

# **Mothers of Children with Chronic Conditions: Supportive and Stressful Interactions with Partners and Professionals Regarding Caregiving Burdens**

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Quatre-vingt-dix mères ont évalué les différentes sources et types de soutien social qui les ont aidées par rapport aux diverses exigences de soins pour un enfant atteint d'une maladie chronique. Les données qualitatives ont été collectées au cours d'entrevues à domicile de mères qui ont des enfants souffrant de diabète, de spina-bifida ou de fibrose kystique. Pratiquement toutes les mères ont décrit les exigences de soins primaires comme étant directement liées à la maladie de l'enfant, à savoir les soins physiques, les soins de santé liés à la maladie, et le développement psychologique et social de l'enfant. De nombreuses mères ont également indiqué qu'elles n'avaient pas assez de temps pour satisfaire à leurs propres besoins secondaires, pour remplir leur rôle dans la famille et au sein de leurs relations, et pour leurs activités de mère en dehors du foyer. Les mères ont fait état de lacunes dans le soutien offert pour le fardeau de soins particuliers. Elles ont rencontré des interactions stressantes avec leurs partenaires et surtout avec les professionnels de la santé.

Ninety mothers appraised the specific sources and types of social support they received in relation to specific types of demands of caring for a child with a chronic condition. Qualitative data were collected during home interviews with the mothers of children with diabetes, spina bifida, or cystic fibrosis. Virtually all of the mothers described primary caregiver demands that were directly related to the child's condition, such as physical care, health care in illness situations, and the child's psychological and social development. Many mothers also reported secondary demands related to their own needs, family roles and relationships, and the mother's activities outside the home. Mothers experienced gaps in the support provided for specific caregiving burdens and encountered stressful interactions with their partners and health professionals in particular.

An estimated 31% of children are affected by chronic conditions (Newachuk & Taylor, 1992). Increasingly, their families have become the primary caregivers, even for children who require very complex care (Desquin, Holt & McCarthy, 1994). Although both parents share the emotional impact of the child's condition, most caregiving is provided by mothers (Anderson & Elfert, 1989; Kazak & Marvin, 1984). Such mothers report the physical and psycho-

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logical strain of caring for their children at home (Havermans & Eiser, 1991; Patterson, Leonard & Titus, 1992), and are at increased risk for health problems such as depression, anxiety, loneliness, and role strain (Florian & Krulik, 1991; Kronenberger & Thompson, 1992; Miller, Gordon, Daniele & Diller, 1992; Quittner, DeGirolamo, Michel & Eigen, 1992; Thompson, Gustafson, Hamlett & Spock, 1992; Vandagriff, Marrero, Ingersoll & Fineberg, 1992). Psychological and social variables such as social support influence women's mental and physical health (Maguire, 1991; Rodin & Ickovics, 1990; Sorensen & Verbrugge, 1987). Social support has an impact on health status, health behaviour, and health services use (Bloom, 1990; House, Umberson, & Landis, 1988). Although support is a key determinant of health and mechanism of health promotion (Rootman & Raeburn, 1994), very little work has been done to identify the nature of social support that mothers experience with respect to particular caregiving burdens. Therefore, the purpose of the current study was to describe the sources, types, and appraisal of social support that mothers received in relation to specific types of demands of having a child with a chronic condition.

### **Conceptual Framework**

The study was based on a conceptualization of social support as a coping resource or source of assistance in coping with stressful situations (Folkman, Chesney, McKusick, Ironson, Johnson & Coates, 1991; Thoits, 1986) and, in particular, the burden associated with the care of children with chronic conditions. Social support, like other coping resources, can lessen the impact of chronically stressful conditions and acute stressors on the health of the caregiver. It can have direct, indirect, and interactive effects on physical and mental health (Bloom, 1990; Dunkel-Schetter & Bennett, 1990; Eckenrode & Gore, 1990; House et al., 1988). For the purposes of this study, social support was defined as a dynamic social process between people in relationships, and consisted of emotional, affirmational, instrumental, and informational assistance provided by family, friends, neighbours, co-workers, indigenous lay helpers, volunteers, self-help mutual aid groups, and health professionals (House et al., 1988).

It is important to distinguish the psychological sense of support from the actual expression and exchange of support (Gottlieb & Selby, 1989): The former may be perceived as potentially available from the social network; the latter, actually delivered and received. Perceived support influences how supportive transactions are interpreted and remembered (Heller, Swindle & Dusenbury, 1986; Lakey & Cassady, 1990). Received support is the recipients' view of support that comes from others (Sarason, Sarason & Pierce, 1990).

