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Mothers' Lived Experience of Parenting an Infant/Young Child with Special Needs in a Rural Context

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Nursing

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MOTHERS' LIVED EXPERIENCE OF PARENTING AN INFANT/YOUNG CHILD WITH
SPECIAL NEEDS IN A RURAL CONTEXT

(Thesis format: Integrated-Article)

By

Lauren Elford

Graduate Program in Nursing

A thesis submitted in partial fulfillment
of the requirements for the degree of
Masters of Science in Nursing

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ABSTRACT

Parenting an infant with special needs requires performing extra care giving duties and mothers living in rural communities face additional challenges obtaining health and social support services. A hermeneutic phenomenological approach was used to explore the lived experience of parenting young children with special needs from rural mothers' perspectives. Semi-structured interviews were conducted with a sample of 7 mothers. Findings revealed an overarching theme entitled *Getting Through It* and 6 subthemes: *Experiencing the Unexpected; Overcoming the Challenges to Mothering; Unconditional Commitment to Child; The Lived Human Relation as Powerful; Being a Care Co-ordinator; and Being Transformed*. Mothers of infants with special needs face unique challenges including long commutes, accessing reliable information about funding and respite services and limited social networking opportunities. The findings can inform nurses, researchers and policy makers developing strategies to mitigate these challenges and better support mothers who have children with special needs in rural communities.

KEY WORDS: Rural, Mothers, Disabilities, Special Needs, Infants, Parenting, Small Town

CO-AUTHORSHIP

Lauren Elford completed the following work under the supervision of Dr. Marilyn Evans and Dr. Marilyn Ford-Gilboe. Drs Evans and Ford-Gilboe will be co-authors of the publication resulting from this work.

PARENTING AN INFANT WITH SPECIAL NEEDS

DEDICATION

This research is dedicated to the extraordinary mothers of children with special needs. I would like to particularly thank the mothers who participated in this study. The stories you have shared have truly been an inspiration to me.

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I would like to thank my thesis committee Dr. Marilyn Evans and Dr. Marilyn Ford-Gilboe. To Dr. Marilyn Evans, I cannot express what sincere gratitude I have for everything you have done for me throughout these years. Your unwavering support and encouragement has meant so much. Thank you for always being there for me, offering your valuable wisdom and guidance every step of the way and being someone I could always turn to when I needed help. You have fostered such growth in me as a researcher and nurse and I am so grateful to have had you as my mentor. To Dr. Marilyn Ford-Gilboe, I would like to sincerely thank you as well for your wonderful support and insightful feedback. I truly appreciate all the work you have done to help me reach this milestone and the encouragement you have provided to me has been so meaningful. It has been such a pleasure to work with you both and I will carry what I have learned from each of you throughout my entire career. Thank you.

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CHAPTER ONE: INTRODUCTION

Geographic location presents many barriers to accessing adequate healthcare and social services needed by individuals and their families. In recent years, research has been undertaken pertaining to rural health and health care access in an effort to better understand the health disparities experienced by Canadians living in rural or small town settings. Rural research on maternal-child health and healthcare services has primarily focused on women's access to medical care, hospitals, birthing centers and midwifery services (Klein, Johnston, Christilaw & Carty, 2002; Kornelsen & Grzybowski, 2006; Lisonkova et al., 2011; Van Wagner, Epoo, Nastapoka & Harney, 2007). While this research is important, other areas of maternal-child health and related support services are in need of attention. For example, parenting a baby with a disability or chronic health condition can be a challenging event for families (Melamed, 2010), particularly in rural settings.

Following birth, infants with special needs may require continuing health intervention and mothers often assume the primary care giving role (Lasby, Newton, & Von Platen, 2004). Research indicates that this care giving experience can be stressful for new mothers (Lasby, Newton, & Von Platen, 2004; Pizur-Barnekow, 2010). In addition, caring for an infant with special needs may be exceedingly troublesome for mothers living in rural areas due to the challenges related to accessing adequate health care and having limited community supports (Laurent, 2002). The purpose of this phenomenological study was to gain an in-depth understanding of the lived experience of parenting an infant/young child with special needs from the perspective of mothers residing in rural/small town Ontario. In this chapter, I briefly introduce the background pertaining to the research problem in order to situate emerging issues and provide a context for understanding this study and its significance to nursing and health care.

Background and Significance

The social determinants of health model recognises that factors such as access to health care services, socioeconomic status, education, early childhood development, gender, social support and disability can have a significant impact on the health of individuals (Mikkonen & Raphael, 2010). Living in rural and remote areas can have a negative effect on a person's health (Leipert, 2005; Romanow, 2002). Results from a longitudinal study conducted in Ontario (Wang, Guttman, To, & Dick, 2009) showed that infants with chronic health conditions who resided in rural Ontario had significantly higher hospitalization and mortality rates as compared to infants with chronic health conditions who lived in urban settings. Distance to specialized paediatric or emergency services and limited access to respite, homecare services and social support networks (Halls, 2008; Lauver, 2010) are characteristics that can make the experiences of mothers caring for their infants with special needs in rural settings unique in comparison to their urban counterparts. Women living in rural Canada experience a variety of health inequities (Sutherns, McPhedran & Haworth-Brockman, 2004) and the chronic stress associated with having a young child with special needs increases the risk of developing mental health problems and chronic illness (Eisenhower, Baker, & Blacher, 2009; Miodrag & Hodapp, 2010). Mothers of children with special needs may experience increased vulnerability and stress at the intersection of rural living and special needs parenting. While some Canadian population based studies (Wang et al., 2009; Yantzi, Rosenberg, Burke & Harrison, 2001) suggest that mothers of children with disabilities living in rural areas experience health disparities, little is known about the lived experience of parenting an infant or young child with special needs in a rural setting.

Data on the prevalence of disability and chronic health problems in Canadian infants is limited but evidence from the United States indicates this population and its associated support

needs are increasing (Holditch-Davis, Shandor Miles, Burchinal, & Goldman, 2010).

Approximately 8.1 % of babies in Canada are born prematurely and 8.3 % are delivered as small for gestational age (Canadian Institute for Health Information [CIHI], 2009). Furthermore approximately 13.6 % of infants born in Canada must be transferred to the neonatal intensive care unit (NICU) as result of health complications at birth (CIHI, 2006). Premature birth increases the risk for adverse health outcomes including developmental, neurological, and learning disabilities, cerebral palsy, respiratory illnesses and various other long-term health problems (Boat, Sadhasivam, Loepke, & Kurth, 2010; Marlow, Wolke, Bracewell, & Samara, 2005). The incidence of disability and chronic health conditions in children has increased in recent decades with the advancement of medical technologies (Holditch-Davis et al., 2010) and increased maternal age (Vincer et al., 2006). Supportive community environments are needed to ensure that these children have equal opportunities to develop and grow throughout their lifespans.

Opportunities for optimal growth and development in the early childhood years are essential for the lifelong adjustment of children with disabilities (Miller, Recsky, & Armstrong, 2004). Due to the nature of childhood disability and chronic health conditions, families that have children with special needs are often extensively connected to the healthcare system for diagnostic and therapeutic purposes. Nurses come in contact with mothers who have children with special needs in a variety of settings such as neonatal intensive care units, specialist clinics, paediatric offices, acute care settings, home visiting, community health centers, public health units, nurse practitioner clinics and mental health settings. As a consequence, nurses are in an ideal position to promote the health of these mothers, their children and families as the context of

the therapeutic relationship provides an important place for fostering trust, empowerment and patient advocacy (College of Nurses of Ontario [CNO] , 2006).

Little is known about mothers' experience of caring for an infant or young child with special needs in a rural context. Eliciting the voices and hearing the stories of these women can increase our understanding of the meaning of the everyday lived experiences from the mothers' perspectives. With an in-depth understanding of the unique circumstances faced by these mothers, nurses can work collaboratively to mitigate some of the challenges associated with special needs parenting in rural and small town settings. It is anticipated that the results of this study will help illuminate the lived experiences of mothers parenting an infant or young child with special needs in rural contexts including the supports necessary to care for their child, themselves and their families. The findings may be useful in informing resource allocation and health policy for families of young children with special needs, and program development in early childhood and maternal health, and address social inequities in rural settings.

Literature Review

Most studies examining the health of mothers who have children with special needs focus on urban mothers and have not been conducted from a Canadian perspective. In this section, I will briefly review the historical context of care for children with disabilities in Canada and current literature on the subject to identify knowledge gaps which will be explored further in Chapter Two . During the 1970's and 1980's, the concept of normalization surrounding individuals with disabilities was embraced by governments in Canada and the United States (Ouellette-Kuntz et al., 2005). The normalization notion regarding disabilities marked the subsequent closure of the vast majority of institutions for persons with special needs within these countries (Lemay, 2009). Normalization is the philosophy that people with disabilities should

have the opportunity to lead normal lives within the community and any necessary social support services should be provided in the community (Heany & Burke, 1995). Today, the primary caregivers of young children with disabilities are their families, particularly mothers. While progress concerning human rights for children with disabilities and their families has come a long way, the social policies to support these families in caring for their children in the community have not been readily adopted (Peter et al., 2007). Implications concerning this trend indicate the need for long term health and social support services to be accessible to family caregivers when they make the transition home with their infants from the hospital. Currently, no homecare policy exists for Canadian children with special needs and their families (Peter et al., 2007) and respite services can be difficult to access (Ray, 2003).

One qualitative study conducted in the U.S. explored the experiences of rural families of children with disabilities (Hall, 2008). Hall explored the experience of six mothers and two fathers living in rural Montana who were parenting a child with special needs. Three main themes were uncovered which included *experiencing disequilibrium*, *becoming expert*, and *learning to live in a parallel world*. *Experiencing disequilibrium* encompassed the emotional struggles that families encountered as they learned about their child's diagnosis as well as the barriers that disrupted normal family life such as separation between husband and wife during infant hospitalization, self imposed isolation from the community to protect the child from communicable diseases, and quitting work in order to take on care needs of the child full time (Halls, 2008). *Becoming an expert* was represented as a positive and empowering transition from experiencing disequilibrium. In this phase families gained confidence in managing their child's condition and actively worked to problem solve and look for new solutions (Halls, 2008). *Living in a parallel world* involved using the rural community for support and being happy for

what they had despite the acknowledgment that their lives were difficult. While Hall's study is useful for understanding many of the unique circumstances faced by rural parents of children with special needs in the United States, a Canadian perspective is needed to understand how this translates within our nation healthcare context.

In Canada, studies looking at the experiences of mothers who have young children with special needs have primarily focused on urban mothers. Ray (2002, 2003) interviewed 34 families consisting of mothers and some fathers in Alberta who had children with disabilities and produced two separate analyses on the data. She found that these families experienced difficulty learning to care for their medically fragile children, maintaining employment and securing respite services. Ray's research suggests that Alberta families who have children with special needs may face barriers to obtaining the support they need yet little is known if similar circumstances exist in rural and small town communities within Ontario. Yantzi, Rosenberg, Burke & Harrison (2001) conducted a secondary analysis of data on 140 families in Ontario who had children with chronic illnesses and needed frequent hospitalization. They also found that distance from hospitals had a serious impact on family functioning and the ability to care for children within the home.

Current literature suggests that having a child with special needs can increase mothers' vulnerability for social isolation and living in rural areas can present additional barriers to social support, such as isolation and travel distant. No studies examining the experiences of social support for mothers of infants with special needs from a Canadian rural perspective were found in the literature review. Additionally, previous research has primarily focused on informal support experiences during childhood. Little is known about access to formal support for mothers who have infants with special needs in rural communities.

Thus, the experience of having an infant with special needs can present challenges for families on individual, interpersonal and societal/systemic levels. There is a need to further explore the experiences of mothers living in rural settings and who have a young child with special needs. This study focused on mothers' experiences because they are the primary caregivers of children in the early years (Chrisholm, 2000; Logsdon, Wisner &, Pinto-Foltz, 2006). Additionally, it has been observed that having a child with special needs seems to affect the health of mothers more negatively compared to fathers of children with special needs (Cairns, 1997; Emerson & Llewelyn, 2008; Olssen & Hwang, 2001). The findings of this phenomenological study have the potential to increase our understanding of mother's health needs and inform practices and policies oriented to ensuring that supports necessary to care for their child, themselves and their families are accessible to all families, regardless of where they live.

