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Primary Caregivers of Children With Chronic Illness and Disabilities: A Descriptive Study of Caregiving and Respite

by

Susan Michelle Neufeld ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial completion of the requirements for the degree of Master of Nursing

Faculty of Nursing

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The undersigned certify that they have read, and recommended to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled "Primary Caregivers of Children With Chronic Illness and Disabilities: A Descriptive Study of Caregiving and Respite" submitted by Susan Michelle Neufeld in partial fulfilment of the requirements for the degree of Master of Nursing.

Dr. Jane Drummond, Supervisor

Dr. Janice Lander, Co-Supervisor

Dr.Gerry Kysela

Dr. Linda Ogilvie

Thesis Approval Date: March 10, 1997

Dedication

This thesis is dedicated to the special children whose families who have welcomed me into their homes as their respite nurse. My thoughts have been with you throughout my studies, research, and writing.

Abstract

Caregiving for children with chronic illness and disabilities by family caregivers at home is widely recognized as an optimal choice for the child and family. In order to promote and maintain the health of the child, primary caregiver, and entire family, respite care has been established as an important caregiving resource. Respite care aims to provide a temporary break from caregiving for the child's primary caregiver to pursue other individual or family activities. The purpose of this study was to describe the characteristics, child care activities, formal respite use, and informal help with care of primary caregivers who use respite care. A descriptive design using written survey methods and convenience sampling techniques was used to answer the research questions. It was found that these primary caregivers perceived little help with their child's care from informal sources and, despite accessing a wide variety of respite services, perceived a limited actual break from caregiving. Furthermore, many perceived the financial costs associated with caregiving to be of difficulty for their family. These findings are then considered in the context of the current literature as well as in terms of implications for nursing and directions for health policy.

Acknowledgements

I want to begin by thanking my supervisor Dr. Jane Drummond for her encouragement and ongoing belief in my abilities. I also want to express my appreciation for my committee members: Dr. Janice Lander for her sound research advice; Dr. Linda Ogilvie for our lively discussions; and Dr. Gerry Kysela for sharing his knowledge about children with exceptionalities and their families. Further, I thank Brenda Query for her wise advice and lived experience, Colleen Bock for her artistic design expertise, Shelly Tkach for her help and feedback, and Heather Morris, Moira Bazin, and Jadwiga Straszynska for their work on the initial literature review. Most importantly, I extend a special thank you to all the study participants who shared their time, knowledge, and experiences as primary caregivers of children with chronic illness and disabilities.

I also gratefully acknowledge the following persons and organizations who have supported my program of studies and my research: The National Health Research and Development Program; The Alberta Heritage Foundation for Medical Research; The Alberta Pediatric Nurses' Interest Group; Province of Alberta Graduate Studentships; The Canadian Nurses Foundation; The Chris Lambert Memorial Trust Fund; and The Hospital for Sick Children Foundation.

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Chapter 1

Introduction

Primary caregivers of children with chronic illness and disabilities and their families may experience many challenges. The demands that most individuals and families face when raising children are coupled with the unique demands that are related to caring for children with chronic illness and disabilities. These unique demands may include daily caregiving activities, increased financial costs, uncertainty about their child's future, and the ongoing need to interface with a myriad of health and social service agencies. To compound these unique challenges, the informal support networks that are present for many primary caregivers, such as spouse, extended family, friends, babysitters, and community groups, may not be available or may not have the resources to assist primary caregivers with their child's care.

Over twenty-five years ago, the demand for respite care emerged as a support resource to provide care for children so that their primary caregivers and families could focus on other activities. Initially, the provision of respite care appeared in response to the deinstitutionalisation movement (Cernoch & Newhouse, 1997). The focus of respite care, at this time, was to provide a break from caregiving in order to maintain continued care in the child's home. Today, care at home for children with chronic illness and disabilities is the norm and the provision of respite care is beginning to be recognised as an essential component of health promotion for children, their primary caregivers, and their families. Despite this recognition, there is inadequate research on primary caregivers who use respite care services, the caregiving activities required to meet their child's needs, and the informal help with their child's care from their spouse, other family members, and non family members that they have. By addressing these areas together, respite care can be examined in the context of informal help with the child's caregiving needs and their primary caregivers' perceptions of experiencing respite.

Purpose of the Study

The purpose of this study is to describe the caregiver characteristics, caregiving activities, and the formal and informal help with child care of primary caregivers of children with chronic illness and disabilities who use respite care. Four research questions postulated below expand on the purpose of the study:

1) What are the characteristics of the primary caregivers who use respite care for their children with chronic illness and disabilities?
2) What are the caregiving activities required to meet their child's needs?
3) What types of respite services do primary caregivers use and how much informal help is available to primary caregivers of children with chronic illness and disabilities who use respite?
4) What are the relationships among primary caregiver characteristics, child specific variables, respite services used, and informal help?

Definition of Terms

Respite Care

Respite care is temporary relief, provided by an outside body, from the demands of caring for children with chronic illness and disabilities. Respite care may be provided in the family home or outside the family home for varying periods of time depending on family needs and resources. While the term respite care is often used by health care and social service professionals, it is also known as relief care, family support, child care, and babysitting.

Respite

Respite is the perception of a break from caregiving that an individual caregiver feels. This feeling of a break may or may not be a direct result of utilizing services that provide respite care.

Children With Chronic Illness and Disabilities

The term "children with chronic illness and disabilities" is used to summarize a broad range of children with varying abilities and care requirements. These children may have a chronic illness, a palliative condition, physical or cognitive delays, behavioural difficulties, dependence on technology such as ventilators or apnea monitors, or a combination of these. What they have in common is that they have needs for care that are beyond those usually expected for children of the same age.

This definition is in keeping with a non-categorical approach to childhood conditions (Perrin, et. al., 1993). Embedded in a non-categorical approach to childhood conditions is the belief that children with similar conditions and medical diagnoses may have very different day to day functioning and needs for caregiving (Canam, 1993; Wallander & Noojin, 1995). It is recognized that these needs are also dynamic in that they vary not only between individuals but within individuals. These variations within individuals may be based on their changing abilities, strengths, resources, developmental stages, psychological health, and physical health.

Primary Caregiver

Primary caregiver is the term used to describe the family member who identifies her or himself as looking after the child's care needs the majority of the time. This may be a biological parent, adoptive parent, extended family member, or foster parent.

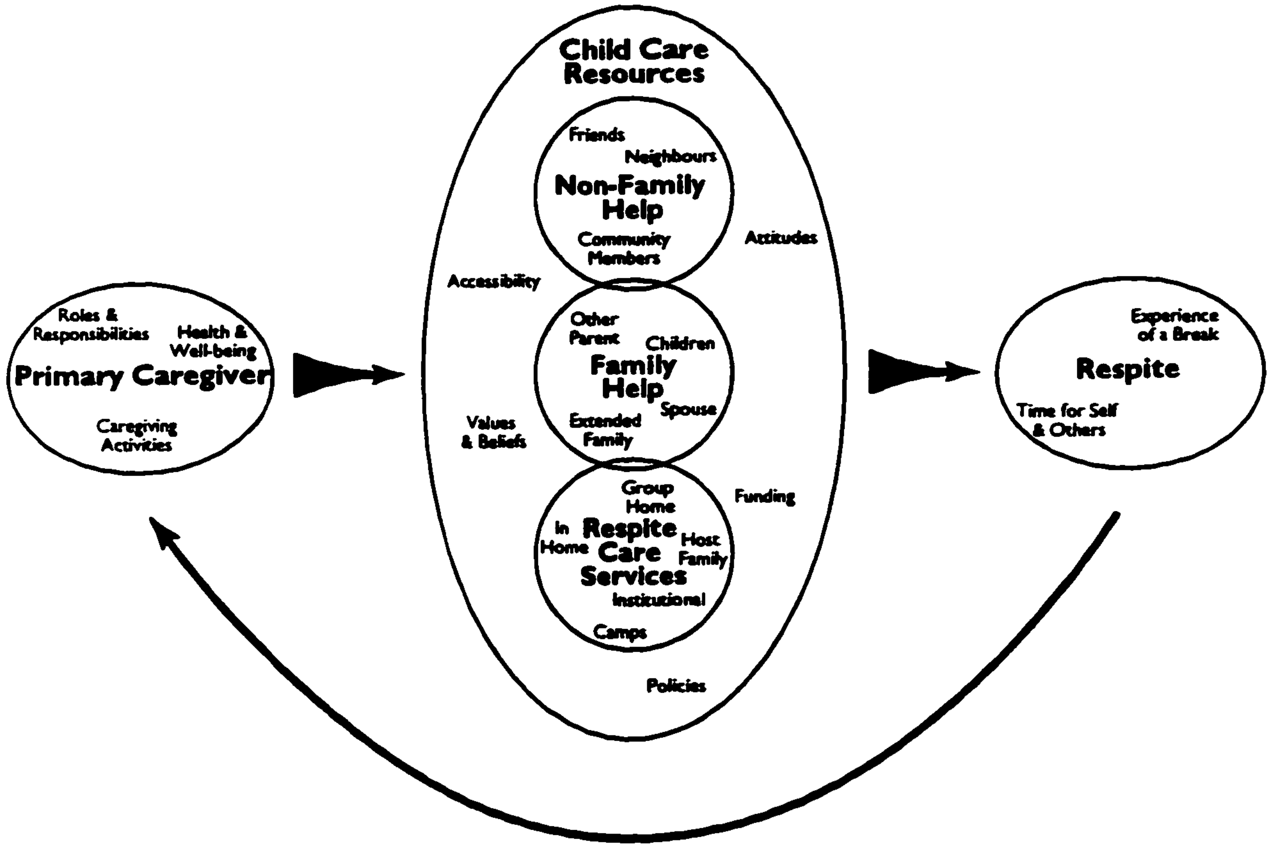
Conceptual Framework

The conceptual framework that was used to guide the questions asked in this study were influenced by my clinical practice as a respite care nurse and the literature on respite care and primary caregivers. As shown in Figure 1, the focus of the conceptual framework are the interrelationships among primary caregivers, their informal help with child care and their formal respite service use (child care resources), and their resultant perception of a break (respite).

The literature that is reviewed in the next chapter is suggestive of the importance of formal respite care on the health and wellbeing of a child's family and primary caregiver. The importance of informal help to the health and wellbeing of primary caregivers is also clear. From my own practice, it was evident that the use of respite services did not necessarily result in the perception of actual respite for the primary caregivers. Therefore, I believe that a perceived break from caregiving and time for other activities requires both an informal network of help with child care and formal respite services.

Figure 1

A Conceptual Framework of Respite



In this framework, informal help and formal respite services are viewed as a part of a greater system of child care resources that include funding and accessibility to these resources. These are further embedded in individual, local, and societal attitudes, values, and beliefs, as well as agency and governmental policies. While these attitudes, values, beliefs, and policies are important components in this framework, their examination was beyond the scope of this study.

Chapter 2

Literature Review

Caregiving by parents of children who have chronic illness and disabilities has been discussed for over three decades. Recent estimates indicate that the majority of children with chronic illness and disabilities are living at home with their parents (Smith, Caro, & McKaig, 1988). According to Statistics Canada's Health and Activity Limitations Survey (1991) there are 534 430 children and youth aged 0-19 living in households who have at least one disability or chronic illness. This number constitutes approximately 7.2% of all children living in Canada. Futhermore, of these children living in households with disabilities, 15% (80 164) have conditions that are considered moderate to severe.

It is widely recognized that dedication, vigilance, knowledge, and skill are required of caregivers who look after their children with chronic illness and disabilities at home (Edgar, 1988; Grant & McGrath, 1990; Hayes, 1992; Starkey & Sarli 1989). Due to the considerable work that may be involved in their child's care, the provision of respite for these caregivers is emerging as an important component in maintaining the health and well-being of the caregiver, the child, and the entire family. Indeed, Friesen (1996) identifies respite care to be "among the key components of family support services" (p. 276).

In this review, selected literature on characteristics of primary caregivers of children with chronic illness and disabilities will be examined. The types of respite care available to families, identified benefits of respite care, and family utilization patterns of respite care will also be reviewed. It will become clear that, despite the presence of literature on the characteristics of primary caregivers of children with chronic illness and disabilities and literature on respite care services available, there has been no work done on linking the two areas.

A total of 56 journal articles and 5 books, obtained from searching computer databases, personal recommendations of professors and fellow students, and manual searching of early intervention, pediatric, and family journals, are included in this literature review. The computer data bases searched include CINHL, PSYCHLIT, MEDLINE and ERIC with the expanded search terms of family, parent, caregiver, chronic illness, handicap, disabilities, and respite. Most of the articles obtained are research in nature with publication dates ranging from 1969 to 1996. Finally, dissertations and unpublished documents by Canadian authors are included. Prior to commencing with a review of the literature, the terms that the authors who are cited in this literature review employ for children and their caregivers will be addressed.

Children. The authors in this review use varying terms to describe the sample of children under discussion. Because of the lack of a consistent operational definition for these children, the terms used by the various authors will be used when a particular study or article is discussed. These terms include children with special care needs, children with chronic illness, children with handicaps, children with developmental delays, and well as a myriad of particular conditions such as autism, Down's Syndrome, and cerebral palsy. Only articles in which children eighteen years of age or younger were considered for this review.

Primary Caregiver. For the purposes of this literature review, the term primary caregiver is used to indicate the person or persons who provide care in the child's home to meet the majority of the child's needs. The primary caregiver may be a mother or father, sibling, grandparent, foster parent, or a combination of these. Many of the authors focused on families, parents, or mothers. Again, the caregiver focus of the authors is explicated through out the review.

Caregivers of Children with Chronic Illness and Disabilities

A number of stressors that may challenge caregivers of children with chronic illness and disabilities have been identified in the literature. These can be divided into four main categories: psychological; social; financial; and physical. To add balance to these stressors, it must also be acknowledged that positive and affirming aspects of caregiving are also identified in the literature. A brief summary of recent work in the area of positive aspects of caregiving will be used to conclude this section of the literature review.

Psychological

The psychological effects of chronic illness and disabilities of children upon parents who are their caregivers have been investigated widely. Feelings of anger, fear, denial, stress, and anxiety are not uncommon (Hymovich, 1984; Canam, 1987; Damarosch, & Perry, 1989; Featherstone, 1980). For example, even parents of a mildly disabled child indicate that they frequently worry about their child (Satterwhite, 1978). There is also evidence supporting claims that parental caregivers are more at risk for stress and/or depression (Cadman, Rosenbaum, Boyle, & Offord, 1991; Fisman, Wolf, & Noh, 1989; Leonard, Brust, & Nelson, 1993; Wood, Siegel, & Scott, 1991).

Leonard, Brust, and Nelson (1993) utilized the Brief Symptom Inventory (Derogatis & Melisaratos, 1983) to measure levels of psychological distress in parents of children with severe disabilities. These children were indicated to be medically fragile or dependant on technology. Of the 57 family participants, 59% of the mothers and 67% of fathers scored at a level that indicated a need for psychiatric intervention. Regression analysis provided further insight in suggesting that increased psychiatric distress was related to a parent's increased family responsibilities.

In a descriptive correlational survey, levels of perceived stress and marital adjustment were measured for parents of three groups of children: those with a chronic illness; those with a handicap; and a comparison group of children without a chronic illness or handicap (Wood, Siegel, & Scott, 1991). Results indicated that parents of children with a chronic illness or a handicap scored significantly higher on perceived stress levels than parents of the comparison group. Furthermore, the stress scores of the parents of the handicapped children and the parents of chronically ill children did not differ significantly. These findings indicate that stress levels in parents are related to the presence of chronic illness or disabilities in their children but do not discriminate between the two categories of conditions.