Interactions with others can be appraised as stressful or supportive (Coyne & Downey, 1991; Coyne, Wortman & Lehman 1988; Gottlieb & Selby, 1989). Most social relationships have both elements because of conflict and obligations for reciprocity (Buunk & Hoorens, 1992; Rook, 1990). It could be useful to construe negative interactions as interpersonal stress (Coyne & Bulger, 1990; Shinn, Lehmann & Wong, 1984). Conflicted support differs from a negative social relationship in that providers offer at least one positive form of support (Barrera & Bacash, 1990). Even successful intimate relationships involve some conflict between partners, including lapses or miscarried support efforts (Coyne et al., 1988; Sarason, et al., 1990), and failed support modes or functions (Eckenrode & Gore, 1990). Reports of low support may often signify the presence of a negative conflictive relationship (Coyne & Downey, 1991). In the current study, the terms conflicted support, absent support, and miscarried support were used to classify problems experienced with support.

### **Literature Review**

Women are more likely than men to be caregivers of relatives (e.g., Lee, 1992; Stoller, 1992; Walker, 1992). A prospective, longitudinal study of women following childbirth revealed that they assume the majority of household responsibilities and child care despite employment, yet receive little emotional support from spouses and others (Gjerdingen & Chaloner, 1994). Tiedje and Darling-Fisher (1993) report that fathers are more likely than mothers to engage in play activities with children.

Mothers' needs for support in caring for ill children have not been studied in depth, despite research that has concluded that social support contributes significantly to such outcomes as the child's behaviour (Hamlett, Pellegrini & Katz, 1992), management of the child's illness (Gibson, 1986), maternal satisfaction (Fagan & Schor, 1993), and ability to manage other family responsibilities (Miller & Diao, 1987). Mothers of disabled children ranked social support as the most important need in managing their child's care (Bailey, Blasco & Simeonsson, 1992). While there are a number of reports suggesting that mothers of children with chronic conditions are at risk for poor mental or physical health (Fagan & Schor, 1993; Florian & Krulik, 1991; Kronenberger, Thompson, 1992; Stein & Jessop, 1984; Thompson, Gustafson, Hamlett & Spock, 1992), little is known about the role of social support in facilitating the mother's adjustment (Eiser, 1990).

Some coping strategies that mothers have reported are dependent on their interactions with family members, friends, health professionals, and other associates. These include seeking information, confiding in others, and seeking guidance (Damrosch & Perry, 1989; Gibson, 1986; Ray, 1988). Several researchers have reported that the major types of support needed or received

by mothers of children with chronic conditions are informational and emotional support (Bailey, Blasco & Simeonsson, 1992; Barbarin, Hughes & Chesler, 1985; Brenner, Norwell & Limacher, 1989; Damrosch & Perry, 1989; Gibson, 1986; Havermans & Eiser, 1991; Malone, 1988; Ray & Ritchie, 1993). Parents have also identified the importance of and variation in the quality of the support that they received from spouses and health professionals (Bailey, Blasco & Simeonsson, 1992; Elliott, 1991; Fagan & Schor, 1993; Havermans & Eiser, 1991; Ray, 1988), and sought support primarily from their spouses (Konstantareas & Homatadis, 1989; Van Cleve, 1989). Marital quality has been linked to reduced maternal depression (Kronenberger & Thompson, 1992; Quittner, et al., 1992). A study by Johnson, Hobfoll and Zalcberg-Linetzy (1993) indicated that satisfaction with social support behaviour by a spouse is mediated by intimacy and indirectly generated by the spouses' knowledge about social support behaviour. However, some studies revealed that parents had conflicting ways of coping that prevented them from gaining mutual support (Gottlieb & Wagner, 1991), perceived decreased spousal support as the child's hospitalizations increased (Barbarin, Hughes & Chesler, 1985), and experienced high role strain related to their spouses' absence and unhelpfulness with care (Quittner, DiGirolamo, Michel & Eigen, 1992). Furthermore, parents have reported inadequate support from health professionals (Chesler, 1991).