Purpose Statement

The purpose of this phenomenological study was to gain an in-depth understanding of the lived experience of parenting an infant/young child with special needs from the perspective of mothers residing in rural/small town Ontario.

Research Question

Overarching question: What is the meaning of parenting an infant/young child with special needs from the perspective of mothers living in rural settings?

Sub- questions:

1. What do mothers identify as needed supports to help them care for their infant/young child?
2. What has been helpful and not been helpful for them in caring for their infant/young child?

Definition of Terms

Rural and Small Town Setting

There is no agreement about how to define rurality. Statistics Canada (2001) provides six definitions which use characteristics such as population size or density, postal code, or distance from metropolitan locations. The Ontario Ministry of Health and Long Term Care [MOHLTC] defines rural Ontario as “places under 30,000 in population and 30 minutes drive from a centre that is larger than 30, 000 in population” (MOHLTC, 2011, p.2). This definition recognises that communities with less than 30,000 residents generally do not have local access to the full range of health services (MOHLTC, 2010). The definition is helpful because it acknowledges that more limited access to services is an important quality of many rural places but the specified driving distance presents a social class bias by assuming that each person in the rural community has access to a vehicle. For the purpose of this study, the MOHLTC definition was adapted to account for transportation disparities and rural and small town setting was defined as “any community with a population of 30,000 residents or less, which does not offer a broad range of health and social services and/or where regular public transportation is not available to access these services in another community”. These conditions acknowledge the practical barriers to obtaining health services for the child due to location and structural inequity. In this way, although a small town may not qualify as ‘rural’ using definitions provided by Statistics Canada, the difficulties obtaining access to specific services may still be comparable to the barriers faced by persons living in more rural areas. Two of mothers in this study were classified as “rural” although they resided in small towns with a population slightly higher than the stated cut off. Because they faced similar barriers to accessing health care in larger communities they were included in this study.

Special Needs

For the purposes of this study, infants/young children with disabilities or chronic health problems were collectively referred to as having special needs. McPherson et al., (1998) define children with special health care needs as “those who have or are at increased risk for a chronic physical, developmental, behavioural or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (p. 138).

Both chronic health problems and disabilities were included in the definition of special needs because each of these conditions may require added support services and significantly impact the health of mothers. In addition, infant disability and chronic health conditions are often interrelated. Infants with disabilities may present with health challenges and young children with chronic illness can also be at an increased risk for developing various disabilities later in life.

Infant/Young Child

Infant/young child was used as it characterizes a span of time when rapid changes occur in growth and development (Allen & Marotz, 2003). Infant/young child included the infant stage (0 to 12 months), toddlerhood (1 to 3 years) and early childhood (3 to 8 years) (Allen & Marotz, 2003). The term infant was used specifically to refer to the children when they were under 12 months old, and the term young child was used as a more flexible designation encompassing all three stages described above.

Declaration of Self in Front of Text

My interest in paediatric disability and maternal health started when I was young and I became close to a family who had a child living with autism. In getting to know this family, I

began to observe some of the joys and challenges that were involved in raising a child with a disability. I saw how relentlessly these parents worked to ensure that their child had equal opportunities for growth and development and observed the sacrifices they made for him. To me, the strength of their endless love and perseverance were inspirational but I had always felt that it was unfair that they had to face so much hardship and use so many personal resources in order to support their child.

A few years later, as I was completing my undergraduate degree in nursing, I had the opportunity to work with children who had disabilities in a classroom setting, as well as adults with intellectual disabilities in an occupational health role. I found each of these experiences to be so rewarding and they served to ignite my passion once again for social justice issues surrounding individuals with disabilities. Through my experience, I have felt that our communities should be better equipped to create supportive environments for persons with disabilities and their families. While working towards my master's degree, I developed an interest in rural women's health. Although I have always lived in urban areas myself, taking a rural health graduate course and learning about what health means for rural women quickly became another passion of mine. Rural areas are often underserved and I began to wonder what parenting a child with special needs looked like for women residing in rural settings. I am currently interested in looking at the experiences of mothers with infants because having a child with a disability is a lifelong journey and mothers are often the primary caregivers in the early years. I feel that exploring how living in a rural area affects the health of mothers and their children who have special needs is an important area for research as it is not well studied within the literature.

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CHAPTER TWO: MANUSCRIPT

Introduction

A growing body of research has examined the role of place and its effects on health. Place based research examines how the environment and geographic location of where we live can impact our lives (Cummins, Curtis, Diez –Roux &Macintyre, 2007) . Rural research has demonstrated that living in small town and rural communities can present barriers to obtaining adequate health care (Crosato & Leipert, 2006; Laurent, 2002). A variety of factors contribute to poor health status experienced by rural populations including distance to medical services, isolation, and poverty (Crosato & Leipert, 2006; Laurent, 2002).

The incidence of disability and chronic health conditions in children has increased in recent years with the use of advanced medical technologies (Holditch-Davis et al., 2010) and increasing maternal age (Vincer et al., 2006). Having a child with special needs often requires families to be connected to a range of specialized health services for ongoing support. These services are generally not offered in rural and small town settings due to the centralized nature of health resource distribution. Consequently, rural parents who have children with special needs may need to travel to larger cities to meet with specialists, undergo pediatric surgeries, or receive hospital care (Halls, 2008; Yantzi, Burke & Harrison, 2001).

Opportunities for growth and development in the early childhood years are essential for the lifelong adjustment of children with disabilities (Miller, Recsky, & Armstrong, 2004). Mothers are valuable members of the healthcare team as their strength and advocacy endeavours foster the optimal health and development of their children (Sousa, 2011). The first years following birth are a critical time for mothers and their babies to establish positive maternal-infant interactions and families learn to adjust to the circumstances of disability within the context of their everyday lives. Maternal perceptions of postnatal support can have a significant

impact on mothers' psychological well being so it is important that mothers are able to access the help that they need (Briscoe, Lavender, & Alfirevic, 2002).

Characteristics of rural settings such as distance to specialized paediatric or emergency services, and limited access to respite, homecare services and social support networks (Halls, 2008; Lauver, 2010) make the experiences of rural mothers of children with special needs unique in comparison to their urban counterparts. Women residing in rural Ontario also experience a variety of health disparities (Sutherns, McPhedran & Haworth-Brockman, 2004) and having a child with special needs increases the maternal risk of acquiring mental health problems and chronic illness (Eisenhower, Baker, & Blacher, 2009; Miodrag & Hodapp, 2010). These mothers may experience increased vulnerability at the intersection of rural living and special needs parenting.

Little is known about the lived experience of mothers who are parenting a child with special needs in rural or small town settings. This study addressed this knowledge gap by making explicit the experiences of Canadian mothers who are parenting infants with disabilities in rural contexts. An in-depth understanding of the meaning of parenting a child with a disability from rural mothers' perspectives will increase our understanding about their specific needs and what initiatives could be undertaken to promote their health. The study results may be used to inform policy makers about key issues faced by rural mothers with infants and young children who have special needs in order to enhance local support initiatives in rural settings.

Literature Review

To examine mothering of infants and young children with disabilities in a rural context a comprehensive literature review was conducted using CINAHL, SCOPUS and Medline databases. Grey literature was also explored to supplement this information. Search terms

including childhood disability, infant developmental disorders, premature infants, special needs, mothers and rural were systematically combined to obtain relevant articles written in English from 1995 to 2013. This date range was used to identify key findings and gaps in the existing knowledge base regarding parenting, children with disabilities and rural studies in the most current literature as well as to ensure that older research was reviewed and included. Both quantitative and qualitative studies were considered. Articles from developing countries were excluded in this analysis as the support needs and experiences of families in these countries with dissimilar health care systems could significantly differ from those living in Canada. The next section will discuss four prominent categories that resulted from the review of the literature: Learning about Child's Diagnosis, Emotional Support, Caring for Children with Special Needs, and Maternal Health.

Learning about Child's Diagnosis

Several qualitative studies have examined parents' experience of learning that their child has a disability or chronic health problem (Barbosa, Chaud, & Gomes, 2007; Golish & Powell, 2003; Green, 2007; Green, 2001; Halls, 2008; Kearney & Griffin, 2001; Landsman, 1998; Sen & Yurtsever, 2007; Skotko, 2005; Wright 2008). A central theme reported in these studies is the grief that occurs upon losing 'the perfect child' (Barbosa et al., 2007; Golish & Powell, 2003; Kearney & Griffin, 2001). Infants with disabilities may have significant health problems, and the stress and uncertainty of having an ill infant can be extremely upsetting for new parents (Barbosa, et al., 2007; Beattie, 2009; Golish & Powell, 2003; Green, 2007; Halls, 2008; Melamed, 2010). Mothers may engage in self blame for their child's condition, even when it is not their fault (Wright, 2008).

While many studies underscore the emotional hardships faced by mothers who have infants with special needs, few seem to acknowledge the positive aspects of a parent's experience. Kearney and Griffin's (2001) interpretive phenomenological study based on semi-structured interviews with six Australian parents explored the joys and challenges of parents who had children with special needs. The researchers found that the parents' sorrow was derived from the attitudes and perceptions of 'others' (peers, health professionals and family members) rather than the child's diagnosis itself. One mother who disclosed feeling joyful about the birth of her baby was labelled as 'in denial' by healthcare providers who felt she should be upset about the child's prognosis (Kearney & Griffin, 2001). Skotko (2005) conducted a mailed survey to describe the reflections of 985 mothers whose children had received a postnatal diagnosis of Down syndrome. Similar to Kearney and Griffin's (2001) findings, mothers were irritated by healthcare providers who emphasized their baby's limitations and neglected to congratulate them at birth or acknowledge the positive aspects of their child. The results of Hall's (2008) interpretive phenomenological study with six mothers and two fathers raising a child with special needs in rural Montana further supported the negative reactions of parents receiving a diagnosis in the initial months following birth of their child. The participants reported "mind numbing shock" (p. 34), being unable to function properly and experiencing a high level of stress following diagnosis. Little is known about responses to birth for rural mothers with infants who have special needs.

Emotional Support

Research highlights the importance of emotional support for mothers of infants and children with disabilities (Briscoe, Lavender, & Alveric, 2002; Bruns & Forester, 2011). Briscoe, Lavendar and Alveric (2002) used semi-structured questionnaires to interview 49

women who experienced a complicated pregnancy and delivery. Their descriptive study indicated the women greatly appreciated social support extended to them throughout the postnatal period. Social support included having health care professionals and family being available when mothers needed them, obtaining sympathy and emotional support, getting practical help with care giving and having a professional to go to for information. Similarly, Bruns and Forrester (2011) used a qualitative mailed survey to examine family support for parents of children with trisomy conditions in Canada, Sweden, England, Wales, Germany and Australia. They found that positive support such as emotional reassurance and practical aid including giving assistance, provided by immediate and extended family members, helped parents cope with the day to day challenges of raising a child with special needs.

Some studies, however, indicated that mothers may experience isolation from family and friends who are unfamiliar or uncomfortable with the special needs of the child (Beattie, 2009; Kearney & Griffin, 2001; Parrish, 2010). Social isolation may be a significant problem for mothers living in rural areas who have infants with disabilities (Halls, 2008; Lauver, 2010). Lauver's (2010) phenomenological study of the lived experiences of ten foster families caring for young children with special needs in the rural North-Eastern United States revealed that parents felt isolated and alone due to limited access to support networks such as extended family members or other parents who shared similar experiences. The findings from another phenomenological study conducted by Halls (2008) which explored rural parents' experience of isolation, indicated that rural mothers assumed the primary care giving role for their babies and had little time for social events or employment. The mothers were also fearful to bring their baby into the community and remained at home to protect them from catching communicable diseases (Halls, 2008). Thus, having a child with special needs can increase mothers' vulnerability for

social isolation and living in rural areas can present additional barriers to obtaining social support.

No studies examining the experiences of emotional support for mothers of infants with special needs conducted from a Canadian rural perspective were found in the literature search. The research cited has primarily focused on informal support experiences during childhood. Little is known about access to formal or informal emotional support for mothers who have infants with special needs in rural communities.