Two more studies support the finding that parents of children with chronic illness and disabilities are at increased risk for depression. As part of the Ontario Child Health Study, Cadman, Rosenbaum, Boyle and Offord (1991) analyzed data taken from 1869 randomly selected families. They found that parents of children with chronic health problems or physical disabilities were more likely to have received 'treatment for nerves'. They also reported lower affect scores on the Bradburn Affect Balance Scale (Bradburn, 1969) for mothers of children with a chronic illness or a physical disability than mothers of children without chronic health problems or physical disabilities. Fisman, Wolf, and Noh (1989) revealed a significantly higher rate of stress and depression for mothers of children with autism. Mothers of children with Down Syndrome had the next highest rates of stress and depression while mothers of children without chronic illness and/or disabilities were measured to have the least amount of depression and stress.

Cohen (1995), using a grounded theory approach, explicated some of the uncertainties and anxieties within the context of caring for a child with a chronic illness. Stimuli that caused anxiety for these caregivers included routine medical appointments, physical variability in the child's health status, evidence of negative outcomes, and nighttime worrying. Parent's expressions of nighttime worrying included feelings of "terror, horror, and panic"(p.71) that would overcome them, causing anxiety and insomnia.

Finally, there is evidence of interaction effects of caring for a child with disabilities, social support, and physical health on caregiver depression. These links between maternal depression, social support, and physical health are supported in a correlational study by Jessop, Riessmann, and Stein (1988). These researchers found that depression in mothers of children with disabilities, while significantly higher than a community sample of mothers, was related to the child's disabiiity or illness only when other stressors such as poor maternal physical health or lack of social support were present. These findings indicate that factors such as social support and physical health need to be considered in discussions of psychological stressors for caregivers of children with chronic illness and disabilities.

Social

The social stressors present for caregivers of children with chronic illness and disabilities can be great. Changes that take place include shifting daily routines, curtailing leisure activities, forgoing vacations, and missing school activities (Gabel, McDowell, & Cerreto, 1983). Ray (1988) suggests that a child's illness plays a role in what activities a family can participate in because parents need to consider issues including: accessibility for wheelchairs; proximity to a hospital; availability of caregivers; possibility of allergens; and suitability of their child's behaviours when planning activities.

Despite the well documented benefits of social support on the health and wellbeing of caregivers of children with chronic illness and disabilities (Florian & Krulik, 1991), caregivers may experience a lack of social support from friends and outside family members (McAnear, 1990; Phillips, 1990; Singhi, Goyal, Pershad, Sunit, & Walia, 1990). The social isolation that is experienced by many parent caregivers is reflected in research findings of parental reports of loneliness and lack of social support (Florian & Krulik; Stewart, Ritchie, McGrath, Thompson, & Bruce, 1995).

There is disagreement in the literature as to the effect of caregiving on the marriage of parents of children with chronic illness and disabilities. Some authors claim that such families are at increased risk for marital disruption (Gabel, McDowell, & Cerreto, 1983) while others dispute this claim (Seligman

& Darling, 1989; Featherstone, 1980; Hauenstein, 1990). That the presence of a child with a chronic illness or disability affects their parent's marriage is a common professional/public belief that many parents feel they must struggle against (Hayes, 1992). Wood, Siegel, and Scott (1991) compared the perceived stress level and marital adjustment between families with a chronically ill child, families with a handicapped child, and those with a child without a chronic illness or handicap. The authors found that parents of children who were chronically ill scored highest on marital adjustment when compared to the other two groups. Therefore, the research on the social consequences of caregiving for the parent's marriage remains inconclusive.

Physical Health

The lives of caregivers may be disrupted by changes in physical health. The two most often identified physical problems that caregivers encounter are fatigue and chronic back pain (Lonsdale, 1978; Satterwhite, 1978; Cairns, 1992). As a child with chronic illness and disabilities gets older, the physical caregiving needs of the child, such as lifting and transferring, bathing, and dressing become increasingly more physically challenging for the caregiver.

The time that it takes to provide caregiving activities results in a decrease of activities essential to physical health such as sleep, recreation, proper nutrition, and relaxation (Bristol, Gallagher, & Schopler, 1988). When mothers were asked how much time their child's care required compared to other children on a variety of tasks, Brust, Leonard, and Spienza (1992) found that they estimated an average 12 hours and 6 minutes per day on caregiving tasks. Interestingly, when caregiving time estimated for each task was totalled, for some parents the total time was calculated to be over 24 hours. This finding either indicates that caregivers are doing multiple tasks at once or that caregivers have difficulty estimating time required for each individual caregiving task. This finding also suggests the magnitude of the caregiving activities that mothers carry out for their child. As Hayes (1992) states about parents of children with chronic illness, "their radar is constantly, ritualistically 'on' " (p.192). This constant monitoring means that a large part of the caregiving time required for children with chronic illness and disabilities involves 24 hours a day of surveillance.

Sleep deprivation is also identified to be prevalent for caregivers of children with chronic illness and disabilities. In a study of parents of children who had learning disabilities, Quine and Wade (1991) found that 66% of parents were awakened during the night to care for their child at least once a week. The interruption of sleep to carry out caregiving activities, coupled with the nighttime fears identified by Cohen (1995), may exacerbate the insomnia and fatigue experienced by caregivers.

At this point it is important to emphasize that the vast majority of primary caregivers of children with chronic illness and disabilities are identified to be mothers. Therefore, the stressors faced by primary caregivers must be examined within the sociocultural context of women in North American society. It is indisputable that many women juggle multiple roles and responsibilities. Mothers of children with chronic illness and disabilities may have the primary responsibility for providing the child's physical care, promoting the child's growth and development, carrying out countless treatment programs, maintaining a household, and negotiating service contracts (Traustadottir, 1991; Turner-Hensen, Holaday, & Swan, 1992; Turner-Henson, 1993). These essential, but unpaid and invisible activities (Anderson, 1990), coupled with a desire or need to re-enter the workforce or to continue paid employment, may result in a "second shift" for mothers (Hochschild, 1989). Hochschild coined the term second shift because, as mothers returned to the workforce, they found themselves completing a second full time job, with little help, in their homes. Therefore, mothers who work in paid employment and are the primary caregiver for their children with chronic illness and disabilities may face a unique set of stressors and concerns.

Financial

In the United States, increased financial costs of raising children with chronic illness and disabilities accrue due to frequent trips to physicians, the purchase of home care supplies, necessity of special diets, cost of medication, need for child care, and increased costs of health insurance (Gabel, McDowell,

& Cerreto, 1983). For children with physical disabilities, costly household renovations, ramps, bath equipment, ceiling tracks, mobility equipment, and assistive devices, while often cost-shared by governmental agencies depending on family income, may account for much of the family's disposable income. Gabel, McDowell, and Cerreto estimated the average monthly out-of-pocket expenses to be 12.5% of the total family income. Furthermore, if outside care is not available, one family member may be forced to quit their job to look after the child at home, thereby increasing financial strains on the family. In Canada, published information is not readily available for the extra financial costs of raising children with chronic illness and disabilities, but as cuts to health and social services persist, the financial burden will ultimately fall to their families.

Positive Aspects of Caregiving

Taylor (1995) states that "parents of special needs children have the opportunity to experience life differently, discover hidden strengths , and become more insightful and caring than would have been possible without their child" (p.150). Recently, authors have been identifying positive and affirming aspects of caregiving (Abbott & Meredith, 1986; Kazak & Marvin, 1984; Turnbull & Turnbull, 1990). In a qualitative study of 14 families of children with disabilities, Traustadottir (1991) used a grounded theory approach to find that many mothers perceived caring as an empowering experience. These mothers indicated that they felt stronger because of their experience of caring for a child with a disability. They also became involved in their communities by advocating for others and supporting social change.

Factors that contribute to a positive outlook in caregiving include the availability of spousal support, the presence of community support, and the use of a variety of coping strategies (Failla & Jones, 1991; Kirkham, Schilling, Norelius, & Schinke, 1986; McCubbin & McCubbin, 1993; McCubbin & McCubbin, 1988). Furthermore Petersen (1984) found that resources such as physical and emotional support, satisfaction with the division of labor related to the care of the child, and sufficient financial and community resources promoted positive aspects of caregiving for mothers.

In summary, the literature on primary caregivers of children with chronic illness and disabilities indicates that they have the potential to be under a great amount of stress. This stress may be manifested psychologically, socially, physically, and financially. There is also evidence of beneficial aspects of caregiving, many of which are enhanced by adequate support and help with child care. The provision of respite care may help ameliorate stressors and allow caregivers to focus on these positive aspects of caregiving. However, a lack of research has been conducted to determine if the reviewed characteristics are descriptive of caregivers who use respite services.

Respite Care

Although the concept of respite care has been in development since the late 1960s, it was not until the early 1980s that it began to emerge as a significant component in the health and well-being of caregivers and families of individuals with chronic illness and disabilities (Upshur, 1983). While many researchers have focused their energies on respite care for primary caregivers of adults with chronic illness and disabilities (Bull, 1990; Lindgren, 1990; Schwartz, 1993; Strang, 1995), there has been little emphasis in the respite literature on primary caregivers of children. When respite is discussed, terms such as child care, babysitting, or relief care may be used, instead of respite care per se, in the child health literature.

Despite the lack of literature on respite for children, respite care is consistently defined for caregivers of children and adults. Respite care is indicated to be a service meant to provide temporary relief from care giving for another individual for a specified period of time. For children and families, this definition has been expanded to include care that meets the care needs of the child, offers the child opportunities for growth and development, strengthens family functioning through stress reduction, and maintains or enhances the quality of life for children and their families (Zimmermann & Walker, 1996).

Types of Respite Care

The described mode and timing of respite delivery varies from short term, emergency services (Short-Degraff & Kologinsky, 1987; Subramanian, 1985), to long term, individually planned services (Butock & Winsberg, 1991; Màrc & McDonald, 1988; Rimmermen, 1989; Russell, 1984; Starkey & Sarli, 1989). Respite care delivery can be divided into three broad categories: home based respite, where an alternate caregiver (ie. Registered Nurse, Licensed Practical Nurse, personal care attendant, or community volunteer) enters the family home; day centre based relief, where the individual requiring care leaves home for a period of time during the day and returns home at night; and out of home respite, which includes host families, residential homes, camps, hospitals, and long term care institutions.

Benefits of Respite Care

There are advantages to each type of respite service (Zimmermann & Walker, 1996). Advantages of in home services include: special equipment needed by the child is not moved; child remains in familiar surroundings; transportation is not necessary; other children may be cared for at the same time; and special facilities are not needed, thus decreasing costs. Advantages of out of home services include: potential for peer interaction; parents have family time with other children; several children can be cared for at the same time; and respite workers can be supervised.

Grant and McGrath (1990) indicate that respite care is the most common service required for families of children with chronic illness and disabilities. These authors found that respite services constitute the third top need when rank-ordering community services by parents of children with chronic illness and disabilities (Edgar, Reid, & Pious, 1988). In their discussion of autism and family stressors, Norten and Drew (1994) emphasize that "respite is not a luxury, but an absolute necessity" (p. 74). Respite care then, is essential help for caregivers of children with chronic illness and disabilities and involves promoting the health of individual family members and supporting family functioning as a whole (Bull, 1990; Knoll & Bedford, 1989; Russell, 1984; Starkey & Sarli, 1989; Upshur, 1983).

Respite care is reported to reduce the burden and stress on families raising children with chronic illness and disabilities and to enhance family coping (Botuck &Winsberg, 1990; Dossetor, Nicol, & Stretch, 1993; Factor, Perry & Freeman, 1990; Marc & MacDonald, 1988; Rimmerman, 1989). Additionally, respite services have been reported to reduce parental abuse of children with handicapping conditions (Cohen & Warren, 1987). Other researchers point out that respite care may delay or even prevent the child from long-term institutionalization (Dossetor, Nicol, & Stretch, 1993; Marc & MacDonald, 1988). Furthermore, out of home respite care services benefit children by providing them with an opportunity to play with other children, thus increasing the child's peer interaction and social competence (Short-DeGraff & Kologinsky, 1987; Starkey & Sarli, 1989).

In a pre and post-test quasi experimental investigation of families who were provided with registered nurse, in home, respite care, Sherman (1995) found that the degree to which a family utilized respite services was positively correlated ($r=.30$, $p<.03$) with family stress as measured on the Impact on Family Scale (Stein & Riessman, 1980). Also, the utilization of this respite service was associated with a reduction of the primary caregivers' degree of expressed symptoms as measured on the Brief Symptom Inventory (Derogatis & Melisaratos, 1983) after six months in the program. A downward trend in the number of days the child spent in hospital was also found as respite care use increased ($r=.40$, $p< .07$). Perhaps more importantly, Sherman found that the qualitative reports from participant parents revealed that respite care provided time for stress relief and for other activities. In fact, the only parental complaints involved the desire for more hours of respite care and a wider range of services. While these results must be interpreted with caution due to the lack of a random sampling, lack of a control group, small sample size, small correlations, and American context, the positive implications of respite care for the health of caregivers and their children are strongly suggested and clearly point to the need for further study.

Utilization of Respite Care

Despite the reported beneficial impact of respite care services, the utilization of respite programs has been shown to be low (Edgar, Reid, & Pious, 1988; Marc & MacDonald, 1988; Salisbury, 1990). Many primary caregivers and their families may be unaware of the existence or availability of services. In addition, some respite programs may be insufficient or inappropriate, thus not meeting caregivers' expectations and needs. Primary caregivers may also perceive respite care as crisis oriented instead of as planned and coordinated programs. The family belief system, guilt and concern about leaving the child with a stranger, loss of privacy, anxiety and fear of separation, or perceiving the respite as a stepping-stone to long-term care placement may constitute reluctant attitudes toward respite care (Dossetor, Nicol, & Stretch, 1993; Edgar, Reid & Pious, 1988; Factor, Perry, & Freeman, 1990; Salisbury, 1990; Short-DeGraff & Kologinsky, 1987; Starkey & Sarli, 1989). Finally, the lack of flexibility in funding of respite care may limit caregivers' abilities to access reliable respite providers (Bergman & Singer, 1996).

There is evidence of a differences between primary caregivers who use respite services and those who do not. Salisbury (1990) studied stress, support, depression, marital adjustment, family support, and the use and non-use of respite care in a sample of 152 mothers seeking an in-home respite service. To be included in the study, the caregivers seeking respite needed to either utilize respite care for at least twelve months or to refuse the respite care after initial measures were taken. The authors used correlational statistical methods to examine the difference between those who used the service and those who did not. It was indicated that mothers who used respite care for at least twelve months had lower incomes, higher stress, and children with greater disabilities than those who did not choose to enroll in the respite care program. The authors were surprised to find that, of those caregivers initially seeking respite, only 30% actually used the service offered. This low level of utilization may have been due to factors such as only a single type of service was offered, a lack of adequately trained respite care providers (the authors indicated that they remunerated the respite care providers $3.50 - 5.00 per hour), or that parents decided to use other services for respite care. Further issues that limit generalization of this study to other caregivers and respite services include the use of a convenience sample, small sample size, and high attrition from the study.

