The Child and Family Living with Complex Health Needs in the Community:
Lived Experiences and Patterns of Coping and Relationship

by

Miriam Anne Duff

A Thesis submitted to the Faculty of Graduate Studies of
The University of Manitoba
in partial fulfillment of the requirements of the degree of

MASTER OF EDUCATION

Department of Educational Administration, Foundations and Psychology
University of Manitoba
Winnipeg

Abstract

This study explored the perspectives of children whose complex health needs included respiratory technology dependence, and that of their parents, regarding community life and helpful patterns of coping and relationship. In-depth interviews were conducted with 7 children (3-18 yrs. old) and 8 parents. Survey data collected from 31 parents contributed to a convergent mixed methods design. Findings showed that children viewed themselves as normal, but experienced "a constricted life". Parents' active engagement in their child's life, as system navigators and advocates, was necessary to ensure their child's wellbeing. Key relational components included "authentic engaged presence", caring, competence, communication and collaboration. Effective coping patterns included reliable social support and both emotion-focused and problem-focused strategies. Contextual factors significantly affecting parental coping and relationships included family structure and child’s dependence on invasive respiratory technology (tracheostomy). Respite reported inadequate. Findings have practice and policy implications for health, respite and education systems, professionals and parents.

Acknowledgements

I gratefully acknowledge funding support provided through the Joseph-Armand Bombardier Canada Graduate Scholarship - Master's (2008, SSHRC reference 766-2008-0229), and a Faculty of Education Graduate Student Research Scholarship (2009).

I wish to express my appreciation and admiration to the children, youth and parents who contributed so vitally to this study and my learning, it has been a privilege.

I am very grateful to my advisor and thesis committee: Professor Riva Bartell, for taking me on and skillfully guiding me in pursuing the questions that mattered to me, facilitating numerous funding applications, and for your deep, empathic appreciation of my subject matter. Dr. Louise Giles for your professional caring, ongoing interest, encouragement, and collaborative engagement. Professor Zana Lutfiyya, for your encouraging interest in my focus, valuable contribution to my thesis writing process, and generously sharing your perspectives regarding people, qualitative research, and the disability field. I am also grateful to Professor Rob Renaud, for skillfully guiding me in my quantitative research, containing my explorer's spirit with patience and humour. Thanks also to Monica Sirski and Rasheda Rabbani, for coaching in SPSS software.

I am grateful to the pediatric facility and staff who permitted me access to study participants, and to the scale authors for permission to use their instruments in my study. I also wish to acknowledge Carla Hoeppner, my transcriptionist, for preparing countless pages of verbatim transcripts with precision and speed.

Thanks especially to my family, George, Matt and Justin, who lived through this with me, supporting, encouraging and often bearing with me! Thanks to my parents, Bill and Mary, wider family, friends, child lifer's and colleagues, particularly Lorna Martin.

It takes a village to raise a child.

- African Proverb

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Chapter One - Overview of the Study

Advances in modern medical care and technology have resulted in a significant increase in the number of children surviving previously fatal or life-shortening health conditions. Children who require respiratory support to ensure they maintain sufficient oxygen levels in their body have benefited particularly, due in part to efforts made during the poliomyelitis era in the 1930-50s – with the first generation of children to be supported by technology (Rollins, Bolig & Manahan, 2005). Children may require mechanical ventilator support for a variety of reasons: at birth (e.g., due to prematurity, congenital anomalies), as the result of injury (e.g., spinal cord injuries), due to an ongoing health condition (e.g., bronchial-pulmonary dysplasia, neuromuscular disorders), or due to a progressive, life-threatening disease (e.g., Duchene's Muscular Dystrophy, spinal muscular atrophy). However, once their acute health needs are met, many can achieve a level of stability that allows them to leave hospital, even with complex and long term ventilatory support[1] needs.

Transitioning children with complex needs[2] to the community is a relatively new health care trend, driven by economic and resource management policies, as well as by the need to provide the most suitable living environment for the child. Many children have left the institutional care they languished in, to not only survive, but also thrive in their own communities (Capen & Dedlow, 1998). This is possible due to parents and other caregivers, who undertake the advanced training necessary to deliver the child's care at home. While "going home" is certainly cause for celebration, it is also a road fraught with difficulties and challenges, as both the family caring for their child and their receiving community must adjust to this new way of living together.

Statement of the Problem

Life at home confronts the child and family living with complex health needs with considerable adaptation and adjustment issues. These are related to the extent of specialized care routines, services, personnel, and equipment that will be required in day-to-day living, as well as, the social perception and accessibility issues they encounter in the community. Parents will bear much of the stress and responsibility for their child’s success. This is particularly the case if their child's needs include invasive respiratory technology, such as a tracheostomy (trach), either alone or in addition to mechanical ventilation. Dependence upon any kind of respiratory technology requires monitoring, specialized knowledge, care, supplies and a higher than typical level of involvement with the child's health care team (child's pediatrician, respirology department, and others as needed). However, respiratory technology that is invasive requires a magnitude of care that is far more constant and specialized in nature. Caring for a child with a trach includes constant monitoring, strict adherence to daily care regimens, specific knowledge, supplies and greater involvement with the health care team. Furthermore, school-aged children who have a trach must be accompanied to school by a registered nurse who has specific training in caring for their needs. If a mechanical ventilator is part of the child's complement of technological support additional training, responsibilities, equipment and supplies become necessary.

Due to the extraordinary extent of care required to ensure the child's safety, respite services become a necessity in order to support the child's life in the community. Respite is typically provided in the family home and at the child's school by specially trained caregivers. Respite coverage allows the parent to rest, attend appointments, and engage in other activities that they could not otherwise manage. This added dimension requires adjustments by the parents, as they strive to find the best way to sustain their role and family life, while learning to build effective working relationships with their child's health care, community respite and education teams. Contextual factors such as family structure, parent gender-based differences and the extent of the respiratory technology may also have an important bearing on this process.

The extraordinary risks and efforts these children and their parents undertake in order to pursue a normal life in the community call for the need to ensure that the care provided is both responsive and effective from their perspective. The scarcity of specialized resources and funding combined with the high support levels required amongst these families, underlines the mutual need for building compatible relationships. Becoming informed about the children and parents' perspective on what life is like, and the patterns of coping and relationship that work for them, could help to foster program planning and service delivery that is responsive to the child and family's needs in an efficacious way.

I found very scant literature available regarding the perspectives and needs of these children and their families, making understandings about them difficult to attain. Furthermore, until recently, much of the literature regarding children and parents who live with chronic health conditions has been grounded primarily in a deficit-based perspective focused on the dysfunctional aspects of life with chronic illness (McCubbin, McCubbin, Paterson, Cauble, Wilson and Warwick, 1983; Bugental, 2003). A gap in awareness regarding the coping and relational strategies used by families who are managing well has been specifically acknowledged, with calls for further research. The need for further understanding regarding effective interaction patterns, particularly in the relationship between the family and the health care team has been noted (Kazak, Rourke and Crump 2003; Rollins et al., 2005 & Power, DuPaul, Shapiro and Kazak 2003). I plan to begin to address these gaps by exploring them in this study with some of these children and their parents, using a strengths-based and context-sensitive approach.

Questions of the Study

I have developed study questions to pursue a better understanding of what life is like for these children and their parents, thus the first and overarching question seeks to explore their lived experience using a qualitative approach. My subsequent questions are directed to exploring their perspectives regarding helpful patterns of coping and relationship, both of which make up an important aspect of their experiences. I particularly sought to gain details regarding the parents' perspectives, given the significance of their caregiving and system-mediating role to their child's wellbeing.

The questions reflect my decision to use a mixed methods approach in exploring the parents' experience, in order to obtain the breadth and depth of knowledge that is available when using multiple perspectives. For example, in addition to gathering qualitative data (depth), I have gathered quantitative data by way of a survey package that included quantitative scales about parents' coping patterns and perceptions of relationship (breadth). The questions of the study are as follows:

1. What is the lived experience of children and their parents who live in the community, with complex health needs that include respiratory technology dependence?
2. What patterns of relationship do these children and their parents experience as being most helpful and effective in their interactions with others, including the service

providers they interact with in the health care, community respite and the education systems that serve them?

3. What patterns of coping do these children and their parents identify as most helpful in managing the stress related to their circumstances, and in their pursuit of a good life for the child, including their ongoing psychosocial development and adjustment to disability?

3.1 Do parents' reported coping strategies vary on the basis of contextual characteristics, for example: family structure, gender, or the extent of their child's respiratory technology (invasive versus noninvasive)?

4. To what extent do parents perceive their child’s health care providers to behave towards them in a family-centred manner?

4.1 Do parents’ perceptions of health care provider's behaviours vary on the basis of contextual characteristics, for example, family structure, gender or extent of their child's respiratory technology (invasive as compared to noninvasive)?

5. What is the nature of relationship that exists between parents' coping patterns and their perceptions of relationship with their child's health care providers, and do contextual variables such as family structure, gender or the extent of their child's respiratory technology make a difference?

6. What is the comparability of the findings obtained from the parents' interview sample data with the results obtained from their survey sample data, regarding lived experience, patterns of coping and patterns of relationship with their child's health care team?

Significance of the Study

The new understandings that I gained from studying children and youth's qualitative data will provide a valuable addition to the limited available literature on their perspectives. Through obtaining this data from a developmental cross-section sample, the new knowledge will be relevant in both its depth and breadth. These new meanings can be used to help inform responsive service provision and also serve as a basis for future research endeavors. Likewise, the findings that I gathered with respect to the parents' lived experiences and the patterns of coping and relationship that they describe as most helpful to them will add to the small existing literature on these parents' experiences. The statistical data gathered from them on the self-report scales used will also be of value for comparison to other parent populations. New understandings regarding the parents' perspective will be of particular relevance to policy and program development, as well as direct service providers, given their relationship to the child's caregiver, advocate and system navigator. The parent's pivotal role in relation to their child's engagement with the various service systems underlines the importance of paying attention and responding to what they say "works for them", as they strive to care for their child in the community. Through this study I also explored the interplay between parental coping and relationship, with due consideration for contextual differences, as these parents strive to raise their child in the context of multi-system engagement. The findings related to this aspect of the study could be used to contribute to the development and evaluation of supports that are attuned to individual differences, further promoting the wellbeing of the children and families who are most vulnerable to distress.

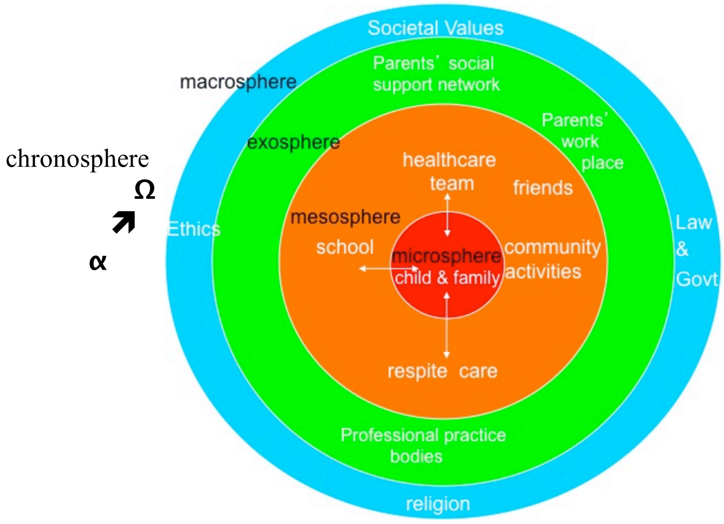
Through this study I hoped to provide a social-historical "snapshot" regarding the current situation of these children and their families. This will be of benefit from a reflective perspective, for both the families and their service providers, as a means to consider how circumstances have improved for these children and their families over time, and in which ways they remain yet to be improved.

The mixed methods approach I have used to explore the perspective of the parents can serve as a comparative example for other researchers studying this population, and particularly demonstrates the interactive, mutually refining process possible when using multiple perspectives. I have also been able to consider the relevance and applicability of theory to understanding the study participants' lived experience, as well as, their patterns of coping and relationship. These are described in the following section.

Theoretical Framework of the Study

The Bioecological Model of Human Development (Bronfenbrenner & Evans, 2000; Berk, 2007) offers a valuable framework within which to understand the situation of the children and families in relation to their various social contexts. Bronfenbrenner et al., conceptualized the child and family along with their complement of biological, psychological and evolutionary characteristics, as nested at the centre of a series of concentric, progressively encompassing spheres, as illustrated in Figure 1 (below).

Figure 1. Bioecological Systems View: Impact on the Family



Beginning with the child and family, the systems view progressively expands to increasingly broader levels of context, ending with society at large, which is ultimately situated in, and affected by the dimension of time. The sphere at the core of this perspective is the microsphere, which contains the biological and psychosocial person of the child and his/her immediate family. This in turn is located within the mesosphere, which consists of the child's community, including the local systems with which he or she interacts directly, including: school, community respite and health care services. The mesosphere is situated within the exosphere, which consists of the parents' workplace, and the institutional structures and professional organizations that dictate professional services and practices, including: health care, respite care, education. The broadest layer is the macrosphere, which is considered to include societal values and institutions including government, law and religion. Finally all of these progressively inclusive spheres are situated within the chronosphere, the dimension of time, which represents the progressive process of change over time.

Bronfenbrenner et al. (2000), suggested that these spheres are not static; but rather direct and constant dynamic interactions, known as proximal processes, are occurring between them, exerting influence that leads to change in each over time. Likewise, on an individual scale, the children develop through active engagement with their immediate environment, by means of reciprocal proximal processes with the people, objects and symbols with which they come in contact. Similarly, their developmental process unfolds within the context of the chronosphere, the passing of time, including the sequence of their psychosocial developmental stages (Erikson, 1963).

Viewing children living with these complex health needs and their families within this framework, it is possible to perceive the way that services situated in the community (mesosphere) permeate the contextual boundary of the family (microsystem) as shown by the arrows in figure 1. Services including respite, ongoing health care, and skilled supervision for children attending school are necessary to maintain these children with their families in the community. This unusual set of circumstances can present real challenges to the child and parents' sense of self-efficacy, and by association, their coping, and relational abilities. The health care, community respite care, and school teams also face challenges in supporting the child, however, they operate within their respective domains, whereas the child and family experience life at the focal point, where all of these efforts intersect.

The parents' ability to cope[3] faced with the stresses inherent in managing their child's situation will have a bearing on their perceived self-efficacy[4] and, therefore, their sense of personal agency[5], both of which are key to successfully navigating adversity. Bandura (1997) described human agency as operating within an interdependent causal structure involving triadic reciprocal causation, meaning that personal factors (including cognitive, affective and biological events), behaviour, and environmental events, all operate as interacting determinants that influence one another bi-directionally (1997, p. 6). It follows, then, that the parents' state has implications for the wellbeing and development of their child, since the parents' sense of personal agency mediates their ability to respond to, and advocate for their child's needs (Bandura, 1997). When beginning life with their child in the community, parents may have a fragile sense of self-efficacy, due to the newness of their caregiving skills, acquired in the shelter of the hospital. This new home context challenges them in balancing recently acquired competencies with the demands of day-to-day living while negotiating new relationships with community service providers. The first few weeks can be particularly exhausting (Wang & Barnard, 2008).

Lazarus and Folkman's (1984) cognitive theory of stress and coping incorporates the role played by self-efficacy and personal agency in coping within their description of the dynamics of stress appraisal. These aspects are incorporated within the individual's secondary appraisal process when, upon identifying a stress, they are determining how they are going to manage the situation. While this process includes the person's consideration of their available coping responses and resources, their decision as to how they choose to manage the stressor ultimately hinges upon their perception of their own capacity to be effective. This conceptualization of the coping process recognizes the critical role played by self-efficacy and personal agency in mediating stressful person-environment relationships, as well as their immediate and long-term outcomes (1986, p. 572). The parent and child's inherently stressful situation provides the impetus for them to acquire robust, emotion-based coping strategies (regulating emotional response to a situation one cannot change), in tandem with problem-focused coping strategies (dealing with the problem that is causing distress) in order to sustain their self-efficacy and tap into their own resilience.

One source of challenge is the stress and conflicts involved in the normal, ongoing relational processes by which the parent, child and various service professionals facilitate the child's life in the community. Baxter (2004) describes this process, within the Relational Dialectics perspective, as moving along in a spiral, composed of the interplay of players' reciprocal interactions and the dynamic tension sustained between them. This shared, interdependent process makes up the "dialogue" of the relationship (Baxter, 2004). The direction the relationship takes depends upon the extent to which its players are able to respond compatibly to each other, managing the relational tensions that arise. If successful, achieving a flexible process of change and growth (progress). If unsuccessful, encountering a conflict-ridden process that obstructs or slows progress (resistance and digression). This interdependence is a central and defining process in relationships that is helpful to understanding how interactions can become compromised. For example, in parent and service provider communication efforts, when information-processing abilities of one party are blunted by ongoing exhaustion, stress and/or poor coping skills, (Buchanan, 1984; Gaynard, 1990; Klein, 1994), the relationship is placed at risk. The ongoing progress or deterioration of the relationship will then depend upon the awareness and compatible responsiveness of the other party to this possibility.

Summary

Children with complex health needs and their parents face extraordinary challenges as they strive to pursue life in the community. Parents must learn to accept and adjust to their child's disability, provide for their ongoing complex care needs within the family context, navigate systems, and manage relationships with service providers and the wider community. This reality is most evident in the case of parents caring for a child with invasive respiratory technology, including a trach. The necessity of their intense ongoing involvement and the uniqueness of the experiences they encounter can lead to feelings of social isolation. Likewise, the child with a trach tends to live in an ironic paradox: "never alone" (Sarvey, 2008) due to constant monitoring, and yet socially constrained by his/her complex health needs and the uniqueness of his/her own lived experience. Service providers' mutually exclusive scopes of practice, combined with scarce resources, limit their awareness and efficacy in meeting the needs of these children and their families. This difficulty is further compounded by the literature's inadequate coverage of these children and their parents' perspectives. To better inform the service providers and systems that are in place to support them, further exploration and understanding is needed.

Through this study, I endeavored to shine a light on the collective perspectives of these children and their parents, using a strengths-based, context sensitive approach. Specifically, I will present the participants' view of what life in the community was like for them, paying particular attention to the patterns of coping and relationship that they found most helpful in day-to-day life and in promoting the child's ongoing growth and development. The patterns of relationship that participants described as being most helpful in their interactions with the professionals and systems that served them were explored, and the connection between parental coping and relationship was considered. I also paid attention to how the child and their family was situated within the current social historical context, acknowledging changing social mores, as reflected in the progressive shifts in government policy, systemic service delivery and educational practices, for example.

The new understandings acquired from this study will likely provide a valuable addition to the literature, as well as, have implications for services, policy and practice. Finally, I hope that the children and parents themselves, will see revealed in the findings, a broader perspective of their collective community of experience, thus affirming their strengths, vulnerabilities, unique knowledge and common humanity.

Chapter Two - Review of the Literature

Children living with complex health needs that include respiratory technology dependence have been entering the community in increasing numbers since the 1980s yet, until recently, there has been a significant paucity of the literature regarding their lived experiences and that of their families' (Kirk & Glendinning, 2004; Wang & Barnard, 2008). Early researchers focused their attention on the medical system's ability to transition and manage the child's complex care needs at home, evaluating outcomes in terms of morbidity and mortality (Canlas-Yamsuan, Sanchez, Kesselman, Chernick, 1993). These were challenging times for the families who took their children home. They were "pioneers", as the availability of specially trained respite care nurses, suitable standards of care, and the coordination of services were limited at best, or nonexistent (Capen & Dedlow, 1998). However, their circumstances were viewed through the lens of the medical model, which addressed their problem as individually-based, rather than considering the individual's context for living and the needs they shared in common with others in a similar position (Bugental, 2003).

Current Knowledge Regarding the Parents' Perspective

The accumulated literature I found described these parents' experiences with distress and difficulty in taking their child with complex health needs home without the benefit of systemic support. During the early days of community integration, parents identified three kinds of stressors: relational difficulties with respite nursing staff, increased financial burdens and the emotional/psychological impact of care (Murphy, 1991). Difficulties with respite nursing staff, such as poor quality care, being disrespected in their parenting role, and loss of privacy, were further complicated by the parents' knowledge that they could not manage their child without the nurses' help. Parents identified the emotional impact as including periodic depression, guilt, self-blame, anger, anxiety about the future, worries about the child dying, feelings of social and emotional isolation and for some parents, a periodic, ongoing sense of loss (sometimes referred to as chronic sorrow).

These themes have continued to emerge in more recent literature. For example, in their meta-analysis, Wang and Barnard (2004) described a changed meaning of home (the microsystem), due to the necessary invasion of specialized equipment, routines and support staff. This perspective was reiterated by parents caring for children with neuromuscular disease who required home mechanical ventilation in their "new perception of normal" (Mah, Thannhauser, McNeil and Dewey, 2008). Kirk and Glendinning's study (2004) found similar difficulties as well as barriers (for example: cumbersome equipment and regimented care routines) that frustrated parents in their pursuit of social support[6], an acknowledged essential coping strategy. Furthermore, parents encountered negative reactions to their child when they did manage to take them out in the community, due to their difference in appearance, and their necessary equipment and procedures. These encounters resulted in further feelings of discouragement and isolation. Wilson, Morse, and Penrod (1998) found the central phenomenon in their study of caregiving mothers to be their "absolute involvement," wherein, mothers dedicated themselves to their child's care at considerable cost to their own health, if they did not have adequate support or opportunities for social engagement. Fleming (2004) acknowledged the mental health problems that parents could face due to perceiving themselves as failing (loss of self-efficacy), when they are simply overwhelmed by the persistent, intensive nature of the caregiving entailed. She emphasized supporting these parents in maintaining their mental health, which represented the essential linchpin for sustaining the wellbeing of their child and family. Toly's (2009) quantitative study regarding mothers of technology-dependent children living at home provided clear evidence for the negative relationship between depression in caregiving mothers and level of family functioning. Toly found that 35% of the variance in family functioning was explained by the level of depressive symptoms (p. 233).

Communication and collaboration emerged as areas of difficulty in the proximal processes amongst the community-based service systems (situated in the mesosphere) and in relation to the child's family (situated in the microsphere). Parents and professionals both reported poor communication between hospital and community-based systems. Parents also described their own expertise of their child being ignored or dismissed by some community health care professionals. Carnevale, Alexander, Davis, Rennick, and Troini (2006) also found that parents felt caught in an unfair position that they could not change, while missing the comfort that kinship with other parents could bring, due to the unique nature of their own experiences. Parents described experiencing distress and heightened vigilance due to poor and insensitive communication with some health care providers, who would make comments or pose questions about their child’s right to live. This unfortunate set of circumstances illustrates the ways in which struggles situated at the level of society's values (macrosphere) can play out in the community (mesosphere), and family (microsphere), while those who accept and learn to live with life-saving technology can become unwitting targets. In spite of all their difficulties, parents in each of the above-mentioned studies, expressed happiness at having their children at home rather than in an institution (mesosphere).

Most studies focused primarily upon parents' negative experiences, with the exception of the following, Murphy (1991) explicitly explored parents' stress and coping, while Wilson et al., (1998) explored the caregiving experiences of mothers, exclusively. Murphy's "pioneer" parents attributed their coping to drawing upon their faith and their previous experiences with adversity for strength in dealing with their situation. Some parents described becoming less reactive to little details, more flexible and "go with the flow," in response to the relentless intensity of their lives. To cope with distress brought on by difficult relationships with respite caregivers in their home, some parents described becoming more actively assertive by teaching respite nurses the caregiving skills they needed to know, negotiating formal boundaries and organizing more formal communication processes with them. Other parents chose a very passive and withdrawn stance, suppressing their feelings, so as not to jeopardize the help they so desperately depended on. Wilson et al., focused on mothers, identifying the same themes as Murphy, and expanding the range of coping strategies employed to include "adjusting to the struggle", that is, putting experience with their child in perspective. Additional strategies described included, "reframing time", or attending only to the present and near future; "facilitating family life", normalizing the child's routines through integration with the family's schedule; and "refusing to 'give up'" by challenging uncertainty related to their child's health status.

Current Knowledge Regarding the Children's Perspective

The children's perspective has received very little attention from researchers, based upon its extremely limited coverage in the literature, thus their experience is virtually unknown (Carnevale, Rehm, Kirk, and McKeever, 2008). The few studies that have paid them some attention are discussed below. Noyes' (2006) major English study consisted of a very heterogeneous group of children, who reported their ventilator to be a great help to them, as it made them feel better, gave them more energy to do things, and, therefore, improved their quality of life. The difficulties they identified were primarily situated in the immediate, as well as, wider community (at the macro and mesosphere levels) and had a direct impact on them. For example, they were frustrated with the physical and service barriers that society put in their way, preventing them from participating fully and affecting their quality of life (inclusion and physical accessibility issues). They were acutely aware of their social isolation and stigmatization, resulting in low self-esteem, and there were insufficient support services to address adjustment issues for those struggling with acquired ventilator dependence.

Carnevale et al., (2006) described children who were quite silent about their experience, with a few exceptions. Those who did share their experiences echoed the preceding themes and particularly mentioned their desire to be viewed as being the same as others. For example, one girl avoided group sleepovers so that others would not be aware of her need to use a ventilator at night. Many children viewed their life to be quite normal, as complex care was just part of their daily routine. However, some children did worry that they were a burden to family while their parents described providing reassurance that they were very much wanted.

Sarvey (2008), by contrast, described encounters with 11 very articulate young participants (7 - 12 years of age), in her phenomenological study. These children, who were ventilator-dependent for a minimum of 8 hours each day, described life as lived “never alone” as they needed the machine and their caregiver in order to live. This appraisal did not appear to impact the self-efficacy of these youngsters, nor did their reports of less than accepting responses from others. The children viewed themselves as normal people entitled to equal treatment, respect, and inclusion with their peers in activities, although all described encountering insensitive treatment from those who perceived them to be different. They described responding to these encounters using assertive, sensitizing language, and providing information about their situation to those unfamiliar with what they were seeing. By acting as educators, they raised the awareness and understanding of others and revealed their own striking resilience, supported by their well-developed self-efficacy and personal agency.

The findings presented in these studies seem to suggest that children may have had more positive experiences than their parents, which may have to do with the qualitative and power differences between the position of care recipient and care provider. For example, the child's world was composed of their immediate experiences, their caregivers and their immediate environment. In facing their adverse circumstances, their resilience would have come from normal aspects of daily life as a child, including attachment to a significant caregiver and experiencing inclusion in their family and community (Masten, 2001). Whereas the parents' world was much more complex, as they had to manage their child's ongoing care and health risks with little rest or support. Furthermore, they also had to continually navigate and negotiate with multiple systems on their child's behalf. Often parents found themselves negotiating from a position of less power yet greater investment, compared to the institutions and professionals with which they dealt on their child's behalf (Carnevale et al., 2008; Kirk & Glendinning, 2004; Noyes et al., 1998; Reeves et al., 2006). The family (microsphere) appeared to be the essential context and source of support for these children towards attaining a good quality of life. This placed significant responsibility upon the parents, while the professionals providing services in the community (mesosphere) played “catch-up” with the introduction of inclusive and family centred, collaborative practices.

The presence of outdated social norms and mores (macrosphere) was also apparent in the parent and children's commonly reported experiences with social stigma and lack of acceptance, demonstrating the state of societal values towards illness, difference and disability. The extent to which wider societal forces dictate the kind of life possible for these children and their families was further illustrated by the recent tragic case of a First Nations child, who was confined to hospital his entire life, despite the collective efforts of his family, health care team and community, due to intergovernmental (exosphere) wrangling and indecision over funding (MacDonald & Attaran, 2007).

Conceptual Linkages

The findings shared in the above literature, provided an opportunity to begin to consider how these children and their parents were situated in relation to the theoretical framework and concepts being employed in this study. Additional literature regarding coping and adjustment provided a context in which to view and consider the experiences of this study's participants.

Contexts, patterns of relationship and change. The layers of context in which children and families encountered negative experiences was very evident in the literature cited. Using the bioecological framework as a point of reference, several of the spheres in which they were situated, are apparent, including the meso-, exo-, and microspheres. However, the emergence of this population, among others, has generated a reciprocal effect over time (the chronosphere). A paradigm shift is underway as evidenced in the professional literature (American Academy of Pediatrics, 2005; Kazak et al., 2003; Powers et al., 2003). Bronfenbrenner's bioecological systems view is becoming the approach of choice at the level of the exosphere (practice and policy-making), supplanting the ill-fitting medical model.

New ways of collaborating between families and service systems have begun to evolve, terms including “family centred care”, “community-based” and “culturally competent” have come to summarize and guide this philosophy of care (Capon & Dedlow, 1998). For example, streamlined case-management services have been introduced to families raising children who live with both complex health needs and cognitive disabilities. Case managers - identified as the chronically missing link in the literature - are now available to assist these families in coordinating services. Furthermore, the guiding principles of family-centred care are placing parents in a more collaborative role on their child’s care teams (Steeds & Nadeau, 2007). A shift has also occurred in the education domain. New governmental policies and laws (macrosphere) are ushering in more inclusive practices (exosphere), reducing barriers and creating more supportive learning communities (mesosphere) in which all can collaborate and learn (Nielsen, 2003; Hutchinson, 2002).

Taken altogether and explained according to Bronfenbrenner's bioecological model, this shift is evidence of a change in societal mores (macrosphere), resulting from proximal processes amongst and between the spheres, likely attributable in large part to the advocacy efforts of many individuals seeking to improve the way that people living with differences are treated. Now, with time (chronosphere), the effects of this shift are becoming evident in each sphere of context that people experience, providing evidence of the progressive nature of development within the systems view.

Coping and adjustment. The literature on coping and adjustment has also moved away from the medical model, with the rise of more ecologically oriented, resilience-based approaches to families coping with chronic illness (McCubbin et al., 1983; Rolland & Walsh, 2006; Walsh, 2003). Using this approach, families are seen as capable of emerging from crises and adversity by tapping into hidden personal and familial strengths and coping mechanisms. For example, McCubbin et al., (1983) found that parents raising children with Cystic Fibrosis value three coping patterns: (i) maintaining family integration, cooperation and an optimistic view of the situation, (ii) maintaining social support, self-esteem and psychological stability, and (iii) understanding the medical situation through communication with other parents and medical staff (p. 368). They found variations in the way mothers and fathers cope and, based upon their findings, set norms (means and standard deviations) for comparison with other populations using parent gender as an independent variable (McCubbin et al., 2003 p. 436). Rolland and Walsh (2006) described similar key processes in family resilience, including: engaging in belief systems such as optimistic outlook, making meaning from adversity and spirituality; organizational patterns, including flexibility, connectedness/cohesion and social and economic resources; and communication/problem solving, including clarity, open emotional expression and collaborative problem-solving.

Neff (2003) has presented a resilience-oriented approach to coping, with similar themes at the intrapersonal level using self-compassion, which entails being kind and understanding to oneself in times of adversity rather than engaging in rumination and harsh self-criticism. Self-compassion is an emotion-focused, self-regulation coping pattern that contributes to the maintenance of self-efficacy and is positively correlated with life-satisfaction, mastery goals, and self-esteem (Ibid). In fact, Leary, Tate, Adams, Allen and Hancock (2007) were able to experimentally induce self-compassion in a large university student sample undergoing an adverse experience with significant positive adjustment outcomes, suggesting that self-compassion has potential value as part of a therapeutic intervention. This coping pattern would also be of relevance to the children and parents being studied, making it worthy of consideration.

Areas Where More Study is Needed

The literature available regarding the experiences of children living with complex health needs that include respiratory technology dependence, and that of their parents, is very limited. While the theoretical literature has been moving away from the problem-focused medical model, towards one that is more holistic and strengths-oriented (Ferguson, 2002), the scant literature regarding these children and their parents remains primarily problem-focused (Wang and Barnard, 2004), and contains a number of gaps.

Gaps regarding coping and relationship. Based upon their meta-analysis, Wang and Barnard (2004) describe the existing literature as lacking emphasis on the social and emotional needs of these children and their parents. Specifically, they call for more research on coping used by children and family members, and particularly note the need for quantitative research studies. Parent-professional relationships are also raised as a very contentious issue requiring further study, particularly with respect to homecare (respite services). Similar concerns regarding interactions between parents and health care professionals have arisen in the literature repeatedly (Carnevale et al., 2006; Kirk and Glendinning, 2004; and Noyes et al., 1999). The resource-intensive nature of care that these children and their families require highlights the importance of this kind of relationship, and the need for further study to address this important aspect.

Absence of strengths-focused studies. Wang and Barnard's (2004) meta-analysis provides acknowledgement of a social-emotional gap in the literature related to understandings about these children and their parents' experiences. While what is known at present relates to the distress these children and their parents encounter, very little is known about what is helpful. This suggests a major gap in knowledge that is grounded in a strengths-based orientation, studying "what works". I believe that the children and their parents themselves are in the most authentic position to contribute to this knowledge base, due to their unique life experiences and perspectives.

Context specific gaps. The context in which the child and his/her parent(s) are situated, and the influence that this may exert upon their experiences, has received very little attention in the literature. Contextual examples typically encountered include, family structure, parent gender, and the extent of the child's respiratory technology dependence.

Family structure. Families headed by single parents (often mothers) confront more challenges than two-parent families due to the logistics of attending to household management, finances, and childcare without a second adult to share the tasks. When a child with chronic complex care needs is part of the family this situation is magnified. For example, McCubbin et al., (1983) identified single parent families as being more "at-risk", in their study of coping in families caring for a child with Cystic Fibrosis, due to the absence of another adult with coping skills, and the single parent bearing sole responsibility for all care (p. 368).

This contextual factor has received little attention with regard to the population being studied. Wang and Barnard (2004) for example, in their meta-analysis acknowledged single mothers' distress and higher risk of poor mental health yet, in their subsequent qualitative parent study (2008), did not attend to family structure. Nor did Wilson et al., (1998) in their study of mothers. Toly (2009) intended to examine this context in her large quantitative study of mothers caring for children with various technology needs. However, despite using face-to-face interviews, her reliance on solely quantitative instruments limited her findings to the instruments' capabilities rather than her participants' experiences. The Feetham Family Functioning Survey that she used proved problematic for participating single mothers, who did not complete spouse-related items, subsequently resulting in too much missing data to conduct analysis on this aspect (p. 230). However, Carnevale et al., (2006) who used both in-depth interviews and naturalistic observations, did consider family structure-related differences in their qualitative study. When viewing the extent of stability present in the study's participating families, they found that all of the families demonstrating observable characteristics of instability ("unraveling") were single-parent families. Financial status was reported to be the sole distinguishing factor (p. e55).

This limited awareness is of concern because a high frequency of marital breakdowns has been noted amongst families caring for a child with complex health needs (Carnevale et al., 2006; Kirk and Glendinning, 2004). Thus, an increasing number of single parent families are likely to emerge in this population, with even heavier responsibilities, yet the literature has given only scant attention to this vulnerable context (Mah et al., 2008; Noyes, 1998). More needs to be understood about the strengths and needs of different kinds of family structure, given the significant responsibility parents undertake in caring for their child.

Gender. A limitation that has been acknowledged in the disability literature is the over-representation of mothers and the relative absence of fathers in caregiver study samples (Traustadottir, 1992). I found a similar pattern in my literature review. Only a few studies had reasonable representation from both mothers and fathers (Carnevale et al., 2006; Kirk and Glendinning, 2004) while others consisted primarily of mothers or, acknowledging their central caregiving role, focused solely on their perspective (McKeever and Miller, 2004; Toly, 2009; Wang and Barnard, 2008; Wilson et al., 1998). This circumstance is consistent with Traustadottir's observation of the gendered nature of caregiving, and the resultant absence of fathers' perspectives or experiences (p. 71) in the research literature, making it a logical area for further attention.

Extent of respiratory technology. The magnitude of care involved in managing a child with a tracheostomy tube is considerably higher than that required by a child who uses mask ventilation (personal communication with B. L. Giles, October 17, 2008). However, the vast majority of studies grouped invasive (tracheostomy) and noninvasive forms of respiratory technology (facemask ventilation) together, sometimes even lumping them together with other kinds of technology (Kirk and Glendinning, 2004; Noyes, 2006; Noyes et al, 1999; Toly, 2008; Wang and Barnard, 2004; Wilson et al., 1998). The sole exception was Carnevale et al., (2006), and they found no systematic differences related to the moral themes raised or the distress experienced, when families were compared on the basis of the extent of their child's respiratory technology. I would argue that, while the moral circumstances for these parents might not be different in nature, the complexity of care and system involvement they encounter certainly is, and ought to receive attention.

Summary

The literature available regarding the perspectives of children who live with complex health needs that include respiratory technology dependence is very limited and in need of further development. This can be addressed most authentically through inviting children and youth who "live the life" to share their experiences. Recognizing that they are the focal point of intense, ongoing care and services, it is important to also consider their experiences and perspectives regarding the patterns of coping and relationship that they have found to be helpful. This participant-focused process, using a strengths-based lens, provides a means to make a valuable contribution to the literature.

The literature on the parents' perspective is more developed, but also tends to be more problem-focused, consistent with the outdated medical model. Therefore, the considerable expertise and perspective many parents develop in the process of raising their child represents an under-acknowledged and untapped source of strength and knowledge. Likewise, little is known about the influence exerted by contextual variables such as family structure, gender, and the extent of the child's respiratory technology. However, the costly, resource-dependent context in which the children and their parents are necessarily situated is often an area of difficulty, with respect to parent-professional relationships, calling for further study, in order to develop better patterns of interaction that are also context sensitive.

Through this research study and the questions I pose, I will endeavor to address some of the gaps that have been raised, beginning with the central overarching question: what are the lived experiences of these children and their parents from their own perspective? I will use a qualitative approach, including in-depth semi-structured interviews with children and their parents to pursue this and subsequent questions regarding their patterns of coping and relationship. I will also give specific attention to parents' perspectives regarding their relationship with their child's health care providers, using a strengths-focused lens, to address the parent-professional relationship gap previously acknowledged.

The availability of survey instruments designed specifically for parents of children with chronic health needs has afforded me the opportunity to also collect parents' input regarding their patterns of coping, self-compassion and perceptions of their child's health care provider relationships in a very systematic and quantitative way. This approach complements the use of qualitative interviews, to provide a more comprehensive overview of the parents' experience, while also allowing for systematic examination of differences related to context. The following chapter provides specific information on how I went about answering the questions of the study using these various approaches.

Chapter Three - Method

The purpose of this study was to explore the perspectives of children who have complex health needs that include respiratory technology dependence and that of their parents, regarding life in the community and the patterns of coping and relationship that they found helpful. In this chapter I discuss the methods I used in order to begin to answer this central question and the subsequent questions that flow from it. To start, I will describe the study's design and sequence of analysis, ethical considerations including my own position in relation to the study and the steps I took to account for it. Then I will explain my participant recruitment method and the samples I created. Finally, I will discuss the samples in relation to the questions of the study, the respective sample participants' characteristics, and the methods I used to collect the data needed to answer my research questions. The reader should note that, for the sake of simplicity, I use the term "parent" to refer to the adult acting as the child or youth's primary care-giver(s); although at times, this included foster parents, a step-parent, or a custodial relative, in lieu of biological parents.

Study Design

To acquire an understanding of what life is like from the perspectives of the children and youth, I chose to use a phenomenological approach, using in-depth semi-structured interviews. To obtain data along the developmental spectrum of childhood, child and youth participants were intentionally selected and approached on the basis of their age and their assent, (with parental consent obtained), to provide a cross-sectional sample. Regarding the parents, I chose to use a mixed methods convergent design (Creswell & Plano Clark, 2011), as a means to further explore the breadth and depth of their experience. To accomplish this, I created two samples; the parent survey sample was recruited from the clinic and was made as large as possible to facilitate better statistical analysis. Voluntary parent participants completed a set of self-report surveys, contributing the quantitative parent data for the study. The second was the parent interview sample, which was a subset of the survey sample; consisting of the parents whose children had been recruited to the child and youth interview sample. The parents in this smaller sample provided the qualitative parent data for the study. Using this mixed methods approach permitted me to gather findings from different approaches and examine them for comparability (triangulation) on mutual topics.

Sequence of data collection and analysis. I collected the data from the parent interview sample and the parent survey sample concurrently, but analyzed each dataset separately. This approach allowed me to keep the two samples' analysis discrete in focus and findings, thereby facilitating comparisons. Additional analyses were conducted subsequent to a review of the initial results, informed by the trends and/or themes emerging in each data set (for example, the distinctly different experiences of single parents). The comparative findings I obtained provided additional information for the mixed methods comparison table (Creswell and Plano Clark, 2011) presented in the Results chapter.

Ethical procedures. I prepared the study's ethical protocol and it, together with the data collection instruments were reviewed by the Education and Nursing Research Ethics Board (ENREB) in March, 2009 (please refer to Appendix A). I also obtained permission to proceed at that time from the health care facility's research review committee and the head of the pediatric respirology department from which I intended to recruit participants.

Reflexivity. I brought to this study myself, as a research instrument, including my own professional background as a child life specialist, serving children and their families in hospital for over 20 years, including those with chronic and complex health needs. In fact, my experiences and the questions that had arisen for me in this work had been the impetus for this research study. While I was not examining the inpatients I currently served, I had developed a professional sensitivity that informed my perspective in approaching the study's community-based participating children, youth and parents. This served as an advantage, as my prior experience contributed to my understanding of their health-related context (for example, the jargon and systems used). Furthermore, my professional activities may have helped to facilitate the study's implementation and recruitment process. However, it was also a disadvantage to me in my position as a qualitative researcher, in that I had to be aware of, and make allowances for, my own preconceived ideas and perspective (Lincoln & Guba, 2003). Therefore, I took precautionary measures to ensure that the trustworthiness of my data and findings were not compromised by my position in relation to the study, as described below.

I chose a purely qualitative approach for the children and youth's perspective, using in-depth semi-structured interviews to collect data from them, due to the sparse literature available on their perspective. However, for the parents I chose to use a mixed methods design, because it facilitated my exploratory intentions, while inherently providing for reflexivity through the use of multiple perspectives (triangulation). The survey data I collected did not convey the depth and nuances of the parents' experiencing that I obtained in the in-depth semi-structured interviews, however, when placed side by side with the interview data's thematic findings it did provide a summative, and useful way to consider the parents' experience from both perspectives (J. Creswell, personal communication, March 24, 2010).

Phenomenological, strengths focused lens. Consistent with the exploratory nature of the study questions, and in consideration of my position outside the lived experiences of these children and parents, I chose to use a phenomenological approach in gathering the qualitative data of the study, with a slight twist. Beginning from a stance of open curiosity, I sought to learn from the children, youth and parents themselves, about their lived experiences, their perceptions of the relationships they had with others, and the meanings they made of these (Bogdan and Biklen, 2007). To this social constructivist orientation, I added a focus on strengths because I was interested in understanding what conditions, characteristics and patterns were present for children and parents who appeared to manage well in the face of adversity, compared to those who struggled.

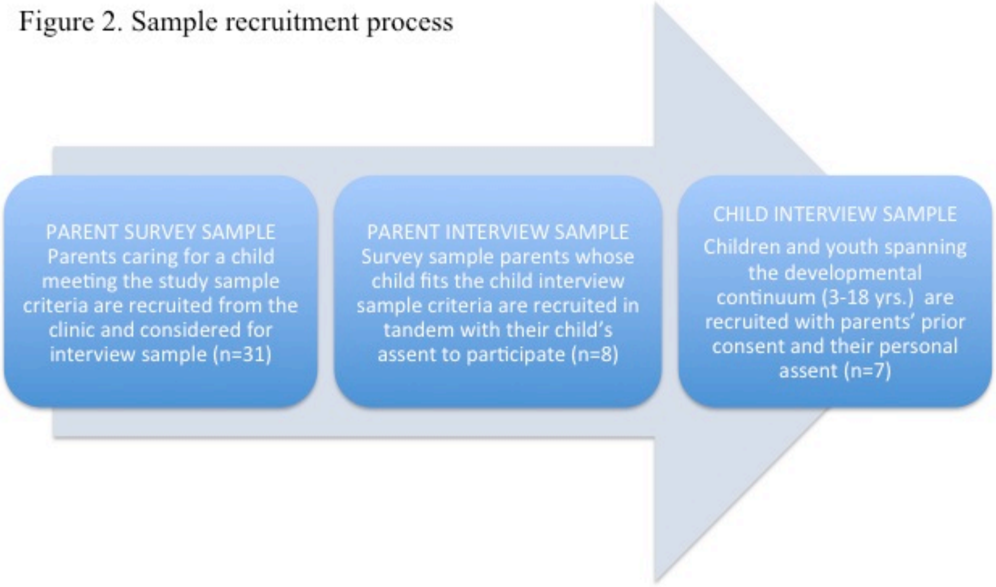
Member-checking and transparency. Mindful of my own bias, as mentioned above, I had representative members (adolescent and parent) review the study design and all research instruments to ascertain their suitability and clarity prior to beginning the study. Copies of the study's qualitative interview schedules, quantitative instruments and scale authors' permissions are provided in Appendix B. During the analysis phase, I also conducted member checking to clarify ambiguous transcript passages, and following analysis I had some members review final thematic findings (I curtailed more ambitious consultation processes due to the practical realities encountered when arranging for participants' extremely limited time simply to do the interviews). I have also maintained my transparency by audio-recording interviews, obtaining verbatim transcriptions, keeping field notes during the interview process and writing personal memos during the analysis process. To further check my work, I have had my advisor read selected transcript portions and review my analysis notes. The trustworthiness of my findings has been further validated by the affirmative feedback received upon review by an individual with extensive experience in the population who did not participate in the study itself.