Woods, Yates, and Primono (1989) reviewed the support of families of the chronically ill and revealed that little attention has been given to appropriate sources of support, the potential negative effects of support, and the possibility of conflict and indebtedness. Studies have typically neglected pertinent factors such as the appropriateness of support for caregiving burdens and supportive and unsupportive interactions involving lay persons and professionals. The current study therefore included an intensive examination of the types of support received from specific sources pertinent to specific burdens, and the mothers' appraisal of that support, with particular attention to interactions with partners and professionals.

### *Research Questions*

The following research questions guided the study: What are the sources and types of support that mothers of children with chronic conditions receive in relation to specific types of caregiving burden, and how appropriate are they? What are the stressful and supportive interactions that mothers of children with chronic conditions experience with their partners and health professionals?



## Method

### *Sample*

Approval for the current study was obtained from the university and hospital ethical review boards. Qualitative data were collected during home interviews with 90 mothers of children who had spina bifida ( $n=30$ ), diabetes ( $n=30$ ), or cystic fibrosis ( $n=30$ ). These conditions entail different degrees of visibility, mobility, and cognitive ability for the child, and different types and extents of caregiving burden for the mother. A sample size of 90 is sufficient to permit comparisons across illness groups, to reflect different ages of children, to capture the diversity of types of burdens and types, sources, and appraisals of support, and to describe the relationship between specific types of burdens and specific types and sources of support. The mothers were randomly selected from the population of children who were being seen for assessment and treatment of their chronic conditions at a tertiary level children's hospital. Within Nova Scotia, among children less than 17 years old who are seen at the hospital clinics, there are 265 children with diabetes, 90 children with cystic fibrosis, and 160 children with spina bifida.

All mothers who participated were English speaking; their children were less than 17 years old and cared for at home with only periodic hospitalizations for treatment or investigations; and all families lived within a two-hour radius of the city. Ten mothers refused to participate and gave their reasons for refusal as family stress, time constraint or disinterest.

The ages of the mothers ranged from 23 to 53 years ( $M = 35.3$  years); those whose children had diabetes were significantly older ( $M = 38.8$  years) than the other mothers. Eighty-one percent of participants were married, 8% divorced, 4% single, 2% separated, and 4% cohabitating. Sixty-seven percent were employed at least part-time outside the home. With the exception of the mothers of children with diabetes, the majority had no post-secondary education. Seventy-one percent of mothers had more than one child. Nearly one-quarter (23.3%) were also dealing with the health problems of other family members. Eighty-four percent of the fathers were employed, and 66% had some post-secondary education.

The ages of the children ranged from 1 to 17 with a mean of 9 years. Fifty-one percent of the children were male and 49% were female. The average time elapsed since diagnosis was 6.4 years. The diabetic group was significantly older ( $M = 12$  years) and had been diagnosed more recently ( $M = 5$  years).

### **Data Collection**

During the interview each mother was asked to describe her current caregiving experience on a typical day and during a recent acute illness of the child, and to describe the impact of her child's care and functional capacity on her own activities and those of the family. Interviewers asked the mother to identify who provided support, what support was provided, and whether this was helpful in managing each situation she described. Thus, this study focused on received support. For example, the questions about a recent illness invited the mother to:

Tell me about the last time your child was ill/in the hospital. How did the episode go? How did the episode affect your family? How did you feel during the episode? Who provided support? What did they do? Was anyone particularly helpful or did any one make you feel better? Was anyone involved too much? Was anyone not involved enough? Did anyone leave you feeling upset or make matters worse?

The semi-structured interview guide also included probes for the mothers' appraisal of positive and negative interactions with their spouses/partners and health professionals. In the final question, mothers were invited to comment on "other kinds of support that might be helpful to mothers who are caring for a child with a chronic condition" (i.e., support needs).

The average length of the audiotaped interviews was one hour. The tapes were transcribed verbatim and the transcripts subjected to content analysis. The unit of analysis was any response from the mother that related to her current experience in caring for her child and that was beyond the usual care required for a healthy child. The unit changed when the content of the discussion changed. Each unit was coded for content related to primary burden (physical care or condition, illness or health care situation, psychological or social development), secondary burden (maternal psychosocial needs, maternal external roles, family relationships and activities, etc.), source of support (spouse, family, friend, etc.), type of support (emotional, informational, instrumental, affirmational, and the specific types of each), and appraisal of support (helpful, reciprocal, absent, miscarried, conflicted). Only manifest content was coded. The category system was based on previously reported types of burdens and supports, and the conceptual framework of social support used for the current study. In addition, the data were scrutinized to assure that the category system was both exhaustive and mutually exclusive of all the interview data pertaining to current demands. The system was assessed for content validity by the research team and an external expert on social support. The content analysis was completed by a research assistant and the project coordinator, in collaboration with and following training by the principal investigators.