Caring for Children with Special Needs

Research indicates that parenting an infant with special needs also includes additional care giving challenges for families. Ray (2002, 2003) interviewed 34 families in Alberta who had children with disabilities ranging from 15 months to 16 years and produced two separate qualitative secondary analyses. In the first analysis, Ray (2002) used an interpretive lens to develop a model titled Parenting and Childhood Chronicity. In the second report, Ray (2003) used a critical lens to explore social and political barriers encountered by parents in order to obtain support for child care. She found that families encountered many challenges to obtaining support for technical care, symptom monitoring, system navigation and daily responsibilities (Ray, 2002). Some mothers reported quitting their jobs to care for their child full-time, while others struggled to balance employment and care giving duties (Ray, 2002; Ray, 2003). Many parents described their experience of caring for children who needed continuous monitoring and how this had harmful effects on their own physical and psychological wellbeing (Ray, 2002). They also expressed frustration with limited respite and homecare services offered to families caring for children who have disabilities (Ray, 2002; Ray, 2003). Although these findings are

informative in terms of understanding challenges parents face in caring for children with special needs the sample was not specifically from a rural context.

Yantzi, Rosenberg, Burke and Harrison (2001) conducted a secondary analysis of data from 140 families in Ontario who had children with chronic illnesses and needed frequent hospitalization. They found that distance from hospitals had a serious impact on family functioning and the ability to care for children within the home (Yantzi et al., 2001).

The literature indicates that many Canadian families who have children with disabilities face barriers to obtain support services. Ray's (2002, 2003) research was conducted with families living in major cities. There is a knowledge gap in understanding how the circumstances of living in rural communities affect access to respite and homecare services for mothers. Yantzi's et al. (2001) quantitative study found that rural families who have children with special needs in Ontario have difficulty functioning yet it is unclear what this experience was like for parents, particularly for mothers. Lastly, each of these studies focused on older children with special needs, not infants or young children. In Ray's (2002) study, while some parents recalled feeling intimidated by care giving activities during the infant years, not much is known about how this affects mothers' parenting experience during the first few years after birth..

Maternal Health

Having a child with special needs increases a mother's risk for experiencing adverse health outcomes, including mental health problems such as depression (Ones, Yilmaz, Cetinkaya, & Caglar, 2005), post traumatic stress disorder (Pizur-Barnekow, 2010), worry (Docherty, Shandor Miles & Holditch-Davis, 2002), decreased psychological and physical wellbeing (Eisenhower, Baker & Blacher, 2009), care giving strain (Green, 2007), chronic stress

(Miodrag & Hodapp, 2010), and decreased immunity (Kuser & Merkle, 2004; Lovell, Moss, & Wetherell, 2012).

Burton, Lethbridge and Phipps (2007) conducted a quantitative analysis of data from the Statistics Canada National Longitudinal Survey of Children and Youth. This survey contained information from a nationally representative sample of families who had children with disabilities from 1994 to 2000 and included self rated scores of overall health for both mothers and fathers (Burton et al., 2007). The researchers hypothesized that in view of the stress experienced by families as a result of care giving strain and financial burden, negative effects on health would be observed (Burton et al., 2007). They also hypothesized that these negative health effects would be more pronounced in families with a child whose condition was chronic, and adopting traditional gender roles of care giving and bread winning would lead mothers and fathers to exhibit adverse health problems differently (Burton et al., 2007). The findings revealed that mothers experienced a significant decline in health particularly when caring for a child with a chronic illness yet this pattern was not found in fathers. Based on these results it appears that Canadian mothers may be at a higher risk of poor health outcomes than fathers as a consequence of caring for children with chronic disabilities over time. Although the data used in this study are somewhat dated, it is useful from a Canadian population standpoint. Examining the effect of place on the health of these mothers would be an important avenue for further investigation.

Hatzmann et al. (2008) explored quality of life in 533 Norwegian parents of children who had chronic conditions (e.g., asthma, diabetes, Down Syndrome, Duchenne muscular dystrophy, end stage renal disease, metabolic diseases, profound multiple handicaps, sickle cell disease, spina bifida and survivors of a brain tumor) and a comparison group of 433 parents with children

following typical development (i.e., children without chronic health conditions). All parents completed a mailed survey containing measures of personal health domains including fine motor function, cognitive functioning, sleep, pain, social functioning, daily activities, sexuality, vitality, positive and depressive emotions, and aggressiveness (Hatzmann et al., 2008). The researchers found that parents of children with chronic health conditions had a significantly lower health-related quality of life in all domains (Hatzmann et al., 2008). This study is unique in that it used a large sample and included a comparison group. It is unclear however, if these findings are generalizable to Canadian parents or to those living in rural settings. In addition, since the study focused on children aged 1-19, the maternal parenting experience during the early postpartum period may not have been adequately captured.

In summary, there is evidence to suggest that parenting an infant with special needs can present challenges for families on individual, interpersonal and societal/systemic levels. The studies examined report that having a child with a disability has negative effects on parenting and maternal health. While having a child with a disability has been found to negatively affect parenting and maternal health, there is some evidence that this experience can also be exceedingly rewarding for parents. Few studies have explored how having a child with special needs could also enhance areas of parenting and maternal health from mothers' perspectives, particularly in rural settings and during infancy and childhood. It is important to focus on these experiences since mothers often take on the majority of care giving for their infants and thus they may suffer the greatest health effects associated with care giving. Furthermore, most of the rural studies were conducted in the United States or other countries. A Canadian perspective is needed to further understand the meaning of parenting a child with a disability in relation to the national healthcare context.

Purpose and Research Questions

The purpose of this phenomenological study was to gain an in-depth understanding of the lived experience of parenting an infant with special needs from the perspective of mothers residing in rural/small town Ontario.

Overarching question: What is the meaning of parenting an infant/young child with special needs from the perspective of mothers living in rural or small town settings?

Sub- questions:

1. What do mothers identify as needed supports to help them care for their infant/young child?
2. What has been helpful and not been helpful for them in caring for their infant/young child?

Methodology

The philosophic lens used to conduct this study was Martin Heidegger's (2002) hermeneutic phenomenology. Translated literally, phenomenology refers to the 'study of phenomena' (Budd, 2005). Moran (2000) defines phenomenology as "... an anti-traditional style of philosophizing, which emphasizes the attempt to get to the truth of matters, to describe phenomena, in the broadest sense as whatever appears in the manner in which it appears... as it manifests itself to consciousness, to the experiencer" (p. 4).

Husserl, considered the Father of phenomenology, espoused the descriptive school of phenomenology. Husserlian phenomenology maintained the viewpoint of Cartesian duality; that is mind and body interact but are separate entities, and used bracketing to achieve objectivity (Cohen & Omery, 1994). By bracketing out prior knowledge and preconceptions, Husserl asserted that the universal essence of being human could be discovered (Cohen & Omery, 1994). Husserl's methodology was considered not appropriate to use for this study since the meaning of parenting an infant with special needs cannot be understood in isolation of the context where it

occurs. Heideggerian hermeneutic phenomenology was considered more suitable for this study as it provides a means to uncover how individuals understand and make meaning of their lived experiences.

Heidegger, a student of Husserl's, believed that the traditional objective scientific method was inadequate for illuminating and understanding the complexities of being in the world and advocated for the possibility of multiple truths in human understanding (Lopez & Willis, 2004). He was interested in the ontology of being in the world (Cohen & Omery, 1994). Heidegger proposed that valuable meanings could be uncovered by interpreting everyday life experiences. He also rejected the premise that the researcher could bracket out prior understandings and knowledge about the phenomenon being studied (Lopez & Willis, 2004; Mackey, 2005). Forestructures help humans to understand one another and create meaning (Mackey, 2005). It is by making our pre-understandings explicit that we can interpret them in relation to our everyday life experiences. This process is termed the hermeneutic circle and involves constant examination of forestructures in order to arrive at new understanding (Mackey, 2005). Consistent with Heidegger's approach, this study did not seek to find one common essence shared by these mothers, but to reveal their multiple realities and gain an in-depth understanding of the thoughts, feelings and experiences of rural mothers caring for infants and young children with special needs.

Heidegger proposed that all meaning is experienced in connection with time and space (Mackey, 2005). Time is experienced as a unifying force by which we are aware of our past, present and future (Mackey, 2005). Time was a particularly important concept to explore in this study as having a baby with special needs presented a time of change for mothers and their families. In addition, elements of time such as waiting for a diagnosis, transitioning to bringing

baby home, or watching children grow and achieve milestones all carry important meaning and shape mothers' overall experience. Furthermore, space represents the notion of spatiality and situatedness (Mackey, 2005). Spatiality can go beyond the geographical properties of our environments and describe the social elements of our location. For example, a mother in a rural setting may live in a remote location but there are often other special elements within this experience. In this study, time and space were explored to understand the meaning of being a mother to an infant with special needs throughout both rural and small town settings.

Methods

Sampling Strategy

Purposive sampling (Morse, 1991) was used to recruit a sample of mothers based on their ability to provide rich in-depth information about the experience of mothering an infant/young child with a disability. Snowball sampling (Patton, 2002), a type of purposive sampling, was also employed to obtain participants with insight into the experience of mothering an infant with a disability. This strategy involved asking participants enrolled in the present study to suggest other mothers of children with special needs suitable for the study and who might be interested (Morse, 1991).

Initial recruitment proceeded through a neonatal follow up program in London as well in various small towns throughout South Western Ontario. To gain entry, the researcher emailed the director at the neonatal follow up program. A presentation was delivered to the program staff which allowed me to connect with health care practitioners working at the clinic and explain the purpose of the study and eligibility criteria. Information letters which included my contact information were left with the healthcare practitioners to distribute to eligible participants.

Women who were interested in participating were asked to contact me directly for more

information. This method was chosen so participants did not feel coerced into participating in the study and it ensured that client confidentiality remained intact. In some cases, interested participants preferred that I contact them and gave consent to do so. In addition to recruitment from the neonatal follow up clinic, recruitment flyers were also posted in libraries, community centers and health clinics in rural and small towns to reach families not connected to specific healthcare services.

In interpretative phenomenological studies, sample size is determined by the quality of or the richness of the data. Once the researcher identifies recurring themes and patterns of meanings from the data, further recruitment is unnecessary (van Manen, 1997). I concluded recruitment when I judged that enough data had been gathered to understand the meaning of caring for an infant with special needs and no new information was illuminated during the interviews. Thus, sample size requirements must be determined by the researcher's judgment of the quality of the data (Sandelowski, 1995). The final sample size for this study was seven mothers.

Eligibility criteria for this study included mothers who had a child between the ages of 6 months and 4 years old living with a disability or chronic health condition. Participants needed to be living in a rural or small town setting. While this study has a special focus on mother's experiences caring for their children during infancy it also includes their experiences as their children became older to illuminate their journeys from initial diagnosis to the present. Two mothers from urban locations were also included to capture unique differences between small town and urban experiences. Participants needed to speak and understand English. The diagnosis of disability may have occurred either prenatally or soon after the child's birth.

Data Collection Methods

The primary strategy of data collection for this study was in depth individual interviews. All participants were offered the choice of participating in interviews by phone (3) or in person (4) at a time and place that was convenient for them. Interviews were audio-taped with the woman's permission and lasted between 30 minutes to two hours. A semi-structured interview guide with open ended questions was used to conduct the interviews (Appendix A). This approach provided flexibility and allowed for open conversations to take place, while having the interview stay focused on specific questions for all participants (Patton, 2002). Interviews were conversational and informal in nature to allow for open dialogue. To start the conversations with the mothers, I asked a general question: Tell me about your experience of finding out your child had a disability/ chronic health problem. Prompts were used to invite the participants to further discuss their experiences. Demographic information was also gathered to describe the sample (Appendix B). Field notes were taken immediately after the interviews to ensure all important observations I made during the interviews were recorded in a timely manner (Patton, 2002). Reflective journaling was used to document my feelings and thoughts that occurred while listening to the mother's stories, and to capture initial impressions gleaned from reading and re-reading the transcripts and throughout data analysis (Laverly, 2003). A second interview was also conducted over the phone for the purpose of member checking (Lincoln & Guba, 2007). During these interviews, I shared my interpretations with the participants to ensure I had accurately captured their experience and invited the women to provide further input.

Data Analysis

Max van Manen's reflections on phenomenological research were used to guide data analysis (van Manen, 1997). The aim of phenomenological analysis is to uncover fundamental themes that help to describe the meaning behind a person's lived experience. Van Manen's four

fundamental life world existentials, lived time, lived space, lived body, and lived human relation were used as a lens to guide analysis.