Participants and Recruitment Procedures

Parents, children and youth attending a technology dependent clinic in the respirology department of a mid-western Canadian pediatric hospital were recruited to the study over the course of 9 months. Study sample criteria consisted of parent(s) who had been caring for a child with long-term respiratory technology dependence in the community for at least six months and who was medically stable at the time. The range of respiratory technology considered included noninvasive mechanical ventilator support delivered by facemask, and invasive technology, tracheostomy (trach) with or without mechanical ventilator support. Recruitment occurred at the level of the parents; intentionally selected children and youth were approached for their assent only after a parent had consented to participate.

Recruitment processes. Consistent with the study's approved ethics protocol, recruitment was on a voluntary basis, and was conducted in a manner that ensured parents perceived their freedom to choose without any coercive undercurrents. I prepared an informational letter about the study, which was distributed by the respirology clinic's desk clerk to eligible parents upon their arrival with their child, on technology dependent clinic days. The clerk also asked parents if they would like to hear more about the study from me directly, and if they agreed, the clerk notified me to follow up (I was a discreet distance away) while they awaited their turn with the clinic's various team members. I provided a brief explanation of the study to them, explaining that it was part of my graduate research, independent from the clinic (although ethically and departmentally approved), and that their participation was on a completely voluntary basis. If they expressed further interest I showed them the survey package and consent form. Based upon the study's mixed methods design, I used the recruitment process to create three samples, as Figure 2 below illustrates.

Figure 2. Sample recruitment process



PARENT SURVEY SAMPLE
Parents caring for a child meeting the study sample criteria are recruited from the clinic and considered for interview sample (n=31)

PARENT INTERVIEW SAMPLE
Survey sample parents whose child fits the child interview sample criteria are recruited in tandem with their child's assent to participate (n=8)

CHILD INTERVIEW SAMPLE
Children and youth spanning the developmental continuum (3-18 yrs.) are recruited with parents' prior consent and their personal assent (n=7)

Recruitment of parent survey sample. When a parent expressed interest in participating, I explained the kind of samples I was creating, provided them with a parent survey package to look over, and a second one if they had a partner that they thought would be interested. If, upon reviewing the survey package they agreed to participate, I reviewed and completed the informed consent form with them and they took the survey package home to complete. Participating families received a cash token of thanks with their survey package.

Recruitment of child and parent interview samples. I discussed the child and parent interview samples with parents who had agreed to participate in the survey sample and their respective children or youth. If they expressed interest, I obtained their contact information. Upon tentatively making selections for the child interview sample, based upon the best cross section of age groupings I could arrange, I made a follow-up phone call to invite the child or youth and their parent(s) to participate in their respective interview samples and, upon confirming their interest, arranged interview appointments.

A total of eight families containing potential parent and child interview sample participants, were approached. Children and parents from six families chose to participate. One family declined to participate citing lack of time and the child’s fatigue from being in other studies, and one parent did not return calls to set up interview appointments, thereby removing her family from the sample. To ensure that the child's right to choose was respected, upon obtaining their parents' consent, the child's verbal assent was sought and, if freely given, only then did their interview proceed. Both of the older adolescents provided their own written consent. Participating parents, children and youth were also made aware at the time of recruitment and again at the time of data collection that they could withdraw from the study at any time without consequence. Participating families received a cash token of thanks in advance of the first interview, which at times was given to the child at the parents' instruction.

Fine-tuning recruitment procedure. When I first began recruiting participants to my study, parents only received the study informational letter from the clinic's desk clerk.

While I also made myself available in the clinic to share more information with any parent who approached me I found this approach to be ineffective on its own. I observed that successful recruitment contacts usually stemmed from a casual conversation between the parent and a clinic staff who knew about the study. Upon reflecting on the many demands made on parents' time and energy during their child's clinic visit, I decided that a letter alone was not the best approach. Information about the study needed to be conveyed to the parent in as accessible and effortless a way as possible. Therefore, I revised the recruitment process to include an opportunity for parents to receive a verbal explanation, as described earlier.

I discussed this adjustment to the recruitment process with my advisor, the supervising doctor and the department head, who granted permission for the change on the basis that it was optional and did not depart significantly from the original plan. Subsequently, the addition of the personal introduction option led to significantly higher recruitment levels. Although some parents elected not to receive a personal explanation, of those that did, many chose to take part in the study. The three study samples that were recruited are described below, in relation to the study questions, participant characteristics, and the data collection techniques used.

Child interview sample. The purpose of this sample was to provide a developmental cross section (early childhood, middle childhood and adolescence) of the perspectives of children and youth who lived with complex health needs in the community that included respiratory technology dependence. Participants in this sample provided qualitative data that responded to the child and youth specific questions of the study. Through in-depth, semi-structured interviews I covered three areas of focus with the children and youth. First, I explored the child or youth's experience living in the community with complex health needs and respiratory technology dependence. I asked him/her about the patterns of relationship that he/she found most helpful and effective in his/her interactions with others, for example, at school, in the respirology clinic and with his/her respite worker. Finally, I explored the patterns of coping that he/she found to be helpful in managing the stress he/she experienced related to his/her circumstances, and in pursuing a good life.

Child interview sample participant characteristics. Seven children from a total of six families, agreed to participate in the interview sample. The participants' ages were as follows: One 3-year-old boy, two girls aged six and seven years respectively, two boys aged 11 and 12 years, one 17-year-old male and one 18-year-old female. All of the children except the 3-year-old boy were attending school full time. Five of the children and youth lived in the same large city, while one boy lived with his single father in a small community just outside of the city. The 17-year-old male had recently moved from his single mother's home in the city to his single father's home in a large town a short distance away.

Extent of child's respiratory technology dependence. The length of the children's dependence upon respiratory technology ranged from six months to 18 years. All of the children except the 11-year-old boy had required a tracheostomy and a ventilator for at least three years in their life. Both youths had been decannulated (had their trach tube removed and their stoma closed) and then relied upon nighttime mask-ventilation. The other children, except the 11-year-old, lived with a tracheostomy and depended on mechanical ventilation either part-time or fulltime, for example, when sleeping or sick.

The 11-year-old boy had just recently been introduced to nighttime mask-ventilation. Other co-occurring conditions made this boy more medically vulnerable than the general population.

Extent of child's dependence upon parent compared to their peers. The children in this sample reflected the variability found in the larger survey sample based upon the parents' report, ranging from being completely independent to almost completely dependent, with most distributed between the two extremes.

Situation of the child in relation to their biological family. Four children lived with their biological families, and three lived in foster families while keeping contact with their biological families. All of the children that were situated in their biological family had experienced the loss of a parent through either divorce or death. The children being fostered had experienced separation from their biological family due to their living arrangement, but did not subsequently experience a similar loss in their foster family.

Racial variation. One child was of mixed race, two were First Nations children and the other four were Caucasian.

Child interview sample data collection procedures. I conducted in-depth semi-structured interviews with each of the children and youth in person, which I also audio-recorded and made field notes about. I was careful to review and confirm the parents' consent and the child or youth's assent prior to beginning the interview. I also terminated the interview when the child or youth indicated that they were finished.

Interviews were held individually, in the company of a parent, or with another child, depending upon the child's preference. Participants were offered the opportunity to use self-expressive means through writing and drawing as part of the interview process, in addition to verbal discussion, following the recommendations made by Bolton, Closs & Norris (2000). Only one child, a very quiet 7-year-old girl given the pseudonym “Anne”, chose to use expressive drawing as part of her interview. She allowed me to keep all but one of her pictures, which she retained to give to her pediatrician. These pictures appear in the qualitative results section.

The 3-year-old child was a nonverbal communicator. In his interview I used the approach described by Noyes (2000) as it was facilitated by his parent, who knew him best and was familiar with his nonverbal cues, including specific facial expressions and limited hand and arm movements. Concurrent with the parent's interpretation, I observed and recorded a description of his nonverbal responses. Interviews with children and adolescents varied in length, ranging from 26 minutes to 2 hours, depending upon the participant's response. The adolescent participants chose complete privacy and gave the longest interviews (each about two hours in length).

When necessary, I made a follow-up phone call, to finish collecting details and comments, or to conduct member checking on an unclear point. I provided each child and youth with my contact information in case they had any further comments they wished to share, however, none made contact in this way. Siblings were not interviewed in this study, due to its limited scope, and reports on their perspectives have been highlighted elsewhere (Baumgardner & Burtea, 1998; Carnevale et al, 2006).

Parent interview sample. The purpose of this sample was to provide the qualitative perspectives of parents caring for children with complex health needs that included respiratory technology dependence, specifically in relation to the study questions. Using in-depth semi-structured interviews, I explored individual parents' lived experiences, patterns of relationship and patterns of coping, including those that helped them to foster their child's development and adjustment to disability. I specifically explored parents' perceptions of their relationship with their child's health care providers. I also listened to parents' descriptions of their patterns of coping, asking what strategies worked well for them. In discussing these questions, I attended to the parents' contextual circumstances. For example, with reference to the context of family structure, I asked parents who were part of a couple about the way in which their partnership was helpful, and I asked single parents where they obtained additional support.

Parent interview sample participant characteristics. Eight parents agreed to participate in the interview sample. Details regarding their context-specific differences are described below. All of the parents except a single father lived in the same large city. The single father lived in a small community with his son just outside of the city.

Family Roles/Gender. The sample consisted of five mothers and three fathers situated in a total of six families (from which the child participants were also drawn).

Family Structure. Parents were situated in a variety of family configurations, including three biological, one blended and two foster families. Each of the biological parents had experienced the loss of their parenting partner due to either divorce or death during their child's lifetime, in contrast to foster parents, who had not. One biological mother, one biological father, and one female custodial relative led single parent families. One foster mother, who had recently married, had also been a single parent for the majority of her child's respiratory technology dependent period. The other four parents in the sample consisted of two couples, a foster mother and father who had been together for over 20 years, and a biological father and stepmother who had been together for less than ten years.

Extent of their child's respiratory technology. All of the parents except one biological father had experience caring for their child with invasive technology, including tracheostomy and either part-time or full-time mechanical ventilation. The remaining father had recently learned to care for his child with noninvasive respiratory technology, specifically, nighttime mechanical ventilation provided via face-mask (CPAP). The parents of the adolescent study participants also had experience with this kind of technology, since their children had been able to move from invasive to noninvasive respiratory technology.

Parent interview sample data collection procedures. I conducted in-depth, semi-structured interviews with each of the parents, making a digital audio recording and field notes of each. I was careful to review and confirm the parents' consent and discussed any questions or concerns they had prior to beginning the interview. I terminated the interview when the parent reached the end of the interview schedule and indicated that they had finished talking. Parent participant interviews were held individually and varied in length, ranging from 1.5 - 2.5 hours, as determined by the participants’ responses. Some parents commented with surprise upon the benefits they experienced in participating (for example, experiencing insight, and catharsis).

When necessary, a follow-up meeting, or phone call, was made to finish collecting details and comments, or to conduct member checking on an unclear point. I provided each parent participant with my contact information in case they had any further comments they wished to share, however none used this option.

Volume of data from interviews and transcription. The interviews I conducted with the child and parent samples generated a significant volume of qualitative data. Child and youth interviews totaled 7 hours and 31 minutes, generating 237 pages of transcripts. The parent interviews totaled 16 hours and 20 minutes, generating 479 pages of transcripts.

Interviews were transcribed verbatim. I transcribed one adolescent interview, a professional transcriptionist, who had signed a confidentiality agreement, transcribed all other interviews, a copy of the agreement form can be found in Appendix B. For the sake of clarity, in long quotes of transcribed data where my comment is included in the passage, I indicated my words by preceding them with "I:" and, in shorter quotes, that appear in the body of the text, I also enclosed my portion in brackets.

Parent survey sample. The purpose of the survey sample was to gather demographic and quantitative data from parents for statistical analysis. I chose pre-established scales with sound psychometric properties that measured the parents' patterns of coping and self-compassion, and their perceptions of their child's health care providers family-centred care behaviours. I used this data to answer quantitative and mixed methods questions of the study. These included an exploration of the kinds of coping and relationship patterns parents engaged in, the extent to which they experienced their child's health care providers to behave in a family-centred manner towards them, and the relationship between parents' coping and their perceptions of relationship, with specific attention to specific contextual variations. This data also allowed me to make comparisons with my relevant qualitative findings, providing a means to exercise impartiality and further refine my analysis. A total of 35 parents agreed to participate in the quantitative portion of the study, 31 parents returned completed survey packages.

Parent survey sample participant characteristics. Survey sample participants consisted of 31 parents who, as an aggregate, were responsible for the care of 22 of the eligible children in the clinic's population (36% of the population at time of recruitment). Due to the exploratory nature of this study, a considerable amount of contextual data was collected about participants and their families via self-report, using the Family Information Checklist. Participants' detailed demographic information appears in Appendix C, (Tables C1-C12 and Figure C1). Brief highlights are presented here.

Family roles/Gender. The sample consisted of 21 mothers (12 biological, 7 foster, 1 custodial relative, and 1 step-mother), and 10 fathers (7 biological and 3 foster). While the fathers represented only one third of the sample, their presence is noteworthy, given how under-represented fathers are in the literature. This development provided the opportunity to examine the role of gender as a variable in the study.

Family Structure. Participants reported living in a variety of different family forms. The sample included both parents from 11 two-parent families (consequently, details they report regarding their children appear twice in the statistics); four parents were the sole respondent from their two-parent families; five parents were situated in single-parent families (four mothers and one father).

Extent of child's respiratory technology. Fifty-eight percent of participants reported caring for a child requiring invasive respiratory technology (tracheostomy 32.3%, tracheostomy and oxygen, 25.8%), which in some cases included mechanical ventilation either full or part-time. The remainder of parents reported their child as requiring noninvasive respiratory technology (mechanical ventilation support delivered by mask). One parent did not specify the type of respiratory technology their child required. Ten percent of participants reported their child to require fulltime mechanical ventilation; fifty-eight percent reported their child to require part-time mechanical ventilation and thirty-two percent reported that their child did not use a mechanical ventilator (please refer to Appendix C: Tables C9 and C10). The majority reported being responsible for providing all care (38.7%) or most care (35.5%) for their child with complex health needs.

Participant Demographics. Participating parents ranged in age from 22 to 62 years (*M* =44 years). The majority of participants lived in an urban setting (80.6%) while a few lived in a rural community or on a farm (19.4%). Family size varied, with the number of children including the affected child ranging from 1-7, and either one or two parents heading the household with the exception of one blended family, which had 2 foster parents and a young single mother.

Fulltime working parents made up forty-two percent of the sample, forty-two percent were stay-at-home parents, a few worked part-time and one parent was attending school. The majority of parents had completed high school (38.7%), some had gone on to further postsecondary training or college (25.8%) and a few had graduated from university (22.6%).

Total family income ranged from less than $20,000 per year to more than $80,000. About half of participants' families reported gross income below $80,000 and half were above. The lower income half of the sample included all of the single parents and some two parent families (both biological and foster), and parents' education standing ranged from incomplete high school to college-level training. The upper half income group comprised solely of two-parent families (biological and foster), and parents' education standing ranged from a high school diploma to a university graduate level degree (for details please refer to Appendix C: Tables C4, C5 and C6).

Child's underlying health condition. Details about the participants' affected children are provided in Appendix C: Table C7. Regarding their child's health condition, the parental report by diagnostic cluster was fairly distributed, when collapsed to reflect actual child numbers, as follows: neuromuscular (29%); respiratory (33%); congenital/syndrome (33%); and other (5%), (refer to Table C8).

Child's level of dependence on parent. Participant parents' reports ranged widely regarding their child's level of dependence on them, compared to their healthy peers, in common functional domains of living. A few children were relatively independent (just under 10%), and a few were completely dependent (3%), the majority of children were reported as being situated between the two extremes. Please see Figure C1 in Appendix C, for further details.

Parent survey sample data collection procedures. All eligible parents who expressed an interest in participating in the study during the recruitment process were provided with a self-addressed stamped envelope containing consent forms, the survey package, and a cash token of thanks. Informed consent was obtained from each of the parents submitting a completed survey package.

Parents returned their completed survey packages either through the mail or by dropping them off during a subsequent respirology clinic visit. I made a reminder phone call to participating parents who were delayed more than a few weeks in returning their survey materials and, when postal rates changed, I offered to pick up their survey package from their home. I also provided replacement survey packages to several parents who requested them (they reported losing track of the original).

Unsolicited input. Noteworthy in this collection process was the extent of unsolicited input provided by several of the mothers who completed the surveys. While many participants (both mothers and fathers) responded to the open-ended questions in the Family Information Checklist (18 of 31 parents), several mothers (only) also chose to add unsolicited comments to the self-report survey instruments. A combined total of 37 comments and one lengthy note were gathered from 5 mothers (combination of biological and foster) who added to their scale responses by writing in the margins and where space allowed. The relevance of their comments to themes arising from parent interviews is briefly discussed in the parents' interview sample findings section. The unsolicited manner in which these mothers chose to share their perspectives adds emphasis to their need to communicate their experiences, transcending the limitations of the survey instruments themselves.

Survey instruments (quantitative). Four data collection instruments were included in the survey package distributed to parents in the survey sample, as well as, a copy of the informed consent agreement that the parents and I had signed.

Family Information Checklist (FIC). When I did not find a data collection instrument that could meet the needs of this study, I created a checklist and had it reviewed by a consulting parent from the participating population, a pediatric respirologist and my advisor, to ensure clarity and ease of use. The checklist provided a means to gather descriptive information about the parent, child and family and also collected the parents' personal opinions on matters related to him/her and their child's situation in a systematic way.

Coping-Health Inventory for Parents, (CHIP) (McCubbin & McCubbin, 1985). This is a 45-item self-report inventory developed for use with parents raising a child with a chronic medical condition, to assess patterns of parental coping behaviour. Notably, this instrument is conceptually aligned with the bioecological framework, as it recognizes and includes multiple contexts. Furthermore, this instrument is grounded as a measure in findings obtained from the population itself. Psychometric properties of this instrument: An analysis of the 45 items with n = 185 parents was conducted using SPSS principal factoring with iterations method, followed by the Scree plot test to determine the final factors. The final factors were rotated using the varimax criterion. The three factors, labeled coping patterns, represented 71% of the variance of the original correlational matrix. Cronbach’s alphas were .79 for Coping Pattern I (Family) composed of 19 behaviours, .79 for Coping Pattern II (Support) composed of 18 behaviours, and .71 for Coping Pattern III (Medical) composed of eight behaviours (McCubbin et al, 1983, p. 363-364). Norms have been generated, based upon parents of children with Cystic Fibrosis and divided by gender (McCubbin et al, 2003, p. 437).

Measure of Processes of Care (MPOC-20) (King et al, 2004). This is a Canadian 20-item self-report questionnaire developed for use with parents of children living in the community with chronic health conditions and disabilities, to measure their perceptions of the extent to which health care professionals use family-centred care behaviours in their interactions with them. This has previously been administered to another local pediatric complex care population with good participation (B. Wharton, personal communication, 2008). Psychometric properties: (*n* = 494 parents), means ranged from 4.08 to 5.40 and the standard deviations ranged from 1.29 to 1.77. Cronbach's alphas for the five subscales in the MPOC-20 ranged from .83 to .90, similar values had been found in previous data sets, indicating good reliability as well as good internal consistency (King et al, 2004, table 5, p. 48). Absence of significant correlations related to family features, demographic characteristics or child's features also provided for the scale's construct validity.

Self-Compassion Scale (SCS) (Neff, 2003). This is a 26 item self-report inventory developed for use with adults to measure the extent to which they treat themselves with kindness and understanding in instances of distress or failure, conceptually, an approach comparable to mindfulness. The scale is correlated with positive mental health outcomes. Psychometric properties: Two studies were conducted in the development of the SCS scale. Sample sizes for these studies were: $n1 = 391$, $n2 = 232$, participants were university students randomly selected from an educational psychology subject pool. The first study descriptive statistics provided: Mean = 18.25 Standard Deviation = 3.75. Confirmatory Factor Analysis found six inter-correlated factors to the scale's 26 items. Internal consistency for the SCS scale was .92. Regarding validity, social desirability was ruled out with an insignificant correlation (r = .05, p = .34). Construct validity was tested by calculating correlations with other scales measuring similar constructs, with significant correlations found between the SCS scale and other scales in the expected direction, for example, SCS scale and Social Connectedness Scale $r = .41$, p < .01. In study 2, the SCS scale's factor structure was re-confirmed; test-retest reliability was .93 (Neff, 2003).

Summary

Using the methods described, I was able to recruit the child and parent samples necessary to pursue the questions of the study using a mixed methods approach. I was successful in gathering the data I sought using the instruments and methods I presented, from each sample. Thus, I have qualitative data regarding the child and youth's perspective on what life is like when living in the community with complex health needs that include respiratory technology dependence, and the patterns of coping and relationship that they experience as helpful. I also have both qualitative and quantitative datasets to further explore the parents' perspective on caring for their child in this context, and the subsequent questions that flow from this central question. In the following chapter I will describe my analysis and present the findings I obtained.

Chapter Four - Results

In this chapter I present the analysis I conducted on the data sets obtained from each of the three samples described in the Methods chapter, including the child interview sample, the parent interview sample and the parent survey sample. I will then address the questions of the study by presenting the results, beginning with the qualitative findings of the child interview sample, followed by the findings of the parent interview sample, and thirdly, presenting the quantitative results of the parent survey sample. Finally, I present a joint display of the parent samples' results, placing qualitative themes arising from the parent interview data side by side with quantitative results from the parent survey data (Creswell and Plano Clark, 2011). This mixed methods comparison table shows the areas of convergence and divergence that are present between the two kinds of data sets, and provides a streamlined view of the parents' perspective with regard to the areas covered.

Analysis of the Parent Survey Sample Dataset

I used the Statistical Program for the Social Sciences (SPSS), version 19, to analyze the data collected from parents via the survey sample's quantitative instruments.

Preparing the database. I coded and manually entered the raw data into a SPSS database from the 31 survey packages completed by parents in the survey sample for analysis. Each completed survey package contained a total of 127 items for a potential total of 3,937 items. Most parents had fully completed their packages, providing a sound data set from which to conduct analysis. I created variables from the raw data to represent the subscale values, in accordance with the instructions provided by the scales' authors. Additional variables were created as needed from the original dataset using SPSS

Transform operations to examine specific characteristics of the sample in relation to the research questions. For example, to calculate the variable, "extent of respiratory technology", I created two categories of respiratory technology: invasive and noninvasive, by grouping information reported by parents on the Family Information Checklist accordingly. Thus, all children reported as having a tracheostomy were placed in the invasive technology group (1) and the remainders were grouped as noninvasive technology (2).

Addressing missing data. I visually inspected the database and checked for missing data. Missing data was assigned a missing data code available through SPSS, in order to ensure that it did not interfere with accurate analysis. I found the missing data I had recorded from the original survey instruments to be infrequent and random. Cases containing missing data were excluded pairwise from any analyses for which they did not have the necessary information. When sample sizes changed due to the exclusion of cases with missing data I have noted the reason in the analysis tables.

Addressing incomplete participant responses. I followed the scale authors' instructions in calculating the scale and subscale variables, facilitating comparisons between this study's findings and their previously published findings and identified norms. The CHIP Scale presented a particular challenge when some participants responded to items they did not use by providing only one response, rather than providing both responses for each item. For example, participants either ranked the item's level of helpfulness (Not helpful = 0 on a scale from 0-3), or indicated that they chose not to use the strategy, either because "Chose not to" or "Not Possible". This ambiguity was resolved by counting the response presented either way as "0" in keeping with the authors' direction, that responses in the "I do not cope" column "are equivalent to 0" (McCubbin, Thompson, and McCubbin, 2001, p. 436). The design of the scale did not provide a means for parents to describe their reasons for not using a particular coping strategy. However, from a research perspective, the responses provided did offer a clear "all or none" indication of the coping strategies that the participants used. I suspect that the nuance in the instrument response choices may be of more relevance when the scale is used on an individual clinical basis. For example, several mothers who had opted not to be considered for the interview sample seemed compelled to communicate their reasons for not using certain coping strategies, by writing an explanation beside individual scale items on several occasions.

The MPOC-20 subscales (King, et al., 2004) were calculated following the instructions received from CanChild at McMaster University, Ontario (personal communication from D. McCauley for CanChild, March 6, 2012). I also chose to calculate a total MPOC scale value for comparison purposes with the CHIP and SCS total scale values. Similar to the manner in which the CHIP overall scale value had been calculated, I arrived at the MPOC-20 total scale value by summing all 20 individual item values together in each case. This method provided for the greatest variability and, therefore, sensitivity possible, as an overall scale value.

The Self-Compassion Scale (SCS)(Neff, 2003) was calculated in two different ways, so that I could accommodate a change in the author's instructions, while retaining the ability to calculate values consistent with previously published findings. Therefore, "Total scale value" was calculated using the method described in Neff (p. 243, 2003), wherein, negative subscale items were reverse scored, after which the six subscale means were computed and summed (range possible: 6-30). An alternate score calculation method accompanying the scale on Neff's website involved reverse scoring the negative subscale items, then calculating the total mean based upon the sum of scores attained for the scale's 26 items (range possible: 1-5), arriving at a "Total scale mean" (Retrieved Oct. 14, 2007 from http://dx.doi.org/10.1080/15298860309027). I have calculated both values for comparison purposes in the independent t-tests. I have used the new calculation method alone for the Ancova statistical analyses.

Statistical tests used for analysis. I made comparisons on the basis of the variables described in the research questions using an independent samples t-test (two-tailed). Relationships between and amongst the variables were examined using one-way between groups analysis of variance (One-way ANCOVA).

I took several precautions to enhance the validity, reliability and accuracy of the results. I was careful to select instruments with good psychometric properties. I retained control of all of the data collection, coding, entry, and analyses presented here. Due to the survey sample's small group sizes, I selected conservative statistical tests and took several precautions in analyzing the data, to improve the likelihood that the results could be considered valid and reliable. For example, I used:

- 95% Confidence Intervals
- Levene's Test for Homogeneity of Variance: variables producing significant results were dropped from statistical analysis.
- Skewness and Kurtosis: I examined these for normality in the overall scales and found them to be within acceptable limits (≤ 1.00), except where noted.
- alpha level for analysis was set at $p \leq .05$.

- the effect size (eta squared) was calculated when the independent samples t-test result was $p \leq .05$ using the formula provided by Pallant (2007, p. 236) and interpreted (contextually), using the guidelines cited as proposed by Cohen (Ibid), in which .01 = small effect; .06 = moderate effect; and .14 = large effect.

Finally, as already mentioned, I viewed the design of the study itself to provide a means to ensure impartiality and thoroughness.

Analysis of the Child and Parent Interview Sample Data Sets

Data collected using qualitative interviews was analyzed in part while I was in the field, using verbatim transcripts of interviews and field notes. The balance of analysis was completed once all of the interviews had been transcribed. I analyzed transcript content manually for themes and patterns within individual interviews and categorically across interviews. I used thematic-coding procedures and the “Find” function in Microsoft Word™. Due to the variability in the terms that participants used to convey similar meanings, I made summary notes to identify key words and phrases indicating emerging themes and meanings. I have taken precautions to ensure that the trustworthiness of my findings is not compromised by my own personal influence in the analysis process, through the measures I described previously in the Reflexivity section of the methods chapter. To protect the identity of the child and parent participants, given the unique characteristics of their situations, I have changed or modified certain details. Furthermore, my use of the term parent refers to the child's parents or, for children in different family arrangements, the people who are caring for the child in the role of parent (for example foster parents, custodial relative, or stepmother). When pertinent I provided additional details specific to the person's context.

Data Integration

I have compared compatible qualitative themes and quantitative results in order to address data integration of the parents' results specifically. A joint display of the two parent samples' results, placing qualitative themes arising from the parent interview data side by side with quantitative results from the parent survey data (Creswell and Plano Clark, 2011) is provided in the final section of the results chapter. The table provides a means to merge the findings, viewing areas of convergence and divergence in the findings arising from the interview sample and survey sample data sets.

Given the considerable volume of data that this exploratory study has generated, for purposes of clarity and flow, the results have been organized into four separate sections and linked to the questions of the study that they respond to, as follows:

The perspectives of the children and youth. This section presents the findings arising from the children and youth's qualitative interviews regarding their lived experiences and the patterns of coping and relationship that they found to be helpful.

The perspective of the parents. This section presents the findings arising from the parents' qualitative interviews regarding their lived experience, the patterns of coping and relationship that they found helpful, with particular attention given to the parent-health care provider/system relationships.

Results arising from the parent sample survey data. This section presents the analyses of data collected from the parent survey sample (n=31) via the survey instruments. Data collected focused on parents' perspectives regarding community support, their patterns of coping, and their perceptions of relationship related to their child's health care providers, specifically regarding range and frequency of family centred-care behaviours.

Mixed methods data comparison. In this section I provide a joint display of the qualitative themes I found in my analysis of the parent interview sample and the corresponding quantitative results I obtained from my analysis of the parent survey sample dataset, grouped according to the relevant study questions. The table shows a consistent convergence of findings between the two approaches. The findings and results are subsequently compared and discussed further, in relation to the literature in the Discussion chapter.

The Perspectives of the Children and Youth

In this section of the results chapter I present the findings I obtained from my analysis of the child interview sample data. I gathered this data through conducting in-depth, semi-structured interviews with child and youth participants. Guided by the question of the study, I explored what their life was like, living with complex health needs that included respiratory technology dependence in the community, and the patterns of coping and relationship that they found helpful. I refer to the sample participants as children and youth because their age range runs from three to 18 years. The seven participants are presented here under pseudonyms and, when necessary, with altered circumstances, to protect their privacy, as follows: Jim (17 years), Marie (18 years), Mike (12 years), Tom (11 years), Anne (7 years), Megan (6 years) and Marcus (3 years). Anne was the only child who chose to draw pictures as an additional method of communication and most of them are featured throughout this section. Although I presented her with a broad range of coloured markers and crayons, she chose to use pink crayon for most of her drawings (deviating once, to colour her foster father's hair black). She allowed me to have all but one of her drawings, which she intended to give to her pediatrician; it depicts her and her doctor standing beside one another in the doctor’s examining room. The three pictures that she shared with me include pictures of her foster family, friends and home.

The two teenagers, Jim and Marie, provided the broadest perspectives, likely due to their life long experience with respiratory technology. Each spent their early years dependent upon a tracheostomy tube (trach) and ventilator and, over time, improved to the point that they were decannulated (had their trach tube removed and the stoma in their neck closed). Jim had his trach removed in primary school and Marie's was removed in high school. Both young people continue to rely upon mechanical ventilation by mask (known as continuous positive air pressure or CPAP) at night.

Mike, Anne, Megan and Marcus also depended upon a tracheostomy and ventilator for most of their lives, although to varying degrees. Marcus was able to be off his ventilator for just 3 hours a day, whereas the other three children only used theirs at night, unless they were sick, in which case they usually required mechanical ventilation fulltime. Tom was a relative newcomer, as he had just started using a nighttime mask and mechanical ventilator (CPAP) in the past year. He did not have a tracheostomy, however, other health and developmental needs required close attention and monitoring by his father and the health care system from birth. During their respective interviews, each child or youth participant shared his/her private world and perspective with me in a sincere and authentic manner.

Approach to the data. I grouped themes emerging from the interviews in relation to the layers of systems present in the children's lives. Bronfenbrenner's bioecological systems theory (Bronfenbrenner and Evans, 2000) provided a useful framework for viewing them. I also considered themes from a categorical perspective, exploring them in terms of the child's lived experience, their personal response to disability, and the patterns of coping and relationship that worked for them in the various domains of their life. Other aspects subsequently considered included the manner in which the passage of time (the chronosphere) shaped the child's development and approach to living, and the factors that appeared to influence his or her attitude and adjustment to living with complex health needs.

Themes arising from lived experience. The themes arising in participants' narratives began very naturally within the child as a person, endeavoring to live his or her life in relation to self and others. This led into themes related to their biological dimension of being, experiencing life with a health condition requiring respiratory technology dependence. All but one of the participating children and youth had experience with a tracheostomy, an invasive form of respiratory technology that also altered how they experienced their lives quite considerably. Concomitant with this circumstance was their perception of living with disability and responding to it, in relation to themselves and others.

I am a person first. All of the participants pursued very typical interests, and relationships for their age (see Figure 3), and the manner in which they approached their experiencing reflected their level of psychosocial development (Erikson, 1963). The young children's perspectives of themselves, situated in their home and family**,** were very concrete, immediate and action-oriented. They related their personhood to what they liked to do, for example, Marcus (3 years old) liked to read books, watch TV shows like "Diego" and engage in activities, such as tactile play with "slime" on his hands, and having time in his stander. A little older, the children's world began to expand. While home and family continued to be important, they

Figure 3. Anne standing by her house

became concerned with their peer group and mastering skills. For example, Anne (7 years old) described her favorite things, "Playing with friends, going to Disney World and....swimming." Adolescents, on the other hand, when speaking about themselves, liked to share their self-concept of themselves, as eighteen-year-old Marie illustrated, "I like to say that I'm very friendly and caring. A little crazy at times (giggling) and I like spending time with my family sometimes and like hanging out with friends...."

"I just want to be normal". One aspect that was most apparent in the children and youth's discourses, particularly as they entered school and became more involved in the larger community, was the reference to their pursuit of normalcy itself. For example, Jim was earnest in this endeavor, "I've always been liking sports like soccer and football and that…a typical guy thing there. I just want to be normal. -- That's pretty much what any kid really wants...." This is not an unusual desire among middle years children and adolescents however, Jim's explanation of "normal" linked to his perspective on life with respiratory technology dependence and, therefore, disability-related difference, an aspect of personal identity that each of these children grappled with.

Living with "the thing in my neck" hard but necessary. All but one of the children had experience living with a tracheostomy, an invasive form of respiratory technology that they could not leave behind at home, like some could their ventilator. Jim and Marie referred to their trach as "the thing in my neck" and described life with any technology as a mixed blessing. Jim acknowledged the trach's help initially, for enabling him to be out in the world, to "be my own person", but he also described it as an entity distinct from himself. Younger children reiterated this ambivalence in simpler terms. Megan, for example, said she didn't like her trach, but when her trach was out: "Then I can't breathe..." [I: How does that feel?] "Feels sad..." [I: What about when the trach is back in?] "...Good." Life with a trach was not easy, as Marie described: "I had a trach pretty much from birth to when I was 16. So it was hard and now that the trach is gone it's much better."

Living with respiratory technology "A constricted life". Participants described a broad range of constrictions that they had experienced in relation to their disability and respiratory technology dependence, as described below.

Constrictions on freedom due to body's dependence. Each recognized his or her need for technology as an absolute imperative. For example, Jim was able to articulate his underlying disability: "there's this machine I hook up to at night to keep me breathing...my brain…shuts down and stops me from being capable of breathing." While Megan offered a more basic description, "Because I can't breathe. I have to have a trach." Even Tom, an 11-year-old who lived with a significant developmental disability and began using night-time mask ventilation just six months prior to his interview was able to articulate what he used and why, [I: What do you need?] "A mask." [I: What does it do?] "Breathe."

Constrictions related to physical limitations of respiratory technology. Participants experienced feeling physically constricted by the equipment. For example, Marie stated, "I still do wear the mask at night, so I still do feel the constriction....It does help, but in a way it doesn't, because it kind of restricts me to do stuff." A minor, yet chronic annoyance was the pulse oximeter monitor, which could ring off several times a night, disrupting sleep: "it's just a beeping noise that…gets on my nerves." (Marie)

Other limitations were much more significant. For example, Jim described putting up with a bully as a little boy, in order to protect his trach, “When I had that in I wouldn't do anything, I’d just let him carry on because I was always afraid of getting it taken out and I couldn’t breathe then” (unfortunately this did not prevent harm). Marie also raised her concern about her CPAP mask-ventilator’s vulnerability to power failures. Its lack of a back-up power supply made her particularly vigilant on stormy nights.

Marie: There are some nights where I kind of just stay up till the storm subsides...

I: What...if the storm happened and you weren’t awake?

Marie: I would stop breathing and then I would wake up quickly but I wouldn’t be able to go back to sleep until the power went back on....I think the ventilator, I think you could if there were batteries available, but with the mask you can’t.

Constrictions due to cumbersome equipment and accessibility issues. Jim recalled how it had bothered him as a youngster, to miss visits to his dad's house after his parents had separated, in part due to the difficulties moving his ventilator: “the machine that I had was as tall as I am…we had to put up ramps and we had to put it into a van because it wouldn't fit into an ordinary car.” While respiratory technology had become considerably smaller over the years, it remained an issue, especially for children who required their ventilator to be wheelchair mounted. Ellen, Marcus’s mother recounted how buildings that lacked universal accessibility had an impact on their life, “we go to my sister’s house...her son and I carry the machine; but I’m not going to carry the machine pretty soon, you know.”

Constrictions due to monitoring requirements. Being monitored and maintaining close proximity to a skilled helper at all times was part of life for children and youth who required invasive technology such as a trach. This severely limited their freedom, including social choices, even among the younger children, as Megan's foster mother explained, while Megan nodded in agreement, "She doesn't like having a trach because she can't go play at her friends by herself. She has to have a nurse or have mom or dad go with her and she hates it."

The compromises in personal privacy and intimacy resulting from this ongoing presence took their toll, particularly for the youth, who so needed and cherished their personal space with their peers,

> I really watched myself and I was not as fun to be with people and they also watched themselves too, because they knew like, people were watching us...the only time that really it was private was when they were at home with me, but still, my parents were there. (Marie)

Constrictions on lifestyle due to disability-related limitations. Constrictions covered a broad range of aspects, for example, Marcus lived with a neuromuscular disorder that significantly limited his mobility thus, with almost fulltime ventilator dependence, his activity choices were very narrow. Ellen explained: "He has it very limited, ...with him getting bigger it's harder to carry him and get him to do things...He has to sit in his chair quite a bit...." This situation added considerable importance to the role school would soon play in broadening his horizons, provided he could obtain a respite nurse to accompany him. At the other end of the spectrum, Jim raised some of the lifelong constraints that he had to accept,

> There are limits on your choices in life…like joining the military…And pretty much I can’t travel around the world without mom…there are these classes I was in, ...they got to go to Europe and Australia…and I didn’t get to go to any of them, because, just because of my condition.

Daily lifestyle concerns, like personal hygiene, were also constraints, particularly for an adolescent girl, as Marie commented: “normal people...would be doing their hair and stuff where I could be cleaning out my trach and making sure the site was not infected” (Marie). Decannulated and on the cusp of adulthood, Marie had new constraints to balance, including rationing her energy to sustain the intentional breathing she used to free herself from ventilator-dependence during the day, and avoiding risk taking, for safety's sake. "I really have to watch myself when I do certain things, example like drinking...because if I was to pass out or like, completely get really drunk, I don’t know what would happen."

Being sick is difficult and lonely. When illness struck, technology dependence increased for most of the children. Those with a ventilator had to be connected to it fulltime, which severely constricted their movement and social opportunities. Mike (12 years old) described how difficult and lonely he found it:

> My allergy comes back and its hard breathing and then I have to go back on my machine.... It’s good but sometimes I cry.... I just don’t want to go on it.... I hate it when in my bedroom. In the family room it’s better because we have more people.

Encountering social exclusion and marginalization in the community. Even when well, once outside of the family home (microsphere), experiences of being isolated from others, physically and/or socially in the community (mesosphere), came up repeatedly in the children and youth's narratives. For example, Jim recounted his experience with marginalization as a young boy with a trach:

> I was still socially...capable of making friends... It's just…. when someone looks at someone, they tend to judge them…and since I had a trach they judged me by that…saw that to be handicapped or retarded or something…so…when people think that, you kind of have limits as to who you can be friends with....

Marie also encountered exclusion in her childhood, in a more veiled form,

> I guess people's birthday parties would be really big. There was one birthday party where we actually combined birthdays even though we were like three months apart. And then it turned out to be a sleepover party and then I was like 'oh' and then I went home.

Marcus attracted uninvited attention and comments when simply going to the mall. Due to his appearance, which included his wheelchair and ventilator, as well as the physical effects of his neuromuscular condition, he stood out visibly and, according to his parent, Ellen, received a lot of marginalizing comments from strangers in public. Ellen described rebuffing unwelcome and inappropriate remarks with ironic humour, "...a lot of times we will be walking and somebody will say 'Aww...poor kid' and I will turn around and I will say 'he's not poor he's got money' and then they just look at me and they start laughing. (Laughing)" She also offered the following interpretation regarding the objectifying treatment Marcus received from others,

> My cousin got him a t-shirt and I love the t-shirt she got him. It says you can't see me...And to me what that shirt means is they see this – the tubes and everything, but there is a little boy here right? A very special little boy.

Removal of trach "opened whole new window in life." Both Jim and Marie had experienced the change that came with being decannulated (having their trach tube removed and the stoma in their neck closed), and moving into life without a trach. They both referred to their dependence upon a trach as something they "had to overcome", and reported experiencing a significant improvement in lifestyle and freedom with its removal. Marie, the most recent to experience this change, offered her perspective,

> Marie: It [the trach] constricted me from doing the things that I wanted to do by myself. An example; go out. Something as simple as going out to a friend's house or going to movies.
>
> I: What did it feel like in your life when that was taken out? What did it do for your life?
>
> Marie: It opened up a whole new window in my life and like wow! Where did this come from?...it was really exhilarating! It was like a really big rush...

New autonomy a capacity building experience, "I can do this!" Marie's description of her new trach-free life suggested that she had discovered of a new dimension to living. Her account of what she could do for herself with her new freedom illustrated the importance of personal autonomy and realized opportunities to the development of self-efficacy,

> I want to do things by myself. I am able to, I have a job right now, I go to work by myself and I'm able to be with friends by myself, I am able to be at home alone by myself...It's really, it's so much better....
>
> Grade 10 like, October of grade 10. That's when the nurses left. That's when I got my cell phone, to some people that's just really weird, like, why is a cell phone such a big significance?…But…it meant that they [her parents] trust me and I can just phone them and be like 'okay I'm here'…So it was kind of a symbolism of it's own, in the meaning of: 'I can do this!'

Marie had found a new way of being an actor in the world, with newly realized capacities and confidence. She was, in essence, set free from a gilded cage. The paradoxical and dialectic nature of her context was very clear**,** the removal of the trach meant that vigilance could be replaced with freedom. No longer requiring the safety of the trach to preserve her life, she was able to live into a part of her life that had not previously been available to her (dead to her). Marie was able to move forward into who she could become on her own in the world.

Response to personal disability. Participating children and youth shared a variety of perspectives on their experience with disability, informed by their level of development, their self-awareness, and the kind of role they attributed to their disability in relation to their life (already alluded to somewhat in the theme on a constricted life). Many of the themes were related to personal identity, a common area of struggle as each child determined what they could or could not accept.

Disability and technology are things to keep hidden. Some children were very aware of, and sensitive to their physical presentation in public, and sought to "cover up" their respiratory technology. For example, 6-year-old Megan's foster mother recounted a time when the little girl was preparing to accompany her foster father on an errand:

> She ran up to her room and pulled a turtleneck over her t-shirt and covered her trach right up and that broke his heart. And he asked her ‘why are you doing that?’ and she said ‘so no one looks at my trach at the store’.

This response suggested that Megan rejected this aspect of herself, and that she feared that others would judge her as different, producing the experience of stigma (Goffman, 1963). Alternatively, viewed from a social role valorization perspective, Megan was enhancing her social image by covering up the part of her that was perceived to be socially devalued by herself and others (Wolfensberger, 1998).

