. However, the management of technical, physical and emotional care for children at home has a direct impact on the parent/family in terms of physical, mental health and emotional resilience. Parents often have been found to experience altered roles, financial burden, marital strain, psychological distress (Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Ling, 2012; Santacroce, 2003; Schuster et al., 2011; Whiting, 2013) and low quality of life (Al-Gamal, 2013). There continues to be the question of how to deliver funded care that has the potential to reduce the physical, emotional and financial burden for parent/family carers (Buhler-Wilkerson, 2007; Shuster et al., 2011).

It is important that home care for seriously ill children with complex medical needs is provided in the context of a child health model of care that is family-centred and that a partnership forms between the child, family and health professionals. Fowler et al. (2012) highlight that nurse partnership activities are not new to nurses who work with parents. Fowler and colleagues (2012) argue that partnership requires nurses to skilfully create the conditions for an effective relationship to emerge. This then provides opportunity for optimal collaboration and coordination to enhance better outcomes in care (Barnes & Rowe, 2008; Denboba, McPhearson, Kenney, Strickland, & Newacheck, 2006; Fowler et al., 2012; Kenny, Denboba, Strickland, & Newacheck, 2011; Price & McNeilly, 2009; Simkiss, 2011; Yarwood, 2008).

The research reported here aims to contribute to the body of knowledge on the topic of health related care for seriously ill children living at home and health service evaluation. This has significance for medical, nursing and allied health professionals who care for seriously ill children and their families.

Background

It has been well established that families benefit from health care that is provided in an integrated and co-ordinated way, particularly when the child is being treated in their home (American Academy of Pediatrics: Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee, 2014; Association for Children with Life-Threatening or Terminal Conditions and their Families, & Royal College of Paediatrics and Child Health, 2003; Ministry of Health, 2010). Many of these children have complex and disabling health needs, sometimes requiring palliation. In response to this, in New Zealand, District Health Boards recommended care models for this group of children (Craig, McDonald, Adams, Reddington, & Wicken, 2010; Paediatric Society of New Zealand 1997; Paediatric Society of New Zealand, 2008; Smith & Overden, 2007).

In accordance with the District Health Board recommendations and due to identified service gaps (Ward, 2005), a Child Health Trust was established in 2004 in New Zealand. Its aim was to provide an integrated model of nursing and psychological care for children with serious complex illnesses, being treated at home. There was recognition that parents/families ultimately carried the burden of care for their children at home. This model is based on the Te Whare Tapa Whā health and wellness model developed by Mason Durie (1996). The model is underpinned by four dimensions representing the basic beliefs of life: te taha hinengaro (psychological health); te taha wairua (spiritual health); te taha tinana (physical health); and te taha whānau (family health).

At the time the Trust was founded, there was no other organisation providing continuity of care to children with illnesses that were predominantly non-palliative. Chronicity and complexity of care demanded service delivery that commenced at the time of the child's diagnosis and to be available throughout the child's

lifespan. While palliative care has significantly developed over the last decade worldwide (Baker, et al., 2008; Ministry of Health, 2012) and hospices provide holistic care there remains a gap in care and research for those with chronic complex conditions. This population group is increasing as more children now survive and the complexity of the illnesses is more intensive on resources and skill.

Carter and Thomas (2011) argue a plethora of agencies and professionals are required to support this population group. In the United Kingdom, challenges for these families have been recognised at a government level, resulting in the implementation of family and child-centred initiatives such as Every Child Matters, the Early Support Programme and Aiming High for Disabled Children (Carter & Thomas, 2011).

Bolitho and Huntington (2006) argue that the New Zealand government has children's health as a priority. These are reflected in strategies and frameworks such as the: Child Health Strategy (Ministry of Health, 1998); He Korowai Oranga (King & Turia, 2002); The New Zealand Health Strategy (King, 2000); and The Primary Health Care Strategy (King, 2001). However, the reality is that caring for seriously ill children in the community has huge impact on families in New Zealand (Barnes & Rowe, 2008), with limited resources available to meet the need. There is much more to do to improve services to this population group.