The process of data analysis began even before the first interview as I reflected on my preconceptions about mothering a child with a disability. This reflective process continued throughout the entire process of data collection. Before the first interview and following each subsequent interaction, I kept a reflective journal of my thoughts, feelings and reactions to what I had learned. Data analysis and member checking also occurred during the interviews where I shared interpretations within the conversation for clarification, feedback, and deeper understanding.

I transcribed each interview verbatim and listened to each audiotape in its entirety while reading along to ensure accuracy. Next, each transcript was initially read in its entirety to give the researcher an overall sense of what was said. The transcripts were uploaded to NVIVO © software and analysed line by line. Initial coding was conducted by highlighting meaning units (i.e. key words and phrases) that were repeated throughout each transcript. These initial codes were organized and collapsed into common categories and finally themes. During this process, I continued asking myself ‘what does this mean?’ and ‘what is the mother telling me?’ to get a clear representation of what the mothers were saying through the text (van Manen, 1997). Van Manen’s life world existentials were used as a lens to which meanings were extracted and analyzed. They are referred to in the findings and discussion of this piece to illustrate the lived experience of parenting young child with special needs to rural mothers. The categories and themes were written and rewritten in consultation with my thesis supervisor until consensus was reached. Constructed themes were presented to participants to ensure the interpretations of meaning were true to their experiences.

Approaches for Creating Trustworthiness

Lincoln and Guba's (2007) four criteria for ensuring trustworthiness, namely, credibility, transferability, dependability and confirmability were used to demonstrate rigor. Credibility refers the degree by which study results remain truthful to the participants' experiences. To achieve credibility, the researcher engaged in in-depth conversation and observations with the participants. Member checking was conducted by presenting the participants with the themes to ensure that the meaning of the experience was captured from the participant's perspective (Lincoln & Guba, 2007). Munhall (2001) asserts that transferability is "obtained when findings fit other contexts as judged by the readers or when readers find the report meaningful in regard to their own experience" (p.300). Transferability was made possible by providing a rich description of the setting and the results and by using direct quotations to represent participants' experiences (Lincoln & Guba, 2007; Munhall, 2001). In terms of dependability, the researcher maintained an audit trail of all methods, ideas and decisions explicit so that others could repeat the process if necessary (Lincoln & Guba, 2007). Finally, confirmability was achieved through creating an audit trail as discussed previously, and triangulating the data (Lincoln & Guba, 2007). Data analysis triangulation occurred by using member-checks, committee member collaboration and author reflexivity (Lincoln & Guba, 2007). Member-checks were carried out through phone interviews with participants to share findings and allow participants to verify that meaning was accurately captured. The researcher also frequently collaborated with her thesis advisory committee while constructing themes from transcripts, ensuring that consensus of the interpretation of meaning was consistent between researchers. Reflexivity is a particularly important part of hermeneutic phenomenology and the researcher made all preconceptions and thoughts explicit by recording them in a journal.

Ethics

Ethics approval was obtained from the Research Ethics Board for Health Sciences Research Involving Human Subjects at Western University and from the Clinical Research Impact Committee at London Health Sciences Center. A thorough explanation of the study and the risks and benefits inherent in participating were outlined for the participants in a letter of information and informed consent obtained prior to the commencement of interviews (Appendix C& D).

During the interviews, participants were assured that they did not have to share anything or answer any questions that made them feel uncomfortable. Participants were informed of counselling services available in their communities if they needed extra support. The data were stored in a locked cabinet in my home and password protected on my computer. Participant identifiers were kept separate from audiotapes and typed transcripts and will not be disclosed in any publication or presentation of findings. Only the researcher and her thesis committee members had access to transcripts. Transcripts and audio tapes will be kept on file for five years following data collection. After this time, they will be destroyed and disposed of to protect confidentiality.

Participants

The following section provides a brief description of each participant. To ensure anonymity, pseudonyms were substituted for the participants' and children's names. Participants ranged in age from 30 to 40 years, with children ranging from one and half years to four years of age. Four mothers were working full-time outside the home while three were stay-at-home mothers. All participants were either married or in a common-law relationship. Household income ranged from under \$25,000 to over \$200,000 annually. Six mothers in the study had

attended college or university. Child diagnoses included hypotonia, developmental delay, a genetic disorder, a ventricular septal heart defect, hearing impairment, visual impairment, and cerebral palsy. Five of the mothers in this study lived in small town or rural areas and two lived in urban settings. Background and contextual information about each of the participants is included on Table 1

Table 1

Characteristics of Participants

Mother	Place	Work Status	Child
Nancy	Rural- small community one hour away from the city	Works full time and commutes to city	-2 year old son Michael -Full term pregnancy -Michael was diagnosed with hypotonia at 3 months of age
Patricia	Small town one hour away from city	Stay at home mom	-2 year old son Tyler -Preterm labour at 30 weeks -Tyler has been diagnosed with a developmental delay. The family is still investigating specific diagnosis.
Amy	Urban	Stay at home mom	-2 year old son Matthew -Premature labour at 28 weeks -Matthew was diagnosed with a rare genetic disorder shortly after birth
Cecilia	Urban	Works full time from home	-4 year old daughter Ariel -Full term pregnancy -Ariel was diagnosed with a hearing impairment at 3 months of age
Karen	Rural- small community 20 minutes away from town	Works full time	-Twin daughters Ava and Emily 2 years old -Premature labour at 28 weeks -Both twins were been

			diagnosed with cerebral palsy one week after birth. Ava's health is most severely affected.
Barbara	Small town- 30 minutes from city	Works full time	-2 Year old son Max -Barbara suffered preeclampsia and went into premature labour at 28 weeks -Max was diagnosed with a ventricular heart defect shortly after birth.
Sarah	Rural- 30 minutes away from city	Stay at home mom	-3 year old daughter Julia -Sarah is a new immigrant to Canada from the Middle East -Full term pregnancy -Julia was diagnosed with a developmental delay at 2 months old

Findings

One overarching theme and six sub themes emerged from the data analysis of the rural mothers' experience with parenting a young child who has special needs. The overarching theme entitled *Getting Through It* illustrated the difficulties mothers experienced in parenting a young child with special needs during the early childhood years. A common sentiment verbalized by the mothers was that even when things got hard, they did what they needed to do and just got through it. Etymologically, the phrase '*getting through*' means to endure or survive an extreme life challenge or ordeal (MacMillan Dictionary, 2105). As the mothers told their stories, they illustrated how they survived the challenges associated with parenting a child with special needs and were fueled by the unconditional love they had for their children, and eventually found joy and happiness along their parenting journeys. From the moment of their child's diagnosis, through to the personal growth the mothers experienced by withstanding the

struggles they encountered, as revealed by the six subthemes, *Experiencing the Unexpected*; *Overcoming the Challenges to Mothering*; *Unconditional Commitment to Child*; *The Lived Human Relation as Powerful*; *Being a Care Co-ordinator*; and *Being Transformed*. Each subtheme is described below accompanied with direct quotes from participants' transcripts to help illustrate the subthemes.

Experiencing the Unexpected

The theme, *Experiencing the Unexpected*, depicts the mothers' reactions when they first learned about their child's health problems and its subsequent impact on their lives as mothers. Both rural and urban women expressed that discovering their child had a disability was unexpected and produced feelings of uncertainty, disbelief and shock. The mothers used words such as "*devastating, scary, traumatic, overwhelming, and emotional*" to describe how they felt at the time. Sarah, a rural mother, recalled that being told her daughter had a disability was a moment she would always remember: "*I don't forget his [Doctor's] words all my life... I feel like, like, my life, it stopped. And I mean I didn't hear nothing...*" During a routine hearing test when Cecilia was initially told her three month old daughter had a hearing impairment she described being very calm at first trying to "*document*" all the information she could at the time. After the appointment she described experiencing a dissociative event where she went to her husband's office but couldn't remember how she got there.

Some women characterized their birth experience as surreal where it was difficult to grasp what was happening. Patricia, another rural mother, explained her experience when she had not felt the fetus move for a few days and decided to travel to the city hospital to determine if something was wrong:

...and that's when they said he needed to be born cause if not, he would have died the next day, if I would have continued on...I don't really think I felt anything just because

we got there and then they are like ‘Oh, you’re having your son today!’ and it is like ‘What?!’. And then it was more like adrenaline when the baby was born because he came out not breathing. It was just like ‘Ok. What just kind of happened, type thing?’

Similarly when Barbara who lived in a small rural town went to the clinic after experiencing back pain at 30 weeks gestation she was told she had preeclampsia and would have to go to an urban hospital and deliver her baby within a couple of days. Barbara described the situation as immediate, very scary, traumatic and out of her control:

So that whole experience was really, really traumatic and really trying ...Certainly it was a scary experience, you really felt like everything was very out of your hands like all of a sudden you didn’t really have control over the situation.

Overcoming the Challenges to Mothering

Overcoming the Challenges to Mothering describes how the mothers moved forward and *got through* after learning about their child’s diagnosis and illuminates some of the struggles they encountered within their daily lives. Mothers whose children remained hospitalized after birth recalled the place of the hospital environment as being very overwhelming, emotional, fatiguing and lacking privacy. Amy, who lived in an urban setting, detailed her experience during the initial weeks with her son in the NICU:

...that was difficult because it was an open unit and there was no privacy. You basically had three feet between the incubator and you were limited in what times you could visit with shift changes and rounds.... it was just exhausting. You go into survival mode and you just do what you need to do to get through every day and be there for your child.

The rural mothers recounted the additional stress associated with not being able to visit their hospitalized babies every day. They described their struggle having to drive long distances and going home at the end of the day. Knowing that they could not come back in the morning to visit their child was very difficult. Patricia stated:

And the travelling back and forth like every other day cause we couldn’t go up every day cause my husband was working and stuff so... cause I don’t drive but yea going up every other day it was difficult to leave.

Karen a rural mother, whose twins with varying degrees of disability were cared for at two separate urban hospitals during their first few months, worried about bonding with her infants before it was time to bring them home. Karen described being unable to see her daughters everyday due to the extensive amount of travelling needed to get to them. In addition she had a toddler to take care of at home and could not spend a lot of time away from her:

It's a little nerve wracking because you almost lose that connection with them a little bit cause you don't have them right away...as a mom...you lose that closeness you, you lose that bond...And that's what the nurses always said you know "when you go home they're gonna be trained to sleep, no worries" and that was the truth. And that was awesome, you know all that work was done for me but at what cost right?

The mothers described caring initially for their infants at home with mixed feelings and emotions. Mothers whose babies remained in hospital for several months after birth recalled feeling very excited when they brought their child home for the first time. This experience was also described as overwhelming for them, knowing there wouldn't be nurses around if they needed them; having to provide technical medical care such as administering tube feedings and medications; and monitoring their child's health status on their own. Barbara remarked living in a rural area far from the city was a concern because if they needed help, it would take emergency workers a longer time to get to their home. She reflected: "*It felt very overwhelming and we did not feel ready but we eventually overcame that.*" In this way living in a rural area added to her sense of uncertainty.

As the mothers continued to care for their babies at home, they described feeling more confident in caring for and meeting their children's needs. Knowing she was able to manage her child's care on her own at home was rewarding for Karen:

... it was I guess it was rewarding just to know that we were actually able to do it. We were actually able to manage everything that needed to be managed and kind of do

everything cause again in the beginning it just seemed very daunting and overwhelming and not something that we could do but we did!

The mothers reported that their day to day lives caring for their child brought many challenges. They mentioned experiencing ‘*good days and bad days*’ with many ‘*ups and downs*’. The mothers reflected on how they coped with these days by remarking ‘*you just do it*’ and ‘*you get through*’. They discussed how keeping a positive attitude and being thankful for what they had helped them through some of the hardest times.

Many mothers indicated that their confidence in caring for their child increased over time, however some still questioned if they were doing a good enough job. When Nancy’s son was initially diagnosed with generalized hypotonia, she expressed self doubts in her abilities to meet her child’s specific needs:

like it would be the end of the day and I’d be putting him to bed and I’d start going through our day in my head and I’d be like ‘I didn’t do enough physio with him.. I didn’t do enough of this’ Right? And so I would start... I spent a lot of time like beating myself up when in reality I was doing those things right?