Need for respiratory technology interferes with "being a normal person". Like Megan, Jim wanted to be "normal", and he viewed his respiratory technology to be what separated him from this desired identity - essentially, keeping him at a distance from "being himself". Even after his trach was gone, he viewed his dependence on the mechanical ventilator in his room the same way, “I still want to be a normal person without that ventilator up there…To a certain extent, that's the only thing I say isn't normal about me…”

"Why me?" Grieving the body’s imperfection. Marie viewed her disability as an injustice and a loss. She grieved the loss of a fully functional body (due to hemiplegia) and what it meant for her: “Even, there is still some days where I’m kind of like, ‘why me?’ - kind of like - ‘why am I the one with a physical disability?’ ”

Disability, identity and concerns about being objectified. This theme, previously referred to in Marcus's encounters with the public, presented itself for Marie in relation to her friendships. Her vigilance around being objectified affected the way in which she approached her relationships. Specifically, she distrusted the sincerity behind some of her peers' friendly overtures, attributing them to the presence of her disability rather than her personhood, as described in the following advice:

> Marie: Watch who you become friends with...notice if they are just there when they think you need them and not just there to be your friend the whole time...If they're...[there] only when you need help or to make themselves to look good or that kind of a thing, then I'm not saying they can't be your friend, but kind of like, don't talk to them about that stuff, and see where that goes, because if they are only there to just to look like the hero.
>
> I: And look for?
>
> Marie: The ones that are actually there for you and want to hang out with you.

Of significance however, was the discovery that Marie made after her decannulation: "A big eye opener when I got the trach out, a lot of people didn't notice....It made me reassured that they knew me for me and not for what they saw." This suggested that while some of her vigilance may have been grounded in experience, some was also likely shaped by her own perceptions of her disability.

Acceptance of disability as part of one's self. Anne, one of the youngest and quietest of the participants, was very matter-of-fact in commenting on her respiratory dependence, which included a trach and an oxygen supply. She stated "it helps me" and "I have to have it." She had recently begun school and was engaged in recreational and social activities in the wider community (mesosphere). Similar to young Megan, her response was very concrete, yet in contrast, much less anxious and self-conscious.

Downside of disability: missing out on choices. This theme was articulated specifically by the adolescents, for whom freedom of choice was a sought after commodity. Marie identified the hardest part of having her disability as knowing that she couldn't "Live like I want to...I guess some experiences…like my friends have had, that I haven't and probably will never." Jim described missing out on aspects of his interior life, for example, "I don't dream…that bothers me because I hear everyone having these crazy dreams...that just sucks!" As well as experiences in his exterior life, "there are limits on your choices in life…like joining the military…And pretty much I can't travel around the world without mom…"

Upside of disability: attention and advocacy opportunities. Both adolescents were at a point developmentally where they could also reflect upon and articulate positives regarding their life with disability. These centred on receiving extra attention and moving out of oneself, in an altruistic way. For example, Marie took up the opportunity to serve a two-year term as an ambassador for children with disabilities. She described her experiences related to this role as significant life highlights, "I have been able to meet people and do things that I probably wouldn't have been able to do…like, go to these big functions and galas and stuff."

Patterns of coping. When asked, child and youth participants described drawing upon a variety of coping strategies to manage daily life and times of adversity, including a very well developed range of emotion-focused strategies and a few problem-focused strategies (as per Folkman et al., 1986). Those individuals whose coping pattern included a balance of both kinds of strategies appeared to fare the best, based upon their own self-reported satisfaction and progress in life. The older children and youth described coping patterns that had moved from passivity to greater action due to their encounters with adversity, providing evidence for the significant role of hope and resilience in these children's lives. Social support was identified as essential to coping with life on a day-to-day basis and in facing difficult circumstances, including parental divorce. Two children also mentioned counselling or mental health therapists as having a significant role in helping them manage.

Each child's personal style played a significant role in the strategies they chose to use, specifically with respect to passive versus active choices. Comparisons to their respective parents' narratives, suggest that intergenerational transmission via modeling had a role. Through lived experience, all were nudged towards becoming actors in the world in order to achieve greater social engagement, self-efficacy and life satisfaction. This movement towards connection with self, others and life was a common experience, consistent with Erikson's theory of psychosocial development, and more recently, with Jordan's relational cultural theory (2010).

Passive personal style. Children and youth with experience using invasive technology, including a tracheostomy, were very passive on first impression. Quiet, but interested in the study, they willingly received my questions and shared their perspectives. Once comfortable with me, a few opened up and shared very personal stories.

Passivity was a characteristic that would have been naturally fostered by the context in which most of these children started their lives, as patients in hospital, tethered to monitors and technology, dependent upon staff and parents for all care. Coming home life would have been a little freer, but they would have remained tethered, physically and socially. Marie’s perspective was illustrative; asked how she told others about her needs Marie shrugged her shoulders and stated, “I just didn’t say anything…kept my mouth shut.” She also described her frustration with feeling powerless as a young child, when others dictated her care and routines, “I felt upset because I had really felt like I had no control of my life and it was being controlled for me and there was just nothing that I could really do about it.” This passivity followed her into adolescence, for example, influencing her management of a significant turning point - getting her trach out,

> I wanted her [stepmother] in the room but I didn’t want to tell my mom so...I just kind of wanted it over and done with... It should have been a good, fun experience and it was just kind of like blah. [Sound effect]....Because of the awkwardness, knowing that someone who is part of my family was not allowed in the room.

Jim's account of his own passivity reflected the more persistent, tragic consequences that could play out when preyed upon by a bully, in his case, for literally years,

> Jim: No one bothered me until he started bothering me [grade 2], so…he still bothered me, even up until I moved out here…Just eight months ago [grade 11]…I didn't talk to anybody about it, I didn't want to. I just learned to put up with it,
>
> I: Has anybody ever seen him bullying you?
>
> Jim: Oh yeah, many people. They all ask: “Why do you put up with it?” I just tell them that I, I put up with it so long I don’t care anymore.

Hope. An inherent and often mobilizing force in the children and youth's narratives was their hope. This was evident, for example, in their developmental drive towards the future, as Jim's plans demonstrated, "I have a goal in my life that I kinda want to reach…I want to start my own business...." Jim also held out hope that one day he would be free of his disability, given his progress to date, "I was the youngest one to get off of that [kind of ventilation] so quickly! So – happy I'm healing faster than everyone else…." Likewise, Marie's description of saying goodbye to her school nurse conveyed the hope that had accompanied her all along the journey to being decannulated, "it kind of was like ‘wow’ and we cried and it was like 'we did it!'"

Responding with resilience. Important as a coping resource in facing adversity, resilience was an inherent capacity in these children from the outset of their lives. As a coping strategy, accessing resilience provided children and youth with a way to make meaning from difficulty so that they could transform it, and in so doing, rise above it with their hope in hand, to respond in an efficacious manner. Exercising resilience often involved becoming more flexible in how they approached a situation, acquiring strength and resourcefulness. For example, when Marie's parents separated, she needed to reach out and actively connect to people, and she found support in her respite nurses and her friends, " It was difficult, but luckily I had people there to talk to."

Becoming an actor in life. When adverse circumstances made acting imperative, children and youth described making choices like Marie did above, tapping into their personal resilience and mobilizing their personal agency in order to act on their own behalf. For example, Jim, who also experienced his parents' separation, explained how he overcame his fear of getting his trach removed, “after my dad separated from my mom…go at least see him…that had a pretty big input into my courage building…and taking out my trach, you know.”

Gradually, with progressively successful experiences, these children and youth became actors in their own lives more fully, replacing passivity with assertiveness. For example, Marie recounted the self-efficacy she experienced upon taking more control over her health care, "As I got older I actually was doing my own trach changes and that kind of a thing. Like my parents were still in the room and everything but ...I knew I could get in faster."

Exercising personal agency was something that every child engaged in, regardless of their limitations, as Marcus's response demonstrated, when encountering people who were uncertain of how to approach him:

> I: When you’ve got someone who is looking at “the outside” [of Marcus], what is it that opens the door to “the inside”?
>
> Sandra (biological mother): His smile.
>
> Ellen (custodial parent): Yes.
>
> I: So when Marcus smiles and looks at people, that changes?
>
> Ellen (custodial parent, nodding): They change, the attitude.

Emotion-focused coping: a well-developed resource. Coping strategies that helped children and youth to regulate their emotion were very useful in circumstances where they had to cope with unchangeable situations (relegating the child to an otherwise powerless position). It is not surprising then, that the range of emotion-focused coping strategies demonstrated by these children and youth was well developed. Among them, several negative forms of emotion-focused coping were reported, including avoidance, distancing, and acting out, with corresponding negative consequences. However, there were also many valuable strategies that these children reported using. Below I provide a few illustrated examples.

Self-compassion. This kind of emotion-focused approach consisted of several strategies, including especially, seeing oneself as part of the human race, putting things in perspective and using humor. Jim's description of how he managed his feelings about his disability illustrate his use of these strategies,

> Not that many people have to put up with this. But, there's a lot of things I don't have, that a lot of other people have to put up with, like hepatitis or chronic diarrhea…good thing I don't have that! (laugh).

Self-expression. This coping strategy facilitated mindfully staying with an experience, through presence and creative expression, which often allowed a more helpful perspective to evolve. Marie described recently beginning a creative writing practice, which was quickly becoming her favorite way of managing difficult experiences and feelings, “talking is still up on the list, but it isn’t, I’d say, like, number one anymore. I guess letting my ‘coming out’ through writing is more so, more than anything now.” Anne also favored the use of creative expression, using drawing as her outlet, for example, during her interview.

Exercising compassion for others. The ability to have empathy for others and to seek to alleviate their suffering, was a coping strategy that Jim made use of when he was thwarted in his efforts to go on a trip with his class.

> I was all pumped on going…I had the money and everything…and my mom wouldn't sign the forms! (big sigh) That *bothered me*! I work so hard...but you got to look at it through her perspective, too. Like, it’s not just me that people have to

> worry about; it's like, if I *died* on that trip, (long pause) it's not my family life that would be scarred, it's also the students and the teachers that would be scarred….

Self-soothing and diversion. Each of the participants had favorite self-soothing activities that they used to comfort themselves, including playing videogames (Mike and Megan) and watching TV (Marcus). Anne named *Toy Story* as a favorite she watched with her family when she was not feeling well, while Marie and Jim were drawn to music, “music tends to soothe me” (Jim).

Role models. Some children and youth talked about fantasy or real-life figures that they identified with in the manner of a role model, seeming to access hope and power through their example. Role models could provide a valuable way of inspiring and teaching new behaviours. The examples provided by these children and youth related more to fantasy than real life, perhaps due to the absence of peers they could look to for inspiration, given their unique circumstances. For example, Jim described emulating the Karate Kid, a movie character who encountered and conquered his bullies, “The teachers tell me I had a lot of discipline...every recess, for about a month, all I did was stand on a pole. Just stood still, with my balance, standing like that on my tiptoes...” Later, on a trip to Las Vegas, he sought out Roy Horn, a popular entertainer whom he knew to have had experience with a trach, “I wanted to see Siegfried and Roy…the guy who got his face torn apart by that tiger.” From Wolfensberger's (1998) social role valorization perspective, this was a way of attaining more positive status, by association with a public figure who had experienced the same kind of socially devalued disability.

Among the younger children, fantasy figures that occupied roles of power and status tended to be the top choice. For example, Anne liked to think about the princesses she saw in Disneyland, whereas Mike liked playing with Star Wars action figures, and took great comfort from engaging in this activity with his sister when he was sick. I situated this theme between emotion-focused and problem-focused coping types because it could belong to either, depending upon whether the role models were engaged to help solve a real life problem or at a fantasy level, as a way to self-soothe through play.

Problem-focused coping. This approach, in which the children or youth took an active role in changing a distressing situation, was considerably less prevalent but present and developing in their narratives. Those who, along with their parents, were more actively engaged in their community, described using problem-focused coping more often, and their strategies almost always involved some form of social interaction, such as communication or accessing social support.

Using assertive communication. This valuable relational skill helped children and youth to approach their problem by telling others what they needed, or by constructively conveying their dislike of something that was happening. For example, Mike explained what he said to people who stared at his trach, “...could you please stop staring at my trach because it’s really bothering me.”

Getting help from an authority figure. This strategy was employed by all of the children and youth, particularly when they were young. Examples included, Megan going to her teacher for help when classmates wouldn't stop staring at her, and Marie going to her parents for help when she had a nurse she just couldn’t get along with. Likewise, Marcus relied upon his parent Ellen (custodial relative), to know how to handle unfamiliar people and situations, “Strangers would come up to him ...and unless she’s the one that says it’s okay, he will not even look at them,” explained Sandra, Marcus's biological mother.

Talking to a friend. Reaching out for some social support, discussed further below, was a valuable strategy that children and youth described using when encountering difficulties. Mike talked about how his friend at school helped him when he was frustrated, and both Marie and Jim described talking with friends when their parents were separating, "the only thing that helped me was my friend" (Jim). Marie also described her good fortune in the respite nurses she had to talk things over with, "They used to be the ones because they would sometimes be with me more than my parents were."

Problem-solving. The children and youth rarely described solving a problem without the help of others. This may have been developmental in part, and due to the dependent behaviour that had been cultivated during their early years, and/or due to having fewer opportunities to hone personal autonomy skills. However, when their own problem solving ability developed, it was useful, as Marie illustrated, in addressing the problem of privacy with her friends, through using the Internet in her room, “having my own computer it’s very helpful.”

Social support. This key coping method was reported by every child and youth, as one that they relied on via formal and informal relationships, to cope with a variety of aspects of their life.

Day-to-day peer and/or family support. The adolescents described using social support for venting, validation, diversion and problem solving. Marie described relying initially upon her school nurses, "...because they would sometimes be with me more than my parents were...now it’s my friends and just venting off each other."

Younger children used social support to attain comfort, belonging and soothing. For example, when Megan was sick she sought physical closeness with her foster mother, or other family members, to read books and snuggle, “Yesterday my mom slept with me.” Tom placed a high value on his relationships with the people in his school, including a young teacher, Quinton (possibly his aide), and his classmates, “...my students is, my kids are Oliver, Ian, and Nate, and Danielle, Bobby, Jenny, and finally Paul.”

Support in facing family breakdown. Both the adolescents reported being devastated by their parents' marital breakdown and struggling to cope. The presence or absence of people who could be supportive to them contributed in an important way to their experiencing. Marie described being able to tap into daily support from her nurses when her parents separated during her junior high school years, "they would be the first one that I would be able to talk to...." She also found peer support,

> ...there was one guy at camp...I was a wreck, I was just getting used to the whole - like my parents aren’t together anymore - and ...I was just really upset ...and ...he was there for me, and he kind of, like, listened.

The harmful consequences of social isolation. Jim by contrast, was considerably younger when his parents separated, and his immediate family was his main source of social support, creating a crisis for him. His family was new to the city and region, thus quite isolated from social supports like extended family. His parents worked full-time, he was bullied at school and his health needs kept him tethered to home and helpers, thereby limiting his opportunities for peer support. He was decannulated (his trach was removed) close to the time his parents separated and thus, he endured the further loss of his school nurse, a potential source of adult attention, support and protection. The conditions were set for disaster, lacking the social assets necessary to support him, Jim spiraled into a very destructive period of withdrawal and depression.

> ...as every little kid does, go through a separation or divorce from their parents, they have some, well, problems just getting through it…so, mine was, I didn't talk for about six months. After that I had to start building up my emotions again…started coming out…I was six and I didn't really start having like, my character come back to me until I was about nine or 10…Oh yeah, when you lose your character it's kind of hard to build it up again so…

My impression of Jim's description was that he had lost his hope. Jim explained that when his older sister discovered the extent of his self-destructive efforts, she alerted his mother, who took him to the doctor for treatment with medication and psychotherapy. Once he had recovered to the point that he could feel hope again, Jim reengaged in an active manner with the support and validation of a close friend, he said, "I can change my life." He also acknowledged the importance of his very close relationship with his sister, particularly in the absence of their mother, whom he described to work during the day and be out often at night: "So me and my sister looked out for each other, so we ended up maturing quicker than any other kid… I cooked, she cleaned, that was the rules. (Laughter)...I could talk to her…"

Dealing with others’ responses to difference. Managing others’ responses to difference was a commonly reported experience among participants who had a trach. The way in which children and youth managed others' responses reflected their personal style (passivity versus assertiveness), their attitude towards their disability, and the coping strategies that they had developed. The approaches they described using are discussed below.

Developing compassion. This response was grounded in a personal caring for others and an understanding of the experience of suffering, based on lived experience. For example, Jim sums up how he transformed his experience with marginalization to a positive end, "...being visually different from everyone…like, it's not the color of your skin, it's just the thing in my neck.... I know how it feels being on the other side of the rope."

Acting as an educator. One of the key aspects of a constructive response to others' reactions was the ability to anticipate and respond to the need people had for information about something new. Once the information was provided then it was possible to move forward in relationship. For example, Anne responded matter-of-factly to her classmates' questions about her respiratory technology stating, "It's okay." Once their questions were answered, everyone moved back into playing together. This example demonstrated a dialectical process of responding to disability.

Using assertiveness. An important skill and coping strategy that each child had to develop was assertive communication. This was particularly valuable during interactions with others in uncomfortable situations and served as a constructive strategy, as Mike demonstrated, in letting others know when they were bothering him, "...could you please stop staring at my trach because it's really bothering me."

Getting help. Being able to seek the support of an authority figure to help when difficulties were beyond the child or youth's control was an important strategy in dealing with difference. For example, when Megan's assertive communication didn't work with her classmates she knew to alert a higher power that could intervene on her behalf, as with any other inappropriate behaviour, “They stare at your trach...I talk to my teacher.”

Expressing feelings. The ability to express one's feelings to others was another important way to communicate personal experiencing. Nonverbal communication could be quite effective, particularly if verbal means were not possible, as Marcus demonstrated when asked how he dealt with people who stared at him. Marcus pursed his lips and looked at the ceiling while his mother explained, “[He] gives looks back...The Jones' look...That's how you can tell when we're upset or we're mad, our lips will go up.”

Patterns of relationship and what mattered. Living in the community, relationships were an integral part of the children and youth's lives, situated in multiple contexts. Their first and most continuous community, that of their family (microsphere), occupied a central role both as a unit and with respect to relationships with parents, siblings and other family members. Friends and school occupied a second very important domain (mesosphere), that increased in dominance as the child matured. Respite care nurses occupied a special part of life at home and school for children who depended upon invasive respiratory technology, including a trach. The child's relationships in the health care system (mesosphere) also continued, although usually decreasing in prominence, especially if the child's technology needs decreased. However, health care remained an important aspect of the child's life, especially from a developmental perspective, as their awareness and desire to participate in their health care management increased.

Authentic engaged presence emerges as central tenet. The children and youth had widely varying experiences in their relationships, modified as they were, by their own unique sets of circumstances, which covered the spectrum in terms of relational wealth. However, as the subsequent descriptions I present will demonstrate, "authentic engaged presence" was the central tenet of relationship that consistently emerged in their descriptions of key supportive relationships, across contexts.

Core relational elements: caring, communication, collaboration and competence. Accompanying the central tenet in any key relationship, were up to four core relational elements, namely, caring, communication, collaboration and competence. While the children and youth described experiencing these elements as part of their relationship with their parent, for example, in some contexts, such as with their teacher, pediatrician or respirologist, they might also be invited to engage in developing them.

The community of the family. The family was the first and most constant community in each child’s life, the ground upon which they were known for themselves, and which served as the repository of their story. The younger children’s perspectives highlighted the role of family in providing caring and nurturance, “At home I like to spend close time and reading books” (Megan). Anne described going to Mommy for help and being comforted by snuggling and physical contact with her parents, for example, when she was sick, "And my daddy come and give me a kiss."

Family as a source of nurturance and presence. The children and youth described important ways that family helped them, including offering encouragement, interest and confidence in their capacity as a person moving into the world, while also providing a comforting refuge when the world overwhelmed them. Jim explained how his family made itself available,

> Well, when I'm at home - nobody really pays attention to you, we all just do our own thing, but when we need each other we all, we are there, that's the thing...We would talk to each other, we'd verbally just walk up and say to the other… we need to talk to you.…And then that will get everyone's full attention, they'll drop what they're doing….

Family as a place of belonging. Being part of a family gave the child a place to learn about relationships and to understand their place in the world (Figure 4). Ellen,

Figure 4
Anne's drawing of her family (left to right):
foster dad and mom, Anne, her foster sister, 2 pet dogs and cat.

Marcus's parent, articulated this well with regard to immediate family, “The two most important people are (myself) and his mommy. Of course hey? (Laughing)" And in terms of extended family, “My family all treats him the same. Like, when the twins come over first thing they do is give him a sippy cup and a toy,” and regarding Ellen’s nephew, “Arthur just has to walk by him and he gets all excited.”

Parent-child relationship about caring, responsive presence. Children and youth described valuing their parents’ authentic engaged presence, including caring, listening, responding and communicating confidence in their abilities (fostering competence). Parents' personal interest and engagement in shared activities was another highly valued aspect of this relationship. While the younger children cited this in concrete “here and now” terms, 18-year-old Marie described this more generally, "Listening to what I had to say and stuff....And actually doing stuff with me I guess....Spending time together. More so the one on one time, rather than - like my sisters were born by this time so." Marie also articulated the importance of her parents’ affirmation and respectful support, particularly when her monitoring needs changed, after her trach came out and the nurses left, "...That’s when I got my cell phone,…it meant that they trust me…So it was kind of a symbolism of it’s own, in the meaning of: 'I can do this'."

Playing together. Parent-child play was another favorite way of being together. Play was a way to enjoy each other through engaging in fun that depended upon the participation of both parent and child.

> His favorite is touchdown, we play touchdown. I take him off the machine [mechanical ventilator] and I put him on me and I carry him and go to bed with

> him, we run and we go “UGH!” (Sound effect) right on the bed and I go: I GOT YOU!! Ya (Ellen, describing one of Marcus's favorite games).

Parent provides a holding environment. Parents performed an important role in helping the child manage times of distress. Jim's description of a turning point he experienced with his mother illustrated the holding environment of attachment that she could provide using authentic engaged presence.

> Jim: I completely forget the reason why I was crying…my mom didn't know why I was crying, but, she ran to my room and got my teddy bear...that was my favorite, ...gave it to me, I held onto it, and she put me on her lap, rocked me back and forth saying “It's all right, Jim, stop crying!” and after I stopped crying, she talked to me ... (long, long pause)…that was actually really a touching point in my life…She was just *there for me,* that's all, she was there for me, I can't tell you what she said…I just remember that being a turning point…
>
> I: What changed?
>
> Jim: My attitude. I matured a little bit and…I…actually helped around the house started cooking and cleaning, dropped video games for awhile…

This interaction was a transformative experience for Jim. His mother's immediate, caring response to his openly expressed need, created a connection for Jim that led to greater productivity and interest in more connection (this is consistent with the process described by Jordan, 2010). This kind of experience also helped him to discover his own personal agency, essential for his own development and progress as a person in the world.

Maintaining accountability and building capacity. Another important aspect of the parent-child relationship was the manner in which parents responded to their child when there was trouble. Jim's story illustrated how his father's authentic engaged presence and attempt at collaborative communication helped them to forge a stronger relationship.

> My dad just sat me down in a chair and he was really upset about...what I was doing over at school. He never got notified about this, ...So he...asked me if there is anything I want to tell him? ...I tried to think for a second, and I say 'No' so he brings it up...and told me what it was, and he told me 'I want you to tell me by the end of the day what you're going to do to change this.'...and, 'I want you to only put it down if you can stay true to what you wrote down.'…The day went by, I had a whole page...of what I could do,...that was the best attention attempt he had at trying to connect with me....That showed me that he actually cares and that he'll always be there for me no matter what the problem is.

Jim's father had discovered the extent of Jim's troubles late in the situation, likely due to living in a separate household. Nevertheless, he addressed the situation by holding Jim accountable for his behaviour. He did not try to solve things, he expected Jim to have the capacity for positive change, set the task before him, then reviewed with Jim what he proposed and pressed him to commit to his own self-constructed course of action.

Sibling as trusted ally. Siblings filled a critically supportive role in the lives of these children, they were the child's first and most constant peer thus, often a key ally. Jim articulated this particularly well in describing his sister's role as his confidante,

> Pretty much she listens until there is nothing else to be said, and then she gives her opinion, she takes everything into account, she gives her straight answer…tells you what she thinks you should do, doesn't care if you follow - she won't push it into you - she'll just tell you what…she thinks is best…*and* she doesn't really tell anyone else.

Here it is possible to see authentic engaged presence at work once again, along with caring, communication, collaboration and sibling-worthy competence (significantly, Jim's mother later described her relationship with her sibling in almost the same terms).

Community-based friendships. Beyond the family lay the world of friends in the community. Their significance was made very apparent by the high proportion of time and attention participants spent discussing these relationships in their interviews. A number of subthemes demonstrated the important role played by friends.

Fostering and affirming identity. Friends provided a relationship in which the child was able to be his/her own autonomous person in the world, experiment with his/her identity, and receive attention and affirmation from peers. For example, Mike explained,

> Mike: I have my best friend I like him...Tim.
>
> I: From school?
>
> Mike: Yes. And he likes Harry Potter....When he was in grade three we met.
>
> I: Does he play with you?
>
> Mike: Yes sometimes....Go to the computers and do scooters...he’s a very good friend and he doesn’t treat me - no bullying....He knows a lot about Harry Potter and I don’t....He listens.

Providing encouragement. The presence of friends at school was given particular prominence in participants' descriptions. Friends could provide reassurance and encourage the child to keep on in the face of difficulty, as Mike acknowledged, in describing how his friend Tim helped him when he struggled with math, "He just explains it’s okay."

Providing opportunities for normal play and socialization. The social worlds these children occupied were very limited, due to their monitoring constraints. Friend-making was more difficult, thus also more cherished when a successful relationship was established. For example, Jim described his first friend, "We found common ground with everything and we ended up being friends...he pretty much just gave me someone to hang out with instead of being cooped up in my house." Anne drew and talked about three friends (see figure 5) she played with on a regular basis, at home, at the playground, and going to each other’s birthday parties. To get around her limited freedom, she explained: “They come to me....”

Figure 5: Anne and her friends

Best friends – it's all about trust. Some of the children and youth had experience with best friends. They described these friendships as offering intimacy and a safe refuge in times of adversity. Best friendships shared significant amounts of common ground and were cultivated over time. Jim described the two people he looked to,

> My sister Melissa or my best friend Ian...I actually tell them anything. I've known them my whole life. I have grown so attached to them; I'm comfortable with any situation, because I know if I was in a life-and-death situation, they'd have my back no matter what! I trust them with my life!

Pets - being a caregiver. Most of the children had pets living in their households, providing an opportunity for them to engage with another being as a caregiver. Megan raised the experience she had with a friend's puppy, illustrating the pleasure and efficacy-building potential of this kind of relationship, "...Ted has a little puppy named Cleo....She's very little....Sometimes I hold her....And sometimes I babysit with Ted. I do some of it. Feed Cleo. Give Cleo some water."

Relationships at school. The child's school provided a domain that was very normalizing, as it was completely removed in focus, from health care and home. The perspectives that these children and adolescents shared portrayed school as an important part of their life, consisting primarily of opportunities for mastery, making friends and occupying the valued role of student. However, it had its downside for some, particularly Jim. He described extensive experiences with difference, bullying and marginalization, with the apparent absence of a concerned or intervening adult. Children, who by their parents' report, were attending schools that practiced inclusion, appeared to have a much better experience. Jim's recent move to a new school and his subsequent experiences suggested that some progress had been made in schools on the bullying front, perhaps due to new anti-bullying and inclusive education practices. Emerging themes in the context of participants' school experience concerned relationships, either with others or in developing their own identity, as described below.

Finding and building friendships. School was an important friendship-making centre in the lives of these children, particularly due to the constraints that their health needs placed upon their freedom in the community. Tom described school as the place where he had all of his friends. Megan talked about playing and learning with her friends at school, “We go in gym and we go on computer, we go to music, sometimes we play kitchen.”

Experiencing self-identity, mastery and valued roles. School provided an abundance of opportunities for children and youth to experience mastery and experiment with different roles. Here, one could try out many different valued and normative roles. Jim enthusiastically described his experience with a welding job-training program he accessed through his school, “I had a jumpsuit...had my name on it too!....It’s in my closet right now....It’s hanging on there as a trophy and my welding gloves also have my name in them.”

Making meaningful connections with teachers and other adults. Children and adolescent participants talked about the importance of teachers in their narratives. The teacher's leadership position situated him/her well to foster an emotionally safe, positive learning community. The teacher could also provide modeling of appropriate social behaviour, and act as an ally on the child’s behalf. Both adolescents described the teachers they appreciated most as those who built meaningful connections by taking an interest in them as people first. For example,

> My one English teacher...he listened to us and he...made the class a lot of fun...when we had an opinion he actually listened to it and...talked about what we had to say...he cared what we had to say. (Marie)

Jim, who had a far more marginal experience, articulated a similar perspective, based upon his contact with a couple of teachers at his new school,

> They…talk to me like a person like, not as a student, but as a person with an ordinary life. Like, after class, they'll…talk to me and after school, while I'm walking home they'll stop and say "Hi" if they see me.…I haven't actually had that with another teacher before….

These examples again demonstrated the tenet of authentic engaged presence, as well as the core elements of caring, communication, collaboration and competence from a teaching perspective (connecting and engaging the student on their own terms).

Being bullied and marginalized. A couple of the children described experiencing marginalization and bullying at school. For Jim, it was a central theme in his narrative. His experience with victimization began early in his school career, when he was concerned with protecting his trach, so would simply submit. Despite his teachers witnessing the aggression, there was a noticeable absence in his account of any action on their part or the administrator's to address the situation,

> Oh yeah, my teachers all see me as a pretty intelligent kid, so I guess I proved them right when I was pretty silent and didn't fight. And then one day when I got the thing [trach] taken out, they were happy for me and then they saw that my plain attitude started changing, I started hanging with different people, started doing nothing in class, a little more aggressive and rowdy, that's pretty much it.

In spite of a new rougher, tougher attitude, Jim described the bully as hounding him for years. However, more recently at his new school, when another bully tried to get things going with him the situation unfolded differently, "Surprisingly, everyone's jumped to my side, whenever he's around! They'll just…if I walk away…they come with me! I don't know why...." This new context was unfamiliar territory for Jim, his old role as victim was no more. He would have to discover who he could become in these new circumstances. The difference in climate suggested the presence of a school culture that did not support bullying.

Managing difference at school. Being stared at and perceived as different by classmates was a common experience for all. School peers were observant and inquisitive, necessitating a response. The manner in which this was handled depended in part upon the child's response (as previously discussed), and in part upon the teacher and the school. For Anne, who accepted her trach and oxygen as necessary, a matter-of-fact explanation to her peers seemed to take care of their need for information, and the matter ended there. In contrast, Megan disliked her trach and was very self-conscious. Her classmates' stares upset her, and when her own request for them to stop didn't help matters, she sought her teacher's help, which involved disciplinary consequences, "...sometimes send them to time out." Action at this point seemed to terminate the marginalizing process before it could gain much momentum. The expectation the teacher communicated through her actions helped Megan's classmates learn more appropriate behaviour.

Anne and Megan illustrated two different ways of responding to disability that mediated the social aspect of their appearance. Of significance in the school context was the supportive, inclusive environment offered to both of these children. The teachers supported them in managing their personal and social circumstance as well as they could, while modeling acceptance and teaching respectful treatment for all.

Nurses as friendly helpers at school. Five of the seven children in this study had experience being accompanied to school by a nurse on a daily basis. The children and adolescents' perspectives showed some variation in the kind of relationship that worked for them with their nurse. Young children were aware of their nurse's presence in the classroom as a helper, but one who sat unobtrusively at the back and let them participate in the life of the classroom with a minimum of interference, as Megan described, "She sits in a chair way in the back....She does it every time." [I: And do you like that?] "Ya."

Marie, by contrast, had required the company of a nurse at school up until the beginning of high school thus, nurses had played an important part in her life. Her description of the nurses that had the most compatible relational approach was strikingly consistent with the tenet of genuine authentic engagement, and more specifically, characterized by a person-first approach,

> ...not just the caring about the health, but actually like, wanting to do stuff with me and like, actually engaging me in stuff....I guess they kept me as a *person* rather than me as the one with the disability first. (Marie)

Providing a compassionate presence while also respecting the child's privacy in difficult times was another important aspect. Nurses who could respect Marie's confidences and who identified with her experiencing were her first line of support in the early days of her parents' breakup, "Just them listening and being there to listen…especially hearing if ...they knew what it was like....It made all the difference in getting through."

Finally, being a partner on the journey was an important aspect of shared experience that allowed Marie to feel that she was not alone, she was supported. Shared hope and collaborative caring was evident in Marie's description of how she and her nurse celebrated her successful decannulation: “...we cried and it was like 'we did it!' "

Community respite relationships. Due to the intensive and ongoing nature of their care needs and their parents' need for respite, children and youth had to learn to navigate additional caregiver relationships, many of which are covered in the subthemes that follow.

Nurses as helpers in normative living. Respite nurses appeared in the children and youth's narratives as helpers in finding and developing community-based friendships. Respite could take place either in or out of the child’s home. Children who lived with their biological family more typically had in-home respite and children in foster homes more often went out of their home for respite services.

Out of home respite has advantages and disadvantages. Some children received respite by going to the nurse’s home, where they might have the opportunity to form friendships with the nurse’s children. This context could also offer children a sort "extended family" experience, and they could enjoy some more normative aspects of friendship, for example, “And sometimes I sleep over there” (Megan).

While the benefits of this arrangement seemed obvious, the playing field was not level; the child was in another’s domain, subject to different values, competition (not necessarily a bad thing) and potentially, bullying. For example, Mike gave this account about watching a show he was not allowed at home,

Mike: I watch it with respite nurse.

Laura [foster mother]: Rob watches it with you?

Mike: Yes.

I: Is Rob a friend or family?

Mike: Well he's family.

Laura [foster mother]: This is one of the respite nurse's four kids. And they spend a lot of time with Mike and his sister."

I: Okay. Do you have fun with the respite nurse and her kids?

Mike: Yes. Sometimes they are being mean to me, sometimes.

In-home respite: child-centred compassionate approach works best. Homecare nurses who attended the child in his or her own home helped the child to build social relationships in their capacity as caregivers, and by taking the child out into the community. For example, Ellen described Marcus deriving great pleasure from his home respite nurses, who approached him with an attitude of friendly companionship and engaged him in activities that were meaningful to him as a three-year-old boy. She also commented on the supportive compassion shown by his respite nurses during appointments when there was bad news, "Mary [respite nurse] helped us a lot. I have to say if it wouldn't have been for Mary we wouldn't have been able to [cope]."

Relationships in the general health care system. While the health care domain occupied a central role in the early part of these children and youth's lives, it did not dominate their narratives. However, as a part of their lived experience, some meaningful relationships did arise. These usually included their pediatrician, one or two allied health staff (for example, a physiotherapist and a behaviour therapist), and the respiratory clinic staff. The core elements of relationship that children and youth consistently identified in these relationships included caring and communication, shown through maintaining a person-first attitude, a warm, friendly approach, and personal caring interest. Other elements included competence and collaboration, specifically, being sensitive to the child's developmental readiness to engage in his/her health care experience and inclusion in a suitably participatory process.

The child's pediatrician and a select few health care providers garnered special attention from participating children and youth. The pediatrician was often their empowering ally, attuned to their developmental level. For example, Anne, at seven years of age, enjoyed her pediatrician's attention and sense of humour, while Marie, at 18 years of age, appreciated her pediatrician's acknowledgement of her right to greater autonomy,

> When I was getting older I started going into the doctor's room by myself, I liked that. It was, especially if my mother was the one that was taking me to the doctor's appointment....I'd say around 15. Started with my pediatrician...[inviting her in]...Or kick the parents out and be like "Is there anything?"

Health care providers who used a rapport-building approach were also singled out for praise. Children who could not engage in the usual banter and activity nevertheless wanted to be included on their own terms. Ellen described the approach that put Marcus at ease the most, when visited by his favorite health care providers, (including his in-hospital physiotherapist and his respite nurses), "You know what, it's the way they talk to him...very soft tones.... Just eye-to-eye contact with him and you know what I think? It's because they aren't scared of him. Most of them squat down to his level." Mike also talked about a therapist he saw in psychiatric services that he had a special affinity for, "Well I really like her...and we talk about feelings." [I: Is she like your counsellor?] "Yes. A behavioral therapist....And Dr. Clark." [I: Does she listen to you?] "Yes."

Respirology clinic relationships. All of the children attended a specialized respirology clinic with their parents on a regular basis. During appointments they saw various team members who checked to see that their respiratory technology was meeting their needs, and to troubleshoot or adjust for any difficulties or changes that presented. Over time, relationships formed with the staff providing the children and youth's care, and, if they required hospitalization, they were likely to see them as inpatients as well. Patterns of relationship that the children and youth identified as working for them in this setting included the following subthemes.

Personal, friendly approach. The doctors' and clinic staff's personal approach was highlighted by children as a valued part of their experience with the clinic, for example, "At the clinic they give hugs and I like talking to Dr. Fellows" (Megan).

Inclusion in health care experience at developmental level of readiness. Young children liked it when staff looked at them, included them in conversation and listened to what they had to say, but also allowed them to defer to their parents as the primary communicators. Seven-year-old Anne, for example, liked to be able to do some things for herself, with some direction from the staff.

Being invited into the conversation. Adolescents wanted "in" on their health care management, sometimes earlier than expected. Marie recalled wanting to be included earlier than when she was, "I guess when I was around…10 or 11, when I actually started understanding all of this." Before she started being invited she described her experience as, "Kind of like they wanted to keep it a secret." Not being included was, "Not so much frightening, but just kind of frustrating. (long pause) Because I was the one that was here....I felt like I was kind of the invisible patient at times." Marie described the following approach that helped to make her feel included and respected,

> Listening when I have concerns and talking about it, and actually involving me and like, rather than just talking to my parents about everything....Especially when it comes to being admitted...it helped me know what I'm getting into rather than just my parents knowing everything.

Note the tenet of authentic engaged presence evident in Marie's description, along with the four relational elements of caring, communication, collaboration and competence.

Using an inclusive approach. The use of inclusive practices was very important to Marcus, for example, who, being wheelchair bound and nonverbal, was unable to approach others or call attention to himself in a direct way. He enjoyed being personally approached by staff in a friendly way, it helped set him at ease. Ellen explained, "The ones that talk to him, - you can tell that - if they talk to him...he's fine; but if they just come in and they are just standing there, he gives funny looks....He doesn't like that..."

Changes over time regarding development and disability. Changes over time (chronosphere) were apparent in the children and youth's narratives with respect to several domains. The developmental process as a force of nature, in its persistent, perpetual unfolding, was most evident in the lives of the children, their families and the systems with which they interacted. Children and youth's perspectives regarding their disability also changed, as did their health condition sometimes, for better or worse. Children and youth also evolved in their coping patterns, as experiences with living in the world drew them out of themselves and into greater action and interaction with the world.

In addition, they benefited from the evolutionary changes in each of the systems that served them.

Growing up and looking to the future. The relentless march of development, accompanied by hope and optimism, were apparent in several of the children and youth's narratives. Young children were concrete and more immediate in their views, for example, seven-year-old Anne, shy and reticent, had just begun Kindergarten, and was learning to communicate her needs, as she stated, using “my words.” Whereas Mike was anticipating his transition from elementary to junior high school with excitement, [I: Are you going to be 13?] “Yes - I am a teenager right?” Meanwhile, Jim and Marie were both on the cusp of entering adulthood, and their perspectives reflected the position they found themselves in. Adolescence for Jim had involved engaging in considerable risk-taking. At the time of the interview he was still struggling to finish school and was feeling the developmental pressure,

> I feel like life's standing still right now…I should have graduated by now, but as soon as I graduate, it's just going to go by so quickly, I just know it…I’ll have a job, I'll have money and then I can do some things that I've wanted to do for awhile,

Like adolescents at his stage, he also held high aspirations for school and work,

> I have a goal in my life that I kinda want to reach…I want to start my own business and mechanic shop, auto painting, have a restaurant and hotel, and renovations place in the back. All those in one compartment.

Marie described maintaining her typically young adult desire for privacy and space, “Pretty much the only time they see me is when I have to do dishes or clean or eat.”

Adjusting to disability over time. Living with disability also had its developmental attributes, and the adolescents were most able to comment on this, given their longer experience and perspective. Jim described holding out hope for an eventual recovery from his condition, encouraged by his body's improvement to date, which was significantly more than the doctors had predicted. He had also noticed a decrease in intensity regarding his fear of lifelong disability, "When I was younger, I actually feared having it my whole life. But now as I'm older, I still kind of have that fear…it's just...it's just vague now, not really as big…."

Marie's growing up process had involved her becoming more actively involved in her own care, progressively taking over responsibility, which in turn had led to increased satisfaction and empowerment, "...once I was able to start doing it for myself it felt a little better because then it felt like I had somewhat of independence, even though it wasn't all there." Recently, she had transitioned to adult services, and with this new arrangement, she described feeling much more in control of her body and health.

The presence of these children in the community has and will continue to shape society's reception and acceptance of difference, thereby influencing the children's perceptions of their experience as well. This evolution also appeared in their narratives, for example in the younger children's more inclusive school experiences. This affirms an ongoing process of change that is in continuous dynamic motion.

Summary of the children and youth's perspectives. The perspectives shared by the seven participating children and youth revealed several themes regarding what life was like for them. Above all, their pursuit of a typical life and their strivings for normalcy were the most dominant. Those that depended upon invasive technology experienced lives that were constricted physically and socially due to the limitations placed upon them by their disability and the respiratory technology they required. Living with disability and dealing with others’ responses were aspects of life that each child and youth grappled with and had to learn to manage. The employment of inclusive practices at school, combined with the child's own personal acceptance of their disability and a matter-of-fact approach to helping others understand, seemed to facilitate positive relationships and patterns of interaction. Despite the ties that bound them closer to the earth than their peers, these children and youth were drawn into active engagement in the world by the pull of community life, their parents' encouragement, and their own developmental drive.

Coping patterns that worked for these children and youth involved learning to move away from the passivity of their early, fragile days, and out towards becoming actors on the stages of their lives. For example, learning to advocate for themselves (caring and communication), and taking over their personal health care when they were ready (collaboration and competence) were efficacy-enhancing endeavors through which these children and youth could realize positive relational growth. Effective coping also meant learning to employ a balance of problem-focused and emotion-focused coping strategies, in order to face adversity, rather than withdraw from, or attempt to avoid it. Being connected to a social support network including family, friends and formal supports when needed (for example, doctor, counsellor, therapist) was essential to help the child or youth manage the stresses of daily life, and particularly critical during times of adversity and vulnerability. When children and youth were confronted with their parents' marital breakdown, the availability of additional social supports was a necessity.

Respite and school nurses, by their presence, were well situated to provide valuable support during these and other times of distress.

Establishing meaningful connections with others was essential. Children and youth's descriptions of the relationships that worked for them were consistently characterized by the central tenet of authentic engaged presence, and included the presence of four core relational elements, namely, caring, communication, collaboration, and competence. Relationships grounded in this approach facilitated mutual respect and trust. The family was the child's first community and refuge from the world. The presence of parents who were available, caring and actively engaged in their child’s life was important to their wellbeing and development. Siblings also played a vital role as the child's first peer, playmate and potential ally.

Systems that served these children well employed inclusive, community-building practices. Professionals that were described as helpful made meaningful connections by approaching the child with a caring, collaborative “person-first” attitude, and a friendly, personally engaging manner. Furthermore, these children and youth articulated their need to be able to participate in their health care management at a level of collaboration that corresponded to their developmental level of readiness.

Each of these children showed that they approached their lives to the best of their ability, given the context in which they were situated, and strove to establish their identity as a person first. By being themselves in the world, these children and youth have collectively built a beachhead, as teachers and pioneers in a community that is continually learning about and adapting to diversity.

The Perspective of the Parents

In this chapter I present the findings obtained from my analysis of the interviews I conducted with the parent participants in the interview sample. These findings respond primarily to the first three questions of the study, which seek to explore the parents' lived experiences, patterns of relationship and patterns of coping that they found helpful in making a good life, and in facilitating their child's development and adjustment to disability. I will begin by providing some specific details about the parents' various contexts, including a comparison of the foster parents' and the biological parents' respective circumstances. I will then briefly review my approach to the data from a theoretical perspective (previously discussed in Chapter One), and describe the manner in which the data is presented. The themes arising in the findings will then be presented beginning with the parents' lived experiences, including the patterns of relationship that developed, and the patterns of coping that they found helpful at the time. Attention is also given to the manner in which parents facilitated their child's development once they had them at home. Following the findings of the parents' lived experiences I will explore their coping patterns more specifically, with particular reference to parents' descriptions of the specific coping strategies they engaged in. Parents' reflections on their changes in perspective and coping over time will then be explored, with some consideration given to the role of counselling and psychotherapy, as a helpful resource frequently mentioned by parents in their interviews.