To assure that the coding was as free from bias as possible, and that it could be replicated by other researchers (Berg, 1989; Holsti, 1968; Wilson, 1985), the reliability of unitizing the transcripts and coding the units was assessed by checking inter-rater and intra-rater agreement of the independent coders. Analysis commenced only after 80% agreement between the coders was achieved. Reliability was re-assessed twice during the analysis period to assure that agreement was maintained at 80%. To assure that no respondent's experience could skew the results, each reference to any burden category or support category in relation to that burden was counted only once per interview. Once coded, the data were analyzed using Ethnograph (Seidl, 1988). Frequencies of mothers' discussions of burdens and sources and types of support were compiled and then a detailed analysis examined the sources, types, and appraisal of support in relation to each burden.

### **Findings**

The data from the three illness groups were analyzed separately and compared. The only significant differences between the illness groups were in the demographic characteristics (i.e., age of diabetic children and mothers, and educational level of diabetic mothers); there were very minimal differences in reports of either burden or support. For these reasons, and as a non-categorical approach to the study of responses to chronic illness has recently been recommended (Perrin et al., 1993), the data were pooled.

#### ***Burden and Related Support***

The mothers' stories clearly illustrated the pervasive impact of the child's condition on the mothers' and families' lives, and showed that the mothers experienced little social support in relation to those demands. The mothers used the terms "burden" and "demand" interchangeably. Virtually all of the mothers described primary caregiver demands such as physical care (100%), health care in illness situations (92%), and fostering the child's psychological (89%) and social (82%) development.

Many mothers described the rigorous, time consuming, and unrelenting daily regime of treatments and management of symptoms. The mother of a child with cystic fibrosis described the demands: "Continuous, everyday, doing two aerosols every day. I stop and think how it must be nice to feed your child and then you don't have to worry no more until snack time and go to bed." For some, however, this care had become routine. Although some of the older children were involved in their own care, this did not appear to lessen the mothers' ongoing vigilance or ultimate sense of responsibility. During their child's most recent episode of illness, they assured that information from health professionals was correct, dealt with the system, advocated

for the child's health care, or arranged appointments. One mother described her experience as advocate for her child's care:

The doctor came down and said "I hear you kicked up a stink down here today." And I said, "yes I did," And he said "well, you did right because... you know her more than they do." And after that everything was fine. Then, I think it took that, they respected me.

Ninety-four percent of mothers found that they lacked time to meet their own needs; they described fatigue, and the need for "me time," respite, or time to maintain their own health. Eighty-nine percent of mothers also described the impact of the child's care on family roles and relationships and the mother's own activities outside the home including employment, volunteer work, friendships, and social functions. Half of the mothers referred to the impact on homemaking (51%) and the relationship with their partners (50%). One mother of a diabetic child described her wish to "sleep in for just one day. You don't realize how much of a pain it is and how much it gets on your nerves to have to get up every morning and fight with a child to take needles and eat her breakfast." Other mothers experienced social isolation and needed to have someone listen to them. Many respondents described the pervasive nature of the child's condition; everything that the family did revolved around the child's needs. Trust in other caregivers was a major issue. As one mother of a diabetic child indicated, "If my husband was to go back to sea, it means that I would have to quit my job...I would not trust him [my child] to anybody else." Many described the considerable effort that it took to arrange an opportunity to get out of the house.

Although many types and sources of support were identified, mothers experienced considerable isolation in the management of their children's illnesses. They also perceived gaps in the availability of peer and health professional support, and revealed that their spouses differed in their abilities to cope and provide support. Almost all respondents referred to their partners (98.9%), immediate family members (94.4%), and health professionals (94.4%) as the key members of their support networks. Many women also discussed support from friends (85%) and illness peer groups (76.7%). All mothers received some form of emotional, informational, instrumental/practical, and affirmational support. However, the latter two were discussed less frequently than the first types of support. The most commonly mentioned forms of support functions were listening (96.7%), understanding (83.3%) (emotional), child care (97.8%) (instrumental/practical), oral explanations (73.3%) (informational), and feedback regarding the child's condition (64.4%) (affirmational).