Informal Help

Informal help with their child's care from spouse, other family members, friends, and neighbours is identified as an essential, yet under received, form of caregiver support (Brust, Leonard, & Spienza, 1992; Marcenko & Meyers, 1991; Stewart, Ritchie, McGrath, Thompson, & Bruce, 1995; Turner-Henson, 1993). However, the research literature on respite care neglects to identify informal sources of help with child care when respite care is discussed (Snowdon, Cameron, & Dunham, 1994). Further research on respite care must take into account the multiple forms and sources of support. Such forms and sources not only need to include formal relief programs, but also the informal caregiving and community programs that provide intermittent breaks from the care provided by the child's primary caregiver. Finally, the perception of this care as helpful and adequate is also important (Beresford, 1994). Caregivers who do not perceive care positively may find that the help available adds to their stress due to their lack of confidence in the abilities of others to safely care for their child (Diehl, Moffitt, & Wade, 1991).

Conclusion

It has been well documented that caring for children with chronic illness and disabilities is a task with the potential for psychological, social, and physical demands beyond those normally encountered by primary caregivers and their families. There is also some support in the literature for the effects of respite in curtailing these demands, yet there is question as to whether or not respite services meet the primary caregiver's need for a break from caregiving.

Characteristics of primary caregivers of children with chronic illness and disabilities who are using respite services are not well documented. Furthermore, the relationships between these characteristics and respite care use have not been explored. The need for adequate descriptions of these caregivers, their caregiving activities, the help they have for their child's care, and the sources of respite that they use are essential to establish a solid base for further study, to plan effective programs, and educate those who are involved in the provision of respite care.

Chapter 3

Research Methods

Design

A quantitative descriptive design using a mail out survey was used to answer the research questions. A single application of a battery of questions was utilized to describe the caregiving activities, caregiver characteristics, respite used, and other instrumental support available to the caregiver. A descriptive design is an appropriate level of design as little is known about caregivers who use respite services for their children with chronic illness and disabilities.

Sample

Primary caregivers residing in Edmonton and surrounding areas who are using respite services for their child with chronic illness and disabilities constituted the population from which a convenience sample was drawn. This convenience sample was composed of primary caregivers who returned a questionnaire. A nonprofit agency specializing in coordinating relief services for persons with chronic illness and disabilities mailed the questionnaire on the researcher's behalf. All of the primary caregivers of children that the agency served who met the criterion for entrance to the study were mailed a questionnaire.

Criterion for entrance into the study included:

1) Child or children have chronic illness and/or disabilities
2) Child or children live in the family or foster family home at least 50% of the time
3) Child or children are less than 18 years of age
4) Family has used respite services in the last 12 months
5) Respondent identifies her or himself as the child's primary caregiver

Finally, while not a criterion for entry into the study it can be assumed that the caregivers who returned their questionnaire could read and write English or had an interpreter available.

Data Collection Procedure

A staff member at the agency sent a total of 299 packages that included an agency newsletter, a letter of introduction to the study, and a questionnaire. The back of the questionnaire was stamped so that it could be folded in half, secured with tape or staples, and mailed. A telephone number for primary caregivers to call if they had any questions or needed another questionnaire was included on the questionnaire. The agency also sent a reminder letter two weeks after the initial mailout to all of the families who received the questionnaire. Appendix A contains the correspondence sent to the primary caregivers.

Of the questionnaires that the agency sent out 20 were returned without a forwarding address. Five persons who received the questionnaire telephoned the researchers to say that they were ineligible. A total of 57 (21%) persons responded by returning completed questionnaires. After analysis of the returned questionnaires for meeting the entrance criterion, two questionnaires were excluded from further data analysis.

Instrumentation

A questionnaire that was designed specifically for this study was developed based on the literature review and following consultation with primary caregivers and persons with experience in the areas of child care, respite, and children with chronic illness and disabilities. Questions included: those pertaining to caregiver characteristics; caregiving activities required to meet their child's needs; and help with child care in the form of respite services and informal help. The final questionnaire is contained in Appendix B. Following are the rationale for the questions contained in the questionnaire.

Activities Required to Meet the Child's Needs.

Open ended questions and a checklist were used to examine caregiving activities. These questions were developed based on a non-categorical approach to defining and classifying chronic health conditions (Perrin et al., 1993). This approach is recognized to reflect the functional status of the child in terms of ongoing care needs instead of medical diagnoses.

Stewart, Ritchie, McGrath, Thompson, and Bruce (1995) found that asking parents to describe a typical caregiving day and a caregiving day when their child was ill revealed their children's physical care needs, care in illness situations, and care related to their social and psychological development. These authors concluded that such open ended questions were useful in determining primary caregiver demands. In establishing the validity of the questionnaire and pretesting the questionnaire, caregivers participating in these phases of the research project objected to the question about how the care changes when their child was ill. These caregivers agreed that illness management was a day to day caregiving need of their child and could be answered as a part of a typical caregiving day. Instead of an open-ended question of illness care, the final questionnaire contained interval level questions about hospitalization and health care appointments to examine this aspect of the child and caregivers experience of illness care.

Primary Caregiver Characteristics. Primary caregiver characteristics were established through demographic questions, a question about health concerns, and a Likert-type scale to measure their health rating. A number of questions were also developed specifically to examine evidence of adequate respite such as enjoying their time with their child, having time for themselves, and having time for others.

Respite Care and Informal Help with Child Care. Formal respite care and informal help with child care were measured using open-ended questions, likert type scales, and checklists. Informal help with child care from family and non family members was determined by addressing available help and satisfaction with that help using questions similar to those developed by Bristol (1983, cited in Marcenko & Meyers, 1991) and Blacher (1993). Amount of respite and services utilized by parents were determined using a checklist format that identified sources of respite available to parents. These sources were determined through the literature review, a regional health authority children's services resource summary, and personal communication with experts working in the area. Reasons for not using respite care was also determined through a checklist adapted from Blacher (1993).

Reliability and Validity

Content validity was addressed by analysing the similarity between the concepts being measured in the questionnaire and those found to be significant as derived from the literature review and the researcher's clinical experience as a home respite nurse. In addition to this, a panel of experts who work in the area scored each item of the questionnaire on its suitability to the population. These experts included parents of children with chronic illness and disabilities, professors in the faculty of nursing and in special education, nurses who provide respite care to children in the community, and the director of the respite coordinating agency. As recommended by Brink and Wood (1994), their responses were analysed to determine the percentage of agreement on each item in the questionnaire.

Following the feedback of the panel and revision of the questionnaire, a pretest mail out was sent to a convenience sample of 10 caregivers. Following completion of the questionnaire, the participants in the pretest were interviewed about length of time to complete the questionnaire, how easy the questions were to read, and their understanding of the questions.

The parents participating in the pretest responded favourably to the questions and completed the questionnaire in 15-45 minutes. Only minor revisions to the questionnaire were required at this time. These revisions were again reviewed by three members of the panel of experts before the final printing of the questionnaire. The revisions included providing further rationale for questions, changing of some open ended questions to categorical questions, and adding categories to the checklists. Finally, the data analysis that was planned for the final sample of parents was conducted on the pretest data. By completing this initial data analysis, data categories, data coding, and data variability were checked, confirmed, and revised where necessary.

Final Data Analysis

The approach to data analysis for Level I research studies outlined by Brink and Wood (1994) was followed. Primarily, content analysis of the open-ended questions was conducted. This was followed by descriptive summaries of the data categories that were determined through the content analysis of the open-ended questions. Descriptive statistics deemed appropriate to the level of measurement for structured questions were then calculated. For example mean, median, range and standard deviation were calculated for interval-ratio level data, while mode and relative frequencies were calculated for ordinal and nominal level data. Data were placed in tables and charts as appropriate. For clarity of understanding, a number of variables were collapsed into categorical variables when placed into tables. The statistical analysis of the data was conducted utilizing SPSS$_{\text{Tm}}$ for windows.

After the initial summary of the data, tests of association between sample characteristics and data categories were conducted. Parametric assumptions such as random sampling, normal population distributions, homogeneity of variance, and interval-ratio level scaling could not be made for this study, therefore a non-parametric correlation coefficient was chosen to examine relationships among the variables. A non-parametric test of association was chosen because non-parametric statistics make fewer assumptions about the data than parametric statistics.

The Kendall-tau b rank-order coefficient was chosen because it is a measure of association between two variables that are measured on at least an ordinal scale, it has an established relative efficiency of .91 with the Pearson product-moment correlation, and it handles tied observations more effectively than the Spearman rank order correlation coefficient does (Siegel & Castellan, 1988). This latter factor was important to consider because there were many tied observations on the variables that were measured on Likert type scales. Nominal level data were coded as dummy variables (Hayduk, 1987) so that they could also be examined in relation to ordinal scales using Kendall-tau b rank-order coefficients. Finally, Pair-wise deletion of missing data was used to preserve an optimal sample size in the calculation of the Kendall tau-b correlation matrix.

Protection of Human Subjects

Protection of human subjects was ensured in a number of ways. The approval of the University of Alberta Ethics Review Committee was sought before contact with any participants was obtained (see Appendix C). All written descriptions of the study were confirmed to be below a grade eight reading level (using Writewriter$_{TM}$). Participants were notified that the return of the questionnaire was voluntary. They were told that they were not obligated to complete certain questions or sections of the questionnaire if they did not want to. Furthermore, both the coordinating agency and city of location of the study will not be published or included in this thesis and related presentations. Return of the questionnaire implied consent to participate in the study.

The only possible risk of the study is that certain questions may have evoked an emotional response for some caregivers. Confidentiality was maintained by explaining to subjects that their name must not appear on the questionnaire, by identifying questionnaires by number, by having the agency send out the questionnaires, and by the agency not providing the researcher with potential participants' names or addresses. Finally, cards with requests for study results were structured so that they could be mailed separately from the questionnaire thereby providing the choice for anonymity.

Participants were assured that any reports, publications, or presentations of findings would not reveal their personal identity. All questionnaires and computer disks with research information will be kept in a locked filing cabinet, accessible only to the researcher. If the data is used in secondary analysis, ethical clearance will first be sought from the appropriate ethical review committee.

Chapter 4

Results

The results of the study are presented according to each specific research question. First, the characteristics of the respondents are described. This description is followed by summaries of both the activities required to meet the child's needs and costs related to the child's care. Then the respite services that the primary caregivers use are identified as is their perceived amount of informal help with their child's care. Finally, correlations among the variables are presented.

What are the characteristics of the primary caregivers who use respite for their child with chronic illness and disabilities?

Characteristics. All of the 55 respondents who identified themselves as the primary caregiver for their child or children with chronic illness and disabilities were women. A small number of primary caregivers cared for two children with chronic illness and disabilities (n=4, P=7%).The remainder of the respondents identified themselves as the primary caregiver of one child with chronic illness and disabilities. Of these women, 76% (n=41) identified themselves as the child's mother, 18% (n=10) as the child's foster parent, and 6% (n=3) as the child's grandparent. One respondent did not clearly specify her relationship to the child. Many of the respondents indicated that they were also primary caregivers of other children eighteen years of age or younger in their household. Fourteen percent (n=9) responded that their child with chronic illness and/or disability was the only child in their household, 44% (n=24) indicated that there were two children living in their household, and 40% (n=22) indicated that there were three or more children living in their household.

The demographic characteristics of the respondents including age, education level, employment status, and marital status are summarized in Table 1. The mean age of the respondents was 41 years with a range of 28 to 60 years and a standard deviation of 7.6 years. Most of the respondents indicated that they were either married or living common law. The respondents were also well educated, with 93% (n=51) indicating that they had completed at least high school and/or trade school. Many respondents also indicated that they were either currently employed or attending school.

Contained in Table 2 are the respondents' estimates of total family incomes before taxes. It is important to note that many of the respondents indicated that their total family income, before taxes, exceeded $20 000 per year. However, 20% (n=10) indicated a total family income under $20 000 which is well below the poverty line for families in Canada (Harvey, Avard, Graham, Underwood, Campbell, & Kelly, 1994).

Table 1

Respondent education level, employment status, and marital status

Characteristic	f	p
Education[a]		
Incomplete High School	4	7%
Complete High School	22	40%
Some College/University	9	16%
Complete College or Trade School	15	27%
Undergraduate University Degree	3	6%
Graduate University Degree	2	4%
Employment Status[a]		
Not Employed	19	35%
Full Time Employed	16	30%
Part Time Student	11	20%
Part Time Employed	4	7%
Full Time Student	2	4%
Retired	2	4%
Marital Status[b]		
Married/common law	39	71%
Divorced	7	13%
Separated	5	9%
Never married	3	6%
Widowed	1	2%

[a]n = 55 [b]n=49

Table 2

Estimated total family income before taxes

Income In 1995	f	p
<10 000	6	13%
10 000-19 999	4	9%
20 000-29 999	8	17%
30 000-39 999	4	9%
40 000-49 999	10	21%
50 000-59 999	10	19%
>59 999	10	20%

n=47

Health Concerns. A checklist format was used to identify the health concerns of the respondents in the last twelve months. The frequency and percentage of responses to the health concerns are contained in Table 3. Only 7% (n=4) of the respondents did not identify health concerns in the past twelve months while 16% (n=9) identified one, 11% (n=6) identified two, and the remaining 66% (n=36) identified three or more. Fatigue was the most common concern followed by back pain and trouble sleeping. Anxiety, depression, and hypertension were also indicated to be concerns. Health concerns, such as specific chronic illness, migraines, and physical injury were among the concerns classified as "other" and were classified as such because each response was unique and/or the concern was not specified by the respondent.

Table 3

Health concerns of respondents in the last 12 months

Concern	f*	P
Fatigue	40	74%
Back pain	29	54%
Trouble sleeping	29	54%
Anxiety	27	48%
Depression	22	41%
High blood pressure	5	9%
Other	14	26%

n=54 *multiple response categories

Kendall's Tau-b correlations were calculated to identify if relationships existed among any of the health concerns. Only two pairs of variables were correlated with a statistical significance of $p<.05$. These were fatigue and back pain ($T=.32$, $p<.02$) and fatigue and anxiety ($T=.36$, $p<.01$). These variables were further explored with contingency tables to reveal that of the 40 respondents who checked fatigue, 63% ($n=25$) also checked back pain and 60% ($n=24$) also checked anxiety. While 38% ($n=15$) checked all three variables, the partial correlation between these variables was not found to be small and insignificant ($T=.07$, $p>.05$).

Following the checklist of health concerns, the respondents were asked to rate their health on a five point Likert type scale from poor to excellent. Only

1 (2%) respondent rated her health as poor while 13 (24%) rated their health as fair, 25 (46%) as good, 12 (22%) as very good, and 4 (7%) as excellent. These findings indicate that, even though the respondents experienced a number of health concerns in the 12 months preceding the questionnaire, 75% rated their health as good to excellent.

Personal Time. Finally, the amount of time that the respondents perceived as having for themselves, their spouse or partner, their other children, and their enjoyment of the time that they spend with their children with chronic illness and disabilities was explored. For the most part the respondents identified that they enjoyed the time that they spent with their children with chronic illness and disabilities and had some time for their other children, but acknowledged little time for themselves, their spouses, and their other family members. In Table 4 the mean and standard deviation of the responses to these time variables are presented. As suggested by Agresti and Finley (1986), these ordinal level variables were treated as interval level variables for summary purposes. Implicit in the change from ordinal to interval level data is the assumption of equal distances between categories, therefore, the results presented in this table need to be interpreted with this assumption in mind.