The parent participants. Eight parents raising children with complex health needs that included respiratory technology dependence participated in the interview sample for the study. All of the parents but one had experience caring for a child with a trach. This remaining participant, a single father, was caring for a child who had just recently begun nocturnal mask ventilation.

The sample was quite heterogeneous, including some specific variations related to family structure. Half of the participants were or had been single parents for the majority of their children's life, including John (biological father), Ellen (custodial biological relative), Laura (foster mother), and Roberta (biological mother) whereas, the other half were parents living in two-parent families, including Don (biological father) and Sherry (step-mother), and Keith and Beth (foster-parents). To protect participants' privacy while staying true to their voices, pseudonyms have been used, and where necessary, circumstances that are not essential to the matter at hand have been altered.

Differences between foster and biological parents. Some qualitative differences appeared between the circumstances of participating foster parents and participating biological parents that must be noted in considering their perspectives.

Foster parents made a conscious choice, in most cases, to parent children with complex health needs, whereas biological parents had to either adapt or choose to place their child in care, and sometimes they had to do both. Often, foster parents, such as the mothers in this sample, had a prior background in nursing, whereas the biological parents had to both learn to care for and adjust to their child's complex health needs. Likewise, foster parents did not traverse the same course of grief and adjustment that biological parents did, and, consistent with their role, they were "paid parents" in contrast to biological parents who had to balance paid work with family responsibilities.

Although foster parents had to work hard to actively recruit, train and schedule their own respite staff, they subsequently found that this gave them the versatility they needed in their arrangements, whereas most of the biological parents had to depend upon a service system. Finally, there was a notable difference in the continuity of the family unit. In this study, both foster families sustained themselves and grew over time with the affected child, whereas, divorce or loss of a parent was a factor in all of the biological families.

These differences may help to explain the greater adversity and distress apparent in the narratives of biological parents, particularly amongst single parents, and especially single working parents. Nevertheless, biological and foster parents shared many themes in common and significantly, converged on the same themes regarding the patterns of coping and relationship that worked for them.

Experience-based differences. The duration, intensity and context of parents' experiences had a bearing upon their perspectives. Roberta and Don were the "pioneers" in the sample, having raised their children with complex care needs from infancy to the cusp of adulthood (17 and 18 years respectively). Their perspectives reflected the extent of their involvement over time (the chronosphere), particularly their encounters with earlier service practices and subsequent changes/improvements to these. Ellen, Sherry and John were the most recently initiated parents, with experiences ranging from four to ten years. They focused their comments more on grief, lifestyle adjustments and their encounters with the more fully evolved service systems. The foster parents in the sample, Laura (a single parent who had recently married) and Keith and Beth (a long term couple), had all fostered children with complex health needs for over ten years. They described many parenting experiences in common with the biological parents, as well as, sharing their own perspectives related to the challenges of fostering children with complex health needs in a changing child welfare system.

Gender. The presence of fathers is noteworthy, due to their frequent absence from the research literature. Three of the eight participants in the interview sample were fathers. The data will show that their perspectives on the various issues covered were very similar to those of the mothers' in this study.

Family Structure. The presence of a mixture of single parents and two-parent couples provided the opportunity to compare and contrast the experiences of parents in each context. Consistent with the significantly greater workload borne by a sole caregiver, the data will show that single parents experienced higher levels of distress, financial difficulties, and social isolation than parents living in two parent-headed households, particularly if they also worked outside the home.

Approach to the data. I employed several theoretical concepts in my approach and interpretation of the data, which I refer to from time to time in the context of the findings, therefore a brief summary is provided here. Bronfenbrenner’s bioecological systems theory of development (Bronfenbrenner and Evans, 2000) provided the overarching theoretical framework for considering the data from a systems perspective. Beneath the level of systems, particular theories were helpful in explaining interactions described at the interpersonal and intrapersonal levels, I describe each of them below.

Relational dialectics (Baxter, 2004). This theory of social interaction provided a good fit with parents’ descriptions of their interpersonal relationships with service providers. Specifically, this theory attended to the interdependent tension present in the pattern of interactions between the players, and its bearing upon the development of the relationship, either as engaged and collaborative or adversarial and alienating. Key elements of relationship consistently emerged in the patterns parents identified as working for them, across service systems.

Social cognitive theory of development (Bandura, 1997). This theory of development was helpful in interpreting parents' relational approaches and developmental changes at the intrapersonal level and subsequently, the interpersonal level. Evidence for the process of triadic reciprocal causation (Ibid), emerged in parents' descriptions of their context (external environment), their personal approach to adversity (personal factors), and their subsequent response (behaviour). This process offered an explanation for how parents' responses were perpetuated or altered in their adverse circumstances through their own responses or a change in the environment (for example, a service professional who facilitated relationship building), all other conditions being equal. Bandura's concepts of self-efficacy and personal agency also helped to describe the dynamics behind parents' choice of response to their context and their subsequent experiences. The importance of these factors to the parent and child's wellbeing cannot be understated, as the data will show.

Coping theory and the concept of resilience. Lazarus and Folkman's (1984) coping theory and the concept of resilience (Rolland & Walsh, 2006) provided a means to understand the parents' intrapersonal response (personal factors) to adversity. Access and utilization of social support, as well as both problem-focused and emotion-focused coping strategies emerged as important components in effective coping patterns. Neff's concept of self-compassion (2003) was used to further consider adaptive emotion-focused coping strategies.

Finally, consideration was given to the parents' experience of change over time, (chronosphere) as the progressive dimension in which the parents' developmental process was seen to unfold, within and across domains, consistent with Bronfenbrenner's theory of development.

Organizing and presenting the data using the parents' narrative chronology. Participating parents tended to share their lived experiences in a narrative, chronological form, thus in the realm of time (chronosphere). Staying true to the participants' voices, this context has been employed as the template for organizing and presenting the data, acknowledging the contextual spheres of parents' experience as they emerge. Perspectives on patterns of coping and relationship arose at times, within these narratives, and are given attention alongside the analysis of the participating parents' lived experiences. Parents' views on facilitating their child's development and adjustment to disability were described in relation to the parent-child relationship and as such their exploration will follow.

Beginning the journey: confronted by the unexpected. The early part of the parenting journey lay primarily in the realm of the biological parents' experience in the sample, with the exception of one foster family, whose child's complex needs were discovered after placement. Participants described initial encounters with their child's complex health needs as difficult, usually situated in a hospital (mesosphere), "...it's a great shock at the beginning" (Don). When asked, many gave a detailed account of their child's circumstances, recalling the passage of time with particular precision, "…when he would go to sleep he would quit breathing. So they rushed him over to Emergency...when he was 24 hours old. So it's been 18 years minus a day… actually they told me he wasn’t going to live" (Roberta). This detailed time referencing consistently appeared, conveying the intensity of their experiences, still present even in recall years later.

Responding to the discovery of the child's needs. Based upon the narratives, time appeared to play a moderating role in parents' experiences related to the discovery of their child's health condition. There appeared to be an inverse relationship between the amount of time it took to discover the child' s complex health needs and the intensity of distress parents experienced. For example, Marcus's family was confronted with his condition in the delivery room: “First thing was, why was God punishing us?!...We didn’t want to accept it” (Ellen). Whereas Anne's difficulties took more time to investigate. Her foster parents had time to build their relationship with the health care team as they worked together to try and help Anne, subsequently attaining a more integrative approach, “It’s still hard but it’s like I always say to people it’s hard work but it’s easy hard work” (Keith, foster father).

Dialectical relationship arises between parent and health care system. Many parents were confronted with their child's complex health needs either during or closely following birth. The presence and interaction of several factors was noted to contribute to the direction of the relationship that developed between the parent and health care team from the beginning. These factors included the influence of time, interpersonal communication, the health system's approach to families, and parental patterns of coping. For example, one parent who was abruptly confronted with her child's needs in the delivery room described her encounter with the health care team as traumatic and alienating.

> It was horrible at the beginning…. I felt like I had been lied to by them...like, I think they knew that something was wrong with baby and they didn't tell us....Why would they have all those doctors there?…When he was born ...they took him right away... Sandra was like 'How's my baby? How's my baby?'…my sister had the video camera there and they wouldn't let her tape them (Ellen).

The attending physician's direct, honest communication in that moment helped to alleviated some of the parent's distress by acknowledging her presence and attending to her need for information, "...to this day I still thank that doctor for the way she said it, …like 'no your baby is not okay' and that's when they showed us that he was blue and that's when they took him" (Ellen). However, the subsequent "disconnection" evidenced by an absence of timely updates or inclusion of the family in their child's circle of care, renewed her feelings of alienation and distress. She responded with assertive advocacy,

> …What time was he born? 12:16 and at 3:00 we still hadn't seen him.... finally about 3:15 I told them I need to know what's wrong with my child and I need to hold him and…they finally let me see him then. (Ellen)

This example illustrated that, even at this early stage in the parent and health care system's relationship, each side had a role to play to keep the interaction moving. Their responses to each other produced an interdependent tension, in the relational dialogue (Baxter, 2004). Active, compatible, relational engagement on the part of both the parent and the health care team were demonstrated to be key for movement forward from the beginning of their relationship, regardless of the family's distress or usual ways of coping.

Life and death decisions not perceived as a choice. Some parents described being compelled to make life and death treatment decisions about their child during the early stage of their care. They described discussions about "choice" being initiated by health care providers, couched in predictions of the child's dire expected outcomes. However, these parents did not perceive a choice, rather, they viewed the preservation of their child's wellbeing to be their first obligation.

> …They painted a pretty bleak picture with life on a ventilator, in hindsight I think I was being encouraged to disconnect him and see what would happen but I'm glad I didn't. [Later in the interview]….I think I knew it right off the hop that ...I couldn't make that choice; it wasn't my choice to make (Roberta, biological mother).

This kind of experience was not exclusive to biological parents,

> And it was put like this to the agency, this child will die eventually if she's not trached and she's not going to be trached unless she has a stable home to go to, …then they looked at me and Keith and said 'will you accept her trached? Because if you won't we will not do her and she will die' and I… said 'of course I will take her trached' (Beth).

These perspectives suggest that parent-child attachment was well established at the outset, and parents viewed their child's situation through a significantly different lens than that of the health care team.

Facing the "unknown". Parents described their ongoing relationship with the unknown as possibly the greatest stressor they encountered. This early, continuous experience was the crucible in which many parents developed their resilience. "Well 'not knowing' is the biggest aggravator" (Don, laughing). The health care team and the parents often faced the unknown as a shared reality, "...they don't know what's wrong with him"

(Ellen). Furthermore, predictions made by the team could be wrong, as Roberta noted, reflecting upon the trajectory of her son's health condition, “None of the prognoses have come true...the medical field before said that brain cells could not regenerate and they’ve learned since then that brain cells can regenerate.”

Acquiring understanding: knowledge is power. Parents described how knowledge of their child’s condition and care helped to alleviate distress, as Don explained, “What helps is having the knowledge... that unknown is the biggest stressor.... you have to explain it to everyone so the better you understood the easier it was on them, too…knowledge is a bit of power.”

Experiencing relief as respiratory technology helps child. Although parents described experiencing many frustrations and challenges related to their child’s technology needs, they also remarked on the significant benefits realized by their children from its use, for example, Keith described his experience with Anne,

> It was going to be easier to manage her airway, that was a huge relief...they decided doing the trach would be more beneficial...because she was using so much energy just to breathe, she wasn’t growing and that’s why she’s still so small now...in the beginning I didn’t really understand everything that was going to be accomplished by doing it but I’m glad they did it...because it’s made a world of difference for her.

Likewise, John described the benefits he saw his son deriving from the use of nocturnal mask ventilation, despite the hassles involved.

> Like in any given year he might be getting another 40 days of education into him that we would have lost otherwise...we all want our kids to be as healthy as possible and as strong as possible. So to me it's a no-brainer. You know?

Coping through seeking social support. Confronted with their child's situation, all of the parents described seeking support from their extended family and friends. Their experiences varied across the continuum; at one extreme a parent described her crushing disappointment when her parents didn't follow through on her request to come,

> ...I didn't realize that my family wasn't there for me, they'd phone me daily but no one ever came out...when I had to decide whether to disconnect Jim or not, I asked my dad to come out and my mom and my dad said they were coming...and they never came....I just felt like they just turned their back on me (Roberta, single biological mother).

Another parent described his parents as either present and overbearing, or unavailable,

> They probably see Tom once a week, but they also go away....So I learned a long time ago that the only person I can rely on is myself.... so everything is set up for that. [Later in interview]....they tend to be very overbearing...like whatever they say goes … sometimes the line has to be drawn pretty hard…. I mean, I've had to stand up and say, "You know what? No" (John, single biological father).

However, in the middle range, several parents described their family to be a mainstay of help and support (this would affirm their personal agency in reaching out to supportive relationships). For example, "My cousin Alex makes a lot of that easier on me…he phones me every day and he asks how we are doing.... He's always been there for me ever since day one..." (Ellen, single parent). And, "I talked to my parents quite a bit, yes" (Don, biological father). Inherent in these descriptions was the presence of consistent, reliable support over time.

My data analysis revealed that parents, who could rely upon family members to support them as they approached their difficulties, coped more effectively. By contrast, parents who found themselves without this level of support were much more alone in managing their distress, and this experience corresponded with a tendency towards withdrawal and isolation. Roberta, a single biological working mother, shared her perspective on what it was like,

> When you’re stressed you don’t have the energy of the mindset...you are just so overwhelmed with everything you don’t even know where to start to find the resources you’d need to pull through a crisis.

Likewise, John, a widowed working single father, described his struggle with loneliness and the vicious cycle of demands that kept him from making new social support connections,

> It’s my situation that depresses me...probably one of the toughest things I face is, um, it's very hard to meet people to start a relationship....Most evenings, you're so tired when you get home, you deal with the kid's stuff and everything and then he goes to bed and usually dad is pretty asleep pretty shortly after. That's life, you know? *That's depressing*…. See I've had the other side.... You know? And so that makes -- that is the depression part of it.

The impact of these experiences highlighted the importance of reliable, socially supportive relationships being available to parents on an ongoing basis, and especially at a time of crisis. Throughout the chronology of the parents' narratives, social support continued to figure largely as an important contributing factor in their effective coping and overall experience.

Locating social support in the health care setting. During the long hours that parents spent with their child in hospital, they became more acclimatize to the system and its people. Immersed in this context, parents described discovering service providers with whom they could build compatible, supportive relationships. Some parents also noted a systemic approach in the setting itself, known as family-centred care that contributed significantly to their coping and adjustment.

Supportive relationships characterized by consistent core elements. Several parents described their trusting relationships with health care providers they had met in the early days and come to count on for valuable support regarding their child's care and treatment. These providers tended to be directly engaged in the child’s treatment, for example, the doctors, including the intensivist, respirologist, pediatrician, and surgeon. General references were also made to the nursing staff and health care team, and specifically, to the inpatient nurse clinician, respiratory therapist and physiotherapist. Helpful characteristics of the approaches used by these providers are exemplified in the following quotes:

> “He answered me straight forward and truthfully, …he sees people’s needs...he had a way of asking things that he didn’t, it wasn’t an attack” (Roberta described her son’s intensivist).
>
> “After being involved with Dr. Alison, the surgeon that did it, then I had no issues with her having other things done...” (Keith).

> “It’s the listening and there was also the reassurance of their confidence…and they had faith in the system” (Don described the doctors and health care team).
>
> “Well, they kept me involved. I was right there with Tom the whole time.…They kept me very informed, as they knew they let me know” (John described the hospital team).

Analysis of these and numerous similar descriptions, revealed a consistent pattern of relationship that parents described to be working for them. This pattern was characterized by the presence of four core elements: caring, communication, collaboration, and competence. The manner in which parents described their interactions with providers who used this pattern revealed the considerable respect and trust that was fostered, and subsequently sustained the parents' hope.

Consistent with earlier descriptions of social support, the continuity of the health care provider's relationship over time (chronosphere), was noted to also reassure and sustain parents, “Just by getting to know the different people that have been involved in her care and just knowing that if she’s sick that that’s the place you want her to be and that makes it easier” (Keith describes his experience with the intensive care unit).

Supportive system-wide pattern of relationship: family-centred care. The introduction of this inclusive approach, which was sensitive to the significant role of the family in the child's life and therefore, in the health care-giving process, established a new, more active role for parents as valued partners in the health care team itself. Don (biological father) recalled being present when the practice of family-centred care was first implemented at his daughter's hospital during the mid-1990s,

> When rounds were happening, you were there and you were involved...that's that knowledge I myself wanted to have. So you had access to it, instead of having to wait and then ask the questions...it was a positive change in everything, .…Trusting… because it was the involvement that …was really very key...to help ease the stress (Don).

Notably, family-centred care possessed the same core elements as parents had described in their supportive relationships with health care providers. Specifically, including the parents in the team conveyed care and respect for their role. Consulting with them in planning for their child's care allowed for valuable communication and collaboration, while acknowledging and engaging the parents' unique knowledge and competencies. Don's acknowledgement of the way in which this facilitated his learning, his relationship with the team, and his coping, provides valuable evidence for the efficacy of a family-centred care approach. It facilitated the child's care while simultaneously supporting the parents' coping and adjustment, through their inclusion in, and active engagement with the health care team. This dynamic process reiterated the important interdependent role of relationships in the parents' early experiences and the need to attend to the nature and quality of those relationships, at both the interpersonal and intersystem (family-health service) levels.

Parenting in the hospital. Once the child's condition was stabilized and their care routine established, he/she still typically remained in hospital for months to years, while his/her body grew bigger and stronger and his/her caregivers trained up and got organized. Therefore, parents had to negotiate their roles in the hospital setting and learn to navigate the system and its players, in contrast to their usual domain, the family home (mesosphere vs. microsphere). If the child's life began with complex health needs, this circumstance interrupted the parenting experience and attachment process as a matter of course, for example,

> Roberta: They had to intubate him and they tube fed him and kept him in an induced comma 'til he was three months old and then they told me I could make a choice to either disconnect him or get a trach and a ventilator. And those were my options.
>
> I: That’s a long time to live with your baby like that.
>
> Roberta: Yes, especially when you can’t pick him up or anything, he’s so tiny.

Learning what's involved to take their child home. The specialized care their child depended upon, lay outside the skillset of most parents, further displacing them in their caregiving role. Training up in a whole new domain of care called upon each parent's hope, time, patience, and courage, "Tell me what I have to do to get him home?’ and they told me that I would have to...pretty much be a First Responder..." (Roberta).

Meanwhile, parents had the other aspects of their life to integrate with this new circumstance, including family and work commitments. Parents whose home community was at a distance from the hospital faced additional complications, including the possibility of a move to be closer to specialized care. Financially, the ongoing costs related with coming to the hospital, such as parking and food, put a strain on household budgets, as Roberta described, “I don’t know how I did it when I look back…you do what you have to.... (Laughing) It’s the parking that killed us.”

Life shared with health care system "an extreme change from normal”. Parents described having to make considerable adjustments to their expectations and approach, due to their child's circumstances and ongoing residence in the hospital. This included incorporating the health care system into their daily life, as Don described,

> So it’s a 180°....Normal life would be where when your children are born they are healthy and they grow up in life...but nothing to the extent of having to be so involved in the medical system and everything that went along with that...

Some parents found their workplace to be a source of stability, “I went back to work because there’s no point in taking maternity leave…I’m glad that I did it the way I did...I needed some normalcy to try to…sort out everything in my own head” (Roberta). Although this choice alleviated distress and contributed to financial sustainability, it drew the parent away from her child. Subsequent sustained absences from the child's side compromised the parent-child bond and could result in a parents' unspoken abdication from their parenting role, reassured by the false sense of security that round-the-clock nursing would provide for the child's needs. This reality however, had significant negative implications for the child who, as I have frequently observed, would often be left living virtually alone in the hospital, with a different set of adult caregivers every 8-12 hours. In one case, comments made by the child about the frequency with which he was left without parental attention at home suggested that the parent-child attachment relationship had been affected in the long term.

Parental distress in the hospital context. Participating parents characterized themselves in hospital as being emotionally vulnerable and uncertain in their interactions with health care providers "You were always concerned and that’s why you know, your support is very important ...especially the first time, when something happened... it was always the stress of what’s going on" (Don). Parents might also carry a lot of worry and self-blame that was easily activated, as single mother Roberta demonstrated, when questioned about her son's prenatal history, "...maybe I just take things too personally but I know...that that means I had to have done something wrong."

A heightened sense of vigilance regarding their child's care and their place as the parent was also evident in parents' narratives. For example Ellen, another single parent, described a distressing encounter with her child's bedside nurse shortly after being transferred to the local pediatric hospital,

> [Discussing the nurse's action] She didn't treat him bad, …she just thought she knew it all…she says that they take care of him how they do it at the other hospital, we take care of them like this…the way she said it just upset me, I cried.

From a relational dialectics perspective, the tension that had originated at the parent's pole in the relationship was thereby primed for any potentially negative encounter that might take place.

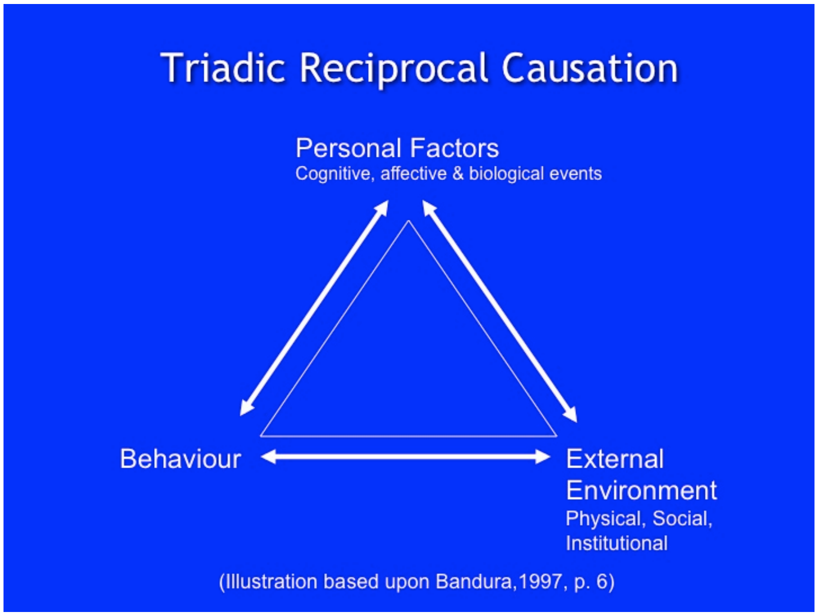
Relational repair through communication and consultation. While Roberta did not describe engaging in any further exchanges with service providers regarding her distress, Ellen on the other hand, described her positive experience with the manner in which the new hospital's observant staff responded to hers,

> Finally somebody said something to me and I just told them honestly what I felt and…they talked to that nurse and then they asked me if I wanted her off of Marcus's care and I said no. She's a good nurse...you can tell that she cares... finally we talked and…she apologized and then I apologized and then it was okay...

Once the dialectic balance was restored, the early relationship-building process that was so important to parent-staff interactions, could move forward.

The intrapersonal dynamics observed here from a relational perspective, fit well with Bandura's (1997) concept of triadic reciprocal causation (briefly described earlier). Ellen's situation could be considered in relation to figure 5 below, the environment side of the triad is represented by the new setting, including the brusque bedside nurse, The personal factors side of the triad is represented by Ellen's hyper-vigilant approach to the new setting, including her self-described way of handling threat: confrontation followed by passive withdrawal. These two sides subsequently set the conditions for the third side of the triad, Ellen's behavioural response: confronting the nurse providing care to her child in a way that she did not agree with and being discounted rendered Ellen powerless.

Figure 6: Process of Triadic Reciprocal Causation



Triadic Reciprocal Causation

Personal Factors
Cognitive, affective & biological events

Behaviour

External
Environment
Physical, Social,
Institutional

(Illustration based upon Bandura,1997, p. 6)

This relational dynamic, without any additive factors, had the potential to become a self-perpetuating cycle of conflict and distress. However, returning once again to the environmental side of the triad, according to Ellen's report, a staff member in the new setting observed her distress and reported it to the nurse clinician. The nurse clinician helped Ellen recover her power as parent, by engaging her in a process of consultation and collaboration regarding her child's care. This facilitative experience altered the second side of the triad, personal factors, by decreasing her perception of threat and thereby reducing her anxiety. Subsequently, Ellen was able to consider a wider range of responses from which to choose, resulting in a constructive change in her behavioural response - the third side of the triad.

Consulting with Ellen on her child's care, the nurse clinician conveyed her acknowledgement of Ellen's competence as a parent and empowered her in that role. By receiving and responding to Ellen's self-expression and efforts at advocacy, she also facilitated Ellen's developing self-efficacy and personal agency. This helped reset the spiral of parent-to-health care service provider relationship in a progressive direction, and the tensions between Ellen and the staff in the new setting were brought to manageable levels. Ellen also discovered her first ally, the nurse clinician, in the hospital setting, sustaining her hope and trust in the system.

> I went to the nurse clinician for everything, like, if I found something that I didn’t like, or if one time Marcus was in pee all night and that I went to her…she would listen and I would trust her that she would take care of it…(Ellen)

Ellen's description of this experience conveyed the presence of the core relational elements of caring, communication, collaboration and competence in this relationship.

Perceived kinship and the importance of boundaries on the ward. Some participants described the hospital ward as a close community where a certain kinship grew. One parent, who described herself as socially isolated, compared the hospital ward to a surrogate family: "… they were the family the baby needs like, when you don't have your own...I think they were a very special team of people… that's what made it easiest." (Roberta). This statement conveyed dual perspectives, on the bright side it appeared to describe a supportive community of caring for the child that was reassuring to the parent. However, on the shadow side, the parent seemed to be on the outside of the description. This may suggest the presence of another slippery slope: the potential for the hospital setting to subsume parental caregiving (actual or perceived), thereby alienating the parent from her role and enabling avoidance-based coping. This speaks to the need for careful attention in delineating the roles and responsibilities of both staff and parents on the hospital ward.

An extraordinary effort to go home. To bring a child with complex health needs home was a logistical feat. Parents could not manage this alone. Here, the family (microsphere) and the support systems in the community (mesosphere) had to collaborate together on a plan of support that would make life manageable.

Family care or foster care? Most of the biological parents described foster placement being raised as a community option by the health care team, while their child was still in hospital. This option was usually offered to parents who had limited access to resources or faced other demands that might make caring for their child with complex needs very difficult to manage. Indeed, half of the children in the study sample had been placed in foster care, with provisions made for regular family visits. Parents who refused this choice were adamant: "I would never give away my child" (John, single working father).

Training up to care for child independently. To take their child home, parents had to learn the skills to provide for their child's complex care needs and be able to demonstrate their competence, under the supervision of their child's health care team. Participants described the trepidation they experienced in undertaking the extensive, specialized training and preparation during the months prior to their child's discharge,

> Doing the training in the hospital to learn how to do take care of the trach and the ventilator – that was a little different but that turned out okay...and doing it on my own – that was a little - that's the part I found a little unnerving in the beginning...I was glad that I had the training, you do need it, but even, if you're not around that every day, like a nurse or a doctor, then it can be a little overwhelming sometimes...(Keith, foster father and layperson).

Through experience-based learning, parents were able to approach and acquire the skills necessary to care for their child independently. They later acknowledged how invaluable this training was, in managing critical events at home,

> The first thing that came was Fran's "…you got to stay calm, calm for yourself and calm for Marcus"…– if it wouldn't have been for that I don't think I would have been able to do it…Fran drilled it in my head (Ellen, single parent).

Acquiring competence contributes to coping. A common observation by participating parents was that in acquiring the knowledge and competence to care for their child, their confidence and coping was greatly enhanced, "you have to know what you're doing... after awhile you get used to it, and then you learn that it's not quite as hard as I thought it was going to be." (Keith).

Preparations at home. Parents had to consider and prepare both the physical and the social/family aspects of the home setting for their child to "come home". For example, there were the physical factors related to accessibility, ease of equipment movement and monitoring, as well as, reasonable proximity to advanced pediatric health care services. Thus, home renovations or even relocation, were a common part of the parents' experience, “From the time he was born, everywhere we lived we had adapted, ready for him to come home” (Roberta). Families that relied upon subsidized housing were at a particular disadvantage, due to the local shortage of accessible housing. This circumstance had implications for the parents' coping, as a residential move for accessibility reasons could put them at quite a distance from their social support network, “Yes I have moved here…way out in Timbuktu. Where you need your passport to come visit (laughing) ....It’s hard because I don’t get as much company as I used to...I’m more like - stuck at home…” (Ellen).

Other family members also had to be prepared for the child's impending arrival. Being aware of and accommodating the affected child’s situation and needs was important for everyone in the household. Parents took steps to prepare the siblings, as in Marie's situation, when she joined her father and stepmother Sherry's household as a teenager,

> We were very open with the boys and we did it with Marie and explained, “you know what happened with Marie?”…If they had questions we would absolutely answer them openly and honestly but there’s no point in dwelling on it (Sherry).

Making a life at home. The child’s arrival at home represented a shift in the spheres of context. Parents who had spent long days at the hospital found themselves more in control as life became centred within their own domain of home and family (the microsphere), “I lived at the hospital and now it’s nice to…have him home with me… I can do what I want to do when I want to do it...I’ve calmed down” (Ellen). However, for parents who had spent less time caring for their child at the hospital (for example, working parents), this shift was more unsettling, as it was accompanied by greater responsibility, “I was terrified to bring him home. I just didn’t allow myself to think about it too much” (Roberta).

"You do what you have to do." To cope and move ahead, parents frequently used this motto. Living with critical health issues day-to-day in the community called upon biological parents’ resilience in particular, to transcend their circumstances and, with their newly acquired skills, help their child to thrive in the community. For example, Ellen stated “I got to deal with what I got, you know, the cards were laid now play them.” After grieving the child's health setbacks, biological parents had to come to a fundamental acceptance of their situation, trust in their own self-efficacy, and look to their child and family's future.

Lifestyle adjustments: “I changed my life.” To accommodate their child's needs and care routines, parents described making significant, often life-altering changes. These included adjusting personal routines such as sleep arrangements, to better monitor their child’s use of mechanical ventilation. One parent slept by his child at night, another parent wore hearing aids so that she could hear the monitor alarms. Some parents gave up their job or changed their career direction in order to work around their child's needs, “...I chose to quit my job because I wanted to take care of Marcus.” (Ellen regarding her decision to go on assistance).

Replacing spontaneity with detailed planning for outings was a common grievance, in terms of lifestyle change, “Somebody saying ‘hey come over’ you just couldn’t just pack up and go right?" (Sherry). Instead, when parents were fortunate enough to have a night out, they had to pay close attention to their respite time, "we hate being on the clock and we all are. This is how much time you have before your respite nurse has to go home, run. There is no spontaneity" (Laura).

“It’s a life of details”. Aside from care regimens and household routines, parents described much of their time and energy being taken up in attending appointments, arranging for supplies and services, and contingency planning. Laura provided the following advice for anyone approaching this lifestyle,

> If you could tell a new family one thing to do, it would be to get…one of those handheld personal data - with a calendar system that syncs to their computer at home, so they’ve got it on them all the time, because you are making appointments like crazy those first couple of years. Get yourself a cell phone you’ll need it, never be alone in the car with these kids if your car ever breaks down (Laura).

Stressors of home life. While parents agreed that life at home was better than when their children were in the hospital, it came with its own variety of stressors to manage. Although parents would openly discuss their own personal stressors when asked, their attention usually turned first to the larger system-based concerns, perhaps because these were not within the parents' control, and they had a direct impact on the child and family.

Respite system-based unilateral decisions. Parents tended to bring forward system-based stressors first, relating to practical aspects of their child and family's life. Unilateral decisions being made without consulting the families regarding changes to respite hours and supply services were frustrating for parents. Two single mothers mentioned being called and told their respite hours were being cut. Sherry described her frustration with the abrupt manner in which she experienced services (including supplies and coverage) to change when Marie was decannulated, "…somewhere at midnight everyone decided to cut everything off, that was a huge eye opener...."

Gaps in accessibility affect safety. The shortage or complete absence of accessibly designed housing facilities was a chronic problem that, by its very presence, provided evidence of a fundamental societal gap (Exosphere). The lack of accessible housing was felt most significantly by families with children who used both respiratory technology and a wheelchair, due to the significant safety issues it created for them. One parent in the sample described facing this situation. Ellen, whose child Marcus had his ventilator mounted on his wheelchair, described one of the hazards her family encountered while living in a second storey apartment, "We're moving again. Downstairs, because this is not good for us when there is a fire... and we've had fires here."

Financial pressure. My analysis of the comments parents made about their financial matters indicated a need for further support to low income parents caring for children with disabilities, and evidence of a systemic response in support of parents who were better off financially, in terms of tax benefits. While the cost of living was a big stressor acknowledged by all of the participating families, single working parents appeared to be the most severely affected. For example, John stated, "security is definitely a stress around us because we live hand-to-mouth. Um, the money we have pays the bills and that's it." Roberta's experience pointed to society's inherent gender-bias, making life difficult for single working mothers, calling upon the sheer tenacity she needed in order to carry on,

> I think the biggest stress in my life was income...I had to work two, three, sometimes four jobs at a time throughout the years... it was hard breaking through in this industry because it’s a man’s industry and no one wanted to pay me very much...

Parents with a higher income welcomed the financial relief that recent changes to federal tax law provided. The disability tax benefit acknowledged and allowed for some of the costs of living that were incurred. Its presence provided evidence of the impact that disability advocates had on shaping governmental policies and nation-wide programs.

> ...There are going to be ongoing costs because of Marie’s handicap, and …we had to compensate for this…but what has changed is the ability to claim a number of things with respect to the government. That has changed…for the good.... (Don).

Likewise, foster parents described a chronic history of significant financial challenges located in the difference between what the child's needs cost and what the agency's budget allotted. Many found themselves having to advocate repeatedly and persistently, in the face of unresponsive caseworkers, at progressively higher system levels on behalf of their foster child and themselves. "I just get upset…to the point where...'Okay, if you’re not going to cover it ...I’ll pay for it out of my own pocket'... if she needs it, she needs it." (Beth). Recent changes in foster funding arrangements had led to some improvements. Once again, a response from higher systems to lower system-based issues had been identified through persistent advocacy and pressure.

Relentlessness of the child's care needs. In their day-to-day lives, parents described a chronic lack of time and energy, due to the relentless cycle of care that their child required. This was overlaid upon an already busy life, particularly in the case of single parents, for example, John appeared to have no home respite services provided, leaving him to manage all aspects of his son's care in addition to his other commitments "Most evenings, you're so tired when you get home, you deal with the kid's stuff ...then he goes to bed and usually dad is pretty asleep pretty shortly after." Parents described managing this stress by treating themselves kindly (self-compassion), making time and space for themselves to clear their heads (mindfulness practices), or connecting with friends (social support), within the limits of what they could manage. Couples described sending each other off for a break, whereas single parents created a break in their day by doing something to soothe themselves at home,

> I don't think when I'm in the bathtub ...that's where I turn everything off...the only thing that I hear is Marcus's breathing...I put his machine on and all I hear is the dun dun dun dun...I just clear my head (Beth).

Impact of care needs on the family. Ongoing care responsibilities also affected parents' availability to other family members, leading at times to feelings of resentment and self-reproach, "One needs *so much care.*…Everything you do is around her… sometimes the other kids suffer because of it" (Sherry). Some parents coped using self-expression and perspective-checking with other family members, who could affirm them in their efforts (social support).

Scarceness of respite and supplies. Despite its importance to parental wellbeing, respite service was described as frequently unreliable, creating significant amounts of distress for the parents who counted upon it most,

> Like Monday's is the stress of when you wake up is there going to be respite care? Because that's my respite care day...you have to realize... nobody phones you no more... I only have three times a week now where I used to have four times a week...Because they can't find anyone to fill it...(Ellen, single parent).

Supplies were another problematic area, reported most frequently by foster parents, who had to advocate for their child's needs with budget-conscious agencies, "They don't look at her and her health as the bottom line, they look at her and her costs sometimes, as the bottom line" (Beth).

Social isolation and loneliness. Social isolation was commonly reported, as a physical and social reality, and was most marked among single parents. Single father John described this as a gap he just couldn't fill at the present time, "my choice is to be with my child as opposed to someone else.…And that's what's more important….It's pretty tough sometimes 'cause you…need adult things, right?"

Laura, formerly a single foster mother, had found a way around the physical isolation, yet continued to experience social isolation, due to the uniqueness of her experiences, compared to her circle of friends,

> After awhile you don't want to talk about it anymore....So you learn not to talk about that very much...or you only talk to certain people, the people who get it...you have to live this life to get it.

Depression. When asked, all parents confirmed experiencing episodes of feeling depressed, in one form or another, and described addressing it in various ways. Some sought professional help, some coped using informal social supports, while others sought time alone or just struggled on, using internal personal resources to manage. For example, Don described using social support, “I haven’t let it totally disable me. I talked to my parents quite a bit yes, now it’s Sherry.”

The experience of loss and sorrow related to the reality of some parents' situations sometimes permeated their perspective. For example, in John's case, having endured the loss of his wife, he had reorganized his life to care for his developmentally disabled infant son, “Everyone has…an expectation of where they'll be and how they'll do, you know....Well, a lot of my stuff will never happen. And that's tough.…See, I've had the other side...that is the depression part of it.”

Laura linked her experience of depression to the social isolation she experienced during her early days, as a stay-at-home single parent, fostering a child with complex health needs along with her own young children, “I wouldn’t say that I’ve ever been clinically depressed but you definitely go through down times…when Mike…and my kids were younger being kind of stuck in your house….Those were some tougher years….”

Mothers in survey sample communicate similar messages in unsolicited notes. Many of the themes that arose in my analysis of the parents' interviews were reiterated in unsolicited comments I found added to the survey instruments by other parents in the survey sample. Due to the consistencies of these themes I briefly comment on this data here.

It was mothers (several) exclusively, who chose to communicate their perspectives by writing about them in the margins and on the backs of various survey pages. This choice suggested the emphatic and expanding nature of their communication efforts, via a low profile and otherwise "form" limited opportunity to express themselves. Similarly to the parents in the interview sample, the content of these comments reflected feelings of being quite alone, burdened with responsibilities for which they received little support, socially isolated and misunderstood by others regarding the extent of their caregiving role. Mothers of children with multiple, significant disabilities viewed their child's future in pragmatic terms. One mother used the survey instruments as a way of holding a conversation - perhaps illustrating how meaningful the opportunity to reflect upon one's experience in this way could be, yet constrained by the survey's limitations. Another mother wrote an extensive note following the Self-Compassion Scale, regarding her struggle to obtain sufficient respite care for her son while she still continued to work. I contacted her to discuss some unclear points in her note and took the opportunity to explore her concerns. She described her deep and abiding concern regarding the extensive marginalization of children and adults who live with nonverbal and developmental disabilities in society and in health care, to the extent that their very right to live is called into question. This comment was very reminiscent of Carnevale et al.'s (2006) parent participants.

Coping at home. The range of stressors parents encountered when their child had moved home required a varied repertoire of coping strategies. To manage circumstances they had no control over, parents consistently described employing emotion-focused coping strategies, including, maintaining hope, exercising self-compassion, developing and utilizing social support and taking personal space to do something soothing or satisfying, "I'll go… do something on my own.... Takes the mind away" (Keith).

Becoming system navigators and advocates. Many disagreeable circumstances faced by children and their parents were changeable but required advocacy, particularly related to system-based components of care. Parents described their child's needs as giving them the reason to step further out into the world as actors, actively asserting themselves and learning to navigate and engage with systems and service providers in solution-focused efforts. For example, Beth described her newfound confidence since beginning her advocacy efforts with the systems on behalf of her foster daughter Anne, "I'll advocate certain things medical wise...it's always worked out well....School board I'm sure I ruffled a few feathers but that was like at administration, it was fine within the teachers' and principals' area...."

Building a peer support network to address system-based shortcomings. Some of the difficulties parents encountered at the systems level called for a more collective effort. This was difficult for these parents due to their full days, unique situation, and limited opportunities for social networking. However, the resourcefulness of parents is not to be underestimated. Laura and a few other similarly situated parents had met each other by happenstance while waiting for appointments with their children. Upon discovering they shared similar difficulties, they realized that their unique training and experience was a strength they could turn to advantage by forming an informal support network. In this way they were able to help make life better for one another. Essentially, these parents exemplified mobilizing group agency in response to a system-based problem, Laura: If a nurse calls in sick, and you have a doctor's appointment that you've been waiting three months to get in and see, you can't drag these children there all the time. Drop them off at my house on the way, we help each other out, we have to…it took a long time to develop those relationships and to figure all this stuff out.

I: And how did you get to know each other?

Laura: Through the hospital we knew each other and we weren't all very close friends at first and then every now and then something will come up with funding and then you would call and you would say 'Okay I've been cut off of suction catheters has that ever happen to you before?'

Parents' approach that works characterized by same core relational elements. In my analysis of the data, I noted a significant pattern in the parents' approach that was also familiar; the parents who had efficacious interactions with systems were those who were themselves actively engaged, and used an open relational approach. Likewise, their relational approach was characterized by the same four elements as the key service providers they had described: caring, which motivated their advocacy efforts; competency, acquired through learning (skills, system navigation, interpersonal relations); as well as, communication and collaboration, both necessary activities in effective advocacy and service coordination efforts.

Family life: "organization was huge". Parents strove to integrate their child's care into the family's daily life, arranging equipment, instituting codes of conduct and setting routines to create a new "normal". For example, in Sherry's large blended family,

> There was an area in our living room/dining room...for Marie’s suctioning machine, it was the rules that nobody touches it...We had four small children then and so you needed to have some rules and boundaries.... we went on vacation and had a crate of medical equipment… And picking up medical supplies.... Organization was huge.…The structure and routine was around Marie’s schedule. So she needed to have her GT feed, so we fit that in…it was normal for us. It was what we did.

Family Identity. When referring to their family, parents used common identity terms that included the child within the larger whole. Here was the child's first inclusive community; while accommodating the child's complex health needs, the family's identity transcended them. A number of key relational themes consistently emerged in the data with respect to family patterns of interaction.

Honest, open communication was described first and foremost as a family practice, for example, “We have a rule in our house… since we’ve become this one big family...we listen to what other people say; everyone is allowed to have their opinion... and we are never ever to be afraid to talk about anything...” (Sherry).

Mutual ways of caring also emerged, for example, Beth described her family, “We are a very...physical family, we are always hugging and kissing and cuddling." Acceptance of self and each other was another common theme, well captured in Beth’s description, “I would just say talk and be open and there are some people that are going to yell and scream and some people will be quiet and you just have to accept people for the way they are.”

Creating shared family memories was another important theme, as these were the building blocks of the family's "story". For example, Roberta, a single working mother, strove to create memories through skating outings and winter picnics, despite the resistance of her children,

> I remember Margaret [older daughter] saying to me..."Why do you make us do these stupid things? Nobody else's mother makes them do this stuff!" and I remember saying to her "one day these are going to be your memories. If you ever get asked if your mom spent quality time with you, you'll remember them very clearly" (laughing) and we sit around now and we laugh about it and she said to me so many times "I'm glad you did it".

Siblings as important resources. Siblings represented the health-compromised child's first true peer, and likely offered them the most normalizing influence, as they approached and engaged them in typical play. Although this could be a good thing, it could also be quite alarming to the parent, as Roberta's experience with two-year-old Jim and his older sister, Margaret, illustrated,

> When we first brought Jim home…I almost took him back to the hospital because I thought she'd kill him, it was awful. (Laughing)… I was in the kitchen …making dinner all of a sudden I hear this "ktunk-ktunk-ktunk"- she had put him in a sled and pushed him down the stairs!

While parents agonized over the inequities experienced by siblings regarding their care and attention due to the pre-emptive health needs of their brother or sister, siblings did not necessarily share their perspective, as Laura, a foster mother discovered,

> I don’t want their whole childhood memories to be we couldn’t do this because of Mike… I’ve talked to the kids more about it over the years and they are pretty quick to point out "but ya mom you were able to be home, you were able to be home for us and we were able to give him a life"…. And they love him.

In fact, older siblings often became part of the child’s caregiving network. Either informally, “we even took Margaret...she had her CPR by the time she was seven” (Roberta). Or formally, “one of them has…taken all the courses…he’s actually one of our respite workers” (Laura). Thus, although siblings undoubtedly found themselves at the "short end of the stick" on countless occasions, the experiences recounted by parents indicated that there were more resilient responses than problems.