The mothers expressed that dealing with the uncertainties regarding their child’s disability and future health and well being was particularly ‘*hard*’. Patricia’s son was not meeting developmental milestones but there was no actual explanation from her doctor. Some mothers were still waiting to find out what caused their child’s disability and the prognosis remained unclear. They shared that it was difficult sometimes for them to move forward not knowing what to expect in the future for their child. One rural mother described her struggle attending scheduled appointments and dealing with the uncertainty of her son’s diagnosis:

...like you never know when you’re walking into an appointment to get good news like sometimes you get surprised with like great news and you’re like “wow that was awesome!” and sometimes you get that news that isn’t so great right? And you never know walking in whether you know what’s gonna happen and so it’s... it’s hard ...
(Nancy)

Some mothers commented that they took things one day at a time to get through it but confided that the worry about their children's futures never really left them. Uncertainty was one of the most difficult aspects of parenting a child with special needs. Barbara used the phrase "*oppressive weight*" to illustrate how she felt as a result of not knowing what kind of limitations her son would face for the future without a diagnosis.

Many mothers described strategies they used to improve their family functioning and adaptation to having a child with a disability. In addition to managing their child's special care needs and going to numerous medical appointments, the mothers mentioned juggling everyday responsibilities, such as full time work schedules, cleaning, cooking and other child care obligations. One urban mother mentioned that hiring a cleaning company helped to greatly reduce the stress she was feeling and gave her more time to enjoy being with her family, another rural mother made a schedule board for her son's medications, and others had weekly meetings with their spouses to divide important tasks.

The mothers confided that much of their energy went into childcare and other obligations so finding time for themselves was challenging. Many discussed how they put their own needs behind all their other priorities. In describing her daily care taking for her son Barbara from a small town stated:

It's really difficult to make time for yourself. Um and I don't, and I probably don't do a very good job of it... of taking time for myself um just, I mean there's a lot being back to work full time. so its um its really challenging to make that time.

The mothers commented that while they recognized the importance of caring for themselves it was difficult for them to put their needs ahead of their child's. Some mothers described trying to make time for themselves even if it was just a few minutes a day. Strategies mothers mentioned

were having a shower, watching a movie at the end of the day, connecting with friends, following Facebook, or joining a book club.

Unconditional Commitment to Child

This theme describes the unwavering love and commitment the mothers demonstrated for their children's well being. It depicts the mothers' reflections on unique aspects of special needs parenting including their child's growth and development, advocacy roles, and hopes for the future. The mothers described the difficulties they encountered when their children become sick or hospitalized but also the tremendous joy in experiencing their children's successes and positive development such as being able to clap for the first time or walk. Embracing these moments became an integral part of "*getting through it*". Nancy stated: *Like clapping right, he just started clapping recently... most parents are like "eh" you know maybe the first time, but every time he claps it's like "Ha!"*

The mothers recounted spending considerable time and energy to ensure their children were given every opportunity to grow and develop like any other child. They commented on the efforts taken to give their children adequate nutrition when they experienced feeding difficulties, performing physiotherapy together, and learning sign language. Two rural mothers described the efforts they took driving their children to school in the city, and an urban mother taught her child the school curriculum during the summer to make learning easier when school started in the fall. When their children met a new milestone the mothers expressed a great sense of accomplishment using words such as '*conquer*', '*joy*', '*happy*', '*rewarding*', '*celebrate*' and '*appreciate*'. These experiences of their children's achievements were common between both rural and urban mothers.

Sarah discussed how her daughter meeting milestones affirmed that she was doing a good job as a mother. She used the analogy of taking a test to describe how happy she felt to see her daughter growing and developing as a result of the daily physiotherapy exercises she practiced with her:

If you read and we go to test, you do great job with the test, and you're so happy that you passed and you say "ok that's my job!" yea that's my work. I was busy, I'm working and I got the results. I push her for something and she got that one, I'm so happy for that.

An excerpt from the book, *A Cup of Comfort for Parents of Children with Special Needs* (Sell, 2009) similarly describes the experience of a mother watching her child meet milestones and the new meaning that it gave to her life. It touches upon the extremes in emotions that mothers feel as they watch their children struggle through hardship and the feelings of accomplishment and pride that ensue when they conquer these obstacles.

After almost a year, Nicholas finally held up his head. That tiny little infant who struggled to breathe was now able to see the world. I felt joy. When his g-tube was removed, and the words "failure to thrive" were removed from his chart, there were tears. No more questions to answer. I felt relieved. When he pushed away his metal walker and took steps for the first time, I wept. Slowly, I began to realize that these tortuous feelings, these hardships were somehow very important for me to experience. For it was these extremes, these awful, uncontrollable feelings and hardships, that gave my life new meaning. (Sell, 2009, p.7)

Some mothers revealed that having a child with special needs changed them to become more assertive and to advocate for their child when they felt they were being treated unfairly. Nancy described herself becoming a 'mama bear' who would do anything to protect her son when it came to his wellbeing. She stated:

...I think no matter what it [being a mother] changes your perspective, at least it should. And changes your focus but when you have a child that really needs you, they all need you but *really* needs you, you have to fight.

In her article entitled *Motherhood Brings Meaning*, Laura Fortgang (2009) also touched on this new found strength for advocacy she discovered within herself as a mother of a child with

autism. She defined herself as a *warrior* who was a force to be reckoned with as she navigated the health and educational systems with her son.

The growth being asked of me through this child has been about trusting my judgment before that of experts and advocating for my child medically and education-wise. He has grown me into a warrior. Not a barbaric warrior, but rather a force to be reckoned with who will draw on whatever strength I may not have even known I had to do right by him. (Fortgang, 2009, p.1)

Some mothers admitted that they went against the advice of others to do what they felt was in their child's best interest. Patricia, a rural mother (?), declined to schedule doctor's appointments for a month in order to give her son and herself some time away from travelling and the medical system and to enjoy her son just being a '*kid*'. Karen disregarded her doctor's advice to wake up her daughter at night to feed her as she felt it was more important to let her daughter sleep.

All the mothers remarked how important it was to offer their children every opportunity to facilitate optimal growth, development and independence for their future. For example, Cecelia, an urban mother, became heavily involved in advocacy activities and speaks to doctors and parents on panels about what she has learned about being a mother of a child with special needs. She talked about advocating for her child when she enrolled her daughter in a French immersion school when people disagreed with her decision because of Ariel's hearing impairment. She reflected that although it can be uncomfortable to go against other people's opinions she persevered, saying, "*my daughter is going to be offered every opportunity my son has been offered*", because she knew what was best for her daughter.

The mothers also shared their hopes and what they envisioned for their children in the future. Some mothers indicated that they were unsure about their child's future and remarked that the most important thing for them was for their children to be happy and that they could

spend time together as a family. Nancy mentioned how the uncertainty regarding her son's prognosis was *'the scariest part'* and it was difficult to know what the future might hold for him. She hoped her son could lead a normal life without having to suffer but had many questions.

And of course ultimately it's does he make enough improvements where he can live a normal life? Right? That's ultimately the, the biggest concern...It's just a matter of when and what challenges he's going to face on the journey. Because when you have kids you don't want them to suffer, right? because you know we are offering him every opportunity and doing whatever we can to help him get there but we don't know where 'there' is.

Karen who resided in a small rural community wanted her daughter to be accepted by her peers when she goes to school. One of her biggest fears was how other children might treat her because of her cerebral palsy. She stated, *I'm terrified for that for her cause you know people can be so mean...* Karen's comments are significant as her child may be the only one with special needs and consequently easily singled out or marginalized.

Mothers described their hopes that their children will be able to make the milestones that will give them independence for the future. A few mothers also expressed concerns about what will happen to their child when they are gone and worried if their children will be able to manage on their own. Amy an urban mother discussed her dreams about the future for her son:

Well I hope that he can live with us for as long as possible well at least until he is 20, I hope. I hope that he can go to college. Um I hope that he can live on his own, whether he has some form of assistance or not, you know we're not young so I worry a bit about what will happen to him when we're gone.

The Lived Human Relation as Powerful

This theme refers to the connections or relationships the mothers had with their partners, family, friends and health care providers and the major impact these connections had on the mothers' lives.

Partner

The relationship with their partners was described by the mothers as one of their most valued sources of support that helped them to *get through it*. A few mothers used the word ‘*team*’ to depict how they and their partner functioned together to take care of their child. In describing the support received from her husband, Sarah, a rural mother, stated:

And my husband he helps me. He says, “... We have to work like a team”.... And after that he says, “Give me your hand” and I give my hand and he says we got to work with her... He gives me more power.

Nancy explained how her fiancé is the only person who truly understands what she is going through because he is going through it with her. Describing her husband’s support Barbara commented that her husband was someone she could go to in order to talk through her concerns and how she benefitted by opening up to him:

...And again like I mean my husband is a really good support. If I am kind of struggling with something I often find when I’m able to talk to him he’s wonderful helping me talk through problems and kind of work through problems reminding me that things... kind of helping me put things in perspective I guess.

Partners also helped with child care and took over various tasks such as attending appointments to allow mothers time for themselves. Cecelia, one of the urban mothers, recalled how her husband would step in to care for the children at critical times:

I remember saying to my husband a few times, “Ok I’ve had too much, I’m done, I need to step away” and he said “Yep, ok. Why don’t you go for a drive, I’ll take care of the kids today, just go take a day to yourself.”...And it was just some recharge time that I needed.

Some mothers discussed how having a child with special needs presented unique challenges in their relationships with their partners. Receiving a diagnosis was also difficult for partners and, at times, differences in responses and coping strategies had the potential to create

stress within marriages. In describing her husband's reaction to their child's diagnosis, Amy, another urban mother, explained:

I think he had a hard time the first year. There were a lot of times I'd be there all day everyday at the hospital and he'd be renovating the house because our son came three months early and there were a lot of things still to be done so we needed to make sure the house was ready. And then he found it really stressful so he took a lot of nights out with the boys. So we found a happy medium now.

Caring for a child with special needs changed the relationship between partners because it often became the main focus in their lives. Appointments, finances and day to day care took priority over connecting as a couple. The division of tasks leaving little time to spend together was a common theme expressed by all the mothers, however rural mothers had even less time due to need for travel time and fewer supports in the rural community. For example, Karen described how having daughters with cerebral palsy created considerable tension in her relationship with her husband:

My husband and I, you know, there was quite a few times where we almost didn't make it through...and it was just very stressful on the relationship and you know you're always talking about one thing and then it's financial things... it takes right over....

The mothers expressed that the added stress, financial burdens, time constraints and shifted focus to the child had the potential to leave partners feeling disconnected with each other at times.

Karen remarked that although having children with special needs initially caused her and her husband to grow apart, the challenge of working together ultimately helped their marriage to become stronger and they have grown considerably closer together. Cecelia commented on attending proactive marriage counselling with her husband to enhance their communication as a couple.

Family and Friends

The mothers also described the support they received from family members and friends, such as, offering understanding, making meals, babysitting, helping with appointments, starting fundraisers and learning sign language. For some mothers, grandparents played a significant role in their children's lives, being highly involved in babysitting and learning aspects of their child's technical and physical care. Barbara, one of the rural mothers, discussed the challenges of finding someone to babysit her son due to his special healthcare needs. She was appreciative when her parents stepped in and learned how to do her son's tube feeds in order to allow her and her husband more time together.

Other mothers remarked how grandparents distanced themselves from their child with special needs and described this experience as being very disappointing and hurtful. Cecelia expressed the difficulty trying to keep a relationship with her children's grandparents:

I finally accepted the fact that I was the only one trying to keep the relationship going ...I know they're scared and I respect that but I also know that my kids don't need me spending all my energy trying to keep a relationship going with them ...with the in-laws

In these instances, their stressful relationships caused feelings of disappointment, rejection, anger, distrust or hurt. Social interactions were particularly challenging to navigate when the person was a grandparent or close contact. The mothers expected grandparents to accept their child and love them unconditionally. When this expectation was not met due to grandparents feeling uncomfortable around their children or choosing not to be involved in their lives this was extremely painful for the mothers.

A few mothers mentioned gaining support from grandparents or other family members was a challenge because they were separated by distance. Sarah, whose parents and extended family lived in another country, stated, *"I don't have nobody. I'm shy a little... nobody to help*

me here.” In this way Sarah discussed how she had very little support in raising her daughter and described often feeling alone and tired from taking on care giving duties on her own in her small rural town.