The types and sources of support were somewhat different depending on the nature of the demand, but specific sources and types of support were lacking for all types of demands. Although partners were the most frequently cited source of support, they typically provided only emotional (e.g., listening) and instrumental support (e.g., caring for the chronically ill child). Health professionals offered support in relation to only physical care and health care demands. At least 20% of the mothers discussed sources and types of support for five burdens (physical care, health care encounters, psychological/cognitive development, personal needs, outside activities). In several cases, these interactions were appraised as stressful.

*Support Related to Physical Care (Primary Burden).* The support received from family (58.9%), partners (55.6%), and friends (24.4%) was almost exclusively instrumental, in the form of helping with the physical care of the affected child. Twenty-eight percent of the mothers who referred to instrumental support from their partners reported that it was stressful because of absence or conflict. The bulk of support from health professionals was informational (31%) and affirmational (21%); no mothers described receiving any emotional or instrumental support with respect to the child's physical care. Only two types of informational support were provided by health professionals: oral explanations about the child's condition, treatment, risks and care management, and suggestions of alternate ways of doing things. Some mothers talked about affirmational support in the form of feedback about the mother's caregiving. One new mother of a child with spina bifida recalled that the public health nurse would call to reassure her that "I was doing a good job ...just for support and just to make sure things are going well." Less than 40% of the mothers discussed support from health professionals and only 56% received help from their partners with respect to this predominant burden.

*Support Related to Health Care (Primary Burden).* Although the major health care demands faced by these mothers, (e.g., dealing with the health care system and advocating for their children) could require informational and emotional support, these types of support were seldom reported. They were received from only two sources: health professionals and partners. Health professionals provided some aspect of all four types of support: practical/instrumental (34.4%), emotional (25%), informational (23.3%), and affirmational (10%). Nevertheless, a significant proportion of the mothers appraised informational (14%), instrumental (13%), and affirmational (12%) support from health professionals as stressful, either because it was absent or inappropriate. One mother of a child hospitalized with cystic fibrosis said:

The parents need to be told what is going on. If you are not there to ask you just don't get the information and that's really too bad... before I got to speak to a [health professional] it was 7 or 9 days...so the communication needs to be worked on.

When the children were ill or hospitalized, partners provided only one type of support: care of the chronically ill child. The mother of a child with spina bifida described her husband's support during the child's hospitalization: "He came to the hospital and he'd tell me to go and do anything. He would take [child] for walks and, you know, be with him." Only 27% of the mothers reported receiving practical support; it was appraised by 4% as stressful, and was not mentioned by 69% of the mothers.

*Support Related to Child's Psychological/Cognitive Development (Primary Burden).* Mothers reported that teachers (31%) and partners (13.3%) provided support related to the child's psychological and cognitive demands. The only type of support identified was instrumental (care of the chronically ill child), and less than one-third of the mothers reported receiving it from any source. Further, many other types and sources of support needed to help mothers deal with their child's behaviour and psychological development were lacking.

*Support Related to Mothers' Personal Needs (Secondary Burden).* Several mothers reported that their personal needs were supported by their partner (41%), friends (30%), and immediate family (24%). These individuals provided support primarily by expressing understanding and listening. For the most part, mothers perceived that these types of emotional support were helpful. However, their sources of support were limited. Only 16% of the mothers reported that they received practical support from their husbands, through care of the chronically ill child. Mothers also reported limited sources of emotional support. Furthermore, other types of emotional support, such as the opportunity to share with others, to have a companion, and to be comforted, were not mentioned. Many mothers described a persistent sense of isolation.

*Support Related to Maternal Activities Outside the Home (Secondary Burden).* Some mothers reported that when they participated in activities outside the home care for the ill child was provided by husbands (24%), immediate family (30%), friends (23%), and sitters (15%). Child care was the only type of support that mothers discussed in relation to this demand. Although nearly 68% were employed outside the home, many received little assistance with housekeeping activities or any other relief.

Details of the specific sources, types, and appraisal of support related to physical care of the child, health care of the child, psychological/cognitive development of the child (primary burdens), personal needs of the mother, and the mothers' roles outside the home (secondary burdens) are being published elsewhere (Ritchie, Stewart, McGrath, Thompson & Bruce, in preparation).