Parents in partnership. Couple-parent participants were cognizant of the value of their partnership, for both themselves as people, and for managing the family. In exploring the manner in which these couples had successfully sustained their relationships, I found several key themes arising in my analysis. Balancing the division of labour was a key activity that these couples engaged in, "if one person wants to take more of that then the other person will probably take on other tasks " (Don). Sharing common goals was another important aspect of the partnership, as in Keith and his wife Beth's choice to foster parent, as Keith described, “We talk about…our plans…ultimate goals...This whole thing...has…got to be right for both people to do it.”

Making relationship maintenance a priority was an essential value held by both of the participating couples. Spending time together away from the children was experienced as rejuvenating. To ensure that this maintenance took place, however, required the availability of respite and the parents' foresight in planning for it. Keeping a regular date night was a common strategy used to care for the relationship, “Deal with yourselves first because if you’re not in a good relationship…then it’s not going to be a good relationship for anybody that you are involved with...” (Keith). Parents were well aware of the potential costs associated with not taking the time to care for their partnership, “…a lot of marriages break up.... you can be all consumed and if you are not willing to give that child up to spend time with your spouse your marriage isn’t going to survive” (Beth).

Parent-child relationship - keeping your eyes on the prize. Parents derived pleasure from their child’s very presence in their lives. This experience in itself emerged in the analysis of the parents' perspectives as hope sustaining. Parents described their experience of their children as providing them with valuable perspective and “built in” rewards. For example, when asked how they coped, these two fathers stated,

Don: “The kids themselves [help me to cope].”

John: “Hug my kid…'cause it makes you realize just what you're doing it all for.”

Parents described sharing a bond of love and devotion with their child, “...his love to me or me to him is unconditional...” (John). This was a core theme across family variations, as reflected in foster father Keith’s explanation, “It’s like they’re your own biological kids, that’s how we treat them....This is a long-term situation....”

Additional subthemes emerged in my analysis with respect to the parent-child relationship, all of which focused on the parents' caregiving role, as described below.

Child's wellbeing a central concern. Parents’ commitment and concern for their children was very clear, as John aptly stated, “…adjust your life not your kid's, but your life to fit.” In fact, parents often related their own quality of life to their child’s wellbeing, thus, they lived very much in the moment. For example, Keith talked about his own life, "It's really good because the kids are doing good…you can't think what it's going to be like two months from now…with the kids it's day to day." By living in this manner, Keith could sustain his hope, because he kept a tight rein on the future.

Safeguarding child's privacy. Mindful of both their child's public and private lives, parents took steps to protect their privacy by carefully managing their personal information, "...certain situations I can tell you when it comes to Mike that I think they are a 'need to know only' basis for his protection… I don't want him labeled or treated differently" (Laura). By doing this, from a social role valorization perspective, Laura protected and enhanced Mike's social image in the eyes of others, thereby helping to reduce any further social devaluation, and facilitating his opportunities for being offered valued social roles (Wolfensberger, 1998).

Accepting the child "as is". Acceptance was an essential part of the relationship for every parent. Some parents had to come to terms with this aspect of their child over time, with help or through their own process. For example, Laura was able to move to acceptance of her foster child after several years, with the help of her counsellor,

> I spent so many years invested in I was going to save this little boy and help be happy… if I could just change my parenting …now Mike is just Mike and I'm okay with that and so is he.

Parent-child attunement. Parents' acute sensitivity to their child's cues was evident in the manner in which they described their child's interactive means, as an actor in life. Effective parent-child attunement was important to developing the child's personal agency, particularly for nonverbal communicators. For example, Ellen described her knowledge of Marcus's distress cues, "The only time that Marcus cries is if he gets scared or if he's hurting. He's not a crier, you can read him good."

This attunement could go both ways however, for example, adolescents were very sensitive to their parents' emotional tone and easily picked up on negative feelings when frustration and resentment surfaced. For example, Sherry described her experience with Marie, when she encountered negative feelings welling up inside, as she adjusted to her new complex-caregiving role at the beginning of Marie's time in the family, "If you had those feelings she picked up on them right away... I think …those feelings … made her feel that she had no control and it was all her fault and that created the depression... ya...the empowerment wasn't there."

Dedicated time together "times you don't mess with.. Sharing quality time was an important aspect of the parent-child relationship that helped refresh the relationship in the face of all the sacrifice and hard work that the child's complex needs demanded. It was the rewarding aspect of the relationship, cherished by both the parent and child. John, a busy hard-working single father provided a good example as he described the delight he derived from the limited periods of time he got to spend with his son Tom,

> When I do have time to actually give him…we tend to do special things. He *loves* me to read to him….So…I read to him and he usually goes to sleep within ten minutes. It's just -- it's a whole comfort thing… it's my special time.

Being drawn towards a more active role in life. Caring for their child with complex health needs, had led to big changes in these parents' personal approach to living. Every parent described his or her experience of moving away from old passive ways and steadily being pulled, or stepping forward, towards a more active role in the world, as Ellen succinctly put it, “I’ve learned to speak out more...because of Marcus.”

Attending to the child’s experience of disability. Inclusion began in the family (Bogdan and Taylor, 1992). Due to the circumstances encountered by some children and families, foster children necessarily received this message from their foster parents (Wolfensberger, 1998, p. 12). The family provided the child's first social learning environment, therefore, acceptance and inclusion as a full participant in this relational context was the beginning of the child's adjustment to living with disability.

Life with technology part of young child’s “normal”. Parents observed their child’s perception of normal to be grounded in their personal world of experience – at least in their early years, when life revolved around the family home. The absence of social comparisons at home provided a realm in which the young child’s disabilities were not a factor in how they were viewed and treated. Participating parents described treating their child on the basis of personhood.

For some children, illness was a part of day-to-day living, “Unless he’s vomiting or something or got a 110°F fever, to him he’s not sick” (Roberta). Children experiencing relatively good health were perceived to be having a positive experience, in spite of their complex care regimen, “…you feel so bad for the kids…then you look at these kids that are running around and playing, it’s sure not bothering them” (Keith).

Social comparisons lead to feelings of difference. Parents observed their child to become more aware of their individual differences as they matured, entered the larger community and took on roles, such as being a student attending school. Here they experienced making and being the object of social comparisons. For some children becoming more aware of their technology-related difference was difficult, leading to self-consciousness and discomfort with their appearance. For example, Laura described her foster son Mike's recent question, "Mike...asked me...do I always have to have a nurse at school with me mom?" and his comments about his trach, "I hate it when people stare at me...people stare at [my trach] all the time mom."

Managing the responses of others in public. Parents raising children who had obvious visible differences reported their frustration with the negative attention their child received from adult strangers in public places. For example, Ellen described taking Marcus, who was nonverbal, wheelchair-bound, trach and ventilator dependent, to the local mall: “Adults stare too much…somebody says ‘poor kid’. I turn around and say ‘he’s got money he’s not poor’ because why would they say that?...It’s…the older [people] that stare the most.” Children responded in a very different manner than their elders, facilitating an opportunity for role valorization and education, as Ellen's next example illustrated,

> We were at Tim Horton’s and some lady actually moved her chair so she can stare at him. So I just turned his chair the other way around. And if kids ask me…I just explain to them that ‘he breathes different than you’ and that’s all I tell them. He needs this machine to help him to breathe…parents tell them ‘no, no’ and I say ‘It’s okay, they’re curious,’…they need to know...if you push them away…then they are more to stare and if somebody explains it to them and then they accept it.

Here, it is possible to see that Ellen acted as an agent for both Marcus and the children. She honoured the children’s need to know with simple, matter-of-fact answers that also normalized Marcus's situation as a person with differences that could be understood and accepted, like any other, in a value-neutral way.

Engagement in community life facilitates integration and social support. Parents who described their families to be well connected and involved in their community's organized activities, also reported experiencing a more inclusive experience. For example, in spite of Megan's self-consciousness regarding her appearance, her mother described her to be a "social butterfly" at the community club's hockey team gatherings,

> …On our hockey team…she's been in three weddings…there isn't anyone who doesn't know who Megan is in our part of the city from the community club… from the day I brought her home, I think she went to a hockey game the next day and she stole everyone's hearts….

Acknowledging "difference" and its place in "normalcy". Some parents described approaching their child's emerging awareness of their disability with an attitude of open acceptance, teaching them to view their differences as a part of normal variation,

> I encourage her to go out…she doesn't see herself any different than any other person really, and that's what we kind of tried to instill...so you're a little different that's still normal....I don't want her to try and not do things because of her disability. I want her to try, if you can't you can't...if you want to try it try it, why not? I've signed her up for ballet and jazz class and, ya, it's a little different, because I have to stand beside her to do it, but she is still trying to do it (Beth).

This approach promoted adjustment by recognizing normalcy as a function of perception, and placing it in the service of the child’s developmental potential. In Beth's example, she provided her foster daughter Anne with a reflection of herself and her disability that was accurate and normalizing. This was Anne's first social point of reference in forming her identity and would guide her attitude and expectations in her interactions with others. The effectiveness of this approach was evident in Anne’s adjustment to her disability. She was able to take a normalizing, educative stance with her peers and was ready to try new things, with the support of her parents, thereby strengthening her self-efficacy and personal agency in the act of living.

Getting on with growing: supporting the child’s development. The main means parents described using to support their child's development was engaging them through their relationship, specifically, by providing them with their own presence. For example, actively engaging and encouraging their child, "You get in there…and do it with her.... Just by the encouragement…not making a big deal...when she can’t do something, but making a big deal when she’s finally able to physically or mentally…do something" (foster father Keith). Some parents also recognized that they were their child's role model and taught by their own example, “I try to provide a good example of being able to deal with the world” (John). Some parents also found ways to share their power with their child, so that he/she could begin to experience some autonomy and personal responsibility through choice making. For example, John described how he promoted Tom's autonomy in a developmentally supportive manner,

> I don't say, ‘This is what you're getting for supper.’ I usually say, you have these choices or, what would you like?…. Sometimes there is no choice, you know,

> sometimes we're taking the car and that's it. You pick the ones that are going to be important.

Likewise, Roberta ensured that Jim was included in health care discussions from an early age so that he would know why he had to do certain things, "...let him hear everything so that he never thought I was saying things to...scare him into the behavior I wanted him to do and I think that was a huge difference."

Parents' perspective broader than child's service specialists'. Parents recognized that**,** aside from underlying developmental impairments, their child's complex health needs and related care impinged upon their developmental progress. For example, frequent illness and hospitalization, low energy, weakness, short attention span, impaired communication, multiple caregivers and confinement related to monitoring, all had a bearing upon the child's developmental progress. Service providers, being limited to their specific scope of service, were not always appreciative of the overall context of the child's life. For example, Roberta described the explanation she gave about her son's delayed potty training when a social worker made a home visit following an anonymous report,

> ...I said 'Look now, the last seven months this is how many caregivers he's had plus I'm working full time,' - he had 32 caregivers... I have no idea who complained about his potty training... At the time I was very offended. I thought the poor little guy…he's tied to his toys so he couldn't play with other kids' ventilators for two years and then finally he has time to run and play and I'm going to make him worry about peeing in a potty? *(Laughing)* Nobody could get that.

The parents' perspective provided a broad overview of the child's life and needs, and they were often called to action as system navigator and advocate on their child's behalf. The parent also did the best he/she could as teacher, guide and gap-filler, in meeting his or her child's social learning and rite of passage needs, as evidenced in the following themes**.**

Delaying school entry to compensate for slower development. Participating parents who were caring for young and middle years children reported intentionally delaying their child's school entry by up to two years, to allow for developmental catch-up time. "We did speech, child development, OT and PT with Mike from the time he was one…and I kept him out of school an extra year so that he could get a year more." (Laura). In some cases parents had to advocate fiercely to have this exception made within a rule-bound school system. Foster mother Beth's example illustrated the extent of advocacy she was obliged to engage in on Anne's behalf,

> ...When she was going to start school…the school system's student placement coordinator…said "Oh because of her [Anne's] age she's got to go into grade one." And I said "No ...we deliberately kept her back last year because she was not ready for kindergarten, her development age is at a four-year-old level...we don't even know if she'll make a half a day.

When Beth's voice was not enough to sway the student placement coordinator's opinion, she had to set aside the affront and pursue support further afield, reaching beyond the school system, in order to be heard. This called upon all of her advocative and navigational powers,

> …I ended up getting the speech therapist involved and the physiotherapist…I phoned up Dr. Lincoln [child development specialist]…to get a doctor's letter …and that didn't really swing a whole lot until I said to her "Well, I'm going to have to go to the Ministry of Education and the Ministry of Health and advocate there".…I actually went as far as phoning the superintendent before they made their decision and this was on a Thursday and I think it was on the Tuesday I got a phone call saying that she's going into kindergarten....And she [student placement coordinator] was dead adamant that there was no way that she was going into kindergarten. Whether the phone call made the difference I don't know. But from a dead adamant that oh she's going, to oh, there's no problem.

Her valiant efforts were rewarded with Anne's successful transition to school at a time that Beth knew would be more suitable, "…right now all the kids in the school are very accepting of her, especially her class" (Beth). This example illustrated how essential it was for parents to have confidence in themselves, to cultivate a strong sense of their personal agency, and to acquire an understanding of how to navigate the systems and advocate successfully for their child.

Balancing safety with strivings for independence. Parents' struggled with their habitual, protective vigilance in their efforts not to hold their child back, but rather, to support his/her growing independence and access to rites of passage, while maintaining some degree of protection from harm. Over-protection was a tendency that several parents acknowledged they had to guard against, "they have to be able to take some risk otherwise we would do nothing in life because we would be afraid to do everything"

(Don). Therefore, when it was time for his daughter to learn to drive, Don had to find a balance that worked for all concerned,

> I won't drive with Marie (laughing) because I will have a heart attack. But...in knowing that she needs to drive we set up the lessons for her…we aren't hovering over her, but we're putting in a controlled situation...someone that is experienced will be able to...get her through that.

Addressing the need for social developmental opportunities. Parents were well aware of the marked curtailment of normal social experiences amongst children living with a trach (invasive technology). The child's ongoing monitoring and supervision needs kept him or her tethered to qualified adult caregivers long after similarly-aged peers had gained the freedom to "go out and play," call on friends, and attend sleepovers. How parents chose to tackle this challenge varied, depending upon their child's age.

The preschool child: Providing an enriched social play environment. When the child wasn't free to go out, parents found ways to bring the community in, particularly if he/she was a single parent. For example, through providing foster care and respite services for other families, Ellen provided meaningful work for herself, and a community of children for Marcus to interact with on a daily basis, under her watchful eye.

> He interacts with the kids...He likes it and I put him on the floor with them and everything...since baby came Marcus screams more. Because he hears baby screaming ...he's making sure he's heard too (laughing)...when the twins come here they go and put a toy in his hand they give him a sippy cup right away ….When Marcus is in his chair they will play with him with the cars and everything ....They did it on their own.

Likewise, Laura opened her house to the children in her neighbourhood on a daily basis, while Roberta moved into a house beside the elementary school, both endeavored to facilitate their children's social opportunities.

The school-aged child: Fostering mastery in making friends. Ongoing monitoring needs meant the school-aged child's range of choices remained very limited at a time when their peers' social horizons were expanding. To promote peer connections within their child's social context, parents described encouraging friendship building at school and hosting follow-up play dates at home. Foster parents also described building in social opportunities through respite arrangements with qualified staff that had similarly aged children,

> His [respite] nurses' kids...are the friendships that he has developed and what I am trying to do more and more is to find kids that he does connect with in his school, and invite them to my house… (Laura).

The adolescent: Fostering personal autonomy and learning to let go. The onset of adolescence presented a particularly challenging crossroads for parents and children, as the press of developmental progress called for the balance of power to change hands. Like others with teenaged children, these parents had to step back and allow their child more autonomy and responsibility. This was not an easy process after years of close monitoring, care and vigilance to ensure their child's wellbeing, and yet the developmental process did not discriminate on the basis of health. Sherry shared this perspective, highlighting the key advocacy role played by Marie's pediatrician,

> She [step-daughter Marie] didn't have control over anything...she just did what everybody said and so ...we try to really, to take a step back, and so we didn't

> remind her that it was bedtime...let her... have those same teenager feelings, that means...we may end up in the hospital because she's got pneumonia because she was too tired to fight it, but...I really truly believe those things that we did is why she's here where she is...Dr. Bell...sitting us down and saying "You've got to stop, she has to start making decisions, you can't protect her, she can't live in a bubble forever." And so that was a huge wake-up call to us. We worked really hard. Even today, when she's 18.

By letting go, and accepting this very typical parent-adolescent unknown, parents allowed normalcy to be introduced. Marie's parents made room for her to become an actor in her own life – a step essential to her individuation process and ongoing developmental progress. Although backing off meant accepting potentially life-threatening risks, the alternative was no less dangerous for Marie. The highly restrictive context in which she had been living had thwarted her developmental strivings, subverting them in an inwardly turned, self-destructive direction, "...she had lots of emotional psychological issues…about control…she had absolutely no say in how she lived her life..." (Sherry). Together, with the pediatrician's encouragement and support, Marie and her parents were able to restore her developmental course.

> The hardest decision as a parent (is) to watch your child fall and have to pick her up…but I know that Don and I are very proud to make that decision that no, at some point, ventilator-dependent for the rest of her life or not,…she wants to be able to live as a normal life as she can and so…everything in our life was about making that happen. (Sherry)

Life in the community: systems of support. Raising a child with complex needs in the community required significant amounts of support. Parents identified this support as being situated in both their informal social network (a few were fortunate to also find peer support), and the formally organized respite services that had been put in place when their child transitioned to the community.

Informal support networks provide significant help. Parents described their network of friends, neighbors and family to be of significant assistance to them as they adjusted to life in the community with their child. Themes arising related to the patterns of relationship parents had with their own key informal support people, and were similar to the children and youth's key adults, in that they adhered to the central tenet of authentic engaged presence. For example, parents described these people as responsive and readily available when needed, "I phoned my brother … he got on his motorcycle and drove straight through… he's always there for me anytime of the day or night..." (Roberta described the family member she knew she could count on in a crisis). They were also good at communication and listening, "… My brother and I are very close.... He listens he hears me and he doesn't tell me what to do" (Roberta). They could also be of some practical help, matching the parent's need to the support they offered. For example, Ellen relied on her sister Olivia to help manage system-based relationships, "...if I need her she'll come... she explains a lot of things to me and it makes it easier for me." Finally, these support people could be trusted and they were a source of consistent caring connection, helping the parents to transcend their daily struggle. For example, John described some special friends of his and his son, "…they phone me before anyone else and they take me out for dinner....And Tom knows them as Papa and Baca and he *adores them*…. Everyone needs to be loved.”

Peer support: “You have to live this life to get it”. Peer support was a theme that sometimes emerged in the form of a wish, particularly among biological parents. A few parents had actually been able to connect with others caring for children with similar health needs. Their mutual insight into what life was like provided a safe arena in which to vent and problem solve, “you only talk to …the people who get it, the people who live your life. Your other families out there who *do* get it…” (Laura). Peer support, when available, was also a valuable coping resource for solving problems through exercising mutual support and group agency, as mentioned earlier.

Formal respite support services helpful and stressful. Biological parents were provided with respite services to relieve them of their caregiving duties for a few hours at a time, in order that they could rest or attend to other needs. Children who attended school and depended upon a trach and/or ventilator also required a nurse to be present with them in the classroom for their safety. While these expectations and arrangements were set out as part of the child's support system in the community, they were accompanied by limitations, including becoming compromised by staff shortages. The themes arising from my analysis of the data suggested that parents experienced their child's formal respite service in terms that were double-edged, both helpful and stressful.

Respite service helps meet basic needs. The relief that respite services provided was essential to support parents who were transitioning their child with complex care needs (that included invasive respiratory technology such as a trach) to the community and to maintaining them in it. For these families, discharge planning for the child was contingent upon respite service availability. Respite service helped parents in several ways, first and foremost, by attending to their basic needs. Skilled relief coverage allowed parents to attend to the essential everyday activities that most people take for granted, for example, grocery shopping, personal appointments and most importantly, sleep. Parents described being chronically deprived of adequate rest due to monitor alarms and other needs, “when homecare comes I just go in the bedroom and close the door and go to sleep so it’s more like I just rest” (Ellen).

Respite staff also made important social connections with isolated parents, offering valued compassion and support in difficult times. Furthermore, the school nurse’s daily presence provided much needed continuity to the parent and child even when ill health disrupted home routines, “…the school nurses are allowed to continue to …take care of Mike in hospital or at home… it allows a little bit of continuity and normalcy for the children and for us” (Laura).

Respite service stressors. Themes related to problematic aspects of respite services also appeared in parents' perspectives. First and foremost was the unreliability of service, which was an ongoing issue and huge stressor for parents, "Is there really going to be respite?...nobody phones you no more...I only have three times a week now, where I used to have four times a week...Because they can’t find anyone to fill it…" (Ellen).

The lack of evening respite coverage was another chronic issue. Parents were often frustrated by their inability to attend programs and recreational opportunities, “I was going to go to [support] group things but it just doesn’t work out for me because they are in the evening…you can’t get respite.” (Ellen). The lack of coordination between support programming and respite service availability highlighted an area requiring attention.

Parents also experienced a lack of privacy, “like living in a reality show” (Roberta). While they acknowledged their need for help, the presence of others in the family home was an uneasy trade-off, “...you live in a glass house for so many years...” (Roberta). This level of exposure was described by some parents to include experiences of being judged by respite staff and, when reported to the system, having to answer to others that came to investigate, rendering them to a very disempowered position in their own home. These events compromised parents' perception of safety and confidence in their relationships with service providers, producing a toxic atmosphere of resentment and distrust in their own home, “you’d feel like you were under attack...” (Roberta).

Respite staff came with their own set of standards and expectations, some of which did not match those of the parents' that were receiving them, yet they depended upon them for much needed relief. Parents who were more dependent upon respite care and more passive in their relational style described coping by adjusting their standards regarding household care and child care to accommodate those of their respite providers’. This was particularly difficult in combination with being judged, as Roberta recounted, “There was sometimes I’d come home and my house would be destroyed. Literally. I remember after the nurses leaving a couple of times just sitting down and crying.” Parents described learning to be more flexible in their standards, while upholding their expectation of caring service, “if they want to do it their way, they do it their way, like…as long as he’s cared for, that’s all I care” (Ellen).

Respite nurses and patterns of relationship that worked. Respite nurses were the most personally involved, and, as such, had a large and significant role to play in the lives of these children and their parents. The characteristics that consistently emerged in parents' descriptions regarding the respite nurse’s approach that worked best for them and their child included clear, collaborative communication between the parent and the nurse and a relaxed personal, caring attitude. In addition, delineation of roles was clear, and there was respect for boundaries between the parent's role and the nurse's. The nurse also displayed competence in providing for their child's care, using an approach that focused on normalizing the child's context, as opposed to medicalizing it, for example, by wearing day clothes and using a discreet approach. Roberta's description provided a succinct example, "they just were a little bit more personable and relaxed. I think the day-to-day clothes were a big difference...For Jim’s sake...it’s less obvious." Roberta also described a communication strategy that helped keep the lines between herself and the nurses clear, "we had a book that we would all write in, ...sometimes he would have two or three nurses in a day so I’d read through...and if there’s any questions...I would respond...."

Parent-to-staff approach requires honesty and respect. The parent-respite nurse relationship went two ways and parents were an equal part of the equation in any successful respite relationship, due to the mutually interdependent dynamic that was at work, forming a relational dialogue (Baxter, 2004). The themes that came up in parents' descriptions of their conduct when forming a successful relationship with their child's respite nurse included, practicing honesty, “I just am honest…then you don’t have a problem...” (Ellen), and practicing reciprocal respect, “It’s a lot about respect...it goes both ways” (Sherry).

Parents also described finding their use of assertive communication to be the most effective in dealing with difficult situations. For example, single parent Ellen, let her respite worker know the pattern of communication she preferred, after learning that the worker had made a report about her to the coordinator, “I had said to her ‘you know I would appreciate that you say it to me instead of going behind my back and saying it to someone else’ – that’s the only incident.”

Resolving relational difficulties between the parent and respite staff. Sometimes respite service relationships did not get off to a good start and adjustments to facilitate their success were necessary. Similar to the hospital setting, collaboration and consultation provided a way to approach success. For example, Ellen acknowledged her discomfort with having face-to-face encounters with her respite care coordinator and suspected that this contributed to the relationship’s poor start. She and her coordinator were able to find a low-key, low-tech approach to mutually repair and rebuild rapport over time,

> You know we did that on the phone so it was easier because we weren’t face-to-face...we got to know one another more…so she knows how I am... I guess she thought I was this mean person, I don’t know, people get the wrong judgment of me I don’t know why…a lot of people say that to me…..

Ellen's comments suggest that individual differences in communication style need to be taken into account when finding a good fit in relationship building. Ellen's description of her experience may be related to being highly sensitized to others’ nonverbal, visually expressed communication, while less conscious of her own. Using the telephone minimized her distress by removing the visual dimension from the interaction on both sides, providing a climate of safety in which she could let down her guard and allow her trust to grow. In relational dialectic terms, this method balanced the tensions at both poles of the relationship, allowing movement forward in the interactive process. While face-to-face meetings remained necessary at times, the positive rapport acquired through this less formal channel appeared to help Ellen and her case manager proceed with greater confidence. This experience, by Ellen's report, appeared to further enhance her self-efficacy in managing other parent-professional relationships.

Effective parent-to-system approach includes active engagement, resilience. Some parents seemed to have consistent success and confidence in managing their system-based interactions. The approach they described using could be summarized as respectfully engaging system stakeholders in a process of collaborative communication and role clarification, from a proactive, assertive stance. For example, biological father Don explained his approach,

> Don: The best thing to do would be to explain our situation...and explain how we would like things to happen. So "If you're coming in the house this is what we are sort of expecting of you." Now...they can explain what their coverage would be or things like that.
>
> I: So you are kind of laying out roles?
>
> Don: Exactly, trying to understand…roles and responsibilities.

Here again, the dialectical nature of the relationship was in evidence, proactive parents recognized that they must be active participants in the relationship to effect change and create a balance. By contrast, parents describing a passive approach did not achieve these results. Instead, they struggled, often experiencing victimization alternating with distress and conflict. "I mean you keep things inside and there are resentments build up" (Roberta).

When the system let parents and their children down, those parents who were able to respond in an active, resilient way (when possible), transcended the problematic situation and experienced empowerment, compared to those who maintained a passive, victim-based perspective. For example, when confronted with the unilateral changes in supply services after Marie's decannulation, step-mother Sherry encouraged her to use the crisis as an opportunity to become more independent, "…you are going to have to maybe push yourself and here's a really good opportunity." Transforming this experience into an opportunity to promote autonomy modeled an approach to living that could foster the child's own long term resilience. This was not possible in every instance as, at times, systems "held all the cards", however, my analysis showed that parents who approached these difficulties with an active, resilient attitude reported more successes.

Working with the child's school. Parents recognized school as a gateway though which their child could move more fully into community life and personhood. Parents had a vital role to play in their child's career at school. Several important themes emerged in my analysis of the parents' narratives, specific to the school setting.

Presence of core relational elements important on both sides. Consistent with other system-based experiences, the core relational elements of caring, communication, collaboration and competence emerged as important features in parents' accounts of providers with whom they were able to form positive relationships. This was also mirrored in the patterns of relationship that effective parents described using to navigate the education system and to engage the school team, thus highlighting the importance of these relational elements to players on both sides of the relationship.

Preparing the school to receive the child. A common practice reported by parent participants, was to meet with the school team prior to the child's admission, to prepare the way for a successful entrance and to support their future progress. Parents who did this described experiencing peace of mind and optimism about the home-school relationship as a mutually respectful and collaborative partnership. For example Anne's foster mother Beth,

> I think it helped at the beginning …we had the big meeting and I explained about her...and just letting them know what’s going on and we haven’t really had any incidences at all...So I think it’s communication…just letting them know…they are very good. Let’s figure it out and we will work on it…(Beth).

Essentially, these parents were acting as advocates and educators on their child’s behalf, to the school team.

By contrast, parents who were not actively engaged in their child's education and took a more passive, less collaborative approach with the school team also described encountering greater adversity in their child's experience and in their own interactions with the school staff. For example, Roberta registered Jim at their local school when he reached the age of entry, expecting the school to accommodate his delays. She was disappointed by the outcome,

> They wanted to put him on Ritalin and I said "No" so that was just downhill from there, they treated him like a pariah... I said 'you know what?....There is nothing wrong with the way he is because he is delayed.'...Give him time to catch up.

Unfortunately, in the absence of a collaborative relationship, the situation deteriorated. Roberta, who had become a single working mother following the breakup of her marriage, reported struggling financially and being socially isolated. School was another stress that she dealt with by trying to continue on. However, Jim was subjected to chronic bullying at school and this affected the whole family,

> I felt like I was sending him out to the lions. I don't know how many times he got beat up on the way home… I'd try to get there to walk him home for lunch …Margaret got really protective.

Positive home-school relationship connected to child's success. Most parents described being very involved in their child's school life. This level of parental engagement, in conjunction with a collaborative, respectful approach to the home-school relationship, facilitated the child's entrance and integration into school. For example, Don characterized his approach to organizing the team relationships Marie required at school,

> ...Understanding Marie and her disability... and…"okay well, you are the school you are going to teach our child, this is what we are expecting from you" and then how to interact…with having the nurse.... I mean the roles and responsibilities of the nurse were understood...the boundaries weren't overstepped....

Parents who were intimidated by the school system and presented a more passive stance struggled, as Roberta's description of her son's individualized education planning meetings illustrated, "I was in those meetings...I don't think I really fully understood, I was overwhelmed with everything...I didn't like the behaviors with the fieldtrips, I didn't know that it was when he was bad he got a field trip." Roberta's comments suggest that some anticipatory support and coaching could have helped her towards making a meaningful contribution to her son's plan, rather than perpetuating her experience of disempowerment and alienation.

School as key social resource. Parents were very cognizant of the opportunities that their child's school presented in the realm of socialization, and encouraged their child to join in their school's community and build friendships:

> The biggest downside for Mike having a trach is he can never go to play at someone else's house, so his friends in his mind are his nurses' kids …and what am I trying to do more and more is to find kids that he does connect with in his school and invite them to my house… (Laura)

Parents seeking additional supports for their child also found the school to be a valuable referral source: "I found some girls through school...to tutor him" (John).

The difference inclusive practice makes to child's experience. The school offered the child their first social community beyond their family, and both the parents and the school had important facilitative roles to play in making this a successful experience. In my analysis of the parent interviews, the parallel but otherwise completely different school trajectories of the two adolescents provided the clearest illustration regarding the significant role played by inclusive practices in the school setting. While other factors certainly played a role in their long-term outcomes, the most noticeable difference between the school experiences of these two young people was their parents' level of engagement and the presence or absence of inclusive practices in the school.

Marie's parents registered her in a community-based private school that practiced inclusion years before it became common practice. She remained in this school system throughout her elementary and middle school years, and entered public high school at a time when inclusive practices were gaining momentum. Whereas Jim's parents placed him in their local public school where, on the basis of the interviews, it was clear that inclusion was not yet being practiced. He became subjected to chronic social marginalization and bullying. Marie, by contrast, experienced social inclusion and made good progress in her academic career, despite having a more visible disability. She successfully graduated from high school and was making plans to go to university. Jim developed behavioural problems and difficulties with his student role, and subsequently engaged in significant risk-taking behaviours and substance abuse as an adolescent. Consequently, he had recently moved to his father's house to get a fresh start, and was working on earning his high school credits at the new school in that community.

School administrator's central role in promoting school climate. Parents' descriptions made it clear that the school's leadership significantly influenced educational practices and, consequently, the quality of their child's school experience. Administrators who did not practice inclusion could create a very inhospitable, even damaging school climate for these already vulnerable children and their families, as illustrated in Roberta's account of her son Jim's elementary school experience. Bullying and social marginalization made up a large part of his school life, and at times appeared to include school staff, either by commission or omission. Roberta recalled being called to the principal's office after Jim, who still had his trach in grade one, was attacked by some grade six boys and his sister Margaret, a grade three student, had stepped in as his fierce defender and gotten into trouble,

> …Like these kids were huge, you know how big grade six kids are compared to grade three're...One had a bloody nose and the other one had a black eye and Margaret is in trouble. I just felt like turning around and going 'My god, if my daughter has to take on Goliath *where were the teachers?*' I couldn't even give her hell... (Roberta).

In grade two, when Jim's trach tube was removed, the bullying continued, this time without a nurse by his side,

> Roberta: The first day he came home all proud that he wouldn't have to have a nurse with him, some kid picked up a tree branch and smacked him right across the face with it and a teacher witnessed it and said that it was a total malicious attack, unprovoked…his face turned all black and he had to go back the next day and sit in the classroom with that kid, meanwhile, six months earlier when he had …coughed and spit some phlegm from his trach onto a little girls' jacket, and her parents…complained…Jim was suspended for a week and I was told I had to dryclean the jacket....
>
> I: And there were no consequences?
>
> Roberta: No! I fought with the school I went right to the school board over that but things like that, that's how he went through school.

Roberta reached the breaking point when Jim was part way through grade six and she reported pulling him out of school with the following parting words to the principal, "I said 'I have no respect for you, I have no respect for the school board for allowing you to work here'...she wasn't back the next year I went to the school board two or three times."

Inclusive climate dependent upon the school administrator. The recent implementation of inclusive school practices is no less dependent upon the administrator's support and promotion, as Laura's account illustrated. When Mike began showing signs of deterioration and distress in his school setting, Laura took her concerns to the education team, including the principal. However, she received a patronizing reception,

> I think they get their back up a lot with "we know what's best, we are the professionals", but you don't know my child. And you tell me everything is great at school, so why does he poop his pants when he has to go to school and he doesn't on the weekends?

When Laura, persisted in obtaining expert help through Mike's foster agency, her actions were met with considerable resistance from the school.

> The school was very offended to have …outside group come in and tell a group of teachers how to handle an FAS…autistic child…nonetheless the nurses that take care of him day-to-day were able to implement all those things and it made massive changes for Mike.

This passivity stood in sharp contrast with the collaboration Laura sought in the home-school relationship, "I would like to be asked as a parent what could be done at school level to make Mike's life better."

A change in school principal halfway through the year led to a turnaround in Mike and Laura's experience. The new principal, a former resource teacher, led a shift to school-wide inclusive practices and took a personal interest in Mike’s academic career. Laura stated,

> This new principal...has made a huge difference in Mike’s life. Huge!…By talking to him...“I want to know what you would like to do. I want to know what you’re interested in and I want you to learn to read Mike.”.…She listens to me and....She’s got Mike’s best interests at heart and she knows what she is doing. I see this principal is being very proactive with Mike and planful in the transition planning.

Laura’s renewed hope and trust illustrates the difference inclusion-oriented leadership can make to the child’s experience, and to the collaborative quality of the home-school relationship.

Role of the classroom teacher. Parents were very cognizant of the classroom teacher’s impact upon their child’s experience both interpersonally, and as a guide for the classroom community. Don described the attributes of an exceptionally caring teacher that his daughter Marie had in elementary and junior high school,

> Asking questions or listening, just general welcoming for the children. She was just a very kind person... she tried very hard to make sure that it was a good environment...warm and in the best way there was the control of the class, presentation of the information so that they could get the most out of the…schooling as possible.…

School counsellor as child's ally. The school counsellor was situated in a good position to mediate the child's school experience and provide support in social skills, for example. During Jim's early years, despite the difficulties he encountered with other staff, Roberta identified the school counsellor as a consistent psychosocial ally and teacher: "I think he was one of the few people that ever reached out." Her use of the active words "reached out" is significant as a descriptor of what worked, the counsellor's active, caring effort to build connection with her son.

> ...He was just amazing he used to bring Jim into his office...he would sit there and play these games with him – board games and he would talk about life and the things he was getting Jim to do; he was teaching him math, he was teaching him science....There was always a counsellor that was very good throughout.

Helpful educators' approaches. Parents articulated several helpful approaches used by teachers and school administrators that instilled their confidence and trust in the home-school relationship. First on the parents' list were educators that demonstrated a caring attitude and shared their goal for their child to have a positive experience, "Everybody seems to care about Anne…they have really listened to us…from the principal on down…so we're really happy" (foster father Keith). Practicing inclusion and community-building with their child in the school setting was another important activity, "It's that no bullying thing, everybody is part of the school so it's one of those things like it's the family-centered care, the schools have gone that way, too" (Don).

Educators who maintained an open, equal and collaborative relationship with parents also earned their respect and trust, "He says 'we don't know we've never had a child like her in the school, so you say whatever you want to us as strong as you want and we'll help' " (Beth quoted her daughter's school principal). When their child was sick, parents appreciated educators who continued to support his or her academic progress "Providing homework or communication, and when they were feeling better … added time…to recover what was missed or…maybe lost...” (Don). When their child was in trouble, parents appreciated educators using a nonjudgmental, solution-focused approach, "The best meetings we had were people who could communicate …without blaming, say 'this is the problem…how can we resolve this?' And you know what?…Jim would give us the answer." (Roberta, discussing the approach at her son’s middle school). When it was time for their child to move on to the next level, parents appreciated educators who ensured a smooth transition, as stepmother Sherry described, “Marie went to her high school as a brand new student, not one wrinkle.” What is noteworthy here, is that all of these approaches are consistent with the kind of sound educational practices that belong in any school.

Managing the child's health in the community. The move to community life was cause for celebration, but also brought new responsibilities, as parents exercised vigilance in monitoring and protecting their child’s health, “He's healthy. And then the other thing is, is I'm on top of everything…you always worry that you're doing enough for your kid” (John). Good health was subject to change, "She’ll change so quickly…when she’s stable you are just waiting for the axe to drop” (Beth). Discernment came with experience, helping parents to determine when to go for help, “…the biggest key for us - she needs to be on her machine more, that’s the key that we know, okay, she’s not doing well...” (Don).

Finding a balance for the child. Parents worked hard to help their child attain a balance between normal life and attending to his or her health, “...when Marie first came into my life she was...very sick and …as she grew stronger...it was really about a balance about everything” (Sherry, step-mother).

Attaining medical stability means a more normal life. The ultimate goal for parents was seeing their child attain medical stability, which they characterized as including a more typical childhood resistance to infection, as Megan's foster mom explained,

> Megan is very stable, she has been through...the standard couple of years out in the community, frequent infection phase that most of these kids go through and...has handled pre-school and kindergarten with really relatively few viruses.

When the child could fight off infections without requiring hospitalization, they could spend more time engaging in typical day-to-day activities, like other children, “It’s when her chest is clear and when she’s able to function and play” (Beth).

Pediatrician an essential health care partner. The child’s pediatrician appeared repeatedly in parents’ narratives as an essential ally, characterized as exhibiting the core relational elements parents identified as working for them. For example one parent described, “They are quick to respond when I call for help….Very personally interactive with the children and great caringfulness” (Laura).

Escalating care needs when the child is ill. When their child was ill the demands upon the parent were significant, “…a cold, his [pulse-oximeter] alarm would be going off like every hour and I’d be up every hour and then I’d still have to go to work...it was like Chinese torture” (Roberta). Parents walked a tightrope between managing their child at home and discerning when to take them to the hospital, “Her breathing you can hear the congestion...suctioning every five-ten minutes when she’s sick is not uncommon ...You would just say okay enough...there’s a line…that you become very aware of” (Sherry).

Deciding to go to hospital and impact on the family. Aside from concern for their child's wellbeing, when parents decided to take him or her to the hospital there were significant implications for family logistics that required organization and social network support. Sherry, Marie's stepmother explained,

> I remember walking around...okay I have to get my groceries done and I need to call my mom because my mom has to be on stand-by...and I need to do my laundry and I need to make sure that I have all the kids' activities and someone's driving them because I'm going to be at the hospital for the next five days. While she was getting sicker that's what we did (Sherry).

Going to hospital a kind of surrender for the parent. Recognizing their child's health needs had exceeded their capacity to help meant parents had to "surrender" control, as Beth summarized, "It's when I can't do certain things about the problems that I have more problems; like when she's sick and I like to fix everything here and then when I can't I have to take her in...." Taking their child into hospital (mesosystem) meant leaving the parents' realm of personal control, security and rhythm that was present in the family home (microsystem).

Connections and disconnections in accessing the health care system. "Connections" and "disconnections" came up as repeating themes in parents' descriptions of their experiences returning to the health care system for outpatient, emergent and hospital care. Connections, or meaningful positive interactions, were characterized by the presence of the core relational elements parents, and most often occurred at the level of interpersonal relationships. The exception at the system level was the pediatric respirology clinic, a new system feature that parents described as remarkably effective.

Disconnections, or negative interactions and gaps in service were characterized by the absence of one or more of the core relational elements and were most commonly located in system-based interactions. Disconnections encountered at an interpersonal level, usually involved health care providers whose priorities were system-centred rather than family-centred. The two thematic areas that were most dominant in parents' discourses about health care are explored below.

Experiences with disconnection in the emergency department. Parents most frequently associated this entry point to the health care system with negative, marginalizing experiences. They described these to begin with an unsafe intake process, in which they and their child were expected to wait for service alongside other sick children, in spite of the significant risk this exposure could involve.

Lack of timely response perceived as lack of caring. Parents also recalled the countless hours they spent managing their child's care in the waiting room, their advocacy efforts disregarded, leaving them feeling disrespected and their child uncared for, “don't put me on a six hour waiting list to teach me a lesson...it's just, it's unreasonable.” said John, a single working father. He lived with his son Tom in a bedroom community a short distance from the edge of the city. John took very few chances when Tom was ill due to previous close calls and the distance of the commute without any help in the car.

Parents' expertise disregarded. Most difficult of all, was the staff's disregard for parents' expertise, particularly when these parents, with their special training and assessment skills knew their child was in jeopardy, “I think that was the biggest emergency; I thought Jim was dying…and no one cared" (Roberta, single working mother). Some parents chose to leave the emergency department and obtain service in their own way,

> I’ve given meds sitting in Emergency...I’ve gone up a couple of times to say she’s getting worse and I’ve been ignored….I’d come home and put her on the ventilator and I’d phone Respirology and…looked after her here (Beth).

Information and referral system missing link in triage process. Upon finally seeing the doctor, the inefficient patient information system made this aspect of the experience incredibly frustrating. The intake process required the parent to give their child’s complex history every time they presented at the emergency department. Sherry, a relatively new initiate as a parent of a child with complex health needs, recounted her point of exasperation after spending hours with Marie in emergency,

> …This resident came in and said “can you tell me Marie’s...” and I just looked at him and I went (sighed) “No. No I can’t, because there’s ten volumes [of old charts] and I can’t relive her past.” I was too exhausted and I think that was the biggest awakening for me ...in that moment I went “Okay I get it!” because I’ve become [an angry parent, like others caring for a child with complex health needs]... an "outsider that came in".

Related to this cumbersome process was the absence of a clear and timely means to access complex care-specific services, as illustrated by Roberta's experience,

> ...Sitting in emergency was a nightmare. I remember one time …I had to hand ventilate him for four hours because there was a bus accident with school children.… After that they told me just go straight up to the ward and let them know I’m there...So I did that the next time … and they got so mad at me in

> Emergency …They said 'we would have notified them you can't be going over our heads.'

Parents' recommendations for improving connection. When asked to envision their ideal emergency department experience, parents described prompt personable, knowledgeable, and coordinated care. This tended to happen when someone who knew their child's health needs saw them in the emergency department, as Sherry described,

> ...We were going to get in right away and we were going to get up right away.... She could be in her own bed in PICU....And she could have her IV [intravenous] faster and we could have her settled and she can be on her ventilator sleeping. Sitting in that ER room for 4, 5, 10, 12, 20 hours is not doing her any good.

One parent, who was a health care professional, helped to expedite the triage process by presenting emergency staff with a home-made summary sheet of her child's complex health issues,

> Sometimes I'll bring in the sheet and...[if] they don't know me...they will go "Who is this written by?" And I'll say I wrote it. "You're in the medical profession?" And I say ya. But if I don't have something like that and depending how I'm talking …they will say, "Well are you sure?" (Beth)

Making connections through the respirology clinic. Parents excitedly described the addition of the respirology clinic to the pediatric health system and its positive impact upon their child's health care service.

> I don't have to sit in Emergency for 8 hours or 12 hours …They developed a department for these kids…you call ahead and you tell them what the problem is

> and they set up a time for you to come [see the respirologist] instead of sitting in Emergency surrounded by other sick kids...(Laura).