Health Care Providers

The mothers described healthcare providers, such as nurses, doctors, care coordinators and physiotherapists, as valuable sources of support. These health professionals provided information, reassurance and emotional understanding. Many mothers developed close relationships with the NICU nurses and trusted that they would take good care of their babies while they were away. These relationships were especially important for rural mothers who trusted these staff members to take care of their children when they could not visit and be with their children every day. Some mothers stated that the nurses became “*like family*” or “*friends*” to them when they were going through difficult times. The relationships that Karen developed with the staff in the NICU were also a pivotal reason she decided to keep her daughter at an urban hospital instead of moving her to one closer to their rural home: “... *they’re the reason why we stayed in [the city] and we didn’t want to go anywhere else because of the connections....*”

Most mothers remarked that they were quite satisfied with the care they received from health care providers in urban settings. They recognized and appreciated practitioners who went above and beyond their roles to provide holistic care not only for their children, but for their family as a unit. Among these women’s narratives however, were also a few stories detailing experiences of relational disconnect with doctors and nurses and insensitivity. Barbara became tearful recalling a conversation she had with a pregnant nurse who declared that although it was difficult to work in the NICU while expecting a baby herself, she wasn’t worried something would go wrong with her pregnancy because she was “*young and healthy*”.

...And I remember my mom and I just looking at each other and we're like "she doesn't get it"... (tearful)... like I had a healthy pregnancy, I...am young and healthy. Like I remember that, um was really difficult... (voice breaks).

Karen also shared a hurtful experience she had with a doctor who on two separate occasions asked her and her husband if they wanted to "keep" their child. She described feeling overwhelmed after these interactions, and being asked more than once was disheartening for her.

Barbara stated: "*They certainly don't mean to be hurtful but maybe don't understand um... [pause]... don't kind of understand how what they say can really... affect you*".

Being a Care-Coordinator

The mothers took an active role in being their children's primary care co-ordinator. All the mothers discussed being extensively connected to the health care and social systems. Navigating appointments, finding information, or accessing funding and respite services took up a great deal of their time in addition to daily care giving duties, creating added challenges to *getting through it*. Managing their children's care needs as well as other family obligations was particularly challenging for the rural mothers. For example, mothers living in the more rural settings described having to frequently travel long distances to attend multiple appointments which impacted their ability to work and generate income. Patricia commented that during one month she only had five days where she was not required to travel to the city for an appointment. Coordinating her child's care proved to be a full time job in itself and prevented her from being able to work.

Being caught between work and family demands was a common struggle described by the mothers and living in a rural area amplified these issues. Sarah was unable to work due to the multiple appointments she needed to take her daughter to. She commuted three times a week to the city to take her daughter to a school for children with disabilities. She also had to stay in

the city until her daughter's school day was over to drive her home again. Sarah described the daily commute as very difficult, and although they would like to move to the city for convenience, they couldn't because of her husband's job. *"[It's] hard, just no choice... we don't have preschool there and we don't have like center over there too. I have to bring her here... I don't have time for work"*. Nancy also discussed how living in a rural area required her to take extra time off work in order to coordinate appointments and afford for driving distances.

I have to take time off work because it's you know an hour away and the appointment will be in the city, it's not a matter of taking an hour off and running my kid to an appointment. It's, I have to take at least half a day... so it makes it a challenge because if we just lived in the city we'd be like "ehh well, you know I'm gonna leave work at 3 and take him to his appointment right?" But I can't do that.

Living in a rural area and being at a distance from the city also created added expenses. Karen stated commuting, parking and eating out became very expensive for her family when they travelled for their child's appointments. Alternatively, urban mothers commented that living in the city made it more convenient for them to attend appointments, support groups and connect with other parents. Amy stated:

Thank goodness we live in [the city]. We have so many appointments, last week we saw four doctors in four days... I'm just so grateful we live in [the city] because we would spend a lot of time travelling here for appointments if we didn't...

Cecilia remarked that living in the city provided the opportunity for her and her daughter to easily attend events and social functions to connect with other families within the deaf community:

When there are events...you know a hearing impairment deaf type of event going on for other children, of course you can always make it. One because I have work flexibility that allows for that and two because it's a five to ten to fifteen minute drive away.

The mothers shared that connecting with other parents who had children with disabilities was a key means for emotional support and obtaining information. Rural mothers expressed facing

more difficulties meeting other parents of children with special needs as their small towns were less equipped to offer these social programs as urban settings were. Nancy stated:

Well it's more challenging in a way because there aren't a lot of people around so there aren't things like local play groups right? Or you know cause like I know that people in the city have like community centers and stuff that they go to.

Patricia commented that having the ability to share experiences and knowledge with other parents through support groups was a valuable resource that her small town was lacking. A common complaint expressed by the mothers was the amount of time and effort it took to access information about the programs, funding or services to which their children were qualified. As there was not always a central place they could access this information, social networking with other moms was a key way of attaining this knowledge. Rural mothers suggested that the construction of online support groups would be a convenient way they could connect with other mothers of children with special needs from their area and obtain this valuable support.

The mothers also described having to repeat their children's health histories as tedious, time consuming and tiring. Each time they saw a new specialist, healthcare provider or program coordinator they had to repeat their child's health history from the beginning. Not only did this take up valuable appointment time, but the mothers also worried that they were forgetting to offer important information. Copies of medical records currently are not easily accessible as hospitals charge fees to have them printed and this was unhelpful for the mothers. Nancy explained:

...like with all the appointments and stuff you feel like all you ever do is reiterate "he was born with this, this is what happened, at this age he did this", right? Like it's just you know it's almost like I should do a recording and hit play and "listen to this and if you have any other questions ask me"

Some mothers suggested that electronic health records being accessible to their child's whole health care team would make care less fragmented and decrease the stress on them.

Being Transformed

This theme depicts the personal growth described by the mothers as a result of parenting a child with special needs. The mothers commented that going through this experience changed their world view, made them stronger, and created a desire to give back to others in similar situations. They mentioned viewing children with disabilities differently than they had in the past and recognizing other families who have children with more severe disabilities and having empathy. Barbara, a rural mother, described how having a child with special needs has changed how she deals with stressful situations and to put them in perspective: *“I now understand what real stress is about because I had you know, I’ve been through it, I’ve lived it. So yeah, a I think the experience has kind of taught us not to stress the small stuff.”*

Karen, another rural mother, reflected how parenting her daughters made her become a stronger person who wants to help others. *“you know like just it makes you a stronger person. Like us we’re doing a fundraiser for [community center] and we just want to help out”.*

Similarly Sarah shared she corresponds with a lady from her home country who also has child with special needs but no rehabilitation services and offers her support and encouragement. These positive reflections served as important affirmations along their journeys and attested to the fact that despite the challenges they encountered along the way, they were thriving and *getting through it.*

Discussion

Being told that their child had a disability was a difficult experience for the mothers. The feelings of numbness, dissociation and loss of control indicate that the initial diagnosis was a very traumatic and inwardly personal experience. These depictions draw upon the feelings and experiences within the lived body as the mothers processed the information being given to them

and what it would mean for their lives. Some studies have explored maternal responses in relation to traumatic birthing experiences and report that PTSD symptoms are relatively common among mothers who gave birth with complications (Elmir, Schmid, Wilkes, & Jackson, 2010; Feely, Zelkowitz, Cormier, Charbonneau, Lacroix, & Papageorgiou, 2011). Although not all mothers experience symptoms to this degree, understanding the gravity of diagnosis and sensitivity of the mothers during this time is imperative to providing compassionate and supportive care. In addition, limited access to ongoing support services in rural settings creates a challenge for meeting the needs of rural mothers of children with special needs (Society of Obstetricians and Gynaecologists of Canada [SOGC], 2012). The SOGC position paper published in 2012 recommends that the social and mental health needs of rural women be considered, particularly regarding that they may be required to leave their familiar communities for extended periods to access health providers and services for their children.

Mothers whose children were transferred to the NICU following birth experienced additional stress and found their initial exposure to the unit overwhelming. The lived space of the NICU is often described as an environment that is highly medicalized, sterile, lacking in privacy, noisy and emotional (Lutz, Anderson, Reisch, Pridham & Baker, 2009). In addition, going home without their babies and being in a lived space physically separated from their child was extremely upsetting. Studies demonstrate that separation of a mother from her newborn following birth is an extremely distressing experience (Wigert, Johansson, Berg, & Hellstrom, 2006). In comparison to their urban counterparts, mothers living in rural settings experienced the additional challenge of travelling long distances to maintain physical contact with their child. Examining how living in a rural area might compound separation issues and negatively impact maternal health and well being requires further investigation. A hermeneutic phenomenological

study specifically focusing on this area for rural mothers could illuminate the phenomenon of being separated from their child in more depth.

The mothers initially felt increased anxiety regarding learning how to effectively meet their children's special health care needs. As the mothers began to absorb their child's diagnosis and were able to provide care for their child independently, a sense of maternal confidence emerged. The etymological meaning of mother is to "take care of" (Etymological Dictionary, 2013a), thus for these mothers it was important to be able to meet their child's extensive medical and developmental needs as a means of fulfilling their maternal role. Feelings of intimidation and self doubt surrounding their child's care subsided as they began to take on these care-giving duties themselves and realized they were capable. Knowing they could meet their child's needs independently was an exceedingly rewarding experience.

Caring for their children in some instances was very strenuous and time consuming, causing the mothers to neglect aspects of their own health and wellness. Ray (2003) described the role of raising a child with a disability as "Parenting Plus". Her description of parents providing care above and beyond what is required while parenting a child following typical development, is consistent with this study's findings. Although the mothers in this study recognized the importance of engaging in self-care they found it difficult to put their own needs ahead of their child's. Prioritizing their child's needs may reflect the internalization of social norms regarding what is the role of a "good mother". Social discourse regarding mothering expects mothers to put their child's needs ahead of their own and women will often sacrifice their own well being for the good of their children (Varcoe & Doane, 2007). Research suggests that women in rural areas also tend to adapt more traditional gender roles (Crosato & Leipert, 2006). Crosato & Leipert's (2006) study examining rural women providing care for elders

exposes important issues relating to care giving strain and multiple role demands faced by these women. A critical analysis examining how rural mothers of children with special needs experience care giving for their children and its relation to gender norms is needed to explore this issue further.

A strategy for enhancing maternal health of mothers of children with special needs would be to offer mothers respite services and valuable time away from care giving to focus on their own health. This strategy draws upon the significance of lived time and the difficulties the mothers encountered to use their time to engage in self care and healthy behaviours. Despite the increased costs associated with caring for a child with special needs in rural settings the participants in this study were not living in impoverished situations. More research is warranted to determine what strategies would assist rural women with limited financial resources or in poverty to engage in self care.

Uncertainty was a common thread interwoven throughout the women's stories regarding mothering a child with special needs. Initially, the mothers struggled with the uncertainty of not knowing what their child's diagnosis would mean for themselves and their families, if their babies would survive, and if they could handle having a child with a disability. The mothers commented that they took things one day at a time to get through it but confided that, within their lived body, the worry about their children's futures never really left them. Uncertainty was one of the most difficult aspects of parenting a child with special needs. Barbara used the phrase "*oppressive weight*" to illustrate how she felt as a result of not knowing what kind of limitations her son would face for the future without a diagnosis. The Merriam Webster dictionary (2013a), defines oppression as "a sense of being weighed down in body or mind". In a review of the literature examining parental uncertainty and childhood illness, Stewart and Mishel (2000) assert

that “Although its intensity may diminish during periods of relative predictability, uncertainty [in childhood illness] never completely resolves [for the parent]” (p.299).

Some mothers had still not received a definitive diagnosis for their child, making moving forward exceedingly difficult. This was a distressing issue identified for both the rural and urban mothers. Having a definite diagnosis increases maternal control over the situation allowing them to have a plan and know what to expect for their child’s future. Lenhard, Breitenbach, Ebert, Schindelbauer-Deutscher, and Henn (2005) report that parents of children with an uncertain diagnosis of disability demonstrate more significant negative psycho-emotional effects compared to parents of children with a diagnosis of Down’s syndrome. These findings reinforce the importance of reducing long wait times with specialists and expediting investigations when a diagnosis is unclear. Providing emotional support and facilitating the implementation of adaptive coping strategies are actions urban nurses in the hospitals and public health nurses in rural areas can take to reduce the psychological impact uncertainty can have on mothers of children with special needs.