### ***Stressful and Supportive Interactions with Partners and Professionals***

**Supportive Interactions.** Supportive interactions were reported predominantly with partners and health professionals. Mothers described the understanding they received from partners. One mother noted "He [spouse] lives the same battle that I do. So he pretty well understands everything." Another recalled that when her child was in hospital "sometimes he [husband] would come and tell me to go home and he would get [the child] ready for bed and stuff like that. So I would leave early and he would stay there." Some mothers described receiving emotional support from health professionals, who expressed respect for the parents' feelings and the significance of their role. They also recalled positive experiences with informational support from health professionals. As one mother indicated, "Everything was explained to us ... it just wasn't taken for granted that I was a nurse and that I knew ... I really appreciated that ... Because basically I was a mother first." Mothers generally valued affirmational support from health professionals. For example, one mother said, "She [nurse] tells me that I'm wonderful, that I'm doing a great job, that I'm a great mother. You know, all those things that you want to hear." Another mother of a child with diabetes reported that "On a few occasions when we've been having problems keeping [my child's] blood sugar in control, I can phone down there [hospital]. [The nurse] will call me back every other day, or so. And we'll try different things. You know, they're very, very helpful and cooperative and always very pleasant." Although many mothers perceived support as being helpful, there were many gaps in the types and sources of support related to specific burdens and many stressful interactions.

**Stressful Interactions.** Mothers of children with chronic conditions seemed more concerned about absent support (83%) and miscarried helping (74%) than about conflicted support (28%). Health professionals and partners were most frequently named as the sources of all types of stressful interactions. For example, health professionals either gave insufficient or inappropriate information. Stressful interactions with respect to physical care demands were experienced with partners, family members, health professionals, and baby-sitters. Typically, this was in the form of absent support; support that was anticipated but did not materialize. One mother explained, "But he [husband] doesn't participate as much as I would like. And I know if I asked him, he would. But I don't feel like I should ask him. I feel like he should volunteer." Another mother reported that:

He [husband] can understand to a certain extent, but they can't really understand exactly what you are going through. If you feel stressed, or you feel exhausted, they can say, "Oh, you're tired. Sit down for awhile." But they don't understand the depth of it sometimes.

Miscarried helping, or support that was not perceived as helpful despite positive intentions, came from a variety of sources. One mother of a child with cystic fibrosis recalled her distress when residents and interns said, "She doesn't look sick." Although the comment might have been intended to reassure the mother about her child, it made her feel less confident in her knowledge of the child's condition. Some people minimized the illness in an attempt to make the mother look at the positive side. Suggestions of other ways to do things were not always perceived as helpful. Occasionally help from family members actually created more work for the mother. One mother reported that when her husband cared for their child, it was often more stressful for her because he worried about his own knowledge and competence to recognize problems. Several mothers described how their partners failed to enforce care regimens, letting the children indulge in poor health behaviours. One mother explained, "he [partner] doesn't keep a very good routine going. Like he gets him (the child) to bed a lot later than he should go." Other mothers described insufficient support from their spouses. As a mother of a child with diabetes described, "I just automatically do it ... for him [husband] to go in and try and get the meals ... I mean he could do it. There's no way he couldn't do it, it's just that I can do it a lot easier."

Conflicted support, that involved critical or condescending interactions, was encountered predominantly with health professionals, but also with family and friends. Mothers experienced stress when information about the child's condition was discussed inappropriately in front of the child, or information about the child's condition or reason for admission was withheld. They perceived that health professionals sometimes communicated in ways that were critical or demeaning of the mothers' caregiving or knowledge of the child's condition. One mother of a child with spina bifida described what a physician said to a resident in her presence. "He said, 'This is what happens when you try to educate the parent.' I just left there so humiliated. He told me there was nothing and it was all in my head." Another mother described a nurse's patronizing behaviour:

Then I had a nurse come in and sit down and say to me that we will take you up to the clinic so you can be re-educated so this won't happen again. If I hadn't been so exhausted, I probably would have ripped her face off.

A health professional left one mother feeling that she had been censured rather than supported: "Instead I came out of there reprimanded for not dealing with it or something." Another mother, who had been terrified during an illness episode, described how a health professional trivialized her experience by saying: "Don't overreact. This is no big thing." Other health professionals communicated information in a seemingly heartless or cruel fashion. One



doctor said to a mother of a child with spina bifida: "The best you can hope for ... Your son is a basket case. In terms of intelligence, you can look for nothing but at the best to be below average." Some husbands or partners found fault with the children's disability. For example, one mother reported that "He complained about her smell, and he complained about this...He is just this weak rat that never could accept the fact that he has a child with a handicap." Likewise, some family members criticized the mother's caregiving.