The Trust is situated in a residential house, containing offices and therapeutic spaces. The Trust employs four clinicians who provide a variety of clinical nursing and psychological cares for the child/family on-site at the Trust, in the family home and in acute inpatient care services. At any time, Trust team members care for 130 – 150 children/families, in terms of symptom management, family counselling/psychosocial support, collaboration/advocacy with non-Trust health professionals, and 24 hour on-call nursing for

management of health crisis.

Within the integrated model of care, Trust team members and non-Trust health professionals strive to meet the needs of the child and their parents/families. This is delivered through effective communication, collaboration and coordination of care. For instance, collaborative home visits or clinic appointments bring together in partnership the child/family and non-Trust health professionals (nurses, paediatricians and allied health workers) and Trust team members. The history of the development of the service and its evolution has been reported elsewhere (Ward, 2009).

Methodology

The aim of the PhD qualitative evaluation study is to investigate the contribution of the integrated model of care to the welfare of the child with a serious complex illness, the child's siblings, parents, and their professional carers. The methodological framework was multi-layered critical realism that incorporated the identification of key 'realist' themes and emergent critical themes. Bhaskar (1975), recognised as the founder of critical realism, was influenced by Marx's work. Bhaskar, (1975) divided critical realism into three domains: the empirical, the actual and the real. The 'empirical' is described as the observable encounter that happens and exists according to our immediate experience. The 'actual' refers to what happens independent of the observer and the 'real' refers to objects, their structures and their causal powers, or the domain that includes mechanisms that produce different events (Alvesson & Skoldberg, 2009). Bhaskar (1975) describes 'reality' as complex, structured and multi-layered.

Pawson and Tilley (1997), influenced by Bhaskar's work, extended the realist belief, going on to create Realist Evaluation which has its roots in realism. Realist Evaluation is concerned with identifying underlying causal mechanisms, how they work and under what

conditions. This produces a closer understanding of what causes change (Pawson & Tilley, 1997). For this study, the realist lens allowed the authors to explore the distinctive nature of the integrated model of care; how it worked, what was involved and what possible causal relationship contributed to the outcomes of care for families (Pawson & Tilley, 1997).

Data collection

Data were collected through three methods: individual interviews, focus group interviews and researcher reflective journaling. Individual semi-structured interviews were conducted with children, who were patients of the Child Health Trust. Separate focus groups were conducted with the child's siblings, parents, and the health professionals involved in care of these children. This article focuses on the focus group data from the health professionals and the identification of realist themes.

Health professional focus group

The focus group was facilitated with open ended questions used to elicit information from participants. Examples of these questions were; "what are some of the differences you see for families once they have started engaging with the Trust", "how is communication conveyed, with you as health professionals, the Trust and the families", "to what extent do you find the Trust helps you find solutions when working with families"? The focus group was audio-recorded, transcribed verbatim and analysed initially for identification of any key emerging aspects and subsequently the development of realist themes.

Participants

Participants for this study were health professionals who referred paediatric patients to the Child Health Trust. They were recruited from the local hospital and community agencies. Fifty-eight health professionals were sent an information pack which included a letter of invitation to contact the research assistant who was

responsible for recruitment and data collection. There were 12 focus group participants from the hospital and community. They comprised of nursing, allied health and medical personnel, thus representing the key disciplines and professional expertise required to provide care for children. The Child Health Trust works with a vast number of health professionals from other agencies. Excluded from the research were those health professionals who were not direct key referrers or who did not work in close collaboration with the Trust team.

Data analysis

Utilising a critical realist approach the de-identified transcript was read and searched to find emerging aspects, repeated patterns that resulted in realist themes. Interpretation and theorising from the whole story and its meaning was sought, with the attention of focusing on the 'what' in the story, rather than 'how' it was told (Braun & Clarke, 2006; Liamputtong, 2010). A systematic approach determined the rigour of data analysis that was applied within the framework of familiarisation, identifying themes, manual coding, mapping and recoding of themes for the purpose of understanding until saturation of these themes had been attained. Reflexive journaling by the first author, kept an ongoing record of experiences and reactions that helped inform the decisions made regarding assumptions and the subject material.