Watching their children grow and master developmental tasks was also deeply meaningful to the mothers. Providing their children with as many tools and skills as they could to facilitate normal development was important to them. Seeing their children struggle with their disabilities was distressing and when their child made a positive step forward, mothers felt tremendous joy. Meeting new milestones symbolized the conquering of a barrier their children had to fight to achieve. It also reaffirmed that their countless efforts to help their child succeed were making a difference and ultimately assisted them to achieve further independence. Similarly, Woodgate, Ateah and Secco (2008) described how parents of children with autism felt a resurgence of hope for the future each time their child met a milestone. The significance these

experiences hold for the mothers is an essential piece of understanding what having a child with special needs means in their lives.

The mothers' descriptions of advocacy were another way unconditional commitment to their children became evident. The meaning of advocacy is "one who pleads another's cause, who helps another by defending or comforting him" (Merriam Webster, 2013b). Advocacy activities ranged from actions such as disagreeing with a doctor's recommendations to more formalized endeavours involving public speaking and counselling other families of children with disabilities. Mothers were willing to fight for their children to ensure they were treated fairly and would do whatever it took to stand up for them if threatened. The words, '*fight*', '*mama bear*' and '*strength*', used by the mothers demonstrated the extent to which mothers were willing to go to defend their children and secure the resources and services they were entitled to.

In Sousa's (2011) critical reflection on advocacy in mothers of children with disabilities a parallel can be drawn to her characterization of the warrior-hero mother. Mothers of children with disabilities may be viewed as altruistic beings who sacrifice their own wellbeing to tirelessly advocate for their children in a system filled with discrimination and injustice (Sousa, 2011). Societal expectations of being a good mother reinforce the stereotype that good mothers do everything they can for their children and put themselves last, while mothers who do not may be viewed as unfit. This may be especially problematic in rural settings where traditional expectations of women and mothers prevail (Leipert, Leach, & Thurston, 2012) Acknowledging that the onus for child advocacy in our healthcare and social systems is not to be placed squarely on mother's shoulders would alleviate some of the burden faced by them. Rural mothers in particular may experience some disadvantages in the pursuit of advocacy in comparison to urban mothers. For example, getting involved through making connections with special interest groups

may be more difficult for them due to their rural location. As nurses, advocating on political, social and interpersonal levels is important in promoting the health of mothers and their children with special needs. For example, nurses can help mothers navigate the healthcare system by ensuring information about support resources are readily available and accessible to them. Nurses can partake in research exposing issues encountered by mothers throughout their advocacy endeavours to generate more understanding about this experience and develop better support initiatives. Lastly, nurses can also join special interest groups and lobby the government for increased services in rural settings for children with special needs and their families.

An integral part of the mothers' experiences caring for their children involved the connections they had with their partners, family, friends and health care providers. This finding draws upon the importance of the lived human relation in the construction of meaning for the mothers while caring for their children with special needs. The word, *connect* means "to join together" or more descriptively to "awaken meaningful emotions, establish rapport" (Entymology dictionary, 2013b). Positive interactions with others made the mothers feel they were not alone. These relationships fostered support on physical, emotional and social levels. They became a great source of strength for them and played an important role in adaptive coping. The most important relationships described by the mothers were those with their partners. Partners offered emotional support when mothers were sad or overwhelmed and helped with care giving, chores and division of tasks.

Spending time with their partners outside of their parenting role was also considered important. Research on the relationship between parenting a child with special needs and marital relationships have shown mixed results. Some studies have documented a high incidence of separation rates and marital discord amongst parents of children with special needs resulting

from added stress (Statistics Canada, 2006). These findings are significant as family breakdown affects the health of its members and decreases parental support (Afifi, Cox, & Enns, 2006; Treloar & Funk, 2008). Other studies indicate that parenting a child with special needs enhances communication and strengthens relationships among partners who are able to overcome challenges together and appreciate reciprocated support (Green, Darling & Wilbers, 2013; Pelchat, Levert & Bourgeois-Guerin, 2009; Kearney & Griffith, 2001). It seems when couples are equipped with adequate communication tools and skills, having a child with special needs can have very positive effects on couple relationships. Having resources in place for these families such as respite services or marital counselling during challenging times are important recommendations made by the mothers in this study to help them enhance family functioning and enrich relationships among partners. Important considerations for rural families include making these resources accessible within their communities.

Experiencing relational disconnect with family members, particularly grandparents and friends, caused feelings of disappointment, rejection, anger, distrust or hurt. Focussing energy back into other healthy relationships and caring for their children were common strategies used by the mothers to distance themselves from disruptive persons. Offering support to mothers in finding positive ways to interact with others is imperative.

For the most part, the mothers were very happy with the relationships they had formed with healthcare providers. They were grateful to members who went above and beyond their roles to care for their families and make them feel supported during times where they felt the most vulnerable. However, experiences of relational disconnect with doctors or nurses who did not understand their feelings or vulnerabilities left the mothers with powerful memories of hurt and disappointment. Upon reflection, the mothers remarked that they did not feel the healthcare

providers had malicious intent, but that they did not understand the impact of their insensitivities. The mothers' stories about their interactions with health providers reveal how words carry significant weight to patients who often look to us for reassurance, understanding, and support. Being mindful of our comments, their meanings and their implications, are crucial aspects to building successful therapeutic relationships (Registered Nurses of Ontario [RNAO], 2002). Austin (2006) argues that as a result of rapidly advancing medical technologies and decreased availability of time to spend with patients the practice of relational ethics in healthcare settings has become easily neglected. Being attuned to how a patient is feeling and cultivating relationships using empathy is the cornerstone of nursing practice and it is our ethical responsibility to uphold this standard of care. Despite other technical duties that often take precedence, taking the time to connect with these mothers to gain an authentic understanding of their unique experience is one of the most meaningful actions a nurse can take to provide support during challenging times. The results of this study indicate the need to advocate for increase nursing positions in primary health care roles, such as nurse practitioners and rural public health nurses, in rural communities to ensure continuity of care for rural women with special needs children and their families.

In addition to intensive care giving and household duties, mothers took on the comprehensive role of being primary care coordinators for their children. Lived time surfaced as a central aspect of the study's findings as the mothers described the extensive amount of time they devoted to their role as their children's central care coordinator. This included many duties such as managing appointments, commuting to see doctors, relaying important health history information to care teams, finding services and funding opportunities their children qualified for, and submitting forms and applications to obtain various supports.

Rural mothers in particular spent considerable time traveling with their child to cities for multiple appointments in order to meet with a range of specialists. Similarly, Lauver's (2010) findings indicated commuting times into cities for frequent appointments posed real challenges in the lives of rural mothers. Two of the mothers in this study were unable to work due to the time they needed to devote for traveling and a third rural mother needed to take entire days off work in order to account for commuting times. This finding suggests that rural mothers who have children with special needs may experience greater financial hardship and less time for family and themselves than their urban counterparts due to added lost employment and time constraints. Further research is needed to explore socioeconomic inequities in rural mothers who have children with special needs and the implications on health.

The study's findings also indicate that living in rural areas created a lived space that can also create disadvantages in accessing services such as special education centers for children with disabilities and limiting mother's opportunities to connect with other parents in similar situations. Urban mothers commented that living in the city affords them the ability to easily attend events and support groups with other mothers who have children with special needs. These connections were valuable not only for obtaining emotional support and validation of their experiences (Solomon, Pistrang, & Barker, 2001), but they were also an important avenue for obtaining information. A common complaint from the mothers was that accessing information about the programs, funding or services to which their children qualified took a great deal of time and effort. As there was not a central place they could access this information, social networking with other mothers was a key way of attaining this knowledge. Rural mothers suggested that the construction of online support groups would be a convenient way that they could connect with other mothers of children with special needs and obtain valuable support.

Ensuring that an adequate infrastructure is in place for affordable and accessible wireless services in rural and remote areas is an important consideration that must be addressed by governments so all mothers have equal access to essential health information and resources.

Transformation is described as a process whereby adaptation to stressful circumstances results in the personal reflection that the experience opened new possibilities and is characterized as growth-promoting (Tebes, Irish, Vasquez, & Perkins, 2004). The mothers' description of being transformed draws upon the adaptive changes the mothers observed within themselves as a unified reflection of the lived time, body, space and human relation they had experienced. Although the mothers faced adverse situations on their parenting journey, they reflected that overcoming these obstacles fostered strength, patience, empathy, compassion and love for their children and others with similar needs.

Mothers were passionate about the issues faced within the new world of childhood disability they found themselves in. Beyond a changed world view, mothers had a desire to give back to other families in their situation and help their community. This phenomenon of giving back is explored by Ahmen (2013) who asserts that the activity of helping other families brings greater meaning to life circumstances parents of children with special needs face. By helping others, what the mothers went through is given a greater purpose and provides a sense of personal fulfillment. These findings suggest that helping rural mothers to connect with other families who have children with special needs could enhance health by giving them an opportunity to share their knowledge and help others, which in turn may be empowering. While this may be more difficult for rural mothers as they are often the only ones in their small towns parenting a child with special needs, rural public health nurses could play an important role in connecting mothers among different communities to support one another. By understanding

some of the positive transformational effects parenting a child with special needs can have, nurses are in a better position to work with these mothers in achieving empowerment and personal growth.

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CHAPTER THREE: IMPLICATIONS AND CONCLUSIONS

This study explored the meaning of having a child with special needs from urban and rural mothers' perspectives. Their stories revealed one overarching theme, *Getting Through It* and six subthemes, *Experiencing the Unexpected; Overcoming the Challenges to Mothering; Unconditional Commitment to Child; The Lived Human Relation as Powerful; Being a Care Coordinator; and Being Transformed*. In this chapter these themes will be briefly elaborated upon followed with a discussion outlining implications for nursing research, practice and policy development.

Getting Through It was a phrase used by many of the mothers to describe their day to day experiences parenting their young children with special needs. This overarching theme included six subthemes which were reflected in the mothers' experiences of parenting. *Experiencing the Unexpected* and *Overcoming the Challenges to Mothering* outlined the mother's stories from feeling disbelief at the initial moments of diagnosis and where they described feeling worried and uncertain about how they would transition home, to how they developed confidence to care for their children's special needs on their own in their rural communities. The theme *Unconditional Commitment to Child* uncovered the joy and rewards mothers experienced parenting their children with special needs. This subtheme revealed also that mothers would go above and beyond being advocates for their children to ensure they were given every opportunity they could to thrive.

The Lived Human Relation as Powerful included the external relationships the mothers had with their partners, family members, friends, and health care providers and which functioned as both supportive and unsupportive to their experience. *Being a Care-Coordinator* described the extra efforts the rural mothers undertook to effectively navigate the social and health care

systems on behalf of their children in addition to their extensive care-giving workloads. Despite the challenges these women faced with parenting a young child with special needs, they all reflected that their experiences changed their world view and helped them to grow and become stronger, more compassionate individuals. The final subtheme, *Transcendental Growth* describes the meaning mothers' have attributed to these experiences and their desire to give back and help other families in similar situations. After exploring the meaning of parenting an infant/young child from rural mothers' perspectives, several implications for nursing research, practice and policy development have become evident.

Implications for Nursing Research

This study adds to the body of nursing knowledge in the areas of rural and maternal health. The findings support previous research that indicate mothers of children with special needs engage in extra work while parenting their child and that although this can be rewarding, mothers often will neglect their own health to put their child's needs first. Mothers confirmed that support from partners, family members and friends were very valuable to them but that formalized support services such as respite and home care were difficult to access, particularly in rural settings. This study's results demonstrated rural mothers face added challenges as they parent their children with special needs. Being situated long distances from specialists, hospitals and community centers necessitated long travel times which significantly impacted their lives. For the rural mothers whose children stayed in the NICU following birth, descriptions of the hardship they faced by being unable to visit their babies on daily basis illuminated an important difference in urban mothers' experiences. Further research is needed to explore how separation from their babies affects maternal health, adjustment and bonding following the birth of medically fragile infants and subsequent hospitalization. For example, a grounded theory study

examining how rural mothers navigate the challenges of mothering while being separated from their infant and take on their mothering role would be an important area for exploration.

Another area that requires further investigation is exploring barriers rural mothers who have children with special needs face to sustain employment. It is well documented in the literature that rural individuals may experience inequities towards obtaining gainful employment and suffer from higher poverty rates (Leipert, 2005). Coupled with the unique demands of parenting a child with special needs and the travel times mothers must allocate for appointments, it seems these factors may put these mothers at further disadvantage for being able to generate their own income. Socioeconomic status is a critical predictor of health (World Health Organization, 2013), thus it is important to investigate this issue further to understand financial impact. Using a critical lens a study focusing on the experiences of low income mothers of children with special needs in rural areas would help to shed more light on some of the barriers faced by this population. A quantitative comparative analysis on house hold income and employment status between rural and urban mothers of children with special needs would also provide more information about income support needs.