Thus, appraisal of support by mothers in the current study revealed that they experienced gaps in support appropriate to specific caregiving burdens and encountered stressful interactions with partners and health professionals in particular.

### Discussion

There were no apparent differences between the three illness groups in the primary and secondary burdens experienced by the mothers, or in the sources, types, and appraisal of social support they received. This finding is congruent with the recently recommended non-categorical approach to the definition and classification of chronic health conditions (Perrin et al., 1993). In keeping with the later onset of diabetes, the only significant differences between the groups were that diabetic children and their mothers were older. It is unclear why these mothers also had a higher educational level.

#### *Specificity of Support for Stressors*

At least 50% of the mothers reported the effect of caregiving demands on their other activities within the home and on their relationships with their partners. That caregivers lack time for their self care and activities outside the home has been described previously only in adult populations (Gottlieb, 1989; Stoller & Pugliese, 1989), with the exception of one small study (Ray & Ritchie, 1993). Others described the impact only in relation to family activities (Teague, 1993), marital relationships, and family functioning (Drotar, Crawford & Bush, 1984; Tomlinson & Mitchell, 1992). In the current study the vast majority of mothers experienced all these secondary demands, indicating that they need to meet all the usual role expectations as well as those related to the child's illness. Nevertheless, neither the mothers nor their partners considered change in maternal or paternal role expectations beyond the care of the ill child. This is consistent with the work of Anderson (Anderson, 1990; Anderson & Elfert, 1989) who reported that the extra burdens of caregiving almost always fall to the mother. Fathers, in another study, never or only sporadically accompanied the child during visits to health care providers (Knafl, Breitmayer, Gallo & Zoeller, 1992). Indeed, mothers usually coordinated the health care services of the child (Desquin et al., 1994). Gottlieb

(1991) also reported the role conflict experienced by family caregivers of seniors with chronic illness. Other factors that have been shown to contribute to maternal strain include severity of the child's illness, problematic behaviours of the child, family conflict, adhering to the prescribed regimen, and conflicted relationships with health professionals (Gibson, 1986; Havermans & Eiser, 1991; Quittner, DiGirolamo, Michel & Eigen, 1992; Thompson, Gustafson, Hamlett & Spock, 1992).

More than 94% of mothers in the current study identified their spouses/partners, immediate family members, and health professionals as key sources of support. Spouses or partners and health professionals have been well documented in previous studies (Barbarin, et al., 1985; Konstantareas & Homatadis, 1989; Ray & Ritchie, 1993; Savedra, Tester & Ritchie, 1987; Van Cleve, 1989) as key members in the social networks of mothers dealing with children's chronic illnesses. Consistent with previous reports, the mothers in this study all described needing and/or receiving emotional and informational support; however, most also discussed affirmational support and needed instrumental support.

The helpfulness of various types of support varied with the specific source of the support and the particular demand or stressor, as Cutrona (1990) proposed in her discussion of optimal matching models. Detailed analysis of the mothers' descriptions showed that specific sources of support were related consistently to the specific types of support and specific stressful situation or caregiving burden for which the support was required.

As in two previous reports (Bailey, et al., 1992; Havermans & Eiser, 1991), mothers of children with diabetes reported a need for practical support with their children's care. It seemed that this care was seen so clearly as part of the mother's invisible work that it was ignored as a major maternal need (Anderson, 1990). However, our study showed that such support is not always available, suggesting that its absence creates stress.

Mothers expected informational and affirmational support from health professionals, particularly in relation to the child's physical care demands and requirements for health care. However, less than one-third of the mothers described receiving such support. Only 25% reported receiving understanding (emotional support) from professionals in illness or health care situations. While some mothers were extremely positive about the information they received, others expressed concerns about the negative interactions they experienced with health professionals and the insufficient or inappropriate information provided. Dakof and Taylor (1990) also reported that health professionals are valued for informational support.

The mothers referred to child care support received from health professionals more than to this support from other sources only when their children were ill or hospitalized. Otherwise, the spouse/partner and the immediate family were the expected or actual sources of support in relation to most caregiving demands. Similarly, studies by Elliott (1991) and Bailey et al (1992) revealed that mothers of children with chronic illnesses found support from family and friends to be more helpful than that from professionals.