When contacting the clinic for help, parents described experiencing care, respect and prompt, responsive service,

> The respirology clinic [staff] listened and always took my phone call seriously….They used a courier service to provide samples for testing and sending prescriptions when I was home alone with the kids. About five years ago they developed the respirology clinic and it's availability to bypass [emergency] early. Five stars for developing the clinic. (Laura)

When their child required emergency hospitalization, the clinic was available to help parents coordinate appropriate services in a timely manner. For example, when Anne was sick and a visit to Emergency didn't produce a timely admission, Beth called the Respirology Clinic's nurse clinician for help, "And she phoned me back twenty minutes later and she goes 'You're coming to Emergency but we have (a pediatric intensive care bed) all ready.' "

Respirology clinic staff's approach characterized by core relational elements. Parents' descriptions of the clinic staff's interpersonal approach were consistent with the pattern of relationship they had previously identified as helpful, it was characterized by the four core relational elements, directed towards both the child and the parent, as Beth articulated,

> I find they listen to me better…they will talk to her [Anne]...especially during appointments. It's the personal touch...it's Dr. Fellows especially...knows her, and same thing with Barb [nurse clinician]....It's the personal knowledge as well...they

> know her better and they know me better… I'd say it's an open…friendly relationship…they were always trying to look out for me.

This was also the case in their contacts with the community-based respiratory therapist,

> The respiratory therapist loves the kids. She is wise and experienced and is a constant professional. She looks right at the kids and asks the child how they feel. She is very patient-centred and cares about making the kids feel comfortable. Willing to try different things to make kids more comfortable and make home life easier. (Laura)

The new respirology clinic, to a large extent, appeared to bridge the gaps parents had identified in the service system, at least during the weekday hours that it was open. This new addition provided evidence of a system-based developmental response, which Bronfenbrenner would situate at the level of the exosphere (health care administration, funding and policy) and mesosphere (direct service), in his bioecological systems model.

Parents' coping themes and patterns. Participating parents' descriptions of their coping experiences were characterized by the presence of several core themes, and particular patterns of coping also became apparent. During their interview, parents also had the opportunity to speak directly about their coping strategies. Don provides a very representative summary,

> I think it's good to...talk in the family, being organized, that's another thing that helps out and understanding, trying to gain as much information as possible so you understand what's going on and what this means and what that means. There is a humor too. The kids themselves and communication,

> and then when things are good you get out and you do things and experience different things so that it doesn't all seem so bad because it's not always bad.

Themes of coping. Some themes were universal, for example, hope was an inherent thread that ran through all of the participants' narratives. Their process of acceptance and adaptation was another predominant theme, whereas grief only presented itself directly in the narrative of the youngest child's parent, and, indirectly, in the narratives of three other parents. Parents revealed their resilience in the face of their difficulties through numerous examples, and every parent acknowledged their cognizance of the impact their own wellbeing had upon their child. Therefore, taking care of themselves and keeping social connections were two themes that also arose in parents' coping discussions.

Hope. This theme was present from the beginning of the parent's journey with his or her child, as a sustaining force, helping parents get through their darkest days. For example, Ellen illustrated how hope permeated even the most pragmatic aspects of parents' early experiences, in her description of Marcus's initial stay in a neonatal intensive care unit, "Yes like the really preemie's are over here and then the ones that have the respiratorial [sic] problems or sick ones are here and then when you go there you are getting closer to going home, that's what we were hoping for."

Once parents made it out of the hospital with their child, hope became a motivating force by which to strive forward in life, helping the child to attain his or her full potential, and often fuelling parents' advocacy efforts on their child's behalf. "It's not a battle won by the big fight, it's by all the little tiny fights everyday."(John, single working father) In fact, enjoying the very presence of their children at home and in their lives (as Don already mentioned), seemed to be parents' living proof that their hopes and hard work were being rewarded, "Just seeing them, just knowing they are doing well and knowing that you have done everything that you could do to get them to this point" (Keith).

Grief. The theme of grief presented itself in the content of a few parents' narratives, but not in the form of chronic sorrow that has been reported elsewhere (Murphy, 1991, Wilson et al., 1998). The children's situations may have initially produced feelings of grief, as evidenced by Ellen in describing her response to Marcus's condition, "First thing was, why was God punishing us?!...What did we do wrong?" However, parents of older children who raised the theme of grief described other aspects in their life than their child. For example, John's grief related to the personal sacrifices he had made to be present for his son, and his grief over the previous death of his wife and mother of his son. Roberta also expressed grief related to feelings of abandonment by her family, "I used to be very close to my family and I don't see them in the same light anymore." Beth referred to the loss of a previous much loved foster child when describing how she coped when Anne was very sick by "talking to Ivy". Regarding their children's ongoing disabilities however, parents appeared to have shifted their energies to the next theme, acceptance and adaptation.

Process of acceptance and adaptation. This was a major focus in parents' coping, and a process that took time, as Ellen explained, regarding her gradual acceptance of three-year-old Marcus's health situation,

> This is how he is and if he gets better thank God you know, if he doesn't, oh well, we have to accept him for what he is and for what he can do and that's it… I think

> we were very negative at first, we didn't want to accept it and that but I think we've accepted it. Like my thing is make the best of it for him.

Besides sharing the above goal in common, a phrase frequently mentioned by parent participants with respect to their process of acceptance and adaptation was, "You do what you have to do," and the closely related parents' mantra: "You get through it" (Don). Fundamental to this attitude was a deep and abiding commitment to their child, belief in their personal ability as a parent and above all, hope.

To help them in adapting, parents described using several strategies that were consistent with Neff's description of self-compassion (2003). A couple of examples were, choosing not to plan too far ahead, just living in the moment*,* "Day to day. Just don't worry about tomorrow" (Keith), and accepting their child's circumstance as a part of the common human condition, "what's done is done and we just have to deal with it and do the best that we can to make sure they survive..." (Keith).

Resilience. Participating parents provided countless examples of struggling well in the face of adversity, transforming barriers into opportunities. Some circumstances were less daunting than others, for example, dealing with the high cost of parking when visiting the hospital, as Roberta recounted during her son's two year stay, "Actually that kept me pretty healthy, I'm so cheap I refused to pay for parking so I don't care if I have to walk a mile I'm going to find a free place to park."

Dealing with the ongoing potential for life-threatening emergencies was something that all parents had to learn to manage. Foster father Keith, a lay-person and primary caregiver, recounted his experiences with two life-threatening episodes he had successfully managed alone with his foster-daughter Anne, "After the first time it was pretty tough, thinking about what could have happened...if we weren't there...how lucky she was and how lucky we were...the next time it happened it...didn't seem as extreme...it didn't take any time at all." Perceiving the good fortune in these adverse events allowed Keith to transcend their distressing nature and build his capacity to manage Anne's care.

Creating a space for their child in the community meant making sacrifices, and finding creative ways to keep life satisfying. For example, Ellen chose to give up her job as a respite worker to care for Marcus fulltime. However, once she got into a routine at home with him, she realized that they both needed something more in their lives, so she began providing respite and foster care to young children in her home, enriching both of their lives, "I was going to put him in daycare but I changed my mind. He interacts with the kids.…I put him on the floor with them and everything and he likes it like that."

Humour. Closely connected to resilience, humour was a feature of every parent's interview. The laughter and jokes often accompanied discussion of emotionally laden content, suggesting that they may have functioned as a "pressure release valve" or "counterbalance" to the emotional weight of parents' difficult experiences. Parents also acknowledged humour's direct value, as a way of coping, "Sometimes that's all you can, is laugh, because there's nothing else that's going to change it" (Roberta).

Learning to go with the flow. An important understanding that all participants described arriving at, was a level of acceptance regarding "what is" for their child, themselves and their life in general, and learning to become more flexible with their expectations and "go with the flow" as John described, "…the one thing I've learnt is control is just a figment of your imagination…you learn everything flows. So you just don't worry.... *You flow"*(John).

Self-care. Parents were distinctly aware of the connection between their own wellbeing and that of their child and family's, as Sherry stated, "not only do you have to keep the disabled child healthy you need to keep the parent healthy...." Finding a way to practice self-care could be a challenge, given the everyday work and care-load that parents had to manage. Fathers described taking on household maintenance projects, exercise or going for a drive, while mothers sought the company of friends, or practiced mindfulness with a quiet bath or yoga, for example. While self-care through social outings was limited by respite shortages, single parents described making alone time to decompress, "You always have to take at least a couple of hours a week even if it's just to soak in a hot tub and burn candles, I did that – what a huge difference" (Roberta). Couples described relieving each other to take some space, planning respite to have time alone, and getting out to engaging in leisure activities after a period of difficulty: "at times it is: 'okay it's been a little stressful let's get out and do this…' We can enjoy ourselves," (Don).

Social connections and support. "People are the main thing" as one participant noted, this theme was a central feature of parents' coping, arising in relation to both emotion-focused and problem-focused strategies, of relevance in both formal and informal domains and many examples of parents' resilient responses. Parents referred to social connections in every sphere of life that was vital to their and their child's wellbeing, including, extended family, friends and neighbors, school staff, coworkers, health care professionals and peers that they had connected with through their children's common health circumstances. My analysis showed that these connections served as a kind of safety net, as parents who reported few connections and greater social isolation also seemed to experience more distress compared to their well-connected peers.

Examining differences in patterns of coping. In considering the parents' narratives, I observed that some parents employed patterns of coping that seemed to be more effective than others in addressing their difficulties and sustaining their child's wellbeing, as well as their own. For example, those whose coping pattern included a range of both problem-focused and emotion-focused coping strategies described greater success with overcoming difficulties they encountered and more satisfaction with the subsequent outcomes they realized. Whereas, those who were more passive, and relied primarily upon emotion-focused strategies, and avoidance-based coping in particular, described conflict and difficulties as an ongoing struggle in their lives.

I also noticed that parents who were well connected socially described more satisfactory relationships with others and had a larger repertoire of coping strategies to draw upon when facing adversity. Bandura's (1997) process of triadic reciprocal causation provided a useful way to examine the interplay between parents' intrapersonal coping choices and responses in relation to the uniquely stressful environment in which they were situated. Using this approach, I began to recognize how both constructive and destructive parent coping patterns could be perpetuated, and to see the essential role of parents' social support connections and opportunities in promoting more adaptive ways of managing their experiences.

Social isolation. Social isolation was a common experience amongst parents, largely due to the uniqueness of their situation. However, some parents were much more isolated than others, either by choice or by circumstance. Isolation in particular arose with greater frequency amongst single working parents who, from a practical perspective, were in a difficult position as the sole adult responsible for their child and household. Limited respite services meant that these parents typically had little or no back-up support, thus they had to rely upon their own resilient solutions to create these opportunities, as Laura described earlier, for example, in having people come to her.

Parent participants who reported feeling lonely or socially isolated also appeared to perceive their circumstances in characteristic ways. For example, they tended to describe situational difficulties in their personal lives as being beyond their control (and sometimes they were). They also reported experiencing high levels of frustration and conflict in their relationships, both personally and in system-based contexts. They tended to approach problems with an "all or none" stance, either taking complete responsibility or none at all; instead, passing on the responsibility to other people or systems. In responding to their child's disability they took an adversarial/blaming view, attributing all or most of their child’s problems to their disability, and celebrating their child's progress as a victory over the disability. For example, "it’s been quite amazing seeing different road blocks he’s come across and accomplished...because you don’t ever expect him to ever reach those... that kind of prognosis ...you tend to raise them a little differently" (Roberta).

The strengths that appeared to sustain these parents throughout their difficult course included their deep and abiding commitment to their child, their persistence, and their hope for the future. The combination of these parents' experiences, environmental limitations, and characteristic ways of perceiving, provided evidence in support of triadic reciprocal causation (TRC) (Bandura, 1997) as the process by which their coping and consequently, their circumstances, could be self-perpetuated or changed.

Triadic reciprocal causation in action. The components and process of TRC (see figure 6, p. 122) were easily identified in these parents' accounts. To cope when feeling overwhelmed, socially isolated parents described using primarily self-soothing, emotion-focused coping strategies, particularly including denial and avoidance (personal component of TRC), "…when things get very, very stressful for me…I tend to -- my nature is to kind of run and hide" (John). When their circumstances did not improve (environmental component of TRC), they reported experiencing further distress, either turned outwardly in relational conflict, or turned inwardly in depressive behaviours (behavioural component of TRC), for example, "...it's my situation that depresses me" (John). This led to further emotion-focused coping and the process repeated itself, perpetuating a negative circumstance.

However, change was possible and could also be explained by TRC. For example, when Laura reached a moment of insight, with the help of her counsellor, and realized she had to accept Mike "as is" rather than trying to "fix him". This intrapersonal shift changed her personal stance in relation to her foster son, positively impacting how she managed other aspects of her family life, "I sometimes actually get a little ticked off at myself...I had a whole pile of other kids in the house too at the time and that was my primary focus for many, many, years." Likewise, when the environment offered social support in the form of an ally, as exemplified by Ellen's connection with her child's nurse clinician, this lowered the degree of threat that Ellen perceived in the environmental component of her situation. The result was that she had more coping choices available to her and, ultimately acquired a new way to cope, with the support of the nurse clinician, through communication and collaboration. That interaction helped to shift Ellen's relationship with her child's health care providers in a more positive direction.

Social context influences perception and coping. In my analysis, I noted that parents who described being actively engaged with their family, friends and community, also tended to describe more active patterns of coping. When they encountered distress they used emotion-focused coping strategies, but usually in tandem with problem-focused strategies, such as assertive communication and seeking social support. For example, in Keith's encounter with emergent events, he would take some space from what had happened and then follow up, "I'm the type of person that will talk about things like that afterwards...I will go deal with it myself [described going for a drive to take some space, then returning and]...I'll ask Beth if there was anything else that I could have done differently.... Just to be let known that you did the right thing."

This variation in coping pattern suggested that parents who were more socially connected had a different understanding of the dynamics involved with problematic situations compared to socially isolated parents, who took a more passive stance. This appeared to be related to each party's respective perception and expectations of the situation, which seemed to reflect their own relational context. Rather than viewing the difficulty as something completely outside and beyond themselves (isolating), socially connected parents perceived a more interdependent, dialectic relationship, in which they had the power to effect a change by the way in which they responded. Therefore, mobilizing their personal agency would be a reasonable way to begin to address a difficulty, even when - and perhaps especially when - the adverse circumstances came from outside of themselves. This suggested that the social-environmental context was important when considering the way in which parents appraised their situation and chose to cope.

To summarize, parents who were more socially isolated in their lives perceived difficulties through a lens consistent with their experience, a remote and isolating viewpoint. Parents who were more socially connected in their lives, perceived difficulties from a more interdependent, relational viewpoint. This situation has implications for practice and further supports the concept of TRC as an interactive process, grounded in the interplay between environmental, personal and behavioural components.

Changes in coping over time. Participating parents shared many insights about the ways in which their coping changed over time. Themes arising in this dimension were developmental in nature, and focused on progressive to transformative learning.

Seeing the big picture. Some parents were able to see how the bigger systems had moved over time, and saw their place in the order of things. For example, Don described witnessing the introduction of family centred care as part of a societal shift,

> It wasn't just the health care system ...it was sort of the country itself, for instance, the pharmacy ads, so you have the right to ask about your medication....I also think that it came to pressure, like the overall pressure of society saying that, "Okay, you know what, you can't close the door on me because that information should be available to me" (Don).

This description seemed to reflect a shift from an institution/system-driven (authoritarian) orientation to a more collaborative, consumer-centred orientation, in response to the cumulative pressure from the masses. This example illustrated the dynamic and dialectical nature of change in the context of relationships between people and systems. This is consistent with the interplay of proximal processes and transformative change in Bronfenbrenner's bioecological systems theory (2000).

The difference experience makes. Parents described how their understanding and confidence grew as a function of successfully navigating new experiences, "It’s the experience that you have gained so you understand more..." (Don). Beth also acknowledged how both past and present experiences informed her coping, “I think maturity, knowledge…a lot of my coping also comes from nursing and seeing kids like this and dealing with tragedies….And even now… you just kind of learn to teach yourselves.”

Parents who had spent so much time organizing and coordinating their child's care also struggled with the unknown due to their child’s complex health needs. However, over time, with plenty of experiences, they learned to loosen their anxious grip and become more tolerant of ambiguity, in part, by recognizing and accepting their own limits. “I don’t need to have all of the answers anymore…a lot of times… I just like to set things aside and let my mind cool off…There are some things that you can’t fix...” (Laura).

Opening up and moving outward into engagement. The transformative developmental process that parents underwent is evident in the opening-up and outward-turning movement that previously passive parents experienced in relation to their world. “Before …I would just keep everything in… if I was upset… now if I’m upset…I’ll say something and I never used to be like that...I just let people walk all over me before.”

(Ellen). Eventually, all of the parents discovered that being engaged in the wider world and using assertive communication could help to improve their circumstances.

> "I didn't know then, now I just find my way to the top somehow...you should always go to someone else, you don't have to feel crappy about anything, just the fact that you are trying to raise your child like that is an accomplishment...I've learned to speak my mind and you know what the best thing is?...I have to say what I have to say now, all those horrible feelings are gone faster (giggled) something gets done faster and you can go on with your day. (Roberta)

Roberta learned that becoming more actively engaged and assertive helped her to feel better about herself and get more of the things she wanted done, demonstrating support once again for the working process of TRC.

Acquiring insight, developing skills as a navigator and advocate. Parents also gained insight, with time and experience, into better ways to engage and get involved in their child's service systems. For example, Roberta acknowledged that a more active role would have helped her son at school,

> …I think even dealing directly with the teachers is important more so than I did, I should have been more involved. Definitely be involved with your child's education and know if there is conflict or if there's problems with the other students.

Parents identify counselling services as valuable resource. When participants were asked what helped them to cope, several immediately identified counselling services as a valuable means by which they or their children had obtained in help. They described counselling being helpful in several ways, including negotiating the parenting partnership, for example, "They...reaffirmed what you should do…it provided the opportunity in the absence of all these children ...to talk about it and to really listen to one another and understand where you are coming from." (Sherry). Counselling also helped parents to gain insight about their situation and move to greater acceptance, as Laura described,

> Isabel, the counsellor… said the most profound thing to me... 'Sometimes we need to stop trying to figure out ways to help somebody fix or change their behaviors and just realize they are the way they are and always will be'... all of a sudden it just hit me, 'you're right,' and I think I let go of trying to fix Mike that night. Now Mike is just Mike and I'm okay with that and so is he… (Laura).

Counselling, in combination with medication, helped Ellen learn to manage change, and come to terms with the grief of her mother's death and her child's complex health condition. She described the therapeutic alliance as key to helping her approach her difficult feelings and move through a process of acceptance and transformation,

> ...I guess just getting things off my chest… having nobody to judge you or anything, I think that's how that helped.... I just feel like I can deal with it now.... I was where..."Maybe I'm doing something wrong" and I have to realize that I'm not doing anything wrong I'm doing what I can and that's it.

Parents described locating counselling services through various means, including their employee benefit program and their family doctor. Only one parent, who was fostering her child with complex health needs, described having access to counselling as part of the supports made available to help her in her parenting role.

Summary of the parents' perspective. Through sharing their perspectives in the interviews, participating parents revealed their lived experiences, including their deep and persistent commitment to their children in the face of their health care difficulties and sometimes differing professional opinions. They talked about the journey from the hospital to home, learning to care for their child, navigate the systems and strive for balance amongst their commitments. Together with their child, they grew further into living in the world as a matter of necessity, negotiating their relationships with the systems that served them and their child and promoting their child's development and adjustment to disability. In each case, these parents showed a remarkable amount of resilience, persistence and fortitude. Although each participant began their journey at their own unique point on the adaptive continuum, over time all moved forward along a similar developmental path.

Some parents' approaches to coping appeared to be more adaptive than others. Being socially connected both informally and formally was important to sustaining the parent and child's wellbeing. Parents described the same central relational tenet and four core elements as the children and youth, in characterizing their key supporters and service providers' patterns of relationship. They also benefited from incorporating these elements themselves into their relationships, often moving in towards these elements as a result of their own interactions with their supportive allies.

Parents who had a strong informal support network, and were able to engage with their child and their child's health care team during the early days, and who also developed competence in advocacy and system navigation, besides mastering their child's care, had an easier time bringing their child into the community. Parents who had a partner or reliable support network and balanced emotion-focused coping with active problem-focused coping, such as assertive communication and advocacy, found life more satisfying and manageable. They were also more effectively able to help their child move into their place in the community, valorizing their role when needed. Parents learned that loosening their anxious grip on life and their child by settling into a more flexible, responsive way of engaging was also important (attaining flow).

Not all parents had the same opportunities or circumstances available to facilitate their process of adjustment and adaptation, and those who were situated in a more socially isolated context experienced more adversity and struggle. Bandura's process of triadic reciprocal causation (1997) provided a useful way to view parents' responses to their circumstances and understand how the processes of perpetuation and change worked. I will discuss the implications of parents' differences of experience later, however, it is important that counsellors and other service providers pay attention to the patterns that these parents have been engaged in, as well as, their contributing factors. In the next section I will present the results of the parent survey sample's data, which approaches questions of the study related to parents' lived experiences, and their patterns of coping and relationship from a quantitative perspective.

Results Arising from the Parent Survey Sample Data

The results of my analyses of the data from the parent survey sample (n = 31) are presented below. This will cover quantitative responses for questions one to five (including sub-questions), with the exception of question two, which was completely qualitative in nature and as such, has been addressed in the parent interview sample section. Results specific to question six are presented in a side-by-side comparison table immediately following the survey results section. I also subsequently discuss the posthoc analysis I conducted regarding "kind of parent", a contextual variable that presented itself in the participant samples and required examination. Please note that when necessary, three decimal places are given to reports of significant results.

Exploring parents' lived experience: perspectives of community support.

In the first question of the study I set out to gather information about the experiences of children living in the community with complex health needs and that of their parents. Specific to this enquiry, parents in the survey sample (n=31) were asked to give their opinion on the extent to which the supports provided in the community were adequate to help them care for their child (see Family Information Checklist, Appendix B). My analysis of the survey data showed that a high proportion of parents (41.9%) rated community supports as being less than adequate (Table 1). Analysis of the responses to a subsequent open-ended question that invited further comments showed that some participants who reported the level of care to be adequate also had some concerns, as one of several comments stated, "We have not had a holiday in 12 years".

Table 1

Parents' Opinion Regarding Community Support Provided

Opinion	Frequency	%
Far below what is needed	5	16.1
Not quite enough	8	25.8
Adequate	8	25.8
Right amount	4	12.9
Very good / none needed	5	16.1
Missing data	1	3.2
Total	31	100.0

When participants were asked to describe the services that were still needed, a large proportion (64.6%) provided recommendations, as presented in Table 2. Respite services emerged as the main area requiring attention (38.7% of the sample, overall). An examination of participants' subsequent suggestions (see summarized notes below Table 2), showed respite staff shortages to be a key issue, including the need for better school coverage and more flexible, versatile respite options, including respite facilities in the community. A smaller proportion of parents also described the need for more specialized support services to facilitate their child's success at school and in life, generally.

Table 2

Parent recommendations for supports still needed

Supports[a]	Frequency	%
No comment	11	35.5
Respite services	12	38.7
Allied health and education services	3	9.7
Financial assistance	2	6.5
Counselling for child	1	3.2
Transportation assistance for appointments	2	6.5
Total	31	100.0

[a] Parents' responses were grouped by category, examples are given in notes below.

Parents indicated a need for additional respite services in general, after school, evenings and nights. Seven specific areas parents raised were:
better coverage for school nurses to ensure child's right to attend school is upheld,
allowance for trained family members to attend school with child if nurse is unavailable,
more nurses to fill vacant respite shifts,
self-administered respite,
services to address daytime needs after child graduates from school,
more out of home respite, including a facility for overnight stays on weekends or holidays, and an affordable camping resort for families with children having complex medical needs.

Parents also sought allied health increases in the areas of speech language pathology, physiotherapy, psychology, and counselling. Education services were also mentioned, including teaching assistants with proper training, behavioural specialists and programming.

Examining parents' patterns of coping. The third question of the study asked what patterns of coping the children and parents found to be helpful in managing their lives and in promoting the child's development and adjustment to disability. To answer this question, I gathered data about the parents' patterns of coping using two self-report scales that were included in the survey package, the Coping Health Inventory for Parents scale (CHIP), (McCubbin & McCubbin, 1985) and the Self-Compassion Scale (SCS), (Neff, 2003). Descriptive statistics and percentages were generated for parents' overall scale scores and subscale scores in each of the scales. Summaries are presented and subsequently discussed below; a more detailed view is available in Appendix C, Tables C11 (CHIP) and C12 (SCS).

Parents' coping patterns as measured by the CHIP scale. The distribution of responses on this scale was slightly peaked (Kurtosis = 1.17) however, with a total range = 88, and *SD* = 22.61, this was considered to be negligible. Participating parents' overall scale mean: *M* = 92.79. The patterns of coping participants reported, according to the CHIP subscale domains, in rank order were,

1. Subscale One: Maintaining family integration, cooperation and an optimistic definition of the situation. 74% (*M* = 42.37).
2. Subscale Three: Understanding the health care situation through communication with other parents and consultation with the health care team. 65%. (*M* = 15.55).
3. Subscale Two: Maintaining social support, self-esteem and psychological stability. 64% (*M* = 34.76).

This pattern suggested that maintaining a positive outlook and using collaboration and communication at the level of the family, and via formal and informal health support networks, were key aspects of these parents' coping patterns. Whereas, personal self-care activities were less attended to, suggesting an area for further exploration, from the perspective of possible barriers, as well as awareness.

Parents' coping patterns as measured by the SCS scale. The SCS scale dataset showed a relatively normal distribution overall. Self-compassion strategies chosen by parents, according to thematic subscale, in rank order were:

1. Common Humanity: 67% (*M* = 3.36).
2. Mindfulness: 65% (*M* = 3.23).

3. Self-judgment (negative subscale): 60% (*M* = 3.03).
4. Over-identification (negative subscale): 58% (*M* = 2.88).
5. Isolation (negative subscale): 56% (*M* = 2.81).
6. Self-Kindness: 55% (*M* = 2.74).

The overall SCS scale percentage score was 62%; Mean value calculated using Neff's 2003 method, total scale value=18.61 (total range possible=6-30). Mean value calculated using Neff's method provided for researchers on her website (refer to methods chapter) produced at total scale mean, *M*=3.08 (total range possible: 1-5).

The rank order of the subscales shows that parents coped most often by looking to the wider human condition, as a way to reframe their experience and keep it in perspective. The second-ranking subscale, mindfulness, provides evidence of parents' ability to stay present in their experiencing without getting swept away by distress. This is a particularly relevant coping strategy for these parents in times of crisis, when they must remain calm and focused in order, for example, to provide essential, life-saving care to the child that is depending on them.

It is noteworthy that the self-kindness subscale attained the lowest score, ranking below the negative scales of self-judgment, over-identification and isolation. This finding would seem to align with the bottom rank attained by subscale 2 of the CHIP Scale, which also concerned itself with maintaining personal aspects of wellbeing. This result, along with the moderate overall scores, suggested that parents actively use self-compassion strategies and also, that there is room for further development. See Appendix C, Table C12 for further details.

Variations in parental coping related to contextual characteristics. In addition to my general enquiry into parents' patterns of coping, I was interested in knowing if certain contextual characteristics of the parents' situation influenced their coping pattern. Therefore, I posed sub question 3.1. Do parents' reported coping strategies vary on the basis of contextual characteristics, such as family structure, gender, or the extent of their child's respiratory technology (invasive versus noninvasive)?

To answer this question I conducted independent samples t-tests using the parents' data from the CHIP scale and the SCS Scale with each of the contextual characteristics using independent variables created from data obtained on the Family Information Checklist, as follows,

- Family structure: I calculated this variable by coding individual cases according to whether they reported their family being headed by a single parent (1) or a couple (2). A limitation must be noted for this variable due to the sample's small group size of single parents ($n = 5$). I pursued analysis following a review of the significant differences in family structure-related experiences arising in my analysis of the parent interview data (qualitative findings). I used Levene's test for homogeneity of variance to ensure that there was sufficient variability to conduct statistical analysis; an insignificant finding on this test was my criteria for proceeding.
- Gender: I coded cases by gender-based family roles: mothers (1); fathers (2).
- Extent of Respiratory Technology: I coded cases according to whether the parent reported their child as having a tracheostomy (1) or not (2).

Family Structure and Coping. I conducted independent samples t-tests to compare the CHIP scale and subscale scores on the basis of family structure, and subsequently, the SCS scale and subscale scores.

In the CHIP scale t-test (Table 3), single parents had lower means than their peers situated in couples on the overall scale and every subscale. The t-test results presented in Table 3.1 (on page after Table 3) show that single parents had a significantly lower CHIP scale mean score (*M* = 65.50) compared to other parents (*M* = 97.16) at $p \leq .01$ (two-tailed); effects size: eta squared = .24.

Single parents also had significantly lower mean scores on subscale 1: Family cohesion/cooperation and optimistic view of situation at $p \leq .001$ (two-tailed); eta squared = .30; and on subscale 3: Communication and collaboration with other parents and health care providers, at $p \leq .01$ (two-tailed); eta squared = .24.

Table 3

CHIP scale and subscale scores contrasted on Family Structure

Group Statistics

Scale/Subscale	family structure (parent #)	N	Mean	Std. Deviation	Std. Error Mean
CHIP Total Scale	1	4	65.50	14.43	7.22
	2	25	97.16	20.64	4.13
Subscale 1 family integration	1	4	28.50	7.32	3.66
	2	26	44.50	8.55	1.68
Subscale 2 Personal	1	4	27.00	7.26	3.63
	2	25	36.00	9.02	1.80
Subscale 3 communication	1	5	10.20	1.10	.49
	2	26	16.58	4.56	.90

Table 3.1

CHIP Scale and subscale scores contrasted on Family Structure

Independent Samples T-test

Scale/ subscale	t	df	Sig. (2-tailed)	Eta squared	Mean Difference	95% Confidence Interval	
						Lower	Upper
CHIP Total Scale	-2.93	27	.00	.24	-31.66	-53.81	-9.51
Subscale 1 family integr.	-3.53	28	.000	.31	-16.00	-25.27	-6.73
Subscale 2 personal	-1.89	27	.07	-	-9.00	-18.77	.77
Subscale 3 health network	-3.07	29	.00	.24	-6.38	-10.63	-2.13

Although single parents were represented in this sample by a very small group, the magnitude of differences in means, at 30% lower, indicated that they had a distinctly different experience than their parenting couple peers in terms of their range, frequency, and kind of coping patterns.

In the SCS t-test I found no significant differences between single parents and couple parent peers. However, upon visual inspection of the means, I noted that single parents' values were consistently higher than that of parents situated in couples on every positive subscale and on the overall scale (single parents: *M* = 20.57, SD = 4.32 compared to parents in couples: *M* = 18.24, SD = 4.33), although they did not attain statistical significance. Single parents also had slightly lower means on every negative subscale compared to their peers in parenting couples. This suggests that single parents may use self-compassion strategies more often than their peers situated in couples. See Appendix C, Table C14.1 to view the comparative means, and Table C14.1 to view the t-test results.

Gender and coping. I conducted an independent samples t-test to compare participants' CHIP scale and subscale scores on the basis of gender. I found no significant differences in the means, as follows: CHIP scale score mothers' *M* = 92.42, SD = 18.94, while fathers' *M* = 93.50, *SD* = 29.53; *t* (27) = -.120, *p* = .91(two-tailed). Mean difference = -1.08; 95% CI = -19.53 to 17.37.

A separate independent samples t-test to compare participants' SCS scale and subscale scores on the basis of gender also resulted in insignificant differences in mean scores: SCS scale score (calculated using Neff's new method), mothers *M* = 3.21, *SD* = .77, while fathers' *M* = 2.81, *SD* = .55; *t* (29) = -1.47, *p* = .15 (two-tailed). Mean difference = .401; CI 95% = -.156 to .958. Therefore it would appear that with respect to this sample of parents, gender was not a significant contextual factor when considered on the basis of the kind of coping patterns parents used.

Extent of respiratory technology and coping. I conducted an independent samples t-test to compare participating parents' CHIP scale's variance, on the basis of whether their child had a trach (invasive technology) or not (noninvasive technology). I found that parents who had a child with a trach attained higher scale and subscale means than their peers, with significant mean differences on Subscale 1: Maintaining family integration/cooperation and optimistic view of situation, as follows: Trach present: *M* = 45.88, *SD* = 7.02, no trach present: *M* = 38.67, *SD* = 11.59; *t* (27) = 2.09, *p* = .05 (two-tailed). The magnitude of the difference in the means (mean difference = 7.22, 95% CI: .13 to 14.30) was large (eta squared = .14). See Appendix C, Table C15 and Table C15.1 for further details.

I also conducted an independent samples t-test for this variable using data from the SCS scale and subscale scores and found significant mean differences. Parents caring for a child with a trach consistently attained higher mean values than their peers on the subscales except for the negative subscales, which they attained lower mean values on (see Table 4). Table 4.1 (on a subsequent page) shows that these parents attained a significantly higher mean value for the overall scale: $p \leq .05$ (two-tailed); eta squared = .17, and significantly lower values on the negative subscales: Self-judgment $p = .04$ (two-tailed); eta squared = .15 and Isolation: $p = .01$ (two-tailed); eta squared = .21. The large effect sizes suggested that this is an aspect of experiencing that is distinctly different for parents raising a child with a tracheostomy. This result indicated that these parents were less self-critical and less inwardly turned in their approach, which would be helpful to coping effectively with their circumstances.

Table 4

Self-Compassion Scale and subscales contrasted on Extent of Respiratory Technology

Group Statistics

Scale/subscale	Extent of RT[a]	N	Mean	Std. Deviation	Std. Error Mean
Self-kindness	1	18	2.91	.70	.16
	2	12	2.37	.85	.24
Self-judgment[b]	1	18	2.79	.77	.18
	2	12	3.45	.84	.24
Common humanity	1	18	3.53	.92	.22
	2	12	2.98	.78	.22
Isolation[b]	1	18	2.44	.95	.22
	2	12	3.40	.93	.27
Mindfulness	1	18	3.29	.84	.20
	2	12	3.08	.84	.24
Over-identification[b]	1	18	2.64	.97	.23
	2	12	3.31	.82	.24
SCS Total scale value (Per 2003)	1	18	3.31	.63	.15
	2	12	2.71	.70	.20

[a] Extent of RT scoring: 1 = child has a trach; 2 = child does not

[b] Negative Scales

Table 4.1

Self-Compassion Scale and subscales contrasted on Extent of Respiratory Technology Independent Samples T-test

Scale/ Subscale	t	df	Sig. (2-tailed)	Eta squared	Mean difference	95% Confidence Interval	
						lower	upper
Self-kindness	1.91	28	.07	-	.54	-.04	1.13
Self- judgment	-2.22	28	.04	.15	-.66	-1.27	-.05
Common humanity	1.70	28	.10	-	.55	-.11	1.21
Isolation	-2.72	28	.01	.21	-.95	-1.67	-.23
Mindfulness	.67	28	.51	-	.21	-.43	.85
Over-identification	-1.97	28	.06	-	-.67	-1.37	.03
SCS Total scale value	2.43	28	.02	.17	.60	.09	1.10

Parents' perceptions of relationship with their child's health care providers. These results related to Study question 4. To what extent do parents perceive their child’s health care providers to behave towards them in a family-centred manner?

To answer this, I analyzed participants' data collected on the 20-item self-report scale, Measure of Processes of Care (MPOC-20). Descriptive statistics for the MPOC-20 data (see Appendix C, Table C13) showed that participating parents perceived family-centred care behaviours used by their child's health care team (respirology clinic primarily, plus pediatrician and any other specialists following the child), to be present to varying degrees, according to the kind of focus as represented in thematic subscales. The findings for this sample's parents were as follows, ranked highest to lowest in frequency, by percentage and mean:

1. Enabling and Partnership (75%) *M* = 5.22
2. Respectful and Supportive care (73%) *M* = 5.23
3. Coordinated and Comprehensive Care (70%) *M* = 4.89
4. Providing Specific Information (67%) *M* = 4.66
5. Providing General Information (53%) *M* = 3.74

(Total possible range of each subscale mean = 1-7).

These scores suggested that direct, personal services for parents were more readily perceived than informational components. This may indicate an area for further exploration and development in consultation with service users.

Variations in parental perception based upon contextual characteristics. Similar to the previous question regarding coping, I wanted to know if contextual characteristics were related to parents' perceptions of their child's health care providers. Therefore, I posed question 4.1. Do parents’ perceptions of health care provider's behaviours vary on the basis of contextual characteristics, for example, family structure, gender or extent of their child's respiratory technology (invasive as compared to noninvasive)?

In order to answer this question I conducted independent samples t-tests to compare the MPOC-20 scale and subscale means on the basis of each of the contextual characteristics, as the independent variables previously calculated. The results of these analyses are presented below.

MPOC-20 scale variance on the basis of family structure. The group statistics (Table 5) showed that single parents had lower means in every subscale of the MPOC-20.

The independent samples t-test results (Table 5.1) also show that single parent participants attained significantly lower means than other parents, related to the subscales: Enabling and Partnership, $p < .01$(two-tailed); eta squared = .26; and Respectful, Supportive Care, $p < .05$ (two-tailed); eta squared = .14; as well as the overall MPOC-20 scale value, $p = .04$ (two-tailed); eta squared = .14.

While acknowledging the single parents' small group size ($n = 5$), I wish to point out that the effect sizes reported are of a significant magnitude, indicating that this area is worthy of further attention and investigation with a larger sample. Consultation with single parents attending the health care setting may be helpful to explore and implement approaches that respond in a supportive way specific to their context. This finding also raised questions about single parents' experiences with coping and the role this may play in shaping their perceptions of relationships with their child's health care providers.

Table 5

MPOC-20 Scale and Sub-scales contrasted on Family Structure

Group Statistics

Scale/Subscale	Family structure	N	Mean	Std. Deviation	Std. Error
MPOC-20	1	5	66.00	42.03	18.80
Scale total	2	26	98.31	28.42	5.57
Providing specific	1	5	3.33	2.17	.97
information	2	25[a]	4.92	1.54	.31
Enabling &	1	5	3.33	2.20	.98
partnership	2	26	5.58	1.26	.25
Providing general	1	5	2.68	2.24	1.00
information	2	26	3.94	1.80	.35
Comprehensive	1	5	3.50	1.92	.86
coordinated care	2	26	5.15	1.68	.33
Respectful	1	5	3.72	2.26	1.01
supportive care	2	26	5.40	1.45	.28

[a] Different N value due to missing data in one case.

Table 5.1

MPOC-20 Scale and Sub-scales contrasted on basis of Family Structure

Independent Samples T-test

Scale/ subscale	t	df	Sig. (2-tailed)	Eta squared	Mean Difference	95% Confidence Interval	
						Lower	Upper
MPOC Scale total	-2.16	29	.04	.14	-32.31	-62.92	-1.69
Providing specific info	-1.96	28	.06	-	-1.59	-3.24	.07
Enabling & partnership	-3.23	29	.00	.26	-2.24	-3.66	-.82
Providing general info	-1.38	29	.18	-	-1.26	-3.12	.61
Compreh., coord., care	-1.97	29	.06	-	-1.65	-3.37	.06
Respectful supportive care	-2.17	29	.04	.14	-1.68	-3.26	-.09

MPOC-20 scale variance on the basis of gender. I conducted an independent samples t-test to compare MPOC-20 scale and subscale means on the basis of gender. Although I found differences, none were statistically significant. For example, on the overall MPOC-20 scale score: mothers' *M* = 88.67, *SD* = 33.35; and fathers' *M* = 102.40, *SD* = 30.00; *t* (29) = -1.10, p = .28 (two-tailed). Mean difference = -13.73, 95% CI = -39.16 to 11.69.

MPOC-20 scale variance on the basis of extent of respiratory technology. I conducted an independent samples t-test to compare MPOC-20 scale and subscale means on the basis of the extent of the child's respiratory technology. The outcome showed that parents with a child who had a trach reported perceiving higher levels of family-centred care behaviours by their child's health care providers than their peers in each of the subscales (see Table C16 in Appendix C). Significance was attained on the subscale Comprehensive Coordinated Care, when trach was present, $M = 5.54$, $SD = 1.64$ compared to when trach was not present, $M = 4.08$, $SD = 1.68$; $t\ (28) = 2.36$, $p < .05$ two-tailed. The magnitude of the differences in the means (mean difference = 1.46, 95% CI: .19 to 2.72) was large, with eta squared = .17. This finding showed that participating parents caring for a child with a trach did in fact experience health care services at a greater level of magnitude. This finding is consistent with the actual magnitude of services required when a parent is managing a child with a tracheostomy, compared to when noninvasive technology is used.

Exploring relationships between parental coping, perception and context. These results relate to question 5. "What is the nature of relationship that exists between parents' coping patterns and their perceptions of relationship with their child's health care providers, and do contextual variables such as family structure, gender or the extent of their child's respiratory technology make a difference?"

To answer this query, I conducted a series of covariance analyses (Ancova), to examine the extent to which parents' coping and their perception of relationship with their child's health care team were correlated to each other, while considering and controlling for variability due to other factors. I considered parental coping as measured by the CHIP scale and separately, as measured by the SCS scale, and present each individually.

Family structure in relation to perception of relationship and coping. Family structure as an independent variable was not present in a sufficient group size for this test. When I conducted Levene's test for homogeneity for this variable I found insufficient variability to proceed with any further analysis. Therefore, I am not able to answer the question with respect to this contextual variable, suggesting a future research direction.

Significant relationship between parental coping and perception of relationship. When conducting the Ancova analysis for gender I found a very strong positive correlation (p < .001) between the two continuous variables, coping as measured by CHIP scale, and perception of relationship, as measured by the MPOC-20 Scale, accounting for 69% of the variance.

Influence of Gender in relation to perception of relationship and coping. Gender as an independent variable was analyzed using Ancova, in relation to coping and relationship (see Table 6). Ancova results showed that gender did not have a statistically significant association with parental coping (as measured by the CHIP total scale value) when parental perception of relationship (as measured by MPOC-20 scale value) was accounted for as the covariate.

Table 6

Analysis of Covariance for CHIP Scale (DV) in relation to MPOC-20 Scale (CV) and Parents' Gender (IV)

Tests of Between-Subjects Effects

Source	Type III sum of Squares	df	Mean square	F	Sig.	Partial Eta squared
MPOC Ttl scale value	9929.59	1	9929.59	59.03	.000	.69
Parent gender	576.16	1	576.16	3.42	.08	.12
Error	4373.54	26	168.21			
Corrected total	14310.76	28				

When the variables were reversed, however, Ancova results showed that once parental coping (as measured by the CHIP scale) was taken into account, gender was correlated with parental perception of relationship at a statistically significant level. Table 7 (below) shows that gender accounted for 18% of the variance. The relationship between parental coping and parental perception of relationship remained dominant, accounting for 69% of the variance. Tables 7.1 and 7.2 below provide further descriptive details about the respective groups.

Table 7

Analysis of Covariance for MPOC-20 Scale Total (DV) in relation to CHIP Scale (CV) and Parents' Gender (IV)

Tests of Between-Subjects Effects

Source	Type III sum of Squares	df	Mean square	F	Sig.	Partial Eta squared
CHIP total scale mean	18729.52	1	18729.52	59.03	.000	.69
Parent gender	1801.47	1	1801.47	5.68	.02	.18
Error	4373.54	26	168.21			
Corrected total	29059.79	28				

Table 7.1

Group sizes of Gender-Based Variables

Between Subjects Factors	N
parent gender mother = 1	19
parent gender father = 2	10

Table 7.2

Descriptive Statistics

Parent gender	Mean	Std. Deviation	N
mothers (1)	84.58	32.38	19
fathers (2)	102.40	30.01	10
Total	90.72	32.22	29

My examination of the mothers' and fathers' means showed that participating fathers had notably higher mean scores than participating mothers. Reflecting upon the possibility that this difference may have been influenced by the distribution of caregiving responsibilities, I conducted analysis to look at the relationship between gender and the extent of care (both measured in the Family information checklist) provided by the parent reporting. Ancova was not possible as these variables failed Levene's test for variability. However, the t-tests I was able to conduct without compromising variability criteria both produced insignificant results. Therefore, I have speculated that the difference I found between mothers and fathers may be related to gender-specific variations in how relationships between parents and health care providers are perceived and managed by parents and/or health care providers. It is worth noting that evidence in further support of this gender-based variation presented itself in the data collection process with the survey sample. While compiling the survey data I came across several surveys completed by mothers exclusively, in which they had written notes on the survey instruments, alluding to their difficulties in coping. More detail is provided in the parents' interview sample findings section.