Table 4

Responses to time variables

Question[a]	M	SD
I enjoy the time I spend with my child with special needs[b]	4.4	1.06
I have time for my other children[d]	3.4	1.01
I have time to spend with my spouse or partner[c]	2.9	0.98
I have time to do things for myself[b]	2.7	1.04
I have time for other family members[e]	2.7	0.97

[a] Measured on a six point scale where 1= never, 2=seldom, 3=sometimes, 4=often, 5=usually, and 6=always [b]n = 55 [c]n = 46 [d]n = 51 [e]n=52

What are the activities required to meet the child's needs?

Child Characteristics. The respondents cared for a total of 59 children. The four respondents who indicated that they were primary caregivers for two children with chronic illness and disabilities responded separately to the child specific variables for each child. To summarize the child demographic variables and caregiving needs, a separate data set was created on SPSS$_{tm}$ for these child specific variables. The children's ages ranged from two to eighteen, with a mean age of ten, with a bimodal distribution at 5 and 12. Child age, sex, and school attendance are summarized in Table 5.

The children whose primary caregivers responded to the questionnaire represented a wide range of medical diagnoses. Many respondents indicated multiple diagnoses for their child. These medical diagnoses included attention deficit disorder, chronic respiratory illnesses, spina bifida, seizure disorders, cerebral palsy, quadriplegia, microcephaly, diabetes, fetal alcohol syndrome, autism, pervasive developmental disorder, non-specified developmental delay, genetic syndromes, and other congenital syndromes.

Table 5

Child age, sex, and school attendance

Characteristic	f	P
Age in years[a]		
2-6	16	27%
6-12	25	42%
12-18	18	31%
Sex[a]		
Female	24	41%
Male	35	59%
School attendence[b]		
Full time	39	72%
Part time	11	20%
No school attendance	4	7%

[a]n = 59 [b]n = 54

Caregiving Activities. Respondents were asked to describe the programs, treatments or other special care that their child requires on a usual day. This question was further subdivided into morning, afternoon, evening, and night care to guide the respondents' answers to the question. Most of the respondents provided detailed accounts of a usual caregiving day for their child. As presented in Table 6, activities of daily living, medication administration, and various physical therapy and behavioural programs comprise a large portion of the children's caregiving needs.

Table 6

Care that the children require on a usual day

Activity	f	P
Activities of Daily Living	33	59%
Complete Assistance	21	39%
Partial Assistance	12	20%
Medication administering and monitoring	24	41%
Constant monitoring and supervising	14	26%
Physical therapy	13	24%
Behaviour management programs	13	24%
Gastrostomy tube feedings	9	17%
Skin and pressure point care	6	11%
Care related to sensory deficits	6	11%
Special diet preparation and monitoring	5	9%
Bowel program	5	9%
Intermittent catheterization	4	7%
Oxygen administration and related care	4	7%
Chest treatments/inhalant administration	4	7%
Tracheostomy care	1	2%
Insulin dependant diabetic meilitis care	1	2%
Ostomy care	1	2%

n=55

For summary purposes, activities of daily living encompassed feeding, toileting, bathing, dressing, and other personal care. Activities of daily living were considered as "complete assistance" if the respondent used such statements as "totally dependent", "needs are those of an average baby", and "she requires about the same amount of daily living skills as an eight month old". "Partial assistance" was used when respondents identified that their child completes activities of daily living with their assistance using terms such as "self-care with prompting" or "help with activities".

Time for Care. As shown in Table 7, the respondents estimated differing amounts of time that they spent attending to the care needs of their child. Some children were estimated to require care more than 16 hours per day. This time appears to be consistent with the detailed accounts of usual caregiving days provided by the respondents and the finding that 20% (n=11) primary caregivers indicated that their child requires various types of care during the night including continuous gastrostomy tube feedings, repositioning, and attending due to frequent awakenings.

Table 7

Hours per day primary caregiver estimates attending to their child's care needs

Hours per day	f	P
1-3 hours	9	16%
4-7 hours	14	24%
8-11 hours	16	28%
12-15 hours	7	12%
16 + hours	12	21%

n=58

Other Variables. Other indicators of the children's health care needs such as times hospitalized, days in hospital, and health related appointments are summarized in Table 8. Only a small percentage of the children required hospital care in the twelve months prior to completion of the questionnaire. Those who did require hospitalisation spent between 1 and 44 days in hospital with a mean of 17.9 hospital days and a standard deviation of 16.00. The maximum number of times hospitalized was 10, with a mean of 2.4 times and a standard deviation of 2.33. Despite the limited hospitalizations, health related appointments appear to dominate the picture for these children as indicated by a mean of 14.3 appointments and standard deviation of 15.91. One primary caregiver of a young child indicated 80 appointments in twelve months.

Table 8

Child's hospitalization and health appointments in the last twelve months

Characteristic	f	p
Number of times hospitalized[a]		
0	38	64
1	10	17
2	6	10
3 or more	5	9
Total number of in hospital days[c]		
0	38	66
<7	8	14
7-14	4	7
>14	8	14
Health related appointments[d]		
0	2	4
1-6	18	32
7-12	17	30
12-24	14	25
> 24	6	11

[a]n = 59 [b]n = 54 [c]n = 58 [d]n = 57

Finally, costs associated with the child's care are summarized in Table 9. The most frequently identified cost that was present for the respondents' families was child care for their children with chronic illness and disabilities. Child care was followed by costs related to medications and transportation.

Over twice as many respondents identified that the extra costs related to their child's needs resulted in financial difficulty for their family (n=36, P=69%) than those who indicated that financial costs did not result in financial difficulty for their family. This financial difficulty is correlated with income (T=-.53, p<.001) indicating that fewer respondents with higher incomes perceived that the extra costs of their child's care resulted in financial difficulty for their family. This is further evidenced in the finding that 100% (n=18) of the respondents who indicated that their total family income before taxes was less than $30 000 also indicated that the extra costs related to their child's care resulted in financial difficulty for their family.

Table 9

Extra costs related to caregiving

Cost	f*	P
Child care for the child with special needs	43	78%
Medications	34	62%
Transportation and parking	34	62%
Loss of work for respondent	33	60%
Equipment and supplies	30	55%
Child care for other children	19	35%
Loss of work for another family member	9	16%
Other	14	25%
No extra costs are present	2	4%

n=55 *multiple response categories

What types of respite services do primary caregivers use and how much informal help is available to primary caregivers of children with chronic illness and disabilities who use respite?

To determine the respite services that the respondents utilized, they were asked to identify the various services that they had used in the previous twelve months, indicate the amount of time they used each service, and identify how their use of the services changed with the growth of their child. To determine the amount of informal help with child care, the respondents were also asked to rank the amount of informal help from their spouse or partner, other family members, non family members, and, if applicable, the child's other parent or parents on five point Likert-type scales. Finally, to determine outcomes of respite, the respondents identified their perception of having enough of a break from caregiving, reasons for not having the break they need, and how they would change the respite care that they currently receive.

Respite Services. The frequency and percentage of responses to the types of respite services that the primary caregivers used in the twelve months preceding the completion of the questionnaire are presented in Table 10. The time frames varied from individual to individual and were therefore summarized using the ranges of time identified by the respondents. Most of the respondents identified that they used multiple forms as sources of respite care. Twenty one percent (n=12) identified two sources, 36% (n=20) identified three sources, and 16% (n=9) identified four or more sources of respite.

Table 10

Respondent use of particular types of respite services

	Use[a]	
Service	f	p
In Home Care	40	73%
Formal Respite	30	55%
Babysitter	24	44%
Host Family	22	40%
Camps	17	31%
Group or Residential Homes	14	26%
Institutional	7	13%
Other	7	13%

n=55 [a]multiple responses

The majority of respondents used some form of in home respite care either in the form of formal services or regular in home babysitting. This in home care ranged from occasional use of less than once a month to daily use totalling over 40 hours per week. Respondents who used host family respite ranged from a week or two at a time per year to every second weekend. Group home use ranged from four to thirty days per year. The respondents who used institutional respite care ranged from two days per year to one weekend per month plus two weeks per year. Over night camps were used for one week to two weeks during the summer while day camp use ranged from five days of day camp to eight weeks of day camp.

A total of 34 respondents (62%) identified changes in requirements for respite care with the growth of their child. These changes are summarized in Table 11. A number of respondents indicated that their need for respite care had increased over time with the growth and development of their child. For example, one primary caregiver wrote "up until the age of eleven we never used it. Now as my child has grown so much I find myself more tied down. Grandparents are wonderful but they are not getting any younger. Having a fourteen year old dependant handicapped child is like having a fourteen day old newborn". Another respondent wrote "the years of care wear you down as your child gets bigger, stronger, and needs more activities. This requires the little energy that is left. Years of put off household jobs pile up to create feelings of resentment towards child's high needs. There is never enough respite to catch up". Finally, one primary care giver wrote "I thought it was hard when she was little. Now we have more problems both medical and behavioural. I feel very overwhelmed. When she is out of our home I sleep a lot."

Another change that some respondents identified to occur with the growth of their child was increasing difficulty in finding appropriate caregivers. These primary caregivers wrote about losing treasured caregivers and their difficulty in finding persons able to lift and transfer their child. This difficulty in maintaining consistent caregivers is exemplified in the response of one primary caregiver that "I go through a lot of host families - eight in six years. People find him a lot of work".

Table 11

Changes respite care requirements with the child's growth

Change	f	P[a,c] changes	P[b,c] total
Change in requirement indicated by respondent	34	100	62
Need for respite has increased and/or child's requirements for care have increased	13	36	24
Increased difficulty in finding appropriate caregivers/increase in caregiver turnover	9	27	16
Need for respite care has decreased and/or child's requirements for care have decreased	4	12	7
Decreased quality or quantity of care	4	12	6
Decreased stress when using respite	2	6	4
Increased stress when using respite	1	3	2
Increased funding for respite care	1	3	2

[a]n = 34 [b]n=55 [c]multiple response categories

Other changes identified included decreased requirements for respite, decreased quality or quantity of care, conflicting levels of stress including increased stress when using respite and decreased stress when using respite, and increased funding for services. The four respondents who identified that their requirements for respite care have decreased over time wrote that their child or children had matured, gained greater independence, and/or that the child's health had improved. Decreased quality of care and decreased amount of care relative to what the family needed were also identified as changes over time. Stress level was a change for three primary caregivers over time. One respondent also wrote "I actually get more stressed" in using respite while two others wrote "I feel more relaxed about someone else caring for her. I don't feel so much the supermom" and "I feel more comfortable with relief care".

The changes that the respondents identified that they would make to the respite care that they were currently using are summarized in Table 12. The availability of qualified staff was the most cited concern. One primary caregiver asked for "someone very reliable, very available, and who doesn't mind working for their pay and missing sleep. Need to be comfortable with treatments, feedings, signing, lifting, etc.". Others asked for "more specialized care" and "better training for staff". One respondent wrote about her concern over the need for educated caregivers as she has "four hours a month and [I] need almost the full time just to train them. Before I know it they are not available and I must find someone else to train". This lack of qualified caregivers to provide in home care was further evidenced in the statement that "experience has shown that there are not adequately trained persons available to provide in home care who are reliable and trustworthy". One parent emphasized that the lack of qualified caregivers was not due to a lack of funding as she "received a generous amount of money but couldn't find quality child care".

Increased access to care was also an issue for a number of primary caregivers. For example one respondent wrote "there has to be more group homes and relief places available". Eliminating long waiting lists, access to in home support, and care "available at the times it is needed and not by appointment" were all evidence for changes that related to accessibility of care. A number of respondents would also increase their frequency of their use of respite care if they could. As one respondent summarized "the only thing that I would change is that I get more of it". Times when respondents would increase the frequency and amount of care included weekends, evenings, holidays, and after school care.

Less frequently identified changes that respondents would make included increased funding, increased short term emergency care, and reimbursement for family caregivers. Some respondents (n=7) also took the opportunity to identify positive aspects of the services that they were currently using or that they would not change anything. Expressions like "I am happy with [a specific service]", "no changes" and "we are extremely lucky" provide evidence for the satisfaction these that respondents had with their current respite services.

Table 12

What primary caregivers would change about the respite care that they are currently using

Change	f	P[a,c] changes	P[b,c] total
Would make a change	39	100	71
Increase available qualified caregivers	18	46	33
Increase access to respite and relief services	11	28	20
Increase frequency of use	10	26	18
Increase funding for respite and relief care	5	13	9
Have care available on short notice	4	10	7
To use funding to reimburse family members for care	1	3	2

[a]n = 39 [b]n=55 [c]multiple responses

Informal help with child care. To determine the amount of informal help with their child's care and how happy the respondent was with this help, five point likert-type scales were used. Contained in Table 13 are the mean and standard deviation of the amount of help and happiness with this amount of help, with the ordinal level scale interpreted as if the categories were equidistant and therefore at an interval level.

From the table on informal help with their child's care from spouse, family, and non family members, it is clear that few of the respondents perceived that they had adequate help with their child's care from informal sources with the exception of spousal help which is moderate. These findings are further indicative of a lack of participation in their child's care by a parent or parents who are separated from their child. All of the mothers whose spouse or partner was not the child's other parent and all but one of the foster mothers indicated that they received "no help" from their child's other parent or parents. Cross tabular comparison showed that the foster mothers indicated that they were happier with this amount of care than the mothers ($\chi^2=10.31$, $p<.05$).

Table 13

Help and happiness with amount of child's care from informal sources

		Help[a]		Happy[b]	
Source	n	M	SD	M	SD
Spouse or Partner	50	3.16	1.50	3.16	1.56
Child's Other Parent(s)[c]	19	1.16	0.50	2.47	1.58
Other Family Members	55	2.35	1.19	2.82	1.44
Non-Family Members	55	1.86	1.11	2.62	1.38

[a] 5 point scale where 1=no help and 5=all I could ask for [b] 5 point scale where 1=not happy and 5=very happy

[c] If different than spouse or partner

Respite outcomes. That the primary caregivers perceive experiencing an adequate break from caregiving is central to the purpose of respite care as well as an indication of the informal help that they have with their child's care. The frequencies and percentages of responses to the primary caregivers' perceptions of adequate breaks from caregiving are summarized in Table 14. In this sample of primary caregivers who use respite care, the majority (n=42, p=76%) identified that they have limited breaks from caregiving as evidenced by the combined categories of never, seldom, and sometimes.

Table 14

Categorical responses to perceiving adequate breaks from caregiving

Perceived break	f	p
Never	1	2%
Seldom	17	31%
Sometimes	24	44%
Often	5	9%
Usually	7	13%
Always	1	2%

n=55

The frequency and percentage of responses to the checklist of reasons primary caregivers feel that they do not have adequate breaks from caregiving are summarized in Table 16. Most respondents checked more than one response to this question indicating that they encounter multiple barriers to getting adequate time off from caregiving. One respondent identified that she always had adequate breaks from caregiving and was therefore not included in the analysis.

The lack of people or agencies to provide care for their child was the most frequently checked item and was closely followed by uncertainty in the ability of others to properly look after the child. These findings were consistent with the previously discussed finding that many primary caregivers wanted increased access to respite care and more qualified caregivers. Lack of funding was also frequently identified item, although funding was not identified previously as something the respondents would change about the respite care that they currently access. Many respondents also checked that their child's physical or behavioural needs were not accommodated by many respite care services, again confirming the problem of access to appropriate services with prepared personnel.

Table 15

Reasons for not getting enough of a break

Reason	f[a]	P
Lack of people or agencies to provide care for child	28	52%
Unsure of the ability of others to care for child	27	50%
Lack of funding	22	41%
Child's behavioural or physical needs not accommodated	16	30%
Lack of knowledge about services available	6	11%
Do not want to use services	1	2%
Other	2	4%

n=54 [a] multiple response categories

What are the relationships among primary caregiver characteristics, child variables, respite services used, and informal help?