Ethical considerations

As the first author is employed by the Trust and close to the work, a research assistant that was not associated with the Trust joined the research team specifically for participation recruitment, data collection and de-identifying the original data. The study was approved by the Australian Catholic University Ethics Committee, Melbourne (201327V).

Findings

Health professionals willingly shared their perspectives

of the integrated model of care used by the Children's Care Trust. Participants viewed the integrated model of care as both positive and a vital aspect of care delivery. Participants discussed what they valued as attributes of the Children's Health Trust in providing the integrated model of care to children and their families. They also acknowledged the attributes they valued in their relationships with the Trust. There were five themes that characterised perspectives of the integrated model: collaboration between health providers, transparent communication, expert skills, support amongst colleagues and access to after-hours care.

Valued Attributes of the Integrated Model of Care
Collaboration between health providers

Participants in this study perceived the integrated model of care to complement their ability to provide care. Under the auspices of the integrated model of care the Trust team members worked with the parents and families to provide emotional support. Participants reported this as a very important aspect of care. Non-Trust health professionals reflected that previous to the integrated model of care, they had endeavoured to appropriately respond to emotional disclosures. They now believed their responses did not necessarily result in the best family outcomes. Clear role definitions and boundaries between non-Trust health professionals and Trust team members have resulted in greater efficacy of care provision. Non-Trust health professionals are now free to use their own scope of skill, knowledge and expertise to best effect.

One participant stated:

> The integrated model of care kind of complements our service. Prior to [the integrated model of care]...families would disclose something to you and so we would try and deal with it possibly not in the best way. I find now that I go in and do my job which is to check medical interventions and knowing that

'that' [emotional support] is taken care of... parents don't need to talk to me about it. [The Trust] is more appropriate, so it complements, and they know that they are there for the emotional support and they are very good with boundaries on what their role is and what our role is.

Another participant stated:

> My job is to go in and work with the child who is acutely unwell, and a lot of the time I will be in a room with a child who is extremely unwell and in fact the [Trust member] will often come and sometimes take the parents from the room, or sit with the parent in the room, and it actually allows me to focus on just the child, which is, as far as I am concerned really my main job,... knowing that the family have that support. [They] are there at the same time as me, as I am providing more of the medical care for the child.

Effective Communication

Communication with the Trust team members was strongly valued by study participants. They reported that effective communication was essential when multi-agencies were involved with a child's care. This transparent communication facilitated the attainment of child/family carers' goals. Participants were highly appreciative of the role of Trust team members as a mouthpiece for the child/family. They thus received important information about responses to care, and were able to appropriately vary the care. Participants reported that this transparent communication supported their professional relationships with families. This then enabled further very useful conversations regarding the care of the child.

One participant said:

> I often talk [with the Trust team member after she has had] a meeting with a family... and she will say, I have spoken with mother and gained

her permission, and there is always that, mum is aware that this is what I am going to tell you.... if she feels that there is something that I need to know to help me give better care, and better support, then she has no hesitation in asking their permission, and seeking me out and telling me and that has worked really well you know, time and time again. So it's a very transparent process.

Study participants noted the important communication role provided by Trust team members in the event that a sick child was hospitalised. Parent-carers were often unsure how to relinquish their care role and allow health professionals to take the lead. An admission to acute care provides the parent-carer with a period of respite. During this time they were encouraged by Trust team members to be fully in their role as parent. Participants described the Trust team as being committed to finding workable solutions for families, and working hard to ensure the voices/needs of the child, parent and family were heard.

It was stated that:
> *...it links back to patient advocacy, so when you have got a family who have a long-term hospitalisation and there are difficulties for parents to know what their role is and when they don't agree with the consultant or some of the medical decisions [the Trust team members] have worked alongside us really well, and alongside the family really well in order to provide the best care for the baby and the family.*

Another participant shared:
> *In patient meetings, [inclusive of parents, the Trust team members] are very skilled at saying... 'Now what I am hearing is'... there is a lot of validation so that everybody that is sitting around that table is very clear about*

what is being said, and what is being reflected. There is always a plan at the end of it, I think they are very skilled at that....and they have the knowledge and the skill to bring people back and settle them down... communication wise they have got it.