Implications for Nursing Practice

The WHO (2013) defines health promotion as “the process of enabling people to increase control over and to improve their health. It moves beyond a focus on individual behaviour towards a wide range of social and environmental interventions.” (p.1) Nurses are in an optimal position to promote empowerment and health promotion for rural mothers of children with special needs as they come into contact with them throughout the healthcare system. For example rural nurses may encounter children with special needs at rural well baby clinics or from school referrals. It is important for nurses to understand the meaning of parenting an infant

with special needs from rural mothers' perspectives because the intricacies of these stories are often not evident at the point of care. Being aware of the challenges and barriers rural mothers may face may assist nurses in gaining a greater understanding of their experiences and enhance therapeutic relationships.

The findings from this study suggest that following traumatic deliveries and at the time of diagnosis, mothers are vulnerable to experiencing high levels of stress. Assessing how mothers are coping and accessing necessary resources if they need additional support are key actions nurses can engage in to provide comprehensive care. Rural mothers, in particular, struggle with additional emotional and financial challenges due to long driving distances and being separated from their newborns if hospitalization is required. Nurses need to understand the powerful impact the relationships they establish with the mothers can have when the diagnosis is made. Successful therapeutic relationships enable empowerment and offer reassurance and hope when mothers are feeling uncertain (MacKean, Thurston, & Scott, 2005). It is very important that we as healthcare providers are mindful of our words and comments when working with mothers of children with special needs as insensitive treatment damages trust and has the potential to negatively impact the bonding process.

In delivering quality health care nurses must advocate for their patients (CNO, 2006). At the individual level, nurses can speak up for rural mothers who have children with special needs within their practice areas and help connect them to relevant services or funding opportunities they may qualify for. They can also support mothers by helping them to make time for their own needs and focus on their health by assisting to connect them with respite services. In hospital settings nurses can develop and implement strategies that facilitate connectedness between rural mothers and their children during hospitalization, for example, by providing mothers with

updates about their baby's progress in the form of pictures and journaling new developments, being available to talk on the phone or perhaps improvising, setting up video conferencing calls for mothers to connect from home, and advocating for reduced financial costs for visitation, such as parking vouchers. Nurses working in rural communities can connect mothers of children with special needs to other parents and facilitate peer support. An important role a rural public health nurse could play would be to connect families they know who are parenting children with special needs from different communities together. They can also take on some of the roles involved in care coordination in an effort to save mothers valuable time searching for resources and information. Nurses can also advocate for these mothers on a societal level by lobbying politicians and being active in special interest groups to secure the provision of added services mothers have indicated would be helpful for them, such improved infrastructure for internet services.

Implications for Health Policy Development

Several recommendations for policy development were identified based on these mothers' storied experiences of caring for a young child with special needs in a rural context that would help them care for their children and enhance health for themselves and their families. For example, a role our provincial education system could fulfill would include having local transportation in place for children in rural communities to access special education centers to ensure that they are offered equal opportunities for learning and development as their urban counterparts. The construction of online support groups by the Ministry of Health and Long Term Care is another way that rural mothers expressed that they could gain opportunities to access peer support and expert information. Online support groups have demonstrated in the literature to be a beneficial means of obtaining emotional, instrumental and informational

support and can be particularly helpful for health promotion purposes to those living in rural areas (Evans, Donnelle, & Hume-Loveland, 2012). While there are currently no studies examining the use of support groups for rural mothers with children who have special needs, rural research has explored the use of online support groups in rural individuals suffering from depression with favourable results (Griffiths & Christensen, 2007). Rural public health nurses might encourage and work with mothers who want to reach out and help and support others who are parenting a special needs child to establish a peer led support group in their rural communities.

A more centralized approach to rural health care may also alleviate some of the burden experienced by rural mothers. An example of restructuring services could include the creation of care teams where families can meet with a variety of healthcare providers in one visit, reducing the need for extra trips to see each specialty separately. Ideally this system would also provide mothers with a central care coordinator who could provide information about programs, services and funding, reducing the need for mothers to search for information and miss out on important opportunities.

Reducing wait times to see specialists for investigations and treatment was another suggestion both rural and urban mothers expressed was important to them. Waiting for a diagnosis and treatment plan for months or years had a real impact on mental health and adjustment. Furthermore, having electronic health records available to each member of their children's care team was another suggestion the mothers made for increasing continuity of care. Having the onus on the mothers to report each event in their child's health history to every new person was described as exhausting, tedious and time consuming. Mothers worried that they would forget to disclose an important piece of information and felt that going through these

stories took up valuable appointment time. Our provincial health care system could play an important role by devoting more resources to the undertaking the construction of electronic personal health records that could be available and accessible to a wide range of health care practitioners.

Policy construction to allow for mothers of children with disabilities increased paid time off from their workplaces for appointments and child care could help rural mothers to sustain employment and enhance their socioeconomic status. In addition, the provision of extra funding for respite and homecare services is an essential part of allowing mothers, both rural and urban, a break for themselves to focus on their own health and wellbeing. These resources are also necessary to allow partners time to connect with one another outside of their parenting roles and strengthen their relationship for enhanced family functioning.

Strengths of the Study

The strengths of this study are that it served to enrich understanding pertaining to meaning for rural mothers who have infants and young children with special needs in Southwestern Ontario. The sample included mothers from varied socioeconomic and ethnic backgrounds and also compared experiences between rural and urban mothers. Some of the issues identified in the interviews can give researchers, nurses, and policy makers in both rural and urban contexts a more thorough understanding of these experiences and the important steps they can take to improve health and wellness for these mothers and their families.

Limitations of the study

The findings from this study are limited in that they may not be generalizable to all rural mothers who have children with special needs. The experiences captured in the findings however, may help to expose common issues faced within this population. This study was

conducted with mothers from urban, small towns and rural communities in southwestern Ontario. How these findings translate to rural mothers who live in more remote and northern communities remains unclear and is in need of further investigation. Additionally, these findings have focused primarily on the experiences of mothers. Understanding these perspectives from a paternal standpoint is an important perspective to explore as well. Each of the mothers in this study had a partner to help them raise their children and many had financial means for support services. The experiences of single rural mothers and those of low income was not captured in this study and are another significant area to research when understanding health for rural mothers of children with special needs.

Conclusion

In conclusion, though rural mothers who have children with special needs find the experience of mothering very rewarding, they also face significant barriers that may prevent them from attaining optimal health and wellness. The results indicated that there were many commonalities in the experiences of parenting a child with special needs between the rural and urban mothers. However some key differences emerged. For the rural mothers, physical separation from their hospitalized infants, extra time devoted to travelling long distances, extra expenses, employment barriers, and difficulties accessing peer support and information were identified as unique to their mothering experiences. These findings and recommendations can be used by nurses, researchers, and policy makers to promote health for these mothers and enhance access to healthcare and social services in both rural and urban rural communities.

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Appendix A

Semi Structured Interview Guide

Legend: 1,2,3,4,5, 6,7 = Sub Questions

- = probes

Overarching Question: Tell me about what it is like to care for your child.

1. Tell me about your experience of finding out your child had a disability/ chronic health problem.

- How did you feel?
- How were you treated by health care personnel?
- What kind of information were you given?
- How prepared were you to care for your child at home?

2. What was it like for you when your baby came home?

- What were you feeling?
- What was challenging?
- What was rewarding?

3. Tell me about how you manage and who else has been involved in helping you care for your child.

- How have friends and family been helpful/ not helpful?
- Are you receiving any formal help? What has that been like?
- How have health care providers been supportive to you?
- How do you make time for yourself?

4. How do you feel caring for your child has affected your physical or mental health?

5. Tell me about living in a rural area and caring for your child. (**Rural mothers**)

- Has it affected your access to support services?
- What are the challenges?
- What are the benefits?

Tell me about living in this city and caring for your child. (**Urban mothers**)

- Has it affected your access to support services?
- What are the challenges?
- What are the benefits?

6. What homecare or respite services have you accessed?

- What community resources are available to you?
- What resources do you access for support?

7. How has having a baby changed your life?

- What has been a positive change?
- What has been challenging to adjust to?

8. What do you think about when you envision the future for you and your baby?

- What do you wish for him/her?

9. If you could speak to a policy maker about support systems for children with disabilities, what would you want to say to them? What recommendations for change would you make?

If you could speak to another parent about having a child with a disability what would you tell them?

- What do you think is wrong with current systems?
- What is good about it?

Appendix B**Demographic Information**

Age of Mother _____

Age of Child _____

Child Diagnosis _____ When Diagnosed _____

Marital Status _____

Employment Situation _____

Level of Education _____

Income Level _____

Location: Rural Urban

Appendix C**LETTER OF INFORMATION FOR PARTICIPANTS****Academic Supervisor:**

Dr. Marilyn Evans, PhD

Arthur Labatt Family School of Nursing

The University of Western Ontario, London, ON

Investigator:

Lauren Elford, BScN

Arthur Labatt Family School of Nursing

The University of Western Ontario, London, ON

Dear [*insert name*],

My name is Lauren Elford and I am a Masters student in the Arthur Labatt Family School of Nursing at the University of Western Ontario. I would like to invite you to participate in a research study that I am conducting for my thesis exploring what it is like for mothers to parent a young child with special needs in a rural or small town setting.

Research Procedures

If you agree to take part in this study, you will be asked to participate in one interview that will last about thirty minutes to an hour. This interview can take place in person in a time or place that is convenient for you or over the phone, depending on your preference. Your permission to record the interviews will also be requested and some basic information about you and your baby will be taken. Some examples of the things you will be asked in the interview include your experience of learning about your child's diagnosis and taking your baby home, as well as your needs for support and what has been helpful or not helpful for you. After the interviews, I will contact you by phone for a second interview to briefly review some of my findings and ensure

that you have input into the final product of the study. This will be helpful to confirm that your experience has been accurately represented in my interpretation.

Voluntary Participation

Participation in this study is voluntary. You may refuse to participate or refuse to answer any questions that make you feel uncomfortable. You may also decide to leave the study at anytime without any penalties.

Compensation

As a token of appreciation for your time, you will be given \$20.00 for participating. Should you incur any additional costs for participating you will also be fully reimbursed.

Benefits

By participating in this study, you may find it a rewarding experience to share your story of having a baby with a disability or chronic health condition. Additionally, by sharing your story, your voice can also help to create change. This information can be used by other researchers, health care providers or even policy makers to improve support systems in rural and small town communities.

Risks

You may find some of the topics related to your experience to be difficult to talk about. The risk of participating in this research is that it could make you feel upset. If you feel that you require additional support, the researcher will provide you with information about counseling services available in your community.

Confidentiality

Any information obtained from this study will be kept confidential. In the event of publication, any data resulting from your participation will be identified only by a pseudonym. Nothing will be published to identify you such as your real name or your personal demographic information. The data will be stored on a secure computer in a locked room which can only be accessed by the

researcher. After the study is over, the data will be kept secure for five years and then it will be destroyed.

Contact Information

If you have any questions or concerns about the study, please feel free to contact me by e-mail or phone at the contact information provided at the top of this letter.

If you have any questions about your rights as a research participant or the conduct of the study you may contact:

The Office of Research Ethics

The University of Western Ontario

Appendix D



CONSENT FORM FOR RESEARCH STUDY

I have read the letter of information, have had the nature of the study explained to me, and I agree to participate in the study. All questions have been answered to my satisfaction.

Dated in _____, this _____ day of _____, 20_____.

Name of Participant (please print)

Name of Principal Investigator

Signature of Participant

Signature of Principal Investigator

I consent to allow my data to be used in the event of secondary analysis.

Name of Participant

Signature of Participant

Appendix E**Curriculum Vitae**

Name: Lauren Elford

Post-secondary University of Western Ontario

Education and London, Ontario, Canada

Degrees: 2006-2010 BScN

Honours and 2011 Sigma Theta Tau Iota Omicron Chapter, Research Grant

Awards:

2010 Joseph and Vera Byrne 125th Anniversary Alumni Scholarship in Nursing Award

2006-2010 Dean's Honours List

2006 University of Western Ontario Entrance Scholarship

Member of Sigma Theta Tau Iota Omicron Chapter

Related Work Teaching Assistant

Experience The University of Western Ontario

2011-2012