The final part of the data analysis consisted of an exploration of possible relationships among the variables that were measured in the questionnaire. To organize this exploration, three areas were examined as they related to informal help and to respite variables. The three areas that were examined included respondent demographic characteristics, selected child related variables, and respite services used. The respite variables included the perception of an adequate break from caregiving, time for self, family, and others, and enjoyment of the time that the respondent spends with their child. The purpose for grouping these six variables together was that they were consistent with the purpose of respite care, which is to provide a break from caregiving, to promote time for other activities, and to promote healthy caregiver child relationships that can begin with their enjoyment of their time together.

At this point it is important to emphasize that the sample size may be too small to detect significant relationships among the variables. For example, if the efficiency of the Kendall tau-b rank order correlation coefficient (T) is .91 of the more powerful Pearson product moment correlation, then to acheive the conventionally accepted power of .80 with a two tailed Type I risk (a_2=.05) and T=.30, a sample size of 93 subjects would be needed. However, for T=.40, a sample size of 50 would be needed (Cohen, 1988). This means that the sample size in this study is only adequate to detect correlations of at least T=.40 among two variables with a power of .80.

The first set of correlations that were explored were those between respondent characteristics including age, total family income, marital status, health rating, and health concerns and the respite variables. As shown in Table 16, there is little evidence of relationships among these variables. Logically, being married or living common law with one's partner was positively related to having time for ones partner or spouse; however, this relationship was still only found to be moderate. This is reflective of the previous finding that respondents had little time for their partner or spouse overall. There is also an association between married or common law status and time for other children and other family members. Again, having a partner living in the family home may enable the primary caregiver the extra time to spend with other family members. Income was also found to have a small association with time for the respondent's other children and other family members. That a relationship is evidenced between income and time for family and marital status and time for family could also be indicative of the relationship between marital status and income (T=.61 p<.001) and one must note that spurious relationships may exist among the findings and is not controlled in the study design or data analysis. Finally, a positive association is evidenced between the respondent's health rating and their enjoyment of their time with their child, but specific health concerns show no such relationship.

Table 16

Kendall's tau-b rank order correlations of respite variables by respondent characteristics

	Break from caregiving[a]	Time for self[a]	Partner or spouse[a]	Other children[a]	Other family members[a]	Enjoy time with child[a]
Age	-.01 (n=53)	.19 (n=53)	.20 (n=45)	.20 (n=48)	.16 (n=51)	.00 (n=53)
Income	-.03 (n=47)	.20 (n=47)	.23 (n=40)	.29* (n=42)	.28* (n=46)	.12 (n=47)
Marital status[b]	-.03 (n=55)	.23 (n=55)	.37** (n=47)	.26* (n=50)	.28* (n=53)	.21 (n=55)
Employment[c]	.19 (n=55)	.01 (n=55)	.16 (n=47)	-.05 (n=50)	-.28* (n=53)	.28* (n=55)
Health rating[d]	.08 (n=55)	.21 (n=55)	.04 (n=47)	.05 (n=50)	.09 (n=53)	.34** (n=55)
Back Pain	-.04 (n=55)	-.24 (n=55)	.01 (n=47)	.05 (n=50)	-.07 (n=53)	.06 (n=55)
Fatigue	-.09 (n=55)	-.10 (n=55)	-.10 (n=47)	.13 (n=50)	.04 (n=53)	-.09 (n=55)

Table 17 continued

	Amount of help with child's care[a]				Happiness with amount of help with child's care[b]			
	Spouse[c]	Other[d]	Family	Non family	Spouse[c]	Other[d]	Family	Non family
Depression	-.16 (n=50)	.07 (n=19)	-.03 (n=55)	.11 (n=55)	-.24 (n=49)	-.37 (n=19)	-.10 (n=54)	.01 (n=53)

[a] 5 point scale where 1=no help and 5=all I could ask for. [b] 5 point scale where 1=not happy and 5=very happy.
[c] spouse or partner. [d] child's other parent(s)if different from partner or spouse.
[e] 1= not employed and not looking and 0=other (looking for employment, full time, part time, and student)
[f] 5 point scale where 1=poor, 2=fair, 3=good, 4=very good, and 5=excellent
*$p<.05$, two tailed. ** $p<.01$, two tailed. ***$p<.001$, two tailed.

Table 17 contains Kendall's tau-b rank order correlation coefficients for the informal help that the respondents indicated they had and their age, total family income, employment status, health rating, and a number of the specific health concerns. These findings suggest that there are associations between some primary caregiver characteristics and informal help with their child's care. The respondent's age appears to have a small positive association with amount of help and happiness with this amount of help from spouse or partner. Total family income also appears to be associated with this spousal help. That total family income is associated with spousal help with child care may be reflective of traditional sex roles within the family, where the spouse's contribution to child care is embedded in his adequacy as a provider for the family.

The respondent's health rating is positively associated with the amount of spousal and family help but not with how happy the respondent is with that amount of help. Interestingly, the presence of the two most commonly identified specific health concerns, back pain and fatigue, have small negative associations with the amount of help that the respondent perceives that she gets from non family members. This means that those who indicated that they had concerns about fatigue and back pain were more likely to indicate that they received less help from non family members than those without these concerns.

Table 17

Kendall's tau-b rank order correlation coefficients of help by respondent characteristics

	Amount of help with child's care[a]				Happiness with amount of help with child's care[b]			
	Spouse[c]	Other [d]	Family	Non family	Spouse[c]	Other[d]	Family	Non family
Age	.33*** (n=48)	.22 (n=18)	.10 (n=53)	-.04 (n=53)	.31** (n=47)	.33 (n=18)	.16 (n=52)	-.01 (n=51)
Income	.46*** (n=46)	.28 (n=16)	.12 (n=47)	-.16 (n=47)	.35** (n=42)	.38 (n=16)	.17 (n=46)	.05 (n=45)
Employment[e]	.13 (n=50	.26 (n=19)	.16 (n=55	-.12 (n=55)	-.04 (n=49	-.13 (n=19)	-.13 (n=53)	.05 (n=54)
Health rating [f]	.23* (n=50)	.34 (n=19)	.29** (n=55)	.04 (n=55)	.17 (n=49)	.10 (n=19)	.08 (n=54)	.00 (n=53)
Back Pain	.00 (n=50)	-.32 (n=19)	-.20 (n=55)	-.25* (n=55)	.03 (n=49)	.07 (n=19)	-.13 (n=54)	-.05 (n=53)
Fatigue	.03 (n=50)	-.11 (n=19)	-.02 (n=55)	-.42*** (n=55)	.01 (n=49)	.17 (n=19)	-.01 (n=54)	-.16 (n=53)
Anxiety	-.02 (n=50)	-.02 (n=50)	-.10 (n=55)	.00 (n=55)	-.01 (n=49)	-.46* (n=19)	-.26* (n=54)	-.10 (n=53)

Table 17 continued

	Amount of help with child's care[a]				Happiness with amount of help with child's care[b]			
	Spouse[c]	Other[d]	Family	Non family	Spouse[c]	Other[d]	Family	Non family
Depression	-.16 (n=50)	.07 (n=19)	-.03 (n=55)	.11 (n=55)	-.24 (n=49)	-.37 (n=19)	-.10 (n=54)	.01 (n=53)

[a] 5 point scale where 1=no help and 5=all I could ask for. [b] 5 point scale where 1=not happy and 5=very happy.
[c] spouse or partner. [d] child's other parent(s)if different from partner or spouse.
[e] 1= not employed and not looking and 0=other (looking for employment, full time, part time, and student)
[f] 5 point scale where 1=poor, 2=fair, 3=good, 4=very good, and 5=excellent
*p<.05, two tailed. ** p<.01, two tailed. ***p<.001, two tailed.

Child variables evidenced few associations between respite variables or informal sources of help measures. These correlations are presented in Tables 18 and 19. The data from primary caregivers of two children with chronic illness and disabilities (n=4) were excluded from this part of the correlational analysis to maintain independent measures among the correlations. The child's age exhibits a small negative relationship to the primary caregiver's perception of a break from caregiving. This finding indicates that respondents caring for older children perceive less of a break from caregiving than respondents caring for younger children. This association provides support for the previously reported finding of the changing respite needs as the child has grown older. There is no support in the data that the age of the child is related to the amount of informal help that the caregiver has.

Surprisingly, the number of times that the child required hospitalization evidenced a small positive relationship to the primary caregiver's perception of a break from caregiving. This finding raises questions as to the reasons for hospitalization, for example where the hospitalizations for respite purposes, or for illness care, or both? The number of times that the child required hospitalization was also associated with the respondent's happiness with the amount of help with the child's care from the child's other parent or parents (if not the respondent's partner or spouse). Perhaps hospitalization of their child, for these respondents, may be a time when blended and separated families pull together to care for their child.

Table 18

Kendall's tau-b rank order correlations of respite variables by child variables

		Time Variables				
	Break from caregiving[a]	Self[a]	Partner or spouse[a]	Other children[a]	Other family members[a]	Enjoy time with child[a]
Age	-.25* (n=51)	.02 (n=51)	.15 (n=44)	.14 (n=46)	.17 (n=49)	-.18 (n=51)
Hours of care	.07 (n=51)	-.05 (n=51)	-.16 (n=44)	-.16 (n=46)	-.29* (n=49)	.03 (n=51)
Times in hospital	.24* (n=51)	.06 (n=51)	.13 (n=44)	.20 (n=46)	.17 (n=49)	.14 (n=51)
Days in hospital	.17 (n=50)	.04 (n=50)	.05 (n=43)	.19 (n=45)	.11 (n=48)	.08 (n=50)
Appointments	.06 (n=50)	-.08 (n=50)	.07 (n=43)	.04 (n=22)	-.04 (n=48)	-.05 (n=50)

[a] 6 point scale where 1= never, 2=seldom, 3=sometimes, 4=often, 5=usually, and 6=always.
*p<.05, two tailed.

Table 19

Kendall's tau-b rank order correlation coefficients of help by child variables

	Amount of help with child's care[a]				Happiness with amount of help with child's care[b]			
	Spouse[c]	Other[d]	Family	Non family	Spouse[c]	Other[d]	Family	Non family
Age	.08 (n=46)	.02 (n=16)	.05 (n=51)	-.12 (n=51)	.07 (n=45)	.06 (n=16)	.07 (n=49)	-.06 (n=49)
Hours of care	.00 (n=46)	.00 (n=16)	.13 (n=51)	.00 (n=51)	.00 (n=45)	-.26 (n=16)	-.04 (n=50)	-.09 (n=49)
Times in hospital	.11 (n=46)	-.26 (n=16)	-.05 (n=50)	.08 (n=51)	.08 (n=45)	.60** (n=16)	.11 (n=50)	.15 (n=49)
Days in hospital	.04 (n=45)	-.26 (n=16)	.06 (n=50)	.03 (n=50)	.00 (n=44)	.58 (n=16)	.07 (n=49)	.11 (n=48)
Appointments	.16 (n=45)	.10 (n=15)	-.10 (n=50)	.04 (n=50)	.15 (n=44)	.37 (n=15)	.08 (n=49)	.08 (n=48)

[a] 5 point scale where 1=no help and 5=all I could ask for. [b] 5 point scale where 1=not happy and 5=very happy.
[c] spouse or partner. [d] child's other parent(s)if different from partner or spouse.
** $p < .01$, two tailed.

Table 20 contains the correlations between the type of service used by the primary caregiver and the respite variables. The type of service used was coded as 1 for use and 0 for non use. The only type of service that appeared to be related to any of the respite variables was institutional care. The use of institutional respite care has a small positive association with the respondent's perception of a break from caregiving and their enjoyment of their time with their child with chronic illness and disabilities. These findings point to the need for reliable and valid measures to determine the effectiveness of respite services as well as to determine what it is about the services that makes them effective for some primary caregivers and their families and not for others.

Further exploration of the correlations between sources of informal help with the child's care and the group of respite variables is contained in Table 22. The respondent's happiness with the amount of help with their child's care is associated with more respite variables than their actual perception of the amount of help that they have from informal sources. Spousal (or partner) help is associated with enjoyment of the respondents' time with their child on both help scales. Happiness with the amount of help from the child's other parent (if not the respondent's partner or spouse) shows moderate relationships with the respondents time for her other children and her other family members. Happiness with the amount of non family help is positively associated with all of the respite variables except the respondent's enjoyment of their time with

Table 20

Kendall's tau-b rank order correlation coefficients of type of service used by respite variables

	Group Home	Host Family	Institutional respite	In home babysitting	In home formal respite	Summer camps	In home combined
Break from caregiving^{a}	.04 (n=55)	.11 (n=55)	.32** (n=55)	.04 (n=55)	.01 (n=55)	.15 (n=55)	.07 (n=55)
Time for self^{b}	.14 (n=55)	-.13 (n=55)	.05 (n=55)	-.07 (n=55)	-.01 (n=55)	.10 (n=55)	-.03 (n=55)
Time for spouse^{c}	-.07 (n=47)	.10 (n=47)	-.01 (n=47)	.17 (n=47)	.05 (n=47)	.17 (n=47)	.15 (n=47)
Time for other children^{c}	-.10 (n=50)	.08 (n=50)	.18 (n=50)	.06 (n=50)	.06 (n=50)	.02 (n=50)	.08 (n=50)
Time for other family^{c}	.01 (n=53)	.05 (n=53)	.03 (n=53)	.11 (n=53)	.11 (n=53)	.17 (n=53)	-.12 (n=53)
Enjoy time with child^{c}	-.20 (n=55)	-.14 (n=55)	.25* (n=55)	-.01 (n=55)	-.01 (n=55)	-.09 (n=55)	-.05 (n=55)

^{a}5 point scale where 1=no help and 5=all I could ask for ^{b}5 point scale where 1=not happy and 5=very happy
^{c}6 point scale where 1= never, 2=seldom, 3=sometimes, 4=often, 5=usually, and 6=always
*p<.05, two tailed. ** p<.01, two tailed.

Table 21

Kendall's tau-b rank order correlation coefficientsof help by respite variables

	Amount of help with child's care[a]				Happiness with amount of help with child's care[b]			
	Spouse[e]	Other[d]	Family	Non family	Spouse[e]	Other[d]	Family	Non family
Break from caregiving[c]	-.09 (n=50)	-.23 (n=17)	.08 (n=55)	.20 (n=55)	-.01 (n=49)	-.04 (n=19)	.23* (n=54)	.28* (n=53)
Time for self[c]	.15 (n=50)	.12 (n=19)	.10 (n=55)	.18 (n=55)	.16 (n=49)	.20 (n=19)	.14 (n=54)	.23* (n=53)
Time for partner[c]	.35* (n=46)	-.20 (n=16)	-10 (n=47)	.08 (n=47)	.38** (n=46)	.41 (n=16)	.32** (n=47)	.43*** (n=46)
Time for other children[c]	.20 (n=50)	-.05 (n=17)	.07 (n=50)	.02 (n=50)	.25* (n=45)	.50* (n=17)	.35** (n=49)	.24* (n=48)
Time for other family[c]	.12 (n=48)	-.08 (n=19)	.05 (n=53)	.24* (n=51)	.14 (n=47)	.47* (n=19)	.25 (n=52)	.25* (n=48)
Enjoy time with child[c]	.29* (n=50)	-.06 (n=19)	.20 (n=55)	.18 (n=55)	.27* (n=49)	.41 (n=16)	.26* (n=54)	.17 (n=53)

[a] 5 point scale where 1=no help and 5=all I could ask for. [b] 5 point scale where 1=not happy and 5=very happy.
[c] 6 point scale where 1= never, 2=seldom, 3=sometimes, 4=often, 5=usually, and 6=always.
[e] spouse or partner. [d] child's other parent(s)if different from partner or spouse.
*p<.05, two tailed. ** p<.01, two tailed. ***p<.001, two tailed.

their child. Interestingly, that the caregiver perceives a break from caregiving is related to her happiness with family and non family help, but not to spousal help. These relationships are clearly suggestive of the importance in investigating informal sources of help with the child's care when looking at respite services.