Extent of the child's respiratory technology in relation to parental perception of relationship and coping. The Ancova analysis I conducted to examine this contextual variable showed that once parental perception of relationship was accounted for, a positive, statistically significant correlation existed between the extent of the child's respiratory technology and parental coping, as measured by the SCS scale. The variable "extent of respiratory technology", attained significance at $p < .05$; eta squared = .15, in association with the SCS scale total mean (see Table 8). Tables 8.1 and 8.2 provide additional descriptive information.

By contrast, subsequent correlation results for the MPOC-20 total scale value showed almost no relationship to the Self-Compassion Scale, making the aforementioned association quite distinct. This finding may have valuable practical implications for counselling practice.

Table 8

Analysis of Covariance for Self-Compassion Scale (DV) in relation to MPOC-20 Scale (CV) and Extent of Child's Respiratory Technology (IV)

Tests of Between-Subjects Effects

Source	Type III sum of Squares	df	Mean square	F	Sig.	Partial Eta squared
MPOC Ttl scale	.29	1	.29	.66	.42	.02
Extent of RT	2.14	1	2.14	4.87	.04	.15
Error	11.86	27	.44			
Corrected total	14.73	29				

Table 8.1

Group Sizes of Extent of Respiratory Technology Variables

Between Subjects Factors	N
Invasive: child has trach = 1	18
Noninvasive: child does not have trach = 2	12

Table 8.2

Descriptive Statistics

Extent of Respiratory Technology	Mean	Std. Deviation	N
Invasive (1)	3.29	.63	18
Noninvasive (2)	2.69	.70	12
Total	3.05	.71	30

My interpretation of this analysis is that parents caring for a child with invasive respiratory technology used more self-compassion based coping strategies (explaining 15% of the variance in SCS total scale value), than the other parents in the sample.

The Ancova analysis I conducted to explore possible correlations between extent of respiratory technology (as the independent variable) and parental coping (as measured by the CHIP Scale, as the dependent variable), with parental perception of relationship (MPOC-20 scale) accounted for as the covariate, did not find any significant relationship to exist (see Table 9). However, the strong positive correlation between the two continuous variables: parental coping and parental perception of relationship was again very evident.

Table 9

Analysis of Covariance for CHIP Scale (DV) in relation to MPOC-20 Scale and Extent of Child's Respiratory Technology (IV)

Tests of Between-Subjects Effects

Source	Type III sum of Squares	df	Mean square	F	Sig.	Partial Eta squared
MPOC Ttl scale	7897.25	1	7897.25	43.48	.000	.64
Extent of RT	393.24	1	393.24	2.16	.154	.08
Error	4540.66	25	181.63			
Corrected total	13567.25	27				

My interpretation of these results is that parents' coping and their perception of their relationship with their child's health care provider is highly interdependent and as such must be taken into account when considering either variable in the clinical setting. This has implications for practice and future research directions. Furthermore, self-compassion based coping strategies may be an important and distinct feature in the coping patterns of parents who are raising a child with a tracheostomy in the community.

Mixed Methods Comparison of the Findings

I have constructed a side-by-side presentation table (Table 10) of my findings from the parents' interview sample alongside the results I obtained from the parents' survey sample. The table provides a streamlined comparison of the results obtained using qualitative and quantitative approaches and facilitates an answer to question 6: What is the comparability of the results obtained from the parents' interview data sample with the results obtained from the parents' survey sample, regarding lived experience, patterns of coping and patterns of relationship with their child's health care team?

I have grouped the findings and results in the order of the questions posed, according to the themes arising from my study of the parents' perspectives. The table shows a very high degree of convergence between the findings and results of the two respective approaches. For this reason I have chosen to only note areas of divergence, identified with a comment in bold font. For ease of side-by-side presentation in the table, the sets of findings and results are presented in a slightly smaller font.

Following the comparison table I provide a discussion of a posthoc analysis I conducted to explore possible variations that might be attributable to the contextual variable, "kind of parent" specifically considering potential differences between foster parents and biological parents, as this was not considered as part of the initial study questions, but became evident as a categorical variable among the participants in the study's samples.

Table 10

Mixed Methods Comparison of Findings

Topic	**Parents' Interview Findings**	**Parents' Survey Findings**
Lived Experience, Dealing with Scarcity:		
Respite services	Respite shortages and lack of reliability described as a major stress and by parents of a child with a trach.	• 41.9% of parents found respite supports to be inadequate. • 38.7% wanted improvements made to home and school respite services and suggested various means.
Other support services	Parents described having to advocate on behalf of their child for additional services to address needs. Parents described a "life of details" regarding child's many appointments, supply needs.	26% parents recommended provision of more services to help their child and themselves, specifically: o allied health o education-based o behaviour management & counselling o financial (nutrition & supplies) o transportation (attending appointments)
Finances	Single parents described financial hardship as a stressful part of their life.	All single parents were situated in the lower half of the sample's income range.
Coping:		
Family life	Parents emphasized importance of family identity and family life.	CHIP coping pattern subscales scores showed that social supports outranked personal strategies, in parents' ratings, subscales below are ranked from highest to lowest: • CHIP Family focused subscale: maintaining family integration, cooperation and an optimistic definition of the situation: 75% • CHIP health care focused subscale: understanding the health care situation through communication with other parents and consultation with the health care team: 65%
Informal social support	Access to a reliable network of social support (family and/or friends) was key to effective coping. Peer support was highly valued by those who could find it.	
Formal social support, peers and allies in the systems	Relationships with professionals helped parents cope by providing information, encouragement and system navigation help.	

Topic	**Parents' Interview Findings**	**Parents' Survey Findings**
Self-care	All participants acknowledged the importance of self-care - some reported having to learn how. In general, parents did not discuss their personal stressors until asked.	• CHIP Self-care focused subscale: maintaining social support, self esteem and psychological stability: 64% (lowest)
Self-Compassion	Self-Compassion based coping strategies formed part of the coping repertoire of every parent participant.	Data analysis of the Self-Compassion subscales showed parents' use of self-kindness strategies scored lowest at 55%, M = 2.74 Self-Compassion Total Scale Value (per 2003) Percentage = 62% Mean = 18.61, SD = 4.34 Parents coped most often by: • looking to the wider human condition, to keep perspective. • practicing mindfulness: staying present to their experiencing.
Variations in <u>coping based on:</u>		
Family Structure	Single parents described higher levels of distress, social isolation and loneliness than coupled parents. Coupled parents reported connecting to their own informal social network and community more frequently than single parents. Coupled parents reported obtaining support from their spouse in sharing the load, giving them a break and finding time for regular time alone together for self/couple care.	Single and coupled parents showed statistically significant differences: • Single parents had a significantly lower CHIP scale mean than coupled parents: Mean difference = -31.66; eta^2 = .24 • Single parents' scores were significantly lower in: o Family focused subscale: mean difference = - 25.27; eta^2 =.30. o In the Health care focused subscale: mean difference = -10.63; eta^2 = .24 Indicating a very different way of coping. (*small group size: n = 4-5).
Gender	Both mothers and fathers reported using a wide range of coping strategies on a relatively equal basis.	Analysis of gender found no statistically significant differences for either the CHIP scale or the Self-Compassion scale.
Extent of	6 of the 7 qualitative participants had	Parents of a child with a trach had

Topic	Parents' Interview Findings	Parents' Survey Findings
Respiratory Technology:	experience caring for a child with a trach. All parents described their need for social support and their attempts to acquire it. All participating parents described a range of coping strategies that worked for them, including several that were related to self-compassion.	higher CHIP scale and subscale means, attaining significance on Family focused subscale: p = .05 (two-tailed); mean difference = 7.22 CI: 95%; eta^2 = .14 These parents also attained a significantly higher Self-Compassion scale mean value: p = .02 (two-tailed); eta^2 = .17; and attained significantly lower values on the negative subscales: • Self-judgment: p = .04 (two-tailed); eta^2 = .15 • Isolation: p = .01 (two-tailed); eta^2 = .21
Parents' perceptions of their child's health care providers (hcp's) re: family-centred behaviours.	Parents reported a range of experiences in relation to their child's hcp's, including caring connections with respirology clinic; Single parents tended to report more relational difficulties than other parents.	Analyses of parents' MPOC-20 Survey subscale scores showed supportive relational interactions scored higher than information sharing activities, as follows: • Enabling and partnership: 75%, Mean = 5.22. • Respectful supportive care: 73%, Mean = 5.23. • Coordinated and comprehensive care: 70%, Mean = 4.89. • Providing specific information; 67%, Mean = 4.66. • Providing general information; 53%, Mean = 3.74.
Variations in perception <u>related to:</u>		
Family Structure: - single parent compared to two-parent headed households.	Both single and coupled parents described a range of perceptions regarding their child's hcp's. The level of distress in single parent's narratives related to their interactions with hcp's was higher than in coupled parents' narratives and reflected perceptions of feeling disrespected, judged and uncared for.	Single parents had lower means in every subscale of the MPOC-20, attaining significance on: • Enabling and partnership: p < .01 (two-tailed); eta^2 = .26 • Respectful, supportive care: p = .04 (two-tailed); eta^2 = .14
Gender: - comparing mothers and fathers.	No significant differences were noted between participating mothers and fathers' narratives, regarding perceptions of hcp's.	Statistical analysis using an independent samples t-test found no significant differences in parents' MPOC-20 scores on the basis of gender.

Topic	**Parents' Interview Findings**	**Parents' Survey Findings**
Extent of Respiratory Technology	No significant differences were noted in parents' narratives on hcp's related to the extent of their child's respiratory technology - likely due in part to all but one participant being from the child with a trach group.	Statistical analysis using an independent samples t-test found that parents raising a child with a trach perceived higher levels of family-centred care as measured by the MPOC-20, compared to parents whose child used mask ventilation. Significance was attained on the subscale: Comprehensive coordinated care, Mean difference = 1.46, 95% CI; eta^2 = .17 **Divergence attributable to survey sample's greater variability regarding extent of respiratory technology.**
Interdependent relationships:		
Parental coping and perception of relationship	Parents who reported using problem-focused coping strategies, including assertiveness and advocacy also reported less conflict and more collaborative relationships with hcp's.	Ancova analysis showed a very strong positive correlation between Coping measured by the CHIP scale, and parental perception of hcp's as measured by MPOC-20 scale, regardless of other variables: $p < .001$ eta^2 = .69
Coping, perception of relationship and gender	Only mothers added unsolicited qualitative data to the survey instruments. Most messages portrayed caregivers who felt isolated, overwhelmed and under-supported/ misunderstood by family and friends.	Gender accounted for 18% of the variance regarding parents' perceptions of their relationship with the child's hcp's, once parental coping was accounted for in Ancova analysis (CHIP scores). Fathers' scores were higher than mothers'.
Coping, perception of relationship and extent of respiratory technology	Parents raising a child with a trach described using self-compassion based coping strategies in times of crisis as well as, for self-care and day-to-day living.	Parents of a child with a trach had significantly higher levels of self-compassion than other parents, when parental perceptions of relationship were accounted for in Ancova analysis: $p = .04$; eta^2 = .15

Post-hoc analysis of contextual variable "kind of parent." One context that was not addressed in the questions of the study but became evident in the sample was the kind of parent, foster or biological. One third of the parent survey sample participants were foster parents. While fostering represents a distinct difference in the nature of family with its own unique lived experiences, as briefly acknowledged in the parent interview findings, it could also be considered a contextual difference in need of examination. Findings from the parent interview sample indicated considerable differences between the circumstances of biological parents and foster parents. While biological parents recounted their lived experiences with greater levels of distress, themes arising from the interview data were relatively similar with respect to patterns of coping and relationship for both biological and foster parents. However, consistent with my mixed methods approach, I investigated this contextual variable further from a quantitative perspective.

To determine the extent of difference present, I compared the parents' data on the basis of "kind of parent" (biological or foster) for each of the scales I had used in the study, using independent samples t-tests. In my analyses, I found no significant differences between biological parents and foster parents on any of the scales or subscales. I obtained similar results with covariance analyses as no significant differences were attributable to this aspect of the parent samples.

While my conclusions are tentative at best, given the small group sizes (foster parents n=10, biological parents n=20), the results indicated that parenting in this context is basically the same in terms of coping, self-compassion and perceptions of relationship. Whether one enters the parenting role initially by choice or not (foster parents described their foster children as "like their own"), does not appear to significantly influence patterns of coping and relationship. However, given the limitations of the sample size, there may be differences that either, cancelled out or, I was not able to detect.

Summary of survey sample results and mixed methods comparison.

The quantitative results I obtained from my analyses of the parent survey sample data have provided some very specific information about parents' lived experiences, their patterns of coping and their perceptions of their relationship with their child's health care providers (hcp's). The independent samples t-test analyses have shown significant differences in parents' coping patterns on the basis of their family structure and the extent of their child's respiratory technology. Significant differences were also shown in parents' perception of relationship with their child's hcp's, related to these same contextual variables, suggesting that single parents and parents caring for a child with a trach have distinctly different experiences than the other parents in the sample.

Ancova analyses showed a strong positive correlation between parents' coping (as measured by the CHIP scale) and their perception of relationship with their child's hcp's, accounting for 69% of the variability. Gender also emerged as a contextual variable that was significantly correlated with parents' perception of relationship to their child's hcp's, such that fathers perceived more family centred care behaviours than mothers. This result aligned with the negative content of several notes spontaneously added to survey instruments, in margins, by several participants who were exclusively mothers. Self-compassion was shown to have a significant positive correlation with parents who were caring for a child with a trach, indicating that this is an important and distinctive part of these parents' coping repertoire. The effect sizes obtained were all in the large range, suggesting that the results may be of practical value. Caution must be exercised however, given the small group sizes, particularly with respect to family structure.

The side-by-side presentation table showed strong convergence between the parent interview dataset and the survey dataset on the themes covered. This indicated that I had attained good comparability using both qualitative and quantitative approaches to get at the answers to the questions I posed.

In the next chapter I will discuss the meaning of these findings and results in relation to the literature, and with respect to their implications for theory, practice, policy and future research directions.

Chapter Five - Discussion

In this study I set out to explore children and parents' experiences of living in the community with complex health needs that included respiratory technology dependence. I was interested in acquiring an empathic understanding of their lived experiences, and the patterns of coping and relationship that they found most helpful in managing their lives in the community.

The child and youth participants provided me with data that clearly illustrated their perspectives. The convergent mixed-methods approach I used to explore the parent participants' perspectives provided a means to collect a comprehensive range of data using two different, but complementary approaches. While many of the themes in this study were consistent with previously available literature, additional new findings emerged related to psychosocial aspects of children and parents' lived experiences, and particularly, their patterns of relationship and coping.

Several theories were helpful in organizing and making meaning of the data. Bioecological systems theory (Bronfenbrenner and Evans, 2000) provided a useful framework by which to organize and consider the data regarding the multiple systems and contexts in which these children and their parents were situated. Relational dialectics (Baxter, 2004) provided a meaningful way to understand the interactive push and pull of the parents' relationship with service providers and their systems. Additional theories and concepts helpful to interpreting the psychosocial data included Bandura’s (1997) process of triadic reciprocal causation, stress and coping theory (Folkman et al., 1986), social role valorization theory (Wolfensberger, 1998) and relational-cultural theory (Jordan, 2010).

Children and their Parents' Experiences of Living in the Community

Consistent with the current literature (Carnevale et al., 2006; Sarvey, 2008; Noyes, 2006), the seven children and youth who participated in this study provided their perspectives via in-depth semi-structured interviews. Similar to their peers in the literature, they described wanting to be viewed as a person first, and considered themselves to be normal people with normal lives, who ought to be included in all aspects of life and schooling (Sarvey, 2008). They viewed their care regimens simply as part of their daily routine. Likewise, although they found their technology both helpful and necessary to maintaining their quality of life, they also experienced stigma and social isolation from others, due to their differences. Consistent with other research reports, this kind of experience led to feelings of low self-esteem and loneliness (Noyes, 2006).

The children's parents described using a variety of role valorizing measures (Wolfensberger, 1998), to assist their child's integration into the community. Parents who were very engaged in their child's life did more in this regard than parents who were passive or preoccupied with other demands, and their child's success was accordingly affected. The children and youth also described managing others' responses to their difference in a variety of ways, often reflecting the coping styles of their parents. Their responses ranged from passive to confrontational, as well as more matter-of-fact, educative, and assertive responses, similarly reported among Sarvey's (2008) participants.

The children and youth described their experience with their respiratory technology as “constricting,” in that it impinged upon their lives in multiple ways. This description contrasted with that of Sarvey's participants, who described their experience of being "never alone," due to the presence of their mechanical ventilator and requisite caregiver. It appeared that the children and youth in this study were more concerned with how their lives were constrained from widening their horizons, than they were with the infringement on their privacy. Several children were also preoccupied with their body image and self-identity. For example, some children and youth referred to their tracheostomy (trach) as "the thing in my neck," suggesting that they viewed the trach tube as external to who they were and a difference that separated them from their peers. However, to one youth's surprise, when she had her trach removed she discovered that some of her peers hadn't even noticed. Most of the children and youth did not view their disability and technology needs as a part of "normal" and, while they adhered to the treatment plan, they did not accept this aspect of themselves. The exception being, two younger children who had limited experience of the wider community, and whose parents had taught them to view their difference as a part of normal. Thus, it would appear that response to disability was very much an individual endeavor, informed by developmental level, social experience, personal perception and parental attitudes.

The family provided children and youth with their first inclusive community, thus, when marital breakdown occurred, the effects could be devastating. Two youths who shared their contrasting experiences with respect to this circumstance illustrated how important access to reliable social support was, and the need for professional counselling and support to be readily available. For example, one youth found her source of social support with her school respite nurses, while the other youth was not as fortunate, having been decannulated around the same time as his parents' separation and otherwise being quite socially isolated.

Respite caregivers represented an additional relational layer that children and youth who had trach’s had to learn to navigate, including their nurse's family, if they received respite care outside of their home. While they derived benefits from this arrangement, such as experiencing a wider set of peers and having sleepovers, they also encountered difficulties, such as being bullied at times by their respite nurse's children, and having their confidences breached to their parents by the respite nurse. Viewed from a bioecological systems perspective, this respite context situated the child in an undefined realm, where his/her rights and role were unclear.

School provided children and youth with their first important social role, as a student in a learning community. The discreet classroom integration of respite nurses, required by children with invasive respiratory technology, helped to facilitate the child's social integration and level of comfort. Schools that practiced community building, inclusive philosophy and programming provided children with positive social experiences and the opportunity to make friends. Friends were of paramount importance to the social lives of these children, providing normal play and social opportunities, as well as, peer support and affirmation of their identity.

Health care management occupied a large part of these children's lives and they described being interested in being included as active participants in their care and, as they grew older (10 years and up), their health care management. However, they felt left out and overlooked at times. This situation calls for remediation involving the inclusion of children in their care and health care management discussions, as developmentally appropriate.

The challenge for these children and youth was to "grow into" their lives, despite the enforced dependence and life-limiting constrictions placed upon them by their body's health needs. While some developmental delay was typical for these children, they encountered the same developmental pressures as their well peers and faced the same psychosocial tasks. Adolescence had its challenges as protective, vigilant parents had to learn to back off and allow their child to begin to take up some of the responsibilities and decisions for his/her own life. The child found his/her pediatrician to be an ally in this endeavor, collaborating with him/her and educating his/her parents, when necessary, to help them approach this transitional time. Children and youth's perspectives on coping and relationship were similar to their parents, and are therefore addressed together later.

The eight parents who participated in the interview sample for this study described many experiences that were consistent with those already reported in the literature. For example, their encounters with the health care setting similarly included dealing with the unknown, difficult "no-choice" decision-making, learning to undertake their child's complex care and the accompanying anxiety of that responsibility. Parents' accounts made it clear that, from the outset of their health care experience with their child, their relationship with the health care system and its service providers was necessarily dialectical in nature. They also reported experiences with marginalization, for example, encountering devaluing remarks made at times by health care providers about their child's right to live, and having their own expertise regarding their child's care and needs called into question or outright disregarded (Carnevale, 2006; Mah et al., 2008; Wang and Barnard, 2008). Parents felt dislocated and disempowered in their caregiving role while their child was in hospital, and they had to learn to navigate the rules and culture of the health care context (McKeever & Miller, 2004).

The importance of interpersonal interactions as the primary means by which parents navigated their child's care in the health care, respite care and education systems became very clear. Findings from the interview and survey samples' datasets showed that, in most cases, problem solving and mediation occurred at the level of person-to-person interactions. From a strengths-based perspective, parents also described being empowered in their role through their inclusion in face-to-face rounds and health care planning meetings with their child's health care team, using a collaborative family-centred approach. This same process was paralleled in the education system by the adoption of inclusive practices and the cultivation and maintenance of collaborative home-school relationships.

Although these practices were often acknowledged at a system-based level, the success of their implementation remained dependent upon the awareness and day-to-day practices of front line service providers. Thus, this was also the context in which most conflicts arose. For example, when health system-centred priorities displaced family-centred care in staff-to-parent interactions, or when the school's leadership clung to outdated, paternalistic practices.

A positive health care system change identified by parents was the addition of a specialized pediatric respirology consultation service. This service provided them with the most direct and expedient access to skilled, knowledgeable care for their child, and facilitated emergent access to hospital care. Using this service, parents were often able to circumvent the much less appreciative emergency department, where they deplored their expertise being discounted, and reported experiencing alienating and problematic care (also reported by Kirk and Glendinning, 2004). The addition of the respirology service to the health care system exemplified the benefits inherent in addressing a long-standing shared need of many as opposed to the traditional medical model view, which had previously located the problem in the individual (Bugental, 2003).

Upon bringing their child home, parents described experiencing a significant alteration in their home life, consistent with Wang and Barnard's (2004) "changed meaning of home", due to having “a stranger in the house” (the nurse), in addition to new equipment and routines. Other previously reported stressors that they also experienced included financial pressure, supply shortages, and social isolation when respite was unavailable. This often led to feelings of being overwhelmed (Carnevale, 2006; Mah et al., 2008; Noyes, 2006; Wang and Barnard, 2004; Wilson et al., 1998). However, in this study several parents also described obtaining counselling and psychotherapy services to address their personal issues and subsequently experiencing relief. These parents viewed this kind of help to be a valuable coping and adjustment resource.

While glad to have their child under their own roof, parents relied on their persistent hope and resilience in adapting to their new life, with expressions such as, "you do what you have to do" and "it's a life of details." The level of engagement required from the parent to successfully manage his or her child's life at home and in other community contexts was extraordinary, as both the interview and survey data sets showed. From the perspective of bioecological systems theory, the data showed breaches of sub-systems’ boundaries, some with positive and some others, with negative implications. For example, the level of involvement required of the parent on behalf of his/her child in the community, went beyond proximal processes to occupy a new role as system advocate and navigator. The respite nurse also necessarily breached the boundaries between the community and home, as a personal helper who enabled the child to participate in other community contexts, such as school. Thus, the boundaries between home and community (microsphere and mesosphere) were breached from both directions, and this required the family to address and clearly delineate parent and nursing roles, as well as, boundaries related to family privacy. On the other hand, when the parent did not become actively engaged in the systems, or the respite nurse was not available to assist the child in venturing out into the community, the difficulties for the child and parent could become extreme, as will be discussed later.

Social isolation was a common difficulty for parents caring for their child in the community, which they described as frequently being accompanied by feelings of depression. Social isolation came in two forms, its physical form, due to the child's care constraints, respite limitations, and/or accessibility issues (Kirk and Glendinning, 2004; Man et al, 2008), and its social form (Carnevale et al., 2006), due to the uniqueness of the parents' experiencing, compared to their family and friends, "you learn not to talk about some things..." (Laura). Thus, although surrounded by people, these parents could remain personally quite alone in their experiencing. One mother in this study demonstrated her resilient solution to this problem using happenstance opportunities inherent in her child's busy schedule of appointments to connect with other parents and build a peer support network. Together these parents were able to address difficulties each had encountered due to system-based limitations. Here again, problem solving was situated at the level of the personal rather than the system.

This study's strengths-based approach reached beyond the current more problem-based literature, to gather data on parents' resilient responses to living. For example, in managing public encounters with strangers, rather than feeling hurt and more isolated by negative, pitying comments (previously reported by Kirk and Glendinning, 2004), the parents of this study described responding assertively, with role valorization, normalizing explanations and ironic humour. This may reflect a shift in societal mores, as institutions have become more accommodating and where possible, integrative of people who live with disabilities. Thus, parents of this study had higher expectations for their child's inclusion in the community than parents in previous studies. This recent development in the community was poignantly evidenced by one parent's observation that, it was the older people in public places that displayed the most unaccepting and rude behaviour, not the younger ones. Through their ongoing presence in the community, people with disabilities are helping to move society toward a greater level of acceptance. Here then, the role of proximal processes, as articulated in bioecological systems theory, has a place in explaining the occurring changes in attitude and behaviour.

Several parents also described encouraging their child's development and adjustment to disability through engaging with them in a collaborative, present way, and by supporting their participation in typical community-based activities, such as dance classes and sports. These parents modeled the kind of adaptive, empowering optimism that Nagler and Nagler (1999, p. 19) described in responding to life with disability. Rather than problematizing disability, these parents have been moving in a new, more empowering direction.

Helpful Patterns of Relationship

The central importance of interpersonal relationships to navigating the lives of these children and their parents has been emphasized in the preceding discussion. Significantly, when exploring the pattern of relationship each found to be most helpful, their descriptions of key supporters and trusted service providers converged on a common central relational tenet, and four core relational elements.

Central tenet of key relationships: Authentic engaged presence. Children and youth consistently described key people as being "really there" for them, actively engaged and present in the moment, “Listening to what I have to say…actually doing stuff with me…” (Marie). The parents' data described the same characteristics.

Core relational elements. Parents' descriptions of their key support people and service providers reflected four core relational elements (see figure 7). These were also present in older children and youth's descriptions of favorite teachers and pediatricians.

Figure 7. Core Elements of Relationship

Caring
“Caring is part of competency”
- Beth

“...As long as he’s cared for
that’s all I care” - Ellen

Communication
“I think it’s that,
the openness in
the communication.
...It’s the listening.”
- Don

Collaboration
“...We kind of assist
each other.”
- John

Competence
"I think competency comes with caring” - Beth

“...Just the caring and the knowledge.” - Keith

Reciprocal interaction. When children and their parents engaged in relationship with people who used this helpful pattern of relationship, an interesting thing happened. The children and parents themselves, reportedly, began to develop the same four core elements in their own pattern of relationship as they had experienced in the behavior of their key support people (Jordan describes this as "movement toward mutuality", 2010, p. 24). For example, parents acquired competence in their child's health care and in their capacity for communicating and collaborating while they learned to navigate the health care system with a trusted nurse clinician or doctor. Youth also could be seen to develop along these elements of relationship as they became more involved in their own health care management. Thus, this kind of complementary, mutually interdependent relationship (consistent with relational dialectics) was the medium through which adaptive change occurred.

This process aligned conceptually with Jordan's relational-cultural theory, a relatively new theory that I was recently introduced to and found to fit well with the findings in this study. Jordan's theory viewed people as growing through and toward relationship throughout their lifespan (2010, p. 24). This theory fit well with the other relational theories that I was already working with, particularly, by situating human development and wellbeing in the context of interpersonal relationship and acknowledging the mitigating influence of individual contextual factors (for example, gender, race, and disability).

Helpful Patterns of Coping

Parents and children reported similar themes and patterns of behavior that helped them to cope, including hope, which was a sustaining force, and resilience, the capacity to recover from adversity with renewed strength and versatility (Rolland and Walsh, 2006). Common to the children and youth and, sometimes their parents, was their initially passive coping pattern, "I just kept my mouth shut" (Marie). However, adversity and developmental pressures pushed each of them towards becoming larger actors in their own lives. Often, the process of triadic reciprocal causation (Bandura, 1997) appeared to be at work, as they grew in assertiveness through their reciprocal interactions with the environment and specifically, the people around them.

Children and parents whose coping pattern included a balance of problem-focused and emotion-focused strategies also described possessing versatility and resilience in responding to stressors, and subsequently, experienced greater satisfaction with their situations. These children and parents were often situated in two-parent families.

On the other hand, children and parents who favoured primarily self-regulating strategies, such as self-soothing, passive and avoidant responses, tended to experience less success, and described encountering higher levels of adversity and dissatisfaction. These children and parents were often situated in single parent families, and reported far fewer coping strategies that were also more self-focused, and isolating than the latter group. A key additional feature in this context was the absence of social connection and support.

Social support was a feature in the data that consistently aligned with children and parents' wellbeing. Those who reported more frequent experiences with isolation also described responses that perpetuated this situation, including self-isolating thoughts and behaviours that were at times compounded by the effects of bullying and social marginalization. Thus, those children and parents most in need of social support were ironically, more further removed from it, creating significant suffering through deprivation.

One other contextual variable of note was related to the extent of the child's respiratory technology. Parents who were caring for a child with a trach, compared to those who were not, reported seeking support from their family and engaging in significantly lower levels of self-judging and isolating behaviours. While the group size was too small to analyze this trend in relation to family structure, case-wise analysis showed that the two single mothers reporting in this group showed mixed results.

Parents' Perceptions of their Child's Health Care Providers' Behaviour

My comparative analysis of the parents’ interview sample and the MPOC-20 data sets showed that, in general, parents perceived their child's health care providers to behave toward them with a respectful, collaborative and enabling approach, while less frequently providing information. This seemed to suggest that while meaningful relational connections were being made, educational components could receive more attention. Beyond this finding however, context was (again) important, as single parents by comparison, had significantly less positive perceptions of their child's health care providers, and parents caring for a child with a trach had significantly more positive perceptions. The experiences reported by parents caring for a child with a trach aligned with the actual greater magnitude of comprehensive, coordinated care that their child required and received. Likewise, the single parents' less positive perceptions aligned with the experiences they described in their interviews regarding higher levels of distress and more frequently encounters with disrespectful or uncaring behaviour in their contact with health care providers.

The Relationship Between Parental Coping and Perception

My analyses from both data sets showed that parents who coped well also had better relationships with their child's health care providers. When these variables were compared using Ancova analysis in the survey sample data, a strong, positive correlation between parental coping and their perception of relationship with their child's health care provider emerged, regardless of other variables at: $p < .001$ $eta^2 = .69$ This result suggested that coping and parents' perception of their child's health care provider's behaviour were closely related. This was also consistent with the more negative experiences reported by single parents in both of their data sets. When this correlation was viewed in relation to the process of triadic reciprocal causation, both the parent's perceptions and the extent of his/her coping strategies could be seen to have implications for how he or she might behave in the relationship. Therefore, the role played by the environment (as the third side of the triadic process) was clearly important to ameliorating or perpetuating this cycle.

Gender was the other contextual variable to show a significant result in the parent survey sample. Ancova analysis showed that, once coping (based upon CHIP scores) was accounted for, participating fathers had significantly more positive perceptions of their child's health care providers than participating mothers did. Posthoc analysis ruled out distribution of caregiving responsibilities (based on parent report) as a confounding factor. There was no comparable finding in the interview sample data, and the survey sample was small, however, the significance of the result raised the question of possible gender-specific differences in how parents' relationships with health care providers were perceived and conducted. For example, this result may relate to Traustadottir's (1992) observation that women continue to be expected to fulfill the caregiving role in addition to other roles, while remaining in a subordinate position when it comes to divisions of power. Therefore, they may be expected to bear the responsibility for their child's care without receiving sufficient support or recognition and acknowledgement of their authority in decision-making processes. Consistent with this perspective, the notes spontaneously added to the survey instruments by several participant mothers (exclusively), shared themes of being alone in their situation, overwhelmed, under-supported and misunderstood by their families.

Interpreting the Mixed Methods Results: Two Kinds of Experience

While side-by-side presentation of the mixed method results showed good comparability, and thereby enhanced the trustworthiness of the findings, it also clearly revealed two very different kinds of experience amongst participating parents. As previously discussed, some parents**,** most often couple parents**,** were socially well connected and coped using a variety of strategies**.** Other parents, most often including those who were parenting alone, were socially isolated and coped using far fewer, more inwardly-turned strategies that involved far less or no social contact. This second group of parents also reported much less positive perceptions of their child's health care providers' behaviour (the survey results show almost an inversion of the values given by the socially connected parents). What is it that created such a difference?

The most socially isolated parents were single parents, and particularly single working parents, who had either very little or no respite outside of their child's school hours. In both data sets a large proportion of parents identified the shortage and unreliability of respite service as their main concern and stressor. Based upon the voices of these parents, it appears that being alone as a parent, without adequate respite, might have led to such a different experience. Similar to canaries in a mineshaft, these parents were the most vulnerable and thus showed the negative effects first, leading to suffering for both themselves and their child and family.

How does a parent cope in this situation, when there is no perceptible way to obtain relief and their child is relying on them to sustain their life? Lazarus (1977, p. 155) has suggested that emotion-focused coping may provide the self-regulation a parent needs in a chronic situation of threat, by lowering his/her arousal level sufficiently to ensure that he/she can perform when it is imperative. However, this situation is really one of survival, and is not adaptive in the long run. These children and their parents need respite support if they are to cope and manage their community relationships well in day-to-day living. This does not deny the reality that, like others, these parents are also vulnerable to human foibles particularly when under duress, including substance abuse, addiction, abuse and neglect. However, these parents are likely to be monitored much more closely than other parents, for example, by respite care staff, due to the breach in boundaries that their child's support needs has necessitated. In fact, some have described, also being judged much more quickly. By virtue of their child's circumstance they are held accountable to a host of service providers that other parents are not and never will be.

Recently I learned from a local respite service administrator (anonymous, April 20, 2012) that human resource shortages rather than funding are at times the real issue with respect to respite shortages. When there are not enough respite staff willing to fill the shifts, many such positions remain vacant, leaving children and parents who have been promised relief without support. There are also different systems that share responsibility for respite coverage, for example, at school as compared to in the community, and their respective regulations and standards are not harmonized. This situation requires further investigation, clarification and solution.

It is possible to view the relational difficulties between some parents and respite service providers, previously noted in the literature (Wang and Barnard, 2004), and in this study, in relation to the strong relationship found here between parents' coping and their perception of their child's health care provider’s behaviours. Using the concept of triadic reciprocal causation, it is possible to see that the parents' less positive perception of their child's health care provider might influence their interaction with them negatively. However, as this study has shown, the service provider is in a good position to help the parents move into a more positive engagement by conveying authentic engaged presence to them, and exercising caring, competence, collaboration and communication with them. Paired with sufficient, reliable respite this approach could "turn the tide" for socially isolated parents and their children, helping them to attain a better quality of community life. Therefore, it behooves service system policy makers, trainers and direct service providers to learn from the perspectives of these children and youth and their parents about what their life is like in their context-specific circumstances, and the patterns of coping and relationship that work for them.

Limitations of the Study

The small sample size and its composition is an important limitation of this study. In keeping with ethical requirements, all participants were voluntary, introducing potential bias, such as social desirability, and my personal bias, from being so close, professionally, to the circumstances of the participants. Furthermore, several of the participants knew me from prior contact in a different context. While this may have helped them to feel more at ease (as some did tell me), it may also mean that they did not share all of their experiences with me. I did not do any kind of psychosocial screening, therefore any conditions that the children or parents had, that might have influenced their comments were not known to me, except by their disclosure. The self-report measures used to collect quantitative data from the parents' survey sample also limit their validity as they were subject to the interpretations made by parents in responding to the survey instruments.

While I took steps to ensure methodological rigour and selected conservative statistical methods of analysis, the study's exploratory nature, small sample size and regional scope require that the findings be considered as specific to Midwestern Canadian families and tentative in nature, open to further replication.

Implications for Policy

Parents who have a child with a tracheostomy require more support during the initial stages of their child's treatment process, as well as, when they are caring for them in the community. Provision of financial support, employment leaves and respite assistance to parents faced with learning to care for a child with a tracheostomy would assist them in managing their other family needs, and facilitate their presence at their child's bedside where they can focus on attending to him/her and training in his/her care. This makes sense from both a psychosocial and fiscal perspective: On the one hand, preserving the parent-child attachment relationship and on the other, avoiding the skyrocketing costs of extending the child's hospital stay due to delays in the parents' availability. Additional support when the child is living at home in the community is needed to ensure that the family maintains good social connections and to prevent caregiver burnout of the parents. Parents caring for a child with noninvasive respiratory technology who are socially isolated should also be considered for additional respite supports.

A critical examination of existing respite staffing problems and exploration of new ways of providing respite services to children and their families should be undertaken. Respite limitations specific to school attending children should be reviewed and remedied to keep these children in school.

Implications for Practice

The psychosocial findings in this study, while tentative, offer new information that could be of value to parent- and child-professional relationship building efforts, as well as, program planning for health care, respite and other service providers. For example, it would be beneficial to use the approach that children and parents identified as helpful and also, to facilitate formal and informal opportunities for social and peer support network development. The principles of family-centred care and developmentally inclusive practices should guide service delivery as part of routine day-to-day care. Front line workers should be encouraged and supported in persisting with patience and compassion to reach out to parents and children who respond in self-isolating ways.

Counselling and psychotherapy services, including psycho-education (for example, system navigation and assertive communication), should be routinely provided from the outset as part of a comprehensive program of services to support children and parents in managing their complex health care experience. In the health care setting, parent- and child- focused informational materials and distribution processes should be reviewed, updated and developed as needed to keep parents well informed and engaged regarding their child's care and technology needs.

Implications for Theory

Theory is relevant and useful in approaching, understanding and organizing the data. Bioecological systems theory provided a useful way to approach the multisystem levels of engagement that formed the contexts of these children and their families' lives. Separating the systems into their spheres of relevance provided a conceptual means by which to consider their relationship to the child and family, and to view the boundaries that were breached. The multi-system-based role occupied by the parent as advocate and navigator, and the respite nurse as enabler, requires more specific attention.

The central role ascribed to relational interactions in the data highlighted the importance of theory in this domain. The concepts used to interpret the findings worked in a complementary and useful manner. The dynamics inherent in relational dialectics (Baxter, 2004) were apparent from the start of the parents' relationship with the health care system and individual service providers. Social learning theory (Bandura, 1997), and particularly, triadic reciprocal causation, described the process by which parents adapted and adjusted to their child's situation and their environment. Coping theory (Folkman et al., 1986) provided a means to understand what children and their parents did to manage the difficulties that confronted them, and how they arrived at their choice of coping. Relational-cultural theory (Jordan, 2010) acknowledged the central role of interpersonal relationships as the context for human development and wellbeing, consistent with this study's data. It was at the level of interpersonal connection that these children and their parents negotiated their lives in the community, and adjusted to their predicament.

Neff's concept of self-compassion (2003) as an adaptive approach to self-regulation-based coping in the face of adversity was apparent in the lived experiences of the children and parents in this study. Furthermore, it occurred at a significant level in the survey sample data among parents caring for a child with a trach, providing particular evidence for the relevance of this theory to this population.

The ongoing theme of marginalization, while diminished in more recent experiences of these children and their parents, showed that social role valorization theory, (SRV), (Wolfensberger, 1998) continues to provide a highly relevant way of approaching and understanding their circumstances.

Recommendations for Further Research

This subject would benefit from expanded study using a larger sample, perhaps via multi-site study. Fuller representation for each age group and attendance to cultural variables, including aboriginal families, should be included in the sample. Naturalistic observations of parents, children and respite workers in daily life, in addition to other data collection methods, would provide a more comprehensive and validating way to consider their lived experiences.

Further exploration of the experiences of single parents, and single mothers in particular, is called for, especially in view of the trend towards more single parent families caring for children with chronic complex health issues. Obtaining the perspectives of parents who choose to place their child into foster care would also be of value.

Research that explores the difficulties, barriers and opportunities for providing respite services to these children and their parents needs to be undertaken with an empathic approach towards both the families and their respite service providers.

Conclusions

The findings of this study suggest that these children and their parents are ordinary people confronted with extraordinary circumstances due to the child's complex health needs. Like others, they seek to pursue a normal life in the community, but unlike others, they are not able to undertake this journey alone. The advanced supports and monitoring required to ensure the child's wellbeing and safety call his/her parents and/or foster parents into a much larger, more demanding role, that of "extraordinary parenting". However, this is not parenting that can be done well alone, as the African proverb states, "It takes a village to raise a child."

These children and their parents require adequate community-based respite and support services if they are to manage the child's ongoing care well while pursuing life in the community. My analysis of the data showed that this was a difficult undertaking for all concerned and could be especially problematic for parents and children, who are socially isolated. Through providing adequate, reliable respite services, both in-home and in the community, and offering counselling and other support services as needed, children and their parents can more fully engage in community living and partake of the networks of support that are available. Ensuring that parents are adequately supported with respect to respite, social support, financial needs, and supplies will help them fulfill their extraordinary parenting role with greater success and satisfaction.

Children and youth expressed their expectation to be treated as people first and to be supported in their pursuit of a normal life, connected with their family and friends, and included in their community as equals. My analysis of the findings showed that they did their best to manage the constraints that their complex health needs placed upon them, but in some cases, needed help to manage their adjustment to disability and to navigate social relationships and losses, such as parental divorce, in their life. They and their parents benefitted from acquiring and using a balanced range of problem- and emotion-focused coping strategies and becoming more actively engaged in their lives and communities.

Children, youth and their parents also consistently identified key support people as providing them with their authentic engaged presence as well as, their caring, competence, communication and collaboration. By participating in these relationships the children, youth and parents themselves developed similar capacities. Therefore, service providers and support staff will do well to take heed of this information and practice this pattern of relationship for the benefit of all concerned.

For the Children, Youth and Parents

I hope that the new information gathered in this exploratory study will provide a reasonable reflection of the experiences that the child, youth and parent participants have shared with me. I also hope that upon viewing this thesis, they and their peers might gain a fuller appreciation of themselves and their community of experience for validation, celebration, insight and support. Finally, it is my hope that this study's findings may serve to help improve the situation for children and families confronted with these complex health needs, through raising awareness about what their life is like, educating others about what helps and advocating for policies, programs and services that are supportive of their efforts to normalize their lives.

Personal Epilogue

During my career as a child life specialist, I have learned a great deal from children who live with chronic and complex health needs, as well as from their families. They have challenged me to question and explore the best means by which to support people so that they can thrive in the face of adversity, as individuals and as families, rather than be crushed by it. I continue to be inspired by their hope, resilience and relentless drive. It has been a privilege to view the world from the perspective of this study's participants, and to have been allowed the opportunity to learn from them about their lives, and the patterns of coping and relationship that they have found most helpful.

Appendix A

ENREB Ethics Certificate (2 pages)

Consent Form (4 pages)

APPROVAL CERTIFICATE

05 March 2009

TO: **Miriam A. Duff** (Advisor: R. Bartell)
Principal Investigator

FROM: **Stan Straw, Chair**
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2009:006**
"The Child and Family Living with Complex Health Needs in the Community: Lived Experience and Patterns of Coping and Relationships"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement**.** This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- **if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Eveline Saurette in the Office of Research Services (fax 261-0325, phone 480-1409), including the Sponsor name, before your account can be opened.**

- **if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.**

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html**) in order to be in compliance with Tri-Council Guidelines.**

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement**.** This approval is valid for one year only.

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Miriam A. Duff
XXXXXXXXXXXXX
XXXXXXXXXXXXXXXX

Consent Form

Research Project Title: The Child and Family Living with Complex Health Needs in the Community: Lived Experience and Patterns of Coping and Relationships

Researcher: Miriam Duff

I am a graduate student in the Faculty of Education at the University of Manitoba. I am planning to conduct a study, as part of my thesis that looks at the experiences and views of parents and their children who live with respiratory-assistive technology (e.g. tracheostomy, ventilator). I am interested in learning about what it’s like for children and parents who live with these needs and the ways that they find work for them in coping with stresses and in their relationships with the people involved in their lives, including service providers. By better understanding these things more can be known about suitable ways to support these parents and their children in having a good life in the community.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

1. Purpose of the Research

This is a thesis research study that seeks to understand the lived experiences and views of parents and their children living in the community with complex health care needs that require respiratory-assistive technology. This study also seeks to identify the patterns of coping and relationships that these parents and children experience and share about, as working for them in helping them to live their lives well.

2. Research Procedure

Parents who agree to participate in the quantitative portion of the study will be given an envelope containing a Family Information Checklist checklist and three surveys to complete, all of which are labelled with a unique code, to represent the participant, in order to maintain their anonymity on the data set. Participants can complete their survey packages at their convenience and return by mail using the stamped and addressed envelope provided. Participants will receive a token cash amount of $10 in appreciation of their assistance. Participants may choose to withdraw at any time without repercussions.