Expert Skills

Participants acknowledged that medical/nursing knowledge and medical technology have enabled children to survive what were previously fatal conditions. They were also very aware of their need to continually learn and adapt their clinical practice in a rapidly changing care environment. Participants acknowledged that Trust team members demonstrated advanced skills in symptom management, end-of-life care, and family communication strategies. This sharing of expertise, guidance and mentoring was an aspect of the integrated model of care that was highly valued by participants and contributed to their own knowledge and skill base.

One participant stated:
> *[The Trust team members] have the ability to talk things through, raise issues, sometimes about my treatment, perhaps with the child... the nursing background...part of what [they] do is advising health professionals particularly at end of life.*

In relation to one of the Trust team members, the participant further reflected:
> *Because of [her] level of knowledge in terms of symptom management and pain management, and all that stuff she gives a lot of advice to nursing and medical staff about medications and the right path to take.... [this has resulted in] up skilling all of us in our end of life care.*

It was further stated:
> *I think they have skill and sensitivity [in]*

listening to families and also siblings, who can be very young children [about end-of-life care and issues]. They really engage in a positive way with them as well, and can normalise it in a good way for some of those families.

Support amongst colleagues

Study participants reported that Trust team members provided emotional and practical support to children and their families. In addition, much-needed support was extended to themselves as health professionals. Participants reported the heavy burden they experienced at times within the emotionally confronting nature of their care role with children with serious complex illnesses. The collegial support from the Trust team members was very welcome at such times; it enhanced their care delivery and made them feel less isolated and lonely in their clinical work.

For example:

I first began in NICU [the Neonatal Intensive Care Unit] my second week and we had a crisis in the ward, I just freaked you know.... The Trust team invited me back to talk, and really it was a complete debrief... They seem to know when we need them... they just seem to know when you are going through rough times.

After-hours care availability

After-hours support provided by Trust members was recognised by participants as an important component of care for the parent/family. This is particularly in relation to minimising anxiety when their child's condition deteriorated. The participants highlighted the benefit and assurance this provides to families.

One participant stated:

And the after-hours stuff is huge; I think whether it's for a health crisis or an emotional crisis. The family knows that they can call and get [a Trust team member] to talk them through whatever

is going on and advise them what to do... when it is happening, at the time.

Another participant shared:

....when they [the parents] take their baby home from us, they are really scared about what is out there, and to know that they have the home care nurses and they have [Trust team members] who have that 'in the middle of the night stuff', that phone call to ask that question,... it's just so important and brings their anxiety down.

Considering the strong approval for the 24 hour on-call service provided by Trust team members, it was not surprising to see health professionals' anxiety over the vulnerability of the service. Participants were concerned for the welfare of Trust team members in terms of the heavy load that could occur during the overnight call service. They were also concerned about the sustainability of the Child Health Trust and the need for ongoing funding.

One participant reported:

That is a weakness that I know they are aware of. I have spoken to the [Trust team members] many times and it is potentially a big issue, that they provide 24 hour service... probably to the detriment of the [Trust team members'] mental health... I worry a lot about that after-hours service.

Another participant said:

I have tried really hard to get [District Health Board] funding... it is a problem because they have a huge proportion of the clients. I just definitely worry about that after hours stuff, it is a big problem and I know that the [Trust team members] are aware of it.

Discussion

There is an abundance of literature regarding children

who live with serious complex illness and rely on technology for their survival (Dybwik et al., 2011; Elias & Murphy, 2012; Maddox & Pontin, 2013; Schuster et al., 2011). These children are predominately cared for by their parents in the family home, a role that is seen as the 'norm' by health service providers and society in general. Parents provide a 'shadow health care' service on which health professionals have become reliant (Shuster et al., 2011, p.91).