Summary of Results

The primary caregivers who responded to the questionnaire represented broad ranges of ages, educational statuses, and incomes thus resulting in a cross section of individuals from different socioeconomic strata. All were women, most were the child's mother, many were married, had other children living in their households, and most had at least a high school education. Many were also employed or attending school on at least a part time basis. These findings indicate that the primary caregivers who responded to the questionnaire have a number of roles beyond their role as the primary caregiver of a child with chronic illness and/or disabilities.

The children of the respondents all had requirements for care that were beyond those expected for other children of the same age for health maintenance, illness care, or rehabilitation. This was clearly evidenced in their primary caregivers descriptions of a typical caregiving day. Again a good variety of ages, abilities, and medical diagnoses were represented. All of the children were older than two years of age, therefore caregivers of infants with chronic illness and disabilities were not represented in the sample.

Issues that were identified in the literature review such as financial concerns, physical and psychological health concerns, and social isolation also appeared to be of concern to this sample of caregivers. That the extra costs that were related to their child's care resulted in financial difficulty for their families was unanimously identified by primary caregivers with incomes less than $30 000 per year as well as a number of the respondents who had higher incomes. Most respondents identified the cost of child care as among the extra costs that were present for their family. Fatigue was identified as the most common health concern, followed by back pain, trouble sleeping, anxiety, and depression. Finally, limited time for their other children, spouse or partner, family members, and especially themselves appeared to dominate the social picture for these primary caregivers.

Even though lack of time and fatigue were present for these primary caregivers, they did access a variety of respite services for their child, with most using more than one service. While the most frequently identified service took the form of in home care, out of home care, such as host family care, camps, group or residential care, and institutional care were also used. Changes in respite care with the growth of their children included an increasing need for use and increasing difficulty in finding appropriate caregivers. In the respite care that they currently use, many primary caregivers would increase available caregivers, increase access to respite, and increase the amount of time that they use respite.

An exploration of the amount of informal help with their child's care and the respondent's happiness with this amount of help revealed that primary caregivers perceived limited help from various social network members. Help from one's spouse or partner was moderate, while help from other family members and non-family members was indicated to be minimal for the majority of primary caregivers. Finally, when the child was part of a blended or foster family situation, help from their other parent or parents was close to none. For some of these caregivers, they identified that they were happy with the little or no help from the child's other parent, but most identified that they were not happy.

The majority of primary caregivers indicated that they had limited breaks from caregiving. Many felt that this was due to limited persons or agencies to provide child care, that they were unsure of the ability of others to provide care for their child, and that they lacked funding for respite care. These findings, coupled with the limited time that primary caregivers have for persons in their social network, indicate that, despite the fact that they are accessing various forms of respite services, they perceive little actual respite from caregiving.

Finally, an exploration of correlations among the variables points to possible patterns for future research. These patterns include possible relationships among: informal sources of help with the child's care and caregiver characteristics; informal sources of help with the child's care, parent child relationships, time for self, and time for others; informal sources of help with the child's care and perception of a break from caregiving; and type of respite service used and caregiver perception of adequate breaks from caregiving. Furthermore, the data gathered for this study support the view that child specific variables such as care needs, and hospitalizations show little evidence of relationships with time variables, respite variables, and amount of informal help with child care that the primary caregiver identifies.

Chapter 5

Discussion

The women described in this study are the primary caregivers of children with a broad range of needs for care. Most of the respondents were mothers, some were foster mothers, and others were grandmothers. Full and partial assistance with their child's activities of daily living, medication administration, physical therapy, behavioural modification, and constant monitoring or supervising are among the aspects of care that these primary caregivers attend to on a daily, hourly, even minute to minute, basis.

Three general areas of discussion arise from this study of primary caregivers: (1) their limited perceived break from caregiving and limited time for themselves and their family; (2) their lack of informal help with their child's care; and (3) their perception that the costs related to the child's care caused financial difficulty for their family. Questions raised by each of these findings will be addressed, summarized, and compared to current literature. This will be followed by implications for nursing and health care. Finally, strengths and limitations of the study and suggestions for future research will be discussed.

Findings, Questions, and Relevant Literature

The Experience of Respite: Where is it?

The main objective of respite care services is to provide respite or, as respite is defined, a break from caregiving. Although the respondents in this study identified that they used a variety of respite care services for their child, many had specific health concerns (including back pain and fatigue), had little time for themselves or other family members, and perceived that they did not have an adequate break from caregiving. Given these concerns, it can be concluded that these primary caregivers of children with chronic illness and disabilities are not experiencing adequate respite even though they are using respite care services.

Upsur (1979) described the difficulties that families encountered when obtaining respite services. Reasons for this difficulty included not knowing where to get help, reluctance to leave their child with strangers, lack of time to make arrangements, lack of quality of services, expense of care, and complexity of the child's care. Seventeen years later, a variety of respite care services have been established and primary caregivers may know how to access services, but they continue to identify similar difficulties in obtaining respite care. Furthermore, the feeling of respite as a break from caregiving was not present for these primary caregivers.

Strang (1995) found that the experience of respite for primary caregivers of persons with Alzheimer's Disease did not come from using a particular respite care service or even from the hours of care that they had. Their experience of respite came from changes in their environment which enabled them to rest or do other things without having to worry about the safety of the person that they were caring for. Similarly, for primary caregivers of children with chronic illness and disabilities, lack of trust in others to care for their child, inability to afford appropriate respite providers, and concerns about the quality of respite care create a situation where they can not leave their children with a respite care provider without worrying.

Informal Help With Child Care: Where is it?

Clearly, the primary caregivers who responded to the questionnaire utilize formal respite services but experience a limited sense of a break from caregiving. The data collected in this study simultaneously showed a lack of informal help with their child's care. Furthermore, correlational analysis hints at the possibility of a relationship between amount of informal help and respite variables. The ability to have a trusted family member or friend available to provide care for their child may lead to decreased worrying for the primary caregiver and an increased sense of a break from caregiving. The need for this care is essential for times when formal respite care is not available or inaccessable and, where it is present, essential for the primary caregiver to complete the day to day activities that most of us take for granted. For example, the ability to step out to the grocery store for a few minutes or go for a short walk with a friend may only be possible if a family member looks after the child while the primary caregiver is gone.

That informal help with their child's care is inadequate is well supported in the literature (Brust, Leonard, & Spienza, 1992; Stewart, Ritchie, McGrath, Thompson, & Bruce, 1995; Turner-Henson, 1993). For example, Marcenko and Meyers (1991), in their study of social support and mothers of children with developmental disabilities, found limited help with their child's care from various network members. These authors found that, while 96% of mothers rated help with child care as important, most indicated that this help was never or only sometimes received.

Research into the division of child care tasks between mothers and fathers indicate that mothers take on the majority of the caregiving tasks for their children with chronic illness and disabilities (Beresford, 1994; Bristol, Gallagher, and Schopler 1988; Marcenko & Meyers, 1991). This research is not surprising in light of the fact that, even in fairly typical families, studies have shown that male spouses are not doing an equitable share of daily household or child care tasks (Demo & Acock, 1993; Hawkins, Roberts, Christiansen & Marshall, 1994). This discrepancy in the division of household labor was constant across family types, including first marriage, remarriage, cohabiting partners, step families, and dual-and single-earner couples.

The "second shift" for working mothers that Hochschild (1989) identified is a risk for many of the respondents in this study. These primary caregivers were working full or part time, attending school, or looking for work in addition to meeting most of their child's care needs. Given that no association was found between the respondents' perceptions of the amount of help that they perceived and their employment status, a second shift at home with little help from others may be a reality for these women.

Financial Difficulties: In Canada?

The majority of the primary caregivers perceived that the costs related to their child's care resulted in financial difficulty for their families. While this finding was linked to the total family income of the primary caregiver, many respondents with higher incomes also identified that the costs incurred resulted in financial difficulty for their families. Child care for their children with chronic illness and disabilities was a commonly identified cost; however, hidden and even unmeasureable costs such as loss of work for the primary caregiver or other family member and child care for other children were among the extra costs perceived by the primary caregivers.

That financial difficulties may result from the needs that children with chronic illness and disabilities who are living at home appears to be a subject largely ignored in Canada. Given the concerns with the cost of raising a children with chronic illness and disabilities in the United States (Gabel, McDowell, & Cerreto, 1983) it is not surprizing that similar problems were found in a Canadian study. During a time of fiscal restraint, when dual incomes are required to meet the basic needs of many families and assistive technology, treatments, and professional services are expanding in both breadth and expense, Canadians can not assume that current methods of funding are meeting the financial needs of families of children with chronic illness and disabilities.

Implications for Nursing and Health Care

There are a number of implications for nursing and health care that arise from this study. First, the implications for nursing practice will be considered. This will be followed by implications for nursing education. Finally, implications for health policy and programs will be discussed. At this point it is important to emphasize that the findings of this research may not apply to the greater population of primary caregivers of children with chronic illness and disabilities who are using respite care due to the sampling design and small response rate. Hence, these implications for nursing need to be considered with the need for further verification in mind.

Nursing Practice

In addition to a limited sense of respite, primary caregivers who are using respite services indicate physical and psychological concerns. These concerns include fatigue, back pain, anxiety, and depression. Furthermore, a major challenge for primary caregivers is having adequate help from informal sources and finding appropriate respite care providers. Programs of nursing intervention must then address the health concerns of the primary caregivers, the facilitation of access to help from informal sources, and the provision of a formal respite component by adequately trained persons.

As a group, primary caregivers could be at risk for developing a number of health concerns that may be related to the physical and psychological challanges related to looking after their child. Nursing interventions that are targeted specifically for this group could involve assessment of specific health concerns and referral when appropriate, health promotion programs, caregiver to caregiver support groups, and individual counselling. Ideally, given the number of health related appointments that the primary caregiver attends for her child, these interventions could be conducted in conjunction with the child's appointments, in the primary caregiver's home, or with a formal respite component.

Given the current philosophy in health and social science to promote family and community involvement in the care of children with chronic illness and disabilities, there is a need to develop the required attitudes and skills in family members, friends, and neighbours so that they are able and willing to effectively help the child’s primary caregiver. Interventions that are geared to affecting attitudes and skills of these sources of informal help could involve enhancing spousal support by facilitating family problem solving, targeting specific groups in the child's community to promote inclusion of the child and family into existing programs, and providing workshops for the child's family and friends to learn how to safely attend to the child's specific needs.

While registered nurses with experience in child and family health may be ideal respite providers, few funding agencies and even fewer primary caregivers have the economic means to hire registered nurses as providers of respite. Because of this limitation, nurses' skills may be better utilized and more cost effective when supporting families in their decision to access respite care, facilitating access to respite care, addressing specific health concerns, and ensuring that quality respite practices are supported by research. Finally, nurses can take an active role in educating respite care providers.

Nursing Education

The lack of appropriately trained respite providers is a major concern for many primary caregivers and their families (Edgar, Reid, & Pious, 1988; Knoll & Bedford, 1989; Rimstant, 1983; Upsur, 1979). The best way to ensure that respite care providers can deliver safe and effective care for children and their families is to develop education programs specifically for respite providers. Also, to prepare nurses to advocate for families of children with chronic illness and disabilities and play a role in the delivery of respite services, respite, child, and family caregiving components need a place in undergraduate nursing education. Key areas of education for both nurses and respite providers would include knowledge, skills, and attitudes (Orem, 1995).

Knowledge. Knowledge about the needs of primary caregivers, their children, and their families is an important component of any education program. For care providers to respond effectively they need to know about health care needs of children with chronic illnesses and disabilities, assessment of health concerns of the child, primary caregiver, and other family members, family dynamics, the purpose of respite, and mobilization and enhancement of community supports. By knowing about these essential areas, care providers will be better prepared to enable primary caregivers and their families to access the respite care and other caregiving options that best suit their needs and best utilize their strengths and resources.

Skills. Communication skills, assessment skills, and psychomotor skills need to be developed to ensure that respite providers are safe and effective. Communication skills would include effective interacting with adults and developmentally appropriate communicating with children. Sign language would also be an asset, depending on the needs of the children and their families. Assessment skills would be focused on general child and family needs, as well as on changes in the child health status that would require professional intervention.

Finally, psychomotor skills would include assisting with or performing activities of daily living, managing behaviours, following a plan of rehabilitation therapy, administering medications, giving and monitoring gastrostomy feedings, carrying out bowel routines, and preventing skin breakdown. Preceptorship in the family home by a family caregiver and/or a health professional who knows the child and family could also focus on child and family specific needs.

Attitude. A positive attitude toward children, their primary caregivers, and their families must be fostered for all professionals and support workers who are interacting with families. The elements of family centred care that Shelton, Jeppson, and Johnson (1989) articulated are the gold standard of practice for persons working with children with chronic illness and disabilities and their families. These elements include: (1) recognition that the family is the constant in the child's life while the service systems and personal within those systems fluctuate; (2) facilitation of parent/professional collaboration at all levels of health care; (3) sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner; (4) implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families; (5) recognition of family strengths and individuality and respect for different methods of coping; (6) understanding and incorporating the developmental needs of infants, children, adolescents, and their families into health care delivery systems; (7) encouragement and facilitation of parent to parent support; (8) assurance that the design of health delivery systems is flexible, accessible and responsive to family needs; and (9) honouring of the racial, ethnic, cultural, and socioeconmic diversity of families. Nurses and respite providers who have a family-centred attitude would focus on promoting family competencies and decision making capabilities, building family strengths and abilities, and promoting the family's capacity to build a network of resources to meet their individual needs.

Health Policies and Programs

It appears that respite care may be necessary, but it is not a sufficient component of services to families of children with chronic illness and disabilities. To be effective, respite services must be embedded in larger programs that include funding, group activities, counselling, stress management, and other support options (Agosta & Melda, 1995; Covert, 1995). Furthermore, public policy needs to be focused on inclusion of children with chronic illness and disabilities into existing familial and community structures. Finally, program and policy development must be done in conjunction with children, their primary caregivers, and their families. This collaboration needs to happen at all levels of government and in all phases of planning, implementing, and evaluating policies and programs.

Historically, respite programs have been provided in isolation from other support services (Cernoch & Newhouse, 1997). By embedding respite programs in other family support and funding programs, coordinated care that is more responsive to the individual needs of children, their primary caregivers, and their families is possible. Ideally, control over what services the primary caregiver and family wish to access would then be accomplished through the provision of cash subsides to purchase services as they need them.

The role that family members, friends, neighbours, and community groups play in the care of children with chronic illness and disabilities needs to be realized, mobilized, and remunerated. The role that primary caregivers play in the care of their children must be acknowledged at a societal level. This can begin through remuneration or tax deductions for lost or potential employment, strategies for reducing the "second shift" for primary caregivers who choose to work, and other programs of formal recognition. By providing flexible funding for families of children with chronic illness and disabilities, they can purchase help from informal sources such as family members, friends, and existing community resources.