Parents and children who consent (child freely assents) to participate in the interview portion of the study will have interviews arranged at a time and place that suits them. Parents' interviews will be one and one half to two hours total in duration, semi-structured and audio-recorded for later transcription. Children's interviews will be shorter in duration and may include the presence of the parent or the participation of another child, if available and depending upon the parent and child's preference. Children who do not give their assent freely will not be included and, should they express a change of heart, will be supported in exercising their right to exit the interview process as, just like their parents, their input is only meaningful so long as they freely wish to give it (e.g. they will be asked if they wish to continue participating in the study, if they respond by saying "no" they will be withdrawn). Interviews conducted with children will include a range of strategies to invite the child to share their perspective using ways that are meaningful to them, possibly including symbolic play, draw-and-write activities and facilitated communication methods as needed, following recommendations made in Bolton, Closs & Norris (2000).

A follow-up phone call will be made a few days after the interview to review and confirm themes noted to have arisen in the interview and to collect any additional information from the participants that they wish to add to their perspective. Families participating in the interview process will receive a small honorarium of $40 per family in appreciation of their time and assistance.

Collateral audio-recorded interviews with one to two consenting experienced professionals in each of the service systems engaged with these children and parents, including the local education, home care and health care systems will also be undertaken with the same guidelines for confidentiality and at a time and place suitable to the participant.

3. Risk Assessment

There are no undue risks foreseen in participating in this study, it may be that participants will experience some empowerment in describing their experiences and thereby increasing knowledge about the realities of living with their circumstances. Furthermore, participants may benefit from the reflection that is likely to occur as a result of discussion on the study's topics. In the event that a participant experiences distress requiring further attention they will be provided with information for contacting The XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX X

4. Recording devices Interview sessions will be audio recorded to ensure accurate recollection of the data, and later be transcribed by a transcriptionist who has taken an oath of confidentiality. Notes may also be taken during the interviews, these shall be kept in a secure location, and pseudonyms shall be used in place of actual names to protect the interviewee's privacy.

5. Confidentiality
Interviews will be conducted in strict confidence. The confidentiality of participants and the facility will be maintained through the use of pseudonyms. Transcripts, notes and any subsequent publication(s) will also utilize pseudonyms. Should the identity of any individuals or organizations be mentioned during the course of the interview, these will not be included in the notes, transcriptions or subsequent publications. All data, including interview recordings and transcripts will be kept in a locked filing cabinet in a secure location. Interview audio recordings will be erased / deleted once the Master's thesis research study has been completed. All transcriptions and notes and other data will be destroyed within five years of the completion of the research study.
Because children are being interviewed as part of this study, there is the slight possibility that allegations of abuse could arise which would supersede the confidentiality rules of the study and require the researcher to breach confidentiality in respect of the over-riding laws regarding reporting procedures where there is suspicion or disclosure of child abuse or abuse of vulnerable persons. Parents and children need to be informed of this fact.

6. Interview Feedback
Study participants will be contacted a few days after their interview to discuss, clarify and confirm themes noted to emerge in the interview and in order to gather any further information they wish to have included. A summary of the study's findings will be provided to participants who are interested; please complete the tear-off form on the following page to receive information to express interest in receiving a summary and to provide contact information.

7. Participation and Compensation
Each person's participation is completely voluntary and each person is free to withdraw from the study at any time and for any reason with no repercussions. Participants who are involved in completing the survey instruments will be given a token cash amount of $10 at the time they receive the envelope with the coded survey forms. Participating families who take part in the interview part of the study will receive a small honorarium of $40 per family in appreciation of their time and assistance.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Miriam Duff, Graduate Student, Phone: XXXXXXX
Supervisor: Riva Bartell, Ph.D., C. Psych., Phone: 474-9048

This research has been approved by the Education Nursing Research and Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122, or e-mail margaret_bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

____
Participant's Signature Date

____

Researcher and /or Delegate's Signature Date

The Child and Family Living with Complex Health Needs in the Community: Lived Experiences and Patterns of Coping and Relationships

Request to Receive a Summary of the Study's Findings :

☐ I wish to receive a copy of the study's findings when the study is completed.

☐ I wish to be notified if a presentation of the study is being organized for interested families, service providers and members of the public.

Name:____

Address:____

____

Phone:______________________________(optional)

Email:______________________________(optional)

Appendix B

Survey Instruments:

Family Information Checklist (2 pages)

CHIP---Coping Health Inventory for Parents (scale: 4 pages)

McCubbin, H., McCubbin, M., Nevin, R. & Cauble, E. (1983)

Measure of Process of Care (MPOC-20) (scale: 3 pages)

King, S., King, G. & Rosenbaum, P. (2004)

Self-Compassion Scale (2 page scale)

Neff, K. (2003)

Qualitative Instruments and Transcriptionist Confidentiality Agreement:

Interview Guide for Use with Parents (3 pages)

Interview Guide for Use with Children (2 pages)

Form for Transcriptionist's Confidentiality

M. A. Duff, 2009 Ch. & Fam. Living with Complex Health Needs Family Info checklist: pg. 1

Family Information Checklist

To be completed by participating parent ***I.D. code:***_____________

Thank you for your assistance, please check the option that best describes your child and family's situation and/or provide further information in the spaces provided.

Date completed_______________________

1) I am the ☐ mother ☐ father ☐ grandmother ☐ grandfather ☐ foster mother ☐ foster father ☐other (please specify) ___________________________________.

2) My age is_______________.

3) My highest level of schooling completed:(please specify)________________________.

4) For my child with complex health needs I provide: ☐all care ☐most care ☐ some care ☐ other_________.

5) I am ☐ a stay-at-home parent; ☐employed outside home: ☐fulltime ☐part-time ☐other____________.

6) The family living together as a unit includes:

☐two parents ☐single parent -mother ☐single parent -father ☐blended family ☐other_____________.

Total number of children living at home, including child with complex health needs: ____________.

7) Total family income/yr: ☐ under $20,000 ☐$20,000-$29,999 ☐$30,000-$39,999 ☐$40,000-49,999 ☐$50,000-$59,999 ☐$60,000-69,999 ☐ $70,000-79,999 ☐$80,000 and over

8) The family lives in ☐ the city ☐ large town ☐small town ☐rural property/farm ☐remote community

9) My child with complex health needs is: ☐ male ☐female

10) My child's age is:_______________.

11) My child's complex health needs are due to (specify condition)______________________________________.

12) My child has required respiratory technology for (specify how long)__________________________________.

13) My child's respiratory technology needs include (check all applicable):

☐oxygen ☐ mask ☐tracheostomy

Ventilator (CPap, BiPap, LTV etc.) : ☐ fulltime ☐ part-time_________________________(specify times).

Monitors (e.g. pulse oxymeter, etc.)____(specify).

14) My child also uses (check all applicable):

☐ manual wheelchair ☐power wheelchair ☐lift system ☐ gastrostomy feeding pump

☐ hearing aid ☐communication device/system ☐ environmental control system (turn lights on, call, etc)

Other____.

Please continue to next page……………………

15) Compared to other children the same age who do not have complex health needs, my child's abilities are:

☐ similar ☐needs some help ☐ needs a lot of help ☐completely dependent – ***for moving themselves about.***

☐ similar ☐needs some help ☐ needs a lot of help ☐completely dependent – ***for self care and feeding.***

☐ similar ☐needs some help ☐ needs a lot of help ☐completely dependent – ***for communicating.***

☐ similar ☐needs some help ☐ needs a lot of help ☐completely dependent – ***for play and learning.***

☐ similar ☐needs some help ☐ needs a lot of help ☐completely dependent – ***for mood and behaviour.***

☐ similar ☐needs some help ☐ needs a lot of help ☐completely dependent – ***for social interaction.***

☐ similar ☐needs some help ☐ needs a lot of help ☐completely dependent – ***for vision and hearing.***

☐ similar ☐needs some help ☐ needs a lot of help ☐completely dependent – ***for participating in outings.***

16) The resources available to me and my child with complex needs for support, assistance and/or respite include:

☐ Other family members in the household.

☐ Extended family members from outside the household.

☐ Friends and neighbors.

☐ Parent support group (please specify)____.

☐ Case coordinator / Case worker (please specify kind)____.

☐ Social worker or counsellor (please specify kind)____.

☐ Homecare aide / family support worker ______________________approximate # hours/wk.

☐ Homecare nurse___________________approximate # hours/wk.

☐ URIS nurse for school days.

☐ Other (specify)____.

17) In my opinion, the amount of services available to support me and help in caring for my child is:

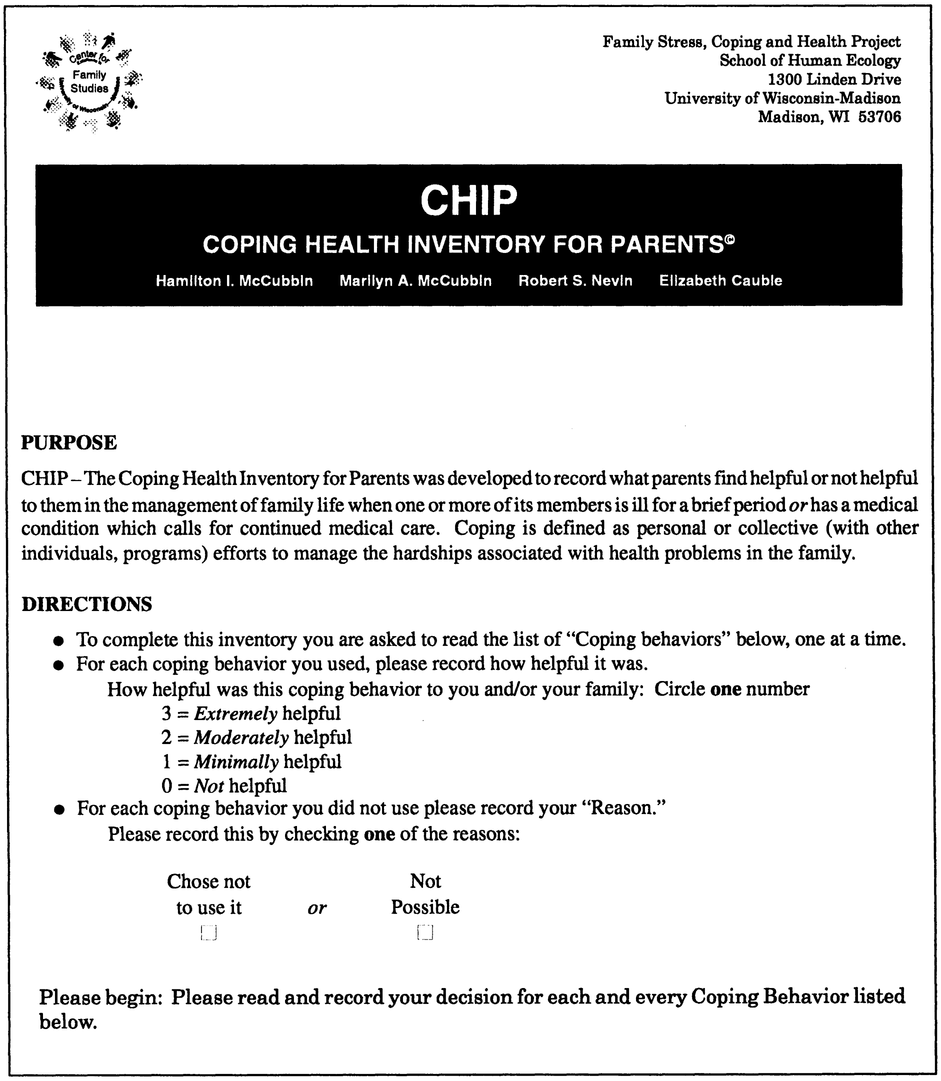
☐ far below what is needed ☐not quite enough ☐ adequate ☐ the right amount ☐ other_____________.

18) The kind of supports that I believe are still needed, if any, are:

____

19) Any other comments:

____



Family Stress, Coping and Health Project
School of Human Ecology
1300 Linden Drive
University of Wisconsin-Madison
Madison, WI 53706

CHIP

COPING HEALTH INVENTORY FOR PARENTS©

Hamilton I. McCubbin Marilyn A. McCubbin Robert S. Nevin Elizabeth Cauble

PURPOSE

CHIP – The Coping Health Inventory for Parents was developed to record what parents find helpful or not helpful to them in the management of family life when one or more of its members is ill for a brief period *or* has a medical condition which calls for continued medical care. Coping is defined as personal or collective (with other individuals, programs) efforts to manage the hardships associated with health problems in the family.

DIRECTIONS

- To complete this inventory you are asked to read the list of "Coping behaviors" below, one at a time.
- For each coping behavior you used, please record how helpful it was.
  How helpful was this coping behavior to you and/or your family: Circle **one** number
    3 = *Extremely* helpful
    2 = *Moderately* helpful
    1 = *Minimally* helpful
    0 = *Not* helpful
- For each coping behavior you did not use please record your "Reason."
  Please record this by checking **one** of the reasons:

Chose not to use it		Not Possible
☐	*or*	☐

Please begin: Please read and record your decision for each and every Coping Behavior listed below.

From *Family Measures: Stress, Coping, and Resiliency Inventories for Research and Practice* by H. McCubbin, A. Thompson, & M. McCubbin, 2003, (CD Format: locked pdf). Honolulu, Hawaii: Kamehameha Schools. Copyright 1983 by H. McCubbin. Reprinted with permission.

Coping Behaviors	Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	I do not cope this way because: Chose Not to	Not Possible
1. Talking over personal feelings and concerns with spouse	3	2	1	0	☐	☐
2. Engaging in relationships and friendships which help me to feel important and appreciated	3	2	1	0	☐	☐
3. Trusting my spouse (or former spouse) to help support me and my child(ren)	3	2	1	0	☐	☐
4. Sleeping	3	2	1	0	☐	☐
5. Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center	3	2	1	0	☐	☐
6. Believing that my child(ren) will get better	3	2	1	0	☐	☐
7. Working, outside employment	3	2	1	0	☐	☐
8. Showing that I am strong	3	2	1	0	☐	☐
9. Purchasing gifts for myself and/or other family members	3	2	1	0	☐	☐
10. Talking with other individuals/parents in my same situation	3	2	1	0	☐	☐
11. Taking good care of all the medical equipment at home	3	2	1	0	☐	☐
12. Eating	3	2	1	0	☐	☐
13. Getting other members of the family to help with chores and tasks at home	3	2	1	0	☐	☐
14. Getting away by myself	3	2	1	0	☐	☐
15. Talking with the doctor about my concerns about my child(ren) with the medical condition	3	2	1	0	☐	☐
16. Believing that the medical center/hospital has my family's best interest in mind	3	2	1	0	☐	☐
17. Building close relationships with people	3	2	1	0	☐	☐
18. Believing in God	3	2	1	0	☐	☐
19. Develop myself as a person	3	2	1	0	☐	☐

Coping Behaviors	**Extremely Helpful**	**Moderately Helpful**	**Minimally Helpful**	**Not Helpful**	I do not cope this way because: Chose Not to	I do not cope this way because: Not Possible
20. Talking with other parents in the same type of situation and learning about their experiences	3	2	1	0	☐	☐
21. Doing things together as a family (involving all members of the family)	3	2	1	0	☐	☐
22. Investing time and energy in my job	3	2	1	0	☐	☐
23. Believing that my child is getting the best medical care possible	3	2	1	0	☐	☐
24. Entertaining friends in our home	3	2	1	0	☐	☐
25. Reading about how other persons in my situation handle things	3	2	1	0	☐	☐
26. Doing things with family relatives	3	2	1	0	☐	☐
27. Becoming more self reliant and independent	3	2	1	0	☐	☐
28. Telling myself that I have many things I should be thankful for	3	2	1	0	☐	☐
29. Concentrating on hobbies (art, music, jogging, etc.)	3	2	1	0	☐	☐
30. Explaining family situation to friends and neighbors so they will understand us	3	2	1	0	☐	☐
31. Encouraging child(ren) with medical condition to be more independent	3	2	1	0	☐	☐
32. Keeping myself in shape and well groomed	3	2	1	0	☐	☐
33. Involvement in social activities (parties, etc.) with friends	3	2	1	0	☐	☐
34. Going out with my spouse on a regular basis	3	2	1	0	☐	☐
35. Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis	3	2	1	0	☐	☐
36. Building a closer relationship with my spouse	3	2	1	0	☐	☐
37. Allowing myself to get angry	3	2	1	0	☐	☐
38. Investing myself in my child(ren)	3	2	1	0	☐	☐

Coping Behaviors	Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	I do not cope this way because: Chose Not to	Not Possible
39. Talking to someone (not professional counselor/doctor) about how I feel	3	2	1	0	☐	☐
40. Reading more about the medical problem which concerns me	3	2	1	0	☐	☐
41. Trying to maintain family stability	3	2	1	0	☐	☐
42. Being able to get away from the home care tasks and responsibilities for some relief	3	2	1	0	☐	☐
43. Having my child with the medical condition seen at the clinic/hospital on a regular basis	3	2	1	0	☐	☐
44. Believing that things will always work out	3	2	1	0	☐	☐
45. Doing things with my children	3	2	1	0	☐	☐

MEASURE OF PROCESSES OF CARE
(MPOC-20)

We would like to understand and measure the experiences of parents who have a child with a disability. In particular we wish to know about your perceptions of the care you have been receiving over the past year from the health care organization that provides services to your child. This may be your local children=s treatment (rehabilitation) centre, your community care access centre, or another organization.

The care that you and your child receive from this organization may bring you into contact with many individuals. The questions on this form are grouped by who these contacts are, as described below.

PEOPLE: refers to those individuals who work directly with you or your child. These **may include** psychologists, therapists, social workers, doctors, teachers, etc.

ORGANIZATION: refers to all staff from the health care organization, whether involved directly with your child or not. In addition to health care people they **may include** support staff such as office staff, housekeepers, administrative personnel, etc.

The questions are based on what parents, like yourself, have told us about the way care is sometimes offered. We are interested in your personal thoughts and would appreciate your completing this questionnaire on your own without discussing it with anyone.

For each question, please indicate how much the event or situation happens to you. You are asked to respond by circling **one** number from 1 (Not at All) to 7 (To a Very Great Extent) that you feel best fits your experience. Please note that the zero value (0) is used only if the situation described does not apply to you.

When answering these questions, we would like you to think about the organization from which you first found out about this study. For easy reference, the name of that organization is:

____.

PEOPLE: refers to those individuals who work directly with you or your child. These **may include** psychologists, therapists, social workers, doctors, teachers, etc.

IN THE PAST YEAR, TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...	**Indicate how much this event or situation happens to you.**							
	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
1. ...help you to feel competent as a parent?	7	6	5	4	3	2	1	0
2. ...provide you with written information about what your child is doing in therapy?	7	6	5	4	3	2	1	0
3. ...provide a caring atmosphere rather than just give you information?	7	6	5	4	3	2	1	0

IN THE PAST YEAR, TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...	**Indicate how much this event or situation happens to you.**							
	To a Very Great Extent	**To a Great Extent**	**To a Fairly Great Extent**	**To a Moderate Extent**	**To a Small Extent**	**To a Very Small Extent**	**Not at All**	**Not Applicable**
4. ...let you choose when to receive information and the type of information you want?	7	6	5	4	3	2	1	0
5. ...look at the needs of your “whole” child (e.g., at mental, emotional, and social needs) instead of just at physical needs?	7	6	5	4	3	2	1	0
6. ...make sure that at least one team member is someone who works with you and your family over a long period of time?	7	6	5	4	3	2	1	0
7. ...fully explain treatment choices to you?	7	6	5	4	3	2	1	0
8. ...provide opportunities for you to make decisions about treatment?	7	6	5	4	3	2	1	0
9. ...provide enough time to talk so you don't feel rushed?	7	6	5	4	3	2	1	0
10. ...plan together so they are all working in the same direction?	7	6	5	4	3	2	1	0
11. ...treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you as "Mom" or "Dad")?	7	6	5	4	3	2	1	0
12. ...give you information about your child that is consistent from person to person?	7	6	5	4	3	2	1	0
13. ...treat you as an individual rather than as a "typical" parent of a child with a disability?	7	6	5	4	3	2	1	0
14. ...provide you with written information about your child's progress?	7	6	5	4	3	2	1	0
15. ...tell you about the results from assessments?	7	6	5	4	3	2	1	0

(Continued on next page)

ORGANIZATION: refers to all staff from the health care organization, whether involved directly with your child or not. In addition to health care people they **may include** support staff such as office staff, housekeepers, administrative personnel, etc.

IN THE PAST YEAR, TO WHAT EXTENT DOES THE ORGANIZATION WHERE YOU RECEIVE SERVICES…	**Indicate how much this event or situation happens to you.**							
	To a Very Great Extent	**To a Great Extent**	**To a Fairly Great Extent**	**To a Moderate Extent**	**To a Small Extent**	**To a Very Small Extent**	**Not at All**	**Not Applicable**
16. ...give you information about the types of services offered at the organization or in your community?	7	6	5	4	3	2	1	0
17. ...have information available about your child's disability (e.g., its causes, how it progresses, future outlook)?	7	6	5	4	3	2	1	0
18. ...provide opportunities for the entire family to obtain information?	7	6	5	4	3	2	1	0
19. ...have information available to you in various forms, such as a booklet, kit, video, etc.?	7	6	5	4	3	2	1	0
20. ...provide advice on how to get information or to contact other parents (e.g., organization's parent resource library)?	7	6	5	4	3	2	1	0

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

Almost never				**Almost always**
1	**2**	**3**	**4**	**5**

_____ 1. I'm disapproving and judgmental about my own flaws and inadequacies.

_____ 2. When I'm feeling down I tend to obsess and fixate on everything that's wrong.

_____ 3. When things are going badly for me, I see the difficulties as part of life that everyone goes through.

_____ 4. When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world.

_____ 5. I try to be loving towards myself when I'm feeling emotional pain.

_____ 6. When I fail at something important to me I become consumed by feelings of inadequacy.

_____ 7. When I'm down and out, I remind myself that there are lots of other people in the world feeling like I am.

_____ 8. When times are really difficult, I tend to be tough on myself.

_____ 9. When something upsets me I try to keep my emotions in balance.

_____ 10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.

_____ 11. I'm intolerant and impatient towards those aspects of my personality I don't like.

_____ 12. When I'm going through a very hard time, I give myself the caring and tenderness I need.

_____ 13. When I'm feeling down, I tend to feel like most other people are probably happier than I am.

_____ 14. When something painful happens I try to take a balanced view of the situation.

_____ 15. I try to see my failings as part of the human condition.

_____ 16. When I see aspects of myself that I don't like, I get down on myself.

_____ 17. When I fail at something important to me I try to keep things in perspective.

_____ 18. When I’m really struggling, I tend to feel like other people must be having an easier time of it.

_____ 19. I’m kind to myself when I’m experiencing suffering.

_____ 20. When something upsets me I get carried away with my feelings.

_____ 21. I can be a bit cold-hearted towards myself when I'm experiencing suffering.

_____ 22. When I'm feeling down I try to approach my feelings with curiosity and openness.

_____ 23. I’m tolerant of my own flaws and inadequacies.

_____ 24. When something painful happens I tend to blow the incident out of proportion.

_____ 25. When I fail at something that's important to me, I tend to feel alone in my failure.

_____ 26. I try to be understanding and patient towards those aspects of my personality I don't like.

From: Development and validation of a scale to measure self-compassion. by K. D. Neff, 2003 *Self and Identity, 2, 223-250.* Self-compassion scale copyright [2003] by K. D. Neff. Reprinted with permission. Self-compassion scale downloaded from selfcompassion.org, October 14, 2007.

The Child and Family Living with Complex Health Needs in the Community:
Lived Experience and Patterns of Coping and Relationships

Interview Guide for Use with Parents

Opening Comments:
Thank you for agreeing to participate in this study about the life experiences of children and families living in the community with complex health needs and their view of the patterns of coping and relationship that work for them.

The purpose of this interview is to get an understanding of *your views* as a parent about what it's like living in your family with your child's complex health needs. I also want to learn about the ways of coping that you find helpful, in dealing with the stresses and hassles in your life and the ways of relating that work for you, when interacting with your family and with the helpers and professionals involved from home care, the school and health care services.

Opening Questions:
Can you tell me a little about your child's condition?

How long has it been this way?

Have you had to move house due to your child's condition or treatment needs?
If so, what has that been like for you and your family?

Transition Questions:
When you recall what it has been like since your child started to need complex care, how would you describe the experience?

What is life like for you now?

What does 'normal' mean for you and your family?

How would you define 'medical stability' for your child, given their condition?

When you were making plans for your child's long term care, were voluntary placement options discussed?
If so, what was that like for you? If not, do you have an opinion to share about this?

Key Questions:

Could you tell me about the kinds of stress you have in your life?

What have you found to be helpful ways to get yourself through when things get difficult

(e.g. anything you do, say or think about, or seek support from others)? Can you share an example?

Who, if anyone, helps you to cope? How do they do this? Can you share an example?

Can you tell me about a time when something you or another person did in a critical moment, made a huge and positive difference to how you coped?

Have you found that your most effective ways of coping have changed over time? If yes, how so?

Has depression been something that you have experienced as part of living with these circumstances?
If so, how have you managed it?

What would you say has been your child's experience, in living with this health condition, compared to yours as the parent (e.g., more positive or more negative)? Could you talk a little bit more about this?

What ways have you found most helpful in supporting your child's growth and development?

When thinking about ways of relating with people in your family, what do you find works the best? Why?
Can you share an example?

What do you find to be the best way of interacting with people outside of your family? for example, with service providers:
With home care/agency staff?
What about with your child's health care team?
What about with your child's school?
Any others?

If you have a problem or you're upset about something what ways that people *interact with you* help the most?
What about when your child is sick or things aren't going well, what ways that service providers interact are most helpful to you? For example:

-With home care/agency?
- With the healthcare team?
- With the school?

Do you feel that you and your family are respected in your dealings with each of these service systems?
Can you tell me a little bit more about how this is for you?

How do you/would you like service providers to interact with you?

Are there things that they are doing now that work really well?
What, if anything, would you like them to do differently?

When you are unhappy with any aspect of the services or interactions you have with people in the systems, what ways are available to you to get things to change? (e.g. a person you can talk to or a mechanism for feedback).

Is advocacy something that you find yourself involved with, due to your child's situation?
If yes, what kind of advocacy? If no, is this because you are satisfied with services or are there other reasons?
Can you talk a little about what this is like for you?
How does this relate to coping for you?
How does this affect your relationships?

Ending Question:

Is there any advice that you would give to a parent starting out in a situation like yours regarding helpful ways to cope?

What about helpful ways of relating both in the family and also with service providers and other people?

Is there anything else you would like to add, regarding your experience or views on ways of coping and interacting with others?

What was it like for you to talk with me about these things?

Thank you for taking the time to answer these questions. I will contact you in the near future to go over the key points of what you shared today and to write down any more thoughts that may come to you and that you want to have included.

The Child and Family Living with Complex Health Needs in the Community:
Lived Experience and Patterns of Coping and Relationships

Interview Guide for Use with Children

Opening Comments:
Thanks for agreeing to talk to me. I'm trying to learn more about what it's like for kids/young people and parents who live with the kinds of health needs you do. I also want to know what ways you find help the best when things aren't going well. The people in your life are important too, and I'm interested in knowing how you like other people to be with you and you with them; like the people in your family, your teachers and classmates at school, the people who help take care of you at home and school, and the doctors, nurses and other people you see at the clinic who help you with your health.

Opening Questions:
Can you tell me a little bit about yourself and who you are as a person (e.g., what you know about yourself, things you like to do, people you are important to, how you spend your time)?

Can you tell me about your health condition?
What's it like for you to live with it?

Transition Question:
What is your life like with the extra equipment to help with breathing (e.g. trach, ventilator) your body needs to stay well?

If there were a time when you didn't have the this extra stuff, how would you say things have changed for you now that you do?

Key Questions:
What have been the hard times in your life, in your experience?
What things helped you a little or a lot when things were like that?
Were there people that helped you too?
- If yes, who? What did they do that helped?
- If no, would you have liked someone to? What could they have done to help?

Were there things that you did or said that helped? Like what?

What's the hardest part of having this health condition?
Are there any good things about it?
Do you have things you do every day to help yourself get along?

Was there ever a time when things weren't going well and you or someone else did or said something that suddenly made things seem a lot better?
Can you tell me about it?

When you're with other people at home, what do they do that helps you feel that you belong and listened to (respected)?
What about at school?
What about at the health clinic?

How do you let other people know what you want or need?
What about things you *don't* want or need?

Have there been times when people have been unkind to you or you felt left out?
What did you do about it? Did anybody else help?

How can you tell who you can talk to about something that's really bothering you?
When you need help who do you get to help you and how do you let them know?
What do they do or say that makes you feel better?

What would you say to another child/young person who is just starting out with a health condition like yours about…

- living with the extra equipment to help with breathing?
- what helps when things aren't going well?
- ways of getting along with other people like helpers, family and friends?

Ending Questions:
Is there anything else you'd like to say about your experiences?

What was it like for you to talk with me about these things?

Thank you for spending time talking with me today, I really liked having the chance to know how you feel about these things. If there is anything else that you want me to know you can call and tell me in the next few days.

Form for TRANSCRIPTIONIST CONFIDENTIALITY

Research Title:
The Child and Family Living with Complex Care Needs in the Community: Identifying Effective Coping and Communication Strategies

Principal Investigator (PI): Miriam Duff phone#XXXXXXXXXXXX
Email: umduff2@cc.umanitoba.ca

As research data transcriptionist in this research, you will have access to confidential information. All participants have been advised that their identities will be kept confidential and secure. Your signature below indicates that you agree to maintain the anonymity of participant(s), and that you agree to keep confidential any and all information revealed during the interview process.

Transcriptionist's Name (please print):
____

Transcriptionist's Signature:
____

Principal Investigator's Signature:
____

Today's Date: ______________________________

Appendix C

Method Chapter - Sample Characteristics collected via Family Information Checklist (FIC)

Table C1

Participant's Family Role

Role	Frequency	%
mother	12	38.7
father	7	22.6
grandmother (custodial)	1	3.2
step-mother	1	3.2
foster mother	7	22.6
foster father	3	9.7
Total	31	100.0

Table C2

Extent of Participants' Involvement in Child's Care

Extent of Care provided	Frequency	%
All care	12	38.7
Most care	11	35.5
Some care	7	22.6
Seldom (child independent)	1	3.2
	31	100.0

Table C3

Family Structure

Family Structure	Frequency	%
Two-parent headed	22	71
One-parent headed:	5	16
(Mother)	(3)	
(Father)	(1)	
(Grandparent)	(1)	
Blended family	4	13
Total	31	100.0

Table C4

Participant's Work Status

Kind of Work	Frequency	%
Stay-at-home parent	13	41.9
Fulltime employment	13	41.9
Part-time employment	3	9.7
Other (student, casual work)	2	6.5
	31	100.0

Table C5

Participant's Level of Education

Highest Level Completed	Frequency	%
Less than High School	4	12.9
High School/GED	12	38.7
Post Secondary College/Technical	8	25.8
University Undergrad. Degree	6	19.4
University Graduate Degree	1	3.2
	31	100.0

Table C6

Total Family Income

Income	Frequency	%
Under $20,000	4	12.9
$20,000-29,999	5	16.1
$30,000-39,999	1	3.2
$40,000-49,999	2	6.5
$50,000-59,999	1	3.2
$60,000-69,999	2	6.5
$70,000-79,999	1	3.2
$80,000 and over	14	45.2
Missing data	1	3.2
Total	31	100.0

Table C7

Household Demographics

Variable	Minimum	Maximum
Number of children in household	1	7
Number of parents in household	1	3[b]
Affected child's age in years	1	19
Number of years child has required resp. tech.	.50	19
Number of Assistive Tech devices in home[a]	0	6
Number of monitors in home	0	1

[a] Examples of Assistive Technology devices: wheelchair (manual or power), lift system, feeding pump, speech valve, hearing aid, communication device/system, environmental control system, cough assist, suction machine, cause-effect switches.

[b] One family had a combination of a single parent and two foster parents.

Table C8

Child's Underlying Diagnosis by Cluster

Diagnosis cluster	Frequency	Percent
Neuromuscular	6	29
Respiratory	7	33
Congenital/Syndrome	7	33
Other	1	5
Total	21[a]	100.00

[a] parent reports were collapsed to reflect actual child numbers.

Table C9

Respiratory Technology and Oxygen[a] Use at Home

Technology/combination	Frequency	%
Oxygen	1	3.2
Mask	9	29.0
Tracheostomy	10	32.3
Mask & Oxygen	2	6.5
Trach & Oxygen	8	25.8
Total	30	96.8
Missing data	1	3.2
Total	31	100.0

[a] Oxygen is a medication used by some children at home with technology.

Table C10

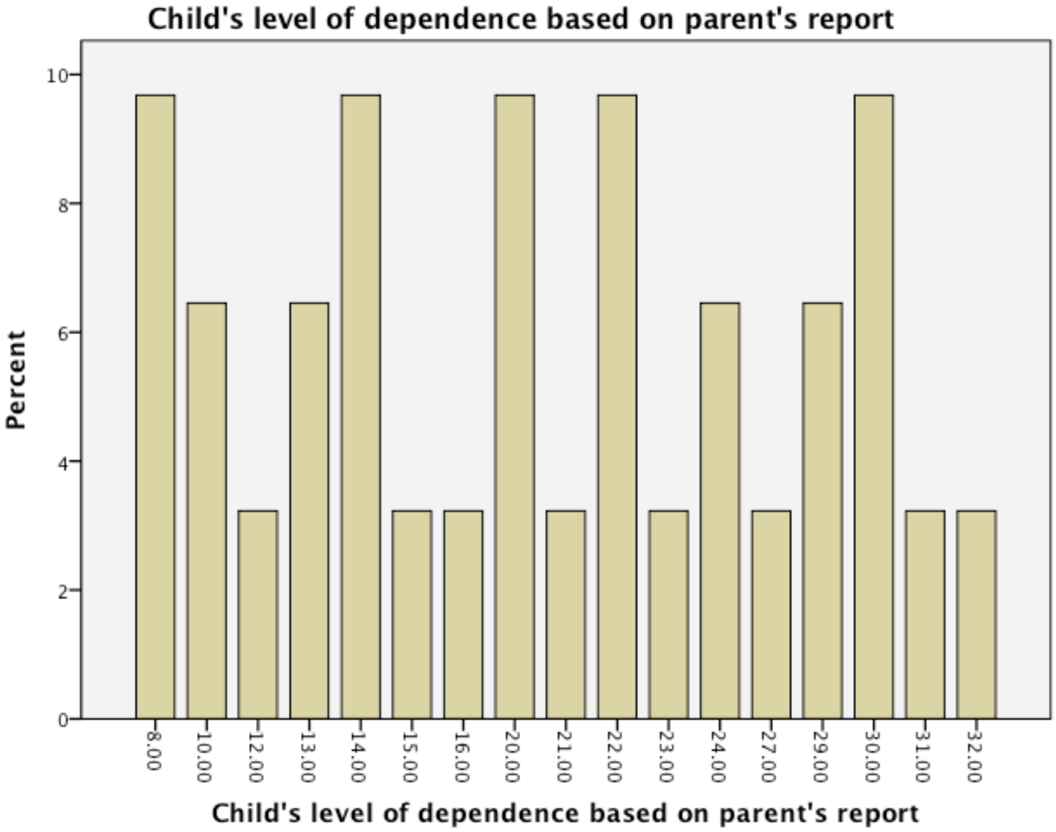
Child's Ventilator Usage

Ventilator Use	Frequency	%
No Ventilator	10	32.3
Fulltime Ventilator	3	9.7
Part-time Ventilator	18	58.1
Total	31	100.0

Figure C1

Parents' Rating of Their Child's Level of Dependence

(based upon aggregated data from Family Information Checklist question 15)



Results Chapter: Data Analysis - Descriptive statistics for self-report scales

Note: Decimal values have been rounded to .00

Table C11

Parents' Patterns of Coping Based upon the Coping Health Inventory for Parents (CHIP). (McCubbin, McCubbin, Nevin and Cauble, 1983)

Scale / subscale	N	Mean	Standard Deviation	%
CHIP scale total[a]	29[b]	92.79	22.61	68.73
Subscale 1 Family integr.	30[c]	42.37	9.96	74.33
Subscale 2 Self/social	29[d]	34.76	9.24	64.37
Subscale 3 Health network	31	15.55	4.82	64.79

[a] CHIP Scale total calculated by summing the 45 item scores, as per the authors' instructions (total range possible = 0 - 135).

[b, c, d] Different N values due to missing data in 1-2 cases.

Table C12

Parents' Patterns of Coping based on the Self-Compassion Scale (SCS). (Neff, 2003)

Scale /subscale	N	Mean	Std. Deviation	%
Total scale (per 2003)[a]	31	18.61	4.34	62.03
Self-kindness subscale	31	2.74	.82	54.80
Common humanity subscale	31	3.36	.93	67.20
Self-judgment subscale	31	3.03	.84	60.06
Isolation subscale	31	2.81	1.03	56.20
Mindfulness subscale	31	3.23	.83	64.60
Over-identification subscale	31	2.88	.96	57.60
Total scale mean[b]	31	3.08	.72	61.60

[a] Total scale value (per 2003) calculated using method described in Neff (p. 243, 2003): negative subscale items are reverse scored, then subscale means (scored out of 5 points) were summed (= out of 30 points).

[b] Total scale mean calculated as per instructions accompanying scale for research use: negative subscale items are reverse scored, then a total mean of the scale items was computed (range possible = 1-5).

Table C13

Parents' Perception of their Relationships with Health care providers' Based on the Measure of Processes of Care - 20 (MPOC-20). (King, Rosenbaum and King, 1998)

Scale / subscale	N	Mean	Std. Deviation	%
MPOC-20 Scale total[a]	31	93.10	32.47	66.50
Providing specific information	30[b]	4.66	1.73	66.57
Enabling and partnership	31	5.22	1.63	74.57
Providing general information	31	3.74	1.90	53.43
Coordinated comprehensive care	31	4.89	1.80	69.86
Respectful and supportive care	31	5.13	1.68	73.28

[a] MPOC Scale Total generated by summing the 20 item scores (Maximum score possible = 140).

[b] Different N value due to case missing data.

Inferential Statistics: Independent Samples T-tests

Note: Decimal values have been rounded to: .00; Eta squared values given for p < .06.

Table C14

Self-Compassion Scale and subscales contrasted on basis of Family Structure

Group Statistics

Scale/subscale	family structure[a]	N	Mean	Std. Deviation	Std. Error Mean
Self-kindness	1	5	3.04	.86	.39
	2	26	2.68	.81	.16
Self-judgment	1	5	3.28	.63	.28
	2	26	2.91	.88	.17
Common humanity	1	5	3.85	.94	.42
	2	26	3.27	.91	.18
Isolation	1	5	3.20	.65	.29
	2	26	3.19	1.09	.21
Mindfulness	1	5	3.60	.76	.34
	2	26	3.16	.84	.16
Over-identification	1	5	3.60	.80	.36
	2	26	3.03	.97	.19
SCS Total scale (per 2003)	1	5	20.57	4.32	1.93
	2	26	18.24	4.33	.85

[a] family structure: single parent household = 1; two or more-parent household = 2

Table C14.1

Self-Compassion Scale and subscales contrasted on basis of Family Structure

Independent Samples T-test

Scale/Subscale	t	df	Sig. (2-tailed)	Mean difference	95% Confidence Interval	
					lower	upper
Self-kindness	.90	29	.37	.36	-.46	1.18
Self- judgment	-.90	29	.38	-.37	-1.22	.47
Common humanity	1.30	29	.20	.58	-.34	1.50
Isolation	-.02	29	.99	-.01	-1.05	1.03
Mindfulness	1.08	29	.29	.44	-.39	1.26
Over-identification	-1.23	29	.23	-.57	-1.52	.38
SCS Total scale (per 2003)	1.10	29	.28	2.33	-1.99	6.65

Table C15

CHIP Scale and subscales contrasted on basis of Extent of Respiratory Technology

Group Statistics

Scale/Subscale	Extent of RT	N[b]	Mean	Std. Deviation	Std. Error Mean
CHIP Total	1	16	99.25	17.81	4.45
Scale	2	12	86.42	26.42	7.63
Subscale 1	1	17	45.88	7.02	1.70
Family integr.	2	12	38.67	11.59	3.34
Subscale 2	1	16	36.19	7.71	1.93
Personal/social	2	12	33.25	11.34	3.27
Subscale 3	1	18	16.61	4.54	1.07
Health network	2	12	14.50	4.94	1.43

[a] Extent of Respiratory Technology (RT) scoring: 1 = child has trach; 2 = child does not.

[b] Variation in N related to cases not included due to missing data for given scale.

Table C15.1

CHIP Scale and subscales contrasted on basis of Extent of Respiratory Technology

Independent Samples T-Test

Scale/ subscale	t	df	Sig. (2-tailed)	Eta squared	Mean Difference	95% Confidence Interval	
						Lower	Upper
CHIP Total Scale	1.54	26	.14	-	12.83	-4.34	30.00
Subscale 1 Family integr.	2.09	27	.05	.14	7.22	.13	14.30
Subscale 2 Personal/ social	.82	26	.42	-	2.94	-4.46	10.33
Subscale 3 Health network	1.20	28	.24	-	2.11	-1.48	5.70

Table C16

MPOC-20 Scale and subscales contrasted on basis of Extent of Respiratory Technology

Group Statistics

Scale/Subscale	Extent of R.T.	N	Mean	Std. Deviation	Std. Error
MPOC-20	1	18	100.06	31.60	7.45
Scale total	2	12	87.33	30.50	8.80
Providing specific	1	18	4.78	1.80	.42
information	2	11[b]	4.67	1.61	.49
Enabling &	1	18	5.59	1.51	.36
partnership	2	12	4.94	1.50	.43
Providing general	1	18	3.86	1.95	.46
information	2	12	3.78	1.80	.52
Comprehensive	1	18	5.54	1.64	.39
coordinated care	2	12	4.08	1.68	.48
Respectful	1	18	5.50	1.62	.38
supportive care	2	12	4.85	1.52	.44

[a] Extent of Respiratory Technology (RT) scoring: 1 = child has trach; 2 = child does not

[b] N variation due to one case being disqualified re: too many "not applicable" responses.

Table C16.1

MPOC-20 Scale and subscales contrasted on basis of Extent of Respiratory Technology

Independent Samples T-test

Scale/subscale	t	df	Sig. (2-tailed)	Eta squared	Mean Difference	95% Confidence Interval Lower	95% Confidence Interval Upper
MPOC Scale total	1.10	28	.28	-	12.72	-11.08	36.52
Providing specific information	.17	27[a]	.87	-	.11	-1.25	1.47
Enabling & partnership	1.15	28	.26	-	.65	-.50	1.80
Providing general information	.10	28	.92	-	.07	-1.37	1.52
Comprehensive coordinated care	2.36	28	.02	.17	1.46	.19	2.72
Respectful supportive care	1.10	28	.28	-	.65	-.56	1.86

[a] Variation is due to one case with missing data being dropped.

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Footnotes: Glossary

[1] **long term ventilatory support:** “any child who, when medically stable, continued to need a mechanical aid for breathing which may be acknowledged after a failure to wean, three months after the institution of ventilation.” (Jardine et al, 1999).

[2] **children with complex needs:** “include those who require a network of health, education, social and other services in their homes and communities. The children in this population have a wide range of physical/medical and developmental needs. These children are often chronically ill, medically fragile and dependent on technology.” (Winnipeg Regional Health Authority, as cited in Steeds & Nadeau, 2007).

[3] **cope:** “refers to the person’s cognitive and behavioural efforts to manage (reduce, minimize, master or tolerate) the internal and external demands of the person-environment transaction.” (Folkman et al., 1986, p. 572).

[4] **perceived self-efficacy:** “ beliefs in one’s capabilities to organize and execute the courses of action required to produce given attainments.” This is a key factor for personal agency (Bandura, 1997, p. 3).

[5] **personal agency:** “the power to originate actions for given purposes” (Bandura, 1997, p. 3).

[6] **resilience:** “the ability to withstand and rebound from disruptive life challenges, becoming strengthened and more resourceful.” (Rolland & Walsh, 2006, p. 527).

[7] **social support:** “social support involves a qualitative exchange of communications in an atmosphere of trust.” This can include information exchanged at the interpersonal level which provides: *emotional support* – the person feels loved and cared for; *esteem support* – the person feels valued and appreciated; *network support* – the person feels

belonging to a network of communication involving mutual obligation and understanding; *appraisal support* – feedback that allows the person to determine how well they're doing with life's tasks; and *altruistic support* – information received in the form of good will from others for having given of oneself. (McCubbin & Thompson, 1987, p. 19).