This study supports Shuster and colleagues (2011) previous finding that parents provide high levels of care in the home, care that in previous years was provided in a hospital setting. Participants in this study acknowledged the heavy demand faced by parent-carers as they manage the long term care of chronic complex illnesses in their child.

Study participants reported the integrated model of care provided by the Child Health Trust to be a vital service for parents and families through its provision of clinical and psychosocial support. The integrated model of care had positive benefits for children, their families and health professionals, one of which was collaboration and communication. The importance of collaboration between service providers should not be underestimated given its role in supporting good outcomes (Yarwood, 2008). Hewitt-Taylor (2012) stresses the need for collaboration and communication to achieve a common understanding between all concerned and to ensure service provision directly meets the needs of parents/families.

Another benefit of the integrated model of care was the expertise provided by the Trust team members to the non-Trust health professionals. This is a significant finding because it is known that clinical expertise leads to positive results for both families and other health professionals providing the care (Carter & Thomas, 2011). Health professionals in this study believed the expertise provided by Trust team members assisted

them to increase their own skills, along with improving care to children and their parents/families. There is a clear need for health professionals who work with children to strengthen their knowledge of paediatric and family health. A shared understanding between all those providing health services and a high level expertise ensures better care for children and their families (Law, McCann, & O'May, 2011). Health professionals in this study found this shared knowledge and competency to be supportive of their care role with seriously ill children and their families.

While after hours care was deemed to be an important benefit to families, study participants also noted that limited resources might eventually reduce this aspect of the IMC provided by the Child Health Trust. Participants stressed the need for further funding and resources for this part of the service to strengthen capacity and ensure sustainability.

Limitations
The first author was an insider researcher, therefore, bias may have been introduced during data interpretation and analysis, when perceiving participants words in a particular way. An external research assistant was invited to join the research team specifically for participation selection, data collection and de-identification of the data to minimise this risk and strengthen the rigour of the research.

Conclusion
There has been a paradigm shift in health care over the last decade due to babies now surviving into childhood. They also now live at home with complex illnesses. This brings a greater demand of care from both parents/families and health professionals involved. Currently parents provide care that was once provided by clinicians, regardless of the complexity of care and the technical skill required. In New Zealand, a Child Health Trust was established in order to assist families in these difficult circumstances. The findings

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presented here are one part of an evaluation of this service. The findings highlight the importance that health professionals place on the contribution that a service such as the Child Health Trust's integrated model of care brings to children with serious complex illnesses, and their families. Health professionals identified benefits to both the children and their families and to themselves as health professionals. These benefits included; transparent communication, support and collaboration between all parties,

expertise in skills and reduced anxiety and fear for children and their parents/families. The findings of this study are important in providing evidence that the service is valued by health professionals. That parents carry a high burden in their caring role is confirmed in this study. The integrated model of care provides a service that is vital in supporting those providing the care; whether that is parents/families or health professionals overseeing this care.

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APPENDIX E: PROGRAM STRATEGIC PLAN

CHILDREN 'S HEALTH ORGANISATION STRATEGIC PLAN - 2011 – 2018

VISION

To establish a foundation of support for children with serious illnesses and their families

MISSION STATEMENT

Te Oranga O Nga Tamariki

'Caring for Children's Wellbeing'

To support seriously ill children and their whānau, and community during their time of need, through counselling, nursing care and education.

VALUES:

- **Resilience -** Strengthening the family unit during the time of illness
- **Support -** Providing meaningful engagement with children, their families, whānau, and extended community through focused and committed support
- **Education -** Delivering the tools to support children with serious illness and their families, every step of the way
- **Respect -** Honouring rights and beliefs, with the highest degree of dignity, equality and trust, and a commitment to the Treaty of Waitangi, recognising the status of Maori as Tangata Whenua
- **Collaboration -** Connecting families and agencies through professional relationships
- **Communication -** Listening to the voice of the child with open, honest dialogue, in partnership with their families
- **Accountability -** Taking responsibility for best practice in both service delivery and fundraising, ensuring transparency and cost effectiveness 3