A number of strategies can be used to enable existing community resources to integrate services for children with chronic illness and disabilities and their families into existing programs. Grants for training personnel, adapting facilities, and collaborating between community agencies would make these resources accessible to children with chronic illness and disabilities and their families. Again, flexible funding to purchase services from general community resources for the child would ensure that the family can choose which services to use. Finally, charitable organizations could be encouraged to fund enhancements to existing community programs so that all people could take part. These strategies would not only mobilize essential help for the primary caregiver and family, but would increase community awareness of the strengths and resources of children with chronic illness and disabilities and their families.

To be effective and responsive to the needs of children with chronic illness and disabilities, a family centred attitude must be central to the development, implementation, and evaluation of policies and programs. This control over policies and programs needs to occur at the local, civic, provincial, and federal levels of community and governmental organizations. The importance of this participation is exemplified in the statement made by Agosta and Melda (1995):

> Actions leading to establishment of an effective family support system begin with the premise that family members must play a vital, if not leading role in the decision making process. Such action is consistent with contemporary thought regarding the need to empower families in ways to ensure the system is most responsive to families (p. 273).

Limitations, Strengths, and Directions for Future Research

Limitations

The primary limitation of this study is the inability to generalize to the larger population of primary caregivers who are using respite services due to non random sampling procedures. This means that the results are specific to the persons who responded to the questionnaire and may not apply to other caregivers. Another limitation is the small sample size which limits the power of statistical tests and may restrict future data analyses such as multiple regression and causal modelling. However, causal modelling has been successfully conducted on sample sizes as small as 50 subjects and new ways of modelling errors related to non-random sampling are discussed in the literature (Hayduk, 1987).

The low caregiver respondence rate to the questionnaire compounds the problems associated with a small sample size. The reasons for the low response rate may be that the primary caregivers were reluctant to discuss themselves and their child's care, that they were too busy to complete the questionnaire, that they felt stigmatized for using respite services, or that they did not perceive any benefit for their child or family in completing the questionnaire. Other reasons may involve literacy problems and language barriers. It should also be noted that the respondents tended to be older and reasonably well educated. Again this could be a result of the study design or social and environmental factors that prevented younger and less educated people from responding. However, the possibility of a sampling bias toward better educated and older primary caregivers remains a real possibility.

In a previous evaluation study conducted by the agency who sent the questionnaires, a response rate of only 18% was obtained even with follow up telephone reminders. This result indicates that the low response rate may be due to characteristics of the primary caregivers who are using respite services and not a fault of the study design. A second reminder letter may have slightly increased the response rate (Jackson, 1988). In communication with the agency who took the time to send the questionnaires it was clear that an extra reminder letter would have placed an extra burden on an already overworked agency staff.

Interestingly, there were no responses from primary caregivers of children under two years of age. Again this could be due to the aforementioned reasons, or that their primary caregivers have not tried to access formal respite services. Beresford (1994) notes that primary caregivers of younger children may still have an abundance of informal help with their child's care and may not feel that they need formal respite services. This should not be assumed however, as many primary caregivers and families of very young children may not even be aware of services or are reluctant to ask for help.

A final limit is that the nature of the questions permits an individual level perspective on a phenomenon that ultimately affects an entire family. A familial level investigation would illuminate challenges and joys present for all family members. However, given that the primary caregivers are mostly women, it must be assured that their unique concerns are not lost in a familial level study.

Strengths

A primary strength of this research study was to provide the opportunity for a large number of primary caregivers with children with chronic illness and disabilities to identify concerns, discuss their child's care, and anonymously discuss their respite care that they currently use. A mailed questionnaire ensured that they could complete it on their own time and think about the questions that they were being asked. The time and effort that went into completing the questionnaire by the 55 women who did respond was very evident. Most importantly, this study illuminates a number of concerns that primary caregivers of children with chronic illness and disabilities who are using respite have and provides direction for nursing practice, nursing education, health care policy and administration, and nursing research.

Direction for Future Research

Because much is assumed and little is known about the effects of respite care on primary caregivers, their children, and their families, there are a number of avenues that nursing research can take. Given the lack of informal help with their child's care, health concerns of the primary caregivers who are using respite care, and limited break from caregiving that the respondents perceived in this study, further descriptive and correlational research into these areas with a greater emphasis on generalizing the findings is necessary.

Valid and reliable outcome measures of adequate respite care also need to be further enunciated and tested. Ideally, such measures would include not only the perceptions of the primary caregiver, but those of the family, child, informal community of support persons, and respite care providers. Furthermore, the measures may vary depending on the expectations for respite and the strengths and needs of the persons involved in the study.

Interventions that are focused on mobilizing, promoting, and enhancing the informal help that primary caregivers have could be developed and evaluated in conjunction with formal respite programs. Furthermore, specific modalities of respite care such as in home respite, group home respite, and institutional respite need to be examined as to what aspects of these types of respite care suit the needs of different children, primary caregivers, and families. New alternatives to forms of respite that are currently in place will also need testing and evaluation. Comparisons between users and non-users of respite care or between those using a service and those on a waiting list for service could be made. A repeated measures approach may be appropriate for studies to evaluate the effectiveness of respite programs over time. Ultimately, a model of respite care and informal help with caregiving, such as the conceptual framework that was used to guide this study, would be substantiated and used to guide our thinking about respite for families of children with chronic illness and disabilities.

References

Agosta, J., & Melda, K. (1995). Supporting families who provide support at home for children with disabilities. Exceptional children, 62 (3), 271-282.

Abbott, D. A., & Meredith, W. H. (1986). Strengths of families with retarded children. Family Relations, 35, 371-375.

Anderson, J.M. (1990). Home care management in chronic illness and the self-care movement: An analysis of ideologies and economic processes influencing policy decisions. Advances in Nursing Science, 12 (2), 71-83.

Beresford, B.A. (1994). Resources and strategies: How parents cope with the care of a disabled child. Journal of Child Psychology and Psychiatry, 35, (1), 171-209.

Bergman, A.L. & Singer, G.H.S. (1996). The thinking behind new public policy. In G.H.S. Singer, L.E. Powers, & A.L. Olson (Eds.), Redefining family support: Innovations in public-private partnerships (pp. 435-464). Baltimore, MD: Paul H. Brookes Publishing Company.

Botuck, S., & Winsberg, B.G. (1991). Effects on mothers of school-age and adult children with severe disabilities. Mental Retardation, 29 (1), 43-47.

Bradburn, N.M. (1969). The structure of psychological well-being. Chicago, IL: Alding Publishing Company.

Brink, P.J., & Wood, M.J. (1994). Descriptive designs. In P.J. Brink and M.J.Wood (Eds), Basic steps in planning nursing research: From question to proposal (4th ed.) p.p.123-140 Boston MS: Jones-Bartlett.

Bristol, M., Gallagher, J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and non disabled boys: Adaptation and spousal support. Developmentai Psychology, 24 (3), 441-451.

Bull, M.J. (1990). Factors influencing family caregiver burden and health. Western Journal of Nursing Research, 12 (6), 758-776.

Cadman, D., Rosenbaum, P., Boyle, M., & Offord, D. (1991). Children with chronic illness: Family and parent demographic characteristics and psychosocial adjustment. Pediatrics, 87 (6), 884-889.

Cairns, I. (1992). The health of mothers and fathers with a child with a disability. Health Visitor, 65 (7), 238-239.

Canam, C. (1987). Coping with feelings: Chronically ill children and their families. Nursing Papers, 19 (3), 9-21.

Canam, C. (1993). Common adaptive tasks facing parents of children with chronic conditions. Journal of Advanced Nursing, 18, 46-53.

Cernoch, J.M., & Newhouse, E.E. (1997). Respite care: Support for families in the community. In H.M. Wallace, R.F. Biehl, J.C. MacQueen, & J.A. Blackman (Eds). Mosby's resource guide to children with disabilities and chronic illness. St. Louis, MS: Mosby.

Cohen, J. (1988). Statistical power analysis for the behavioural sciences. Second edition. Hillsdale, NJ: Lawrence Erlbaum Associates.

Cohen, M.H. (1995). The triggers of heightened parental uncertainty in chronic, life-threatening childhood illness. Qualitative Health Research, 5(1), 63-77.

Cohen, S., & Warren, R.D. (1987). Preliminary survey of family abuse of children served by United Cerebral Palsy Centres. Developmental Medicine and Child Neurology, 29 (1), 12-18.

Cohen, S. (1995). Whatever it takes: Examples of excellence in family support. St. Agustine, FL: TRN.

Damarosch, S., & Perry, L. (1989). Self-reported adjustment, chronic sorrow, and coping of parents of children with Down Syndrome. Nursing Research, 38, 25-30.

Derogatis, L., & Melisaratos, N. (1983). The Brief Symptom Inventory: An introductory report. Psychological Medicine, 13, 595-605.

Diehl, S., Moffitt, K., & Wade, S., (1991). Focus group interviews of parents of children with medically complex needs: An intimate look at their perceptions and feelings. Children's Health Care, 20(3), 170-178.

Dossetor, D. R., Nicol, A. R., & Stretch, D. D. (1993).Hostel-based respite care for adolescent with developmental retardation: The need for "normalized"respite resources. Journal of Child Psychology and Psychiatry, 34(3), 391-412.

Edgar, E. B., Reid, P. C., & Pious, C. C. (1988). Special sitter: Youth as respite care providers. Mental Retardation, 26 (1), 33-37.

Factor, D. C., Perry, A., & Freeman, N. (1990). Brief report: Stress, social support, and respite care using families with autistic children. Journal of Autism and Developmental Disorders, 20 (1), 139-146.

Failla, S., & Jones, L. (1991). Families of children with developmental disabilities: An examination of family hardiness. Research in Nursing and Health, 14, 41-50.

Featherstone, H. (1980). A Difference in the Family: Life with a Disabled Child. New York: Basic Books.

Fisman, S.N., Wolf, L.C., & Noh, S. (1989). Marital intimacy in parents of exceptional children. Canadian Journal of Psychiatry, 34 (6), 519-525.

Florian, V., & Krulik, T. (1991). Loneliness and social support of mothers of chronically ill children. Social Science Medicine, 32 (11), 1291-1296.

Friesen, B.J. (1996). Family support in child and adult mental health. In G.H.S. Singer, L.E. Powers, & A.L. Olson (Eds.), Redefining family support: Innovations in public-private partnerships (pp.239-258). Baltimore, MD: Paul H. Brookes Publishing Company.

Gabel, H., McDowell, J., & Cerreto, M.C. (1983). Family adaptation to the handicapped infant. In S.G. Garwood & R.R. Fewell (Eds.), Educating

Handicapped Infants: Issues in Development and Intervention (pp. 455-493). Rockville, MA; Aspen Publications.

Grant, G., & McGrath, M. (1990). Need for respite care services for caregivers of persons with mental retardation. American Journal on Mental Retardation, 94 (6), 638-648.

Harvey, L., Avard, D., Graham, I., Underwood, K., Campbell, J., & Kelly, C. (1994). The health of Canada's children: A CICH profile, second edition. Ottawa ON: Canadian Institute of Child health.

Hauenstein, E.J. (1990). The experience of distress in parents of chronically ill children: Potential or likely outcome? Journal of Clinical Child Psychology, 19(4), 356-364.

Hayduk, L.A. (1987). Structural equation modeling with LISREL: Essentials and advances. Baltimore, MA: Johns Hopkins University Press.

Hayes, V.E. (1992). The impact of a child's chronic condition on the family system. Unpublished doctoral dissertation: University of California at San Francisco.

Hochschild, A. (1989). The second shift. New York, NY: Viking.

Hymovich, D.A. (1984). Development of the chronicity impact and coping instrument: Parent Questionnaire (CICI:PQ). Nursing Research, 33 (4), 218-222.

Jackson, W. (1988). Research methods: Rules for survey design and analysis. Scarborough, ON: Prentice-Hall Canada Inc.

Jessop, D.J., Riessman, C.K., & Stein, R.E.K. (1988). Chronic childhood illness and maternal mental health. Journal of Developmental and Behavioral Pediatrics, 9, 147-156.

Kazak, A., & Marvin, R. (1984). Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. Family Relations, 33, 67-77.

Kirkham, M., Schilling, R., Norelius, K., & Schinke, S. (1986). Developing coping styles and social support networks: An intervention outcome study with mothers of handicapped children. Child: Care, Health, and Development, 12, 313-323.

Knoll, J., & Bedford, S. (1989). Respite services: A national survey of parent's experience. Exceptional Parent, 6, 34-37.

Leonard, B.J., Brust, J.D., & Nelson, R.P. (1993). Parental distress: Caring for medically fragile children at home. Journal of Pediatric Nursing, 8 (1), 22-29.

Leonard, B.J., Brust, J.D., & Spienza, J.J. (1992). Financial and time costs to parents of severely disabled children. Public Health Reports, 107(3), 302-312.

Lindgren, C.L. (1990). Burnout and social support in family caregivers. Western Journal of Nursing Research, 12(4), 469 - 487.

Lonsdale, G. (1978). Family life with a handicapped child: The parents speak. Child: Care, Health and Development, 4 , 99-120.

Marc, D. L., & MacDonald, L. (1988). Respite care-Who use it?. Mental Retardation 29(2), 93-96.

Marcenko, M.O., & Meyers, J.C. (1991). Mothers of children with developmental disabilities: Who shares the burden? Family Relations, 40, 186-190.

McAnear, S. (1990). Parental reaction to a chronically ill child. Home Healthcare Nurse, 8(3), 35-40.

McCubbin, H. I., & McCubbin, M. A. (1988). Typologies of resilient families: Emerging roles of social class and ethnicity. Family Relations, 37, 247-254.

McCubbin, H.I. & McCubbin, M.A. (1993). Families coping with illness: The resiliency model of family stress, adjustment, and adaptation. In C.B. Danielson, B. Hamel-Bisscll, & P. Winstead-Fry (Eds.), Families, health, and illness: Perspectives on coping and intervention (pp.21-61). St Louis, MS: Mosby.

Norten, P., & Drew, C. (1994). Autism and potential family stressors. The American Journal of Family Therapy, 22(1), 67-76.

Orem, D.E. (1995). Nursing: Concepts and practice. St.Louis, MS: Mosby.

Perrin, E.C., Newacheck, P., Pless, B., Drotar, D., Gortmaker, S.L., Leventhal, J., Perrin, J.M., Stein, R., Walker, D.K., & Weitzman, M. (1993). Issues involved in the definition and classification of chronic health conditions Pediatrics, 91(4), 787-793.

Petersen, P. (1984). Effects of moderator variables in reducing stress outcome in mothers of children with handicaps. Journal of Psychosomatic Research, 28(4), 337-344.

Phillips, M. (1990). Support groups for parents of chronically ill children. Pediatric Nursing, 16 (4), 404-406.

Ray, L.D. (1988). Parents' perceptions of coping with the burdensome home care of their chronically ill child. Unpublished master's thesis, Dalhousie University, Halifax, Nova Scotia.

Ray, L.D., & Ritchie, J.A. (1993). Caring for chronically ill children at home: Factors that influence parents' coping. Journal of Pediatric Nursing, 8 (4), 217-225.

Rimmerman, A. (1989). Provision of respite care for children with developmental disabilities: Changes in maternal coping and stress over time. Mental Retardation, 27 (2).99-103.

Russell, T. (1984). Respite care: A means of rest and recuperation for parents of retarded individuals. The Pointer, 28(3), 4-7.