OUR KEY STRATEGIC DIRECTIONS

1. Maintain our current model of care (comprehensive specialist services available throughout the region).

2. At the leading edge of care models for seriously ill children and their families.

3. Actively involved nationally in policy development in children's health.

4. Organisation name recognised in the community and valued.

5. Sustainability of reputation, team and funding in place

6. Additional resourcing for counselling team so that CEO role is not also required for counselling delivery.

7. Assessment of nursing component and options developed/implemented to ensure sustainability.

8. Capacity to provide advisory services within other areas.

OUR PRIORITIES

1. Every child and young person within the region with a serious, chronic, life-limiting or life-threatening illness receives nursing and psychological care when needed. This support is to optimise their quality of life, from the time of diagnosis and through to bereavement if needed. Their family, whānau and other caregivers are well supported and have gained the skills to ensure they are living the highest quality of life possible.

2. Child Health Trust provides:
   - Specialist psychosocial support
   - Nurse consultation
   - Crisis intervention within the home or hospital
   - Bereavement support
   - Advocacy and liaison
   - One-to-one counselling (children/young people, siblings and parents)
   - Creative therapies, including art, play, music, sandtray
   - Support groups (sibling, music, parents)
   - Workshops, presentations and education to health professionals and schools

3. Child Health Organisation provides a 24 hour 7 day a week crisis service for children at the end stage of their lives to support families caring for their child at home, or in the hospital.

4. Child Health Organisation works collaboratively with other health providers to ensure a continuum of care that is seamless and allows multidisciplinary expertise. Collegial support is

provided to health professionals who work with children who have complex health needs. This is via provision of debriefing, education and supervision. Support is also offered to schools around children and young people's health needs or grief and loss secondary to a child's death.

5. Child Health Organisation is committed to the principles of the treaty of Waitangi and recognition of the status of Maori as Tangata Whenua is evident.

LONG TERM DIRECTION

Child Health Organisation provides care to over 200-220 sick children and their families at any one time to the greater region. The Trust has determined the unique Model of Care should be available to as many families as possible within New Zealand. There are growing demands from other regions for the model and therefore the organisation needs to prepare for the future.

The best approach is to look for opportunities to link with local providers in other regions providing education, mentoring, modelling and supervision to grow and develop services that would meet their region's needs.

Program: Child health organisation – model of care for children with serious illness and their families

Mission: To support seriously ill children and their whānau, and community during their time of need, through specialist nursing care, counselling and education.

Inputs (What we invest)	Outputs (What we do and who we do it to)		Outcomes – Impact (The incremental events/changes that occur as a result of the outputs)		
	Activities	Participation	Short	Medium	Long
Board of Trustees	Nursing care: Symptom management, advice and guidance.	Clients: Child with serious illness Parents of sick child Siblings of sick child Extended whanau of sick child.	Children's symptoms of pain, nausea, seizures and other are managed in a timely way.	Collaborative care, effective communication and coordination have been adopted into workable partnerships between the child with serious illness, their families and health service providers.	Children and their families have optimal care to maintain quality of life.
Staff	Counselling care: individual, relationship and family therapy.	Other agencies and health service providers.	Families gain the psychological support they need in a timely way.	Funding and resources are allocated to continue to develop the program to ensure sustainability.	To maintain the current model of care (comprehensive specialist services available throughout the region).
Volunteers	Therapeutic modalities: art, play and music therapies	Stakeholders such as referrers and funders	Collaborative care with local providers.	The program team is staffed with clinicians who are skilled and knowledgeable in this field.	Be at the leading edge of care models for seriously ill children and their families.
Technology such as computers, phones	Bereavement support		Effective care coordination		Actively involved nationally in policy development in children's health.
Funding for at least one year in advance for sustainability	Advocacy support		Effective communication between families, providers and stakeholders.		Organisation name recognised in the community and valued.
Resources such as cars, supplies for therapeutic modalities such as art and play.	Mentoring of health providers				Sustainability of reputation, team and funding in place.
	Education: workshops and training days.				

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