Salisbury, C. L. (1990). Characteristics of users and non-users of respite care. Mental Retardation, 28 (5), 291-297.

Satterwhite, B.S. (1978). Impact of chronic illness on child and family: An overview based on five surveys with implications for management. International Journal of Rehabilitation Research, 1 (1), 7-17.

Schwartz, V. (1993). Respite care in a geriatric rehabilitation hospital: A support system for caregivers of the disabled elderly. Social Work in Health Care, 18, 193-200.

Seligman, M., & Darling, R.B. (1989). Ordinary families, special children: A systems approach to childhood disability. New York: The Guilford Press.

Sherman, B.R. (1995). Impact of home-based respite care on families of children with chronic illnesses. Children's Health Care,24 (1), 33-45.

Short-DeGraff, M. A.,& Kologinsky, E. (1987). Respite care: Roles for therapists in support of families with handicapped children. Physical and Occupational Therapy in Pediatrics, 7 (4), 3-18.

Siegel, S., & Castellan, N.J. (1988). Nonparametric statistics for the behavioral sciences. Second edition. New York, NY: McGraw Hill Book Company.

Singhi, P.D., Goyal, L., Pershad, D., Sunit, S., & Walia, B. (1990). Psychosocial problems in families of disabled children. British Journal of Medical Psychology, 63, 173-182.

Smith, M.J., Caro, F.G., & McKaig, K. (1988). The role of home care service in family care of developmentally disabled children: An exploratory study. Home Health Care Services Quarterly, 9(1), 117-133.

Snowdon, A.W., Cameron, S., & Dunham, K. (1994). Relationships between stress, coping resources, and satisfaction with family functioning in families of children with disabilities. Canadian Journal of Nursing Research, 26(3), 63-76.

Starkey, J., & Sarli, P. (1989). Respite and family support services: Responding to the need. Child and Adolescent Social Work Journal, 6 (4), 313-326.

Statistics Canada (1991). Health and activity limitations survey. Ottawa Ontario: Author.

Stein, R., & Riessman, C. (1980). The development of an impact on family scale: Preliminary findings. Medical Care, 18, 465-472.

Stewart, M.J., Ritchie, J.A., McGrath, P., Thompson, D., & Bruce, B. (1995). Mothers of children with chronic conditions: Supportive and stressful interactions with partners and professionals regarding caregiving burdens. Canadian Journal of Nursing Research, 26 (4) 61-81.

Starkey, J., & Sarli, P. (1989). Respite and family support services: Responding to the need. Child and Adolescent Social Work Journal, 6(4), 313-326.

Strang, V. (1995). The experience of respite for caregivers of dementia persons. Unpublished doctoral dissertation, University of Alberta.

Subramanian, K. (1985). Reducing child abuse through respite centre intervention. Child Welfare, 55(5), 501-509.

Taylor, E.H. (1995). Understanding and helping families with neurodevelopmental and neuropsychiatric special needs. Pediatric Clinics of North America, 42(1), 143-151.

Traustadottir, R. (1991). Mothers who care: Gender, disability, and family life. Journal of Family Issues, 12(2), 211-228.

Turnbull, A. P., & Turnbull, H. R. (1990). Families, professionals, and exceptionality: A special partnership (2nd ed.). Columbus, OH: Merrill.

Turner-Henson, A. (1993). Mothers of chronically ill children and perceptions of environmental variables. Issues in Comprehensive Pediatric Nursing, 16, 63-76.

Turner-Hensen, A., Holaday, B., & Swan, J.H. (1992). When parenting becomes caregiving: Caring for the chronically ill child. Family & Community Health, 15(2), 19-30.

Upshur, C.C. (1983). Developing respite care: A support service for families with disabled members. Family Relations, 32, 13-20.

Wallander, J.L., & Noojin, A.B. (1995). Mothers' report of stressful experiences related to having a child with a physical disability. Children's Health Care, 24 (4), 245-256.

Wood, T., Siegel, L.J.,& Scott, R.L. (1991). A comparison of stress and marital adjustment with families of chronically ill, handicapped and non-ill/non-handicapped children. B.C. Journal of Special Education, 15 (3), 231-239.

Zimmermann, M. & Walker, D. (1996). Best practices in respite services for children: A guide for families policy makers and program developers. Ottawa, ON: Canadian Association for Relief Care.

Appendix A

Correspondence

University of Alberta
Edmonton
Canada T6G 2G3

Faculty of Nursing
3rd Floor Clinical Sciences Building

Letter of Introduction

Project Title: Caregivers of Children With Special Needs

Dear Parent/Caregiver,

Caring for a child with special needs at home can be a challenge. Parents or caregivers who care for their children are the best people to tell us about this care. In the enclosed questionnaire, we ask parents and caregivers to tell us about:

- themselves.
- the help they have.
- their child's care needs.

We ask that the parent or caregiver who looks after the child the most, complete this questionnaire. This information will help us to know about the caregiving activities of parents and caregivers. It will also be useful for planning relief programs, educating relief workers, and evaluating services.

has sent you this questionnaire on our behalf. We do not have your name or address. Your participation is important to us. If you have any questions, please call Susan Neufeld or Jane Drummond at 492-6410.

Thank you for considering participation in this study. We look forward to your response.
Sincerely,

Susan Neufeld, RN, MN Candidate
and

Jane Drummond

Jane Drummond, RN, Ph.D
Professor, Faculty of Nursing

University of Alberta
Edmonton
Canada T6G 2G3

Faculty of Nursing
3rd Floor Clinical Sciences Building

July 14, 1996

Project Title: Caregivers of Children With Special Needs

Dear Parent/Caregiver,

On our behalf, sent you a questionnaire about caring for a child with special needs.

- If you have sent in your responses, we want to thank you.
- If you have decided not to be in the study, we also want to thank you for your consideration.
- If you have not returned the questionnaire yet, please do so at your convenience.
- If you did not receive the questionnaire or need another one, please call Susan Neufeld or Jane Drummond at 492-6410.

We understand how busy life with children can be. We appreciate the time you have given us.

Sincerely,

Susan Neufeld

Susan Neufeld, RN, MN Student

and

Jane Drummond

Jane Drummond, RN, Ph.D
Professor, Faculty of Nursing

Appendix B

Questionnaire

Project Title

Caregivers of Children With Special Needs

investigator

Susan Neufeld, RN,
MN Candidate

Faculty of Nursing
3rd Floor Clinical Sciences Building
University of Alberta
Edmonton, Alberta
T6G 2G3

supervisor

Jane Drummond, RN, Ph.D

Faculty of Nursing
3rd Floor Clinical Sciences Building
University of Alberta
Edmonton, Alberta
T6G 2G3

Project Title

Caregivers of Children With Special Needs

Information For Parents and Caregivers

Thank you for considering participation in this study. The following is about the study and questions you may ask. Please read this information carefully before completing the questionnaire.

Participation

The parent or caregiver who looks after the child the most is asked to complete the questionnaire.

It will take about 30 - 45 minutes to finish.

Do not write your name on the questionnaire. This is so that your identity cannot be linked to your questionnaire.

You do not have to answer any questions you do not want to.

Cross out any questions that you do not want to answer.

Write N/A beside questions that do not apply to you.

Please try to return the questionnaire before **August 15, 1996.** The back of this booklet is stamped and self-addressed. Simply fold the questionnaire in half, addressed side out, and seal with tape or staples. The return of the questionnaire means you are willing to be in the study.

You do not have to complete the questionnaire if you do not want to. Your services from Coordinating Access for Relief Care will not be affected whether or not you return the questionnaire.

To receive a summary of study results, please complete the enclosed card. It can be mailed separately so your name is not linked to your questionnaire.

What are the risks and benefits of being in the study?

There are no individual risks or benefits of being in the study. We hope that the results will improve services and care for children and their families.

What will happen to the information?

Your name will not be used in this study. Only a code number will appear on any forms or question sheets.

All written answers will be kept in a locked cabinet for at least 7 years.

We will not name you in any articles or presentations about the study.

If other researchers want to use the information in the future, they will need to get further ethical approval.

Who is doing this study?

Susan Neufeld is a Master's of Nursing student at the University of Alberta. Dr. Jane Drummond is her supervisor.

If you have any questions, call Susan Neufeld or Jane Drummond at 492-6410.

Section One

These questions are about your child with special needs

1. Child's Date of Birth ___ / ___ / ___ (day month year) 2. Child's Sex: ☐ Male ☐ Female

3. Child's Medical Diagnosis/Condition (if known) ______________________________

4. List and describe programs, treatments, and other special care that your child needs on a usual day.

Morning:

Afternoon:

Evening:

Night:

5. How many hours a day do you spend attending to the care needs of your child? Circle:

1	2	3	4	5	6
no hours	1-3 hours	4-7 hours	8-11 hours	12-15 hours	16+ hours

6. In the past 12 months, how many times has your child required hospitalization? _____

What is the total number of days that your child spent in the hospital in the last 12 months? _____

7. In the past 12 months, how many times has your child had doctor's or other health related appointments? _____

8. Many families of children with special needs find they have financial costs beyond the costs of raising other children. What costs are present for your family? Check all that apply:

☐ Medication
☐ Equipment and supplies
☐ Transportation / parking
☐ Loss of work for yourself
☐ Loss of work for another family member

☐ Child care for the child with special needs
☐ Child care for other children
☐ Other (specify) ______________________
☐ No extra costs are present

Do these costs cause financial difficulty for your family?

☐ No ☐ Yes

Section Two

These questions are about the help that you have to look after your child with special needs

The next questions are about the help that you have to look after your child with special needs. The questions begin with informal types of help. Then there are questions about the formal services and the relief or respite care that you use. By relief or respite care we mean care for your child that allows you to rest or to do other activities. Relief or respite care can range from a few hours to even a few weeks at a time. It can take place either in your home or outside your home.

1a. How much help with your child's care do you get from *your spouse or partner?* Circle:

1	2	3	4	5
none				all I could ask for

1b. Are you happy with this amount of help? Circle:

1	2	3	4	5
not happy				very happy

Answer question 2 only if the child's other parent (or parents) is not your spouse or partner. Otherwise go ahead to question 3.

2a. How much help with your child's care do you get from *your child's other parent or parents.* Circle:

1	2	3	4	5
none				all I could ask for

2b. Are you happy with this amount of help? Circle:

1	2	3	4	5
not happy				very happy

3a. How much help with your child's care do you get from *other family members?* For example: the child's siblings; grandparents; aunts; and uncles? Circle:

1	2	3	4	5
none				all I could ask for

3b. Are you happy with this amount of help? Circle:

1	2	3	4	5
not happy				very happy

4a. How much help with your child's care do you get from *non-family members?* For example: friends and neighbours. Circle:

1	2	3	4	5
none				all I could ask for

4b. Are you happy with this amount of help? Circle:

1	2	3	4	5
not happy				very happy

9. Below are programs or services that children with special needs and their families may use. Indicate the ones that you use and the amount of time your child spends in them. In the "Time Spent" column, write: hours/day, days/week, days/month, weekends, days/year, or weeks/year.

Program Type	**Check If Used In The Past 12 Months**	**Time Spent**
School or Education Program	☐	________
Host family	☐	________
In home respite/ home relief care	☐	________
Regular in home babysitting	☐	________
Day program / day care	☐	________
Camps	☐	________
Residential relief care / group home	☐	________
Institutional relief care (ie. Rosecrest, nursing home)	☐	________
Other (specify) ________________	☐	________
Other (specify) ________________	☐	________

10. Do you feel that you have enough of a break from caring for your child with special needs? Circle:

1	2	3	4	5	6
never	seldom	sometimes	often	usually	always

What reasons prevent you getting the time off you need? Check all that apply.

☐ Do not know enough about available services
☐ Lack of people or agencies to provide child care
☐ Child's behavioural or physical needs are not accommodated
☐ Lack of funding
☐ Unsure if "others" can care for your child properly
☐ Do not want any services
☐ Other (specify)________________________
____

11. What would you change about the child care, respite care, or relief care that you currently use?

12. How has your use of relief or respite care changed as your child has grown older?

13. Parents and caregivers often ask for relief or respite care so that they can have time to do other activities. Relief or respite care may also help to increase the quality time they have to spend with their child. Below are statements that may reflect feelings that you have about your time with your child and the time you have for others. Circle how often the statements below describe you.

I enjoy the time that I spend with my child with special needs.

1	2	3	4	5	6
never	seldom	sometimes	often	usually	always

I have time to spend with my partner or spouse.

1	2	3	4	5	6
never	seldom	sometimes	often	usually	always

I have time for my other children.

1	2	3	4	5	6
never	seldom	sometimes	often	usually	always

I have time for other family members

1	2	3	4	5	6
never	seldom	sometimes	often	usually	always

I have time to do things for myself.

1	2	3	4	5	6
never	seldom	sometimes	often	usually	always

Section Three

These questions are about you and your family

These last questions are about you and your family. We will use your answers to these questions to provide a general description of the people who respond to this questionairre. We also ask these questions so that our results can be compared to the results of other researchers.

1. Your Date of Birth / / (day month year)

2. Your Sex: ☐ Male ☐ Female

3. Your relationship to the child with special needs ____________________

4. Are you the family member who looks after your child the most? Check: ☐ Yes ☐ No

If No, who looks after your child the most? ____________________

5. What is the highest grade or year of school that you have completed? ______________________

6. What is your current Marital status? Check:

- ☐ Common Law
- ☐ Divorced
- ☐ Married
- ☐ Never married (single)
- ☐ Separated
- ☐ Widowed

7. What is your employment status? Check:

- ☐ Employed Full Time
- ☐ Employed Part Time
- ☐ Full Time Student
- ☐ Part Time Student
- ☐ Not employed / not looking for employment
- ☐ Not employed / looking for employment

8. What is your total family income, before taxes, in 1995? Check:

- ☐ less than $10 000
- ☐ $10 000 - 19 999
- ☐ $20 000 - 29 999
- ☐ $30 000 - 39 999
- ☐ $40 000 - 49 999
- ☐ $50 000 -59 999
- ☐ greater than $59 999

9. Total number of children living in your home: ________

What are the ages of the children: ________ ________ ________ ________ ________

10. Have you had any of the following health concerns in the last 12 months? Check:

- ☐ back pain
- ☐ high blood pressure
- ☐ trouble sleeping
- ☐ anxiety
- ☐ depression
- ☐ fatigue
- ☐ other (specify) ______________________

____

11. Overall, how would you rate your health? Circle:

1	2	3	4	5
poor	fair	good	very good	excellent

12. The remaining space is for you to share what you want about yourself, your child, or the help you have to look after your child.

Tape or Staple Closed *Tape or Staple Closed*

Fold along the line so the address is on the outside.

University
of
Alberta

Susan Neufeld RN, MN Candidate

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University of Alberta
Edmonton, AB
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Appendix C

Ethical Approval

University of Alberta
Edmonton
Canada T6G 2G3

Faculty of Nursing
3rd Floor Clinical Sciences Building

Certification of Ethical Acceptability for Research Involving Human Subjects

NAME OF APPLICANT(S): Susan Neufeld, MN Candidate

TITLE OF PROJECT: "Caregivers of Children with Special Care Needs: A Descriptive Study of Caregiving and Respite"

The members of the review committee, having examined the application for the above named project, consider the procedures, as outlined by the applicants, to be acceptable on ethical grounds for research involving human subjects.

May 8. 1996
Date

Marion Allen, PhD
Interim Chair, Ethics Review Committee

ERC 96-082
5005-02-082