Most frequently mothers received support from their spouses/partners in the form of assistance with care of the child. Although emotional support from partners is typically valued (Dakof & Taylor, 1990), it was described infrequently. In the current study, the most common type of emotional support from partners, reported by 41% of the mothers, was listening to mothers' difficulties with meeting personal needs. Regardless of the type of illness, a consistent pattern of specialization emerged: specific types of support were received from specific sources for particular burdens.

### ***Stressful Interactions***

It has been shown that when people encounter negative interactions such as avoidance or criticism, it can offset supportive functions (Brenner et al., 1989; Malone, 1988). It is noteworthy that negative features of social relationships appear to correlate more strongly than positive features with diminished perceived support and increased psychological symptoms (Coyne & Downey, 1991). A significant number of mothers described receiving stressful support (absent, miscarried or conflicted), particularly from health professionals and partners. Misguided or absent informational support from professionals is detrimental (Eckenrode & Gore, 1990; LaGaipa, 1990). Borkman (1990) distinguished professional knowledge from that based on first-hand experience. Health professionals are socialized to believe that expert solutions take precedence over experiential solutions (Gottlieb & Farquarson, 1985); this fosters asymmetrical professional/layperson relationships (Barbarin & Chesler, 1986; Clarke, 1986; LaGaipa, 1990). One study of families of children with chronic conditions revealed how traditional relations between health professionals and families could be conflicted and disempowering (Chesler, 1991). Thus the negative interactions that some mothers encountered with health professionals may be due to socialization, differences in knowledge and power bases, and the health care system. One study of 41 families of children with chronic illness revealed a type of guarded alliance between parents and professionals (Knafl et al., 1992). Similar findings were reported by Thorne (1993). As the development of reciprocal trust (Thorne & Robinson, 1988) is essential in the relationship between family caregivers and health professionals, more egalitarian relationships that recognize the significant knowledge and skills of mothers are needed. Health professionals need to communicate, be technically competent, exchange information, establish a relationship with

the child, foster parental competence, and be supportive (Desquin et al., 1994; Knafl et al., 1992).

More than 25% of the mothers described stressful interactions with their partners in relation to their children's physical care. This appraisal most frequently arose because the spouse did not contribute to the child's care; mothers seemed more concerned about absent support and miscarried helping than conflict. It has been reported elsewhere that spouses' absence and lack of helpfulness are associated with mothers' role stress in caring for children with chronic or critical illness (Quittner, et al., 1992; Tomlinson & Mitchell, 1992). The effectiveness of support received from spouses may be diminished if it is less than that expected (Cohen, 1992); support expectancy can predict deterioration of spousal relationships (Levitt, Coffman, Guacci-Franco & Loveless, 1993). Conflicted support and miscarried support efforts often occur in intimate relationships (Cohen, 1992; Coyne, et al, 1988; Eckenrode, & Gore, 1990). The most crucial sources of support are intimate or close relationships; yet these relationships have inherent difficulties, particularly when caregiving is required (Coyne, Ellard, & Smith, 1990). Caregivers may become emotionally over involved, overloaded, and over committed; this may lead to negative adaptational outcomes (Baillie, Norbeck, & Barnes, 1989; Coyne, Wortman & Lehman, 1988; LaGaipa, 1990).

In close support relationships, the coping of one partner influences the coping behaviours used by the other (Coyne & Smith, 1991). The mothers described their efforts to maintain their marriages and cope with their spouses' lack of participation in caregiving and ineffective coping with having chronically ill children. The parents of children with a chronic illness exhibited gender differences in coping responses to a common stressor (Gottlieb & Wagner, 1991). Such differences can engender conflict in spousal relationships. Women tend to be exposed more than men to negative interactions, perhaps due to their caregiving roles; yet they benefit more from supportive interactions (Schuster, Kessler & Aseltine, 1990; Shumaker & Hill, 1991). Women have more complex social networks than do men, and are more likely to give all types of support to others (Belle, 1987; Shumaker & Hill, 1991). Reciprocity has a greater influence on women's support satisfaction than men's (Antonucci & Akiyama, 1987). Some mothers in our study expressed concern about lack of reciprocity with their spouse; others seemed to believe that the spouses lack of contribution to child care might be offset by his financial contribution to the family. In intimate long-term relationships immediate or in-kind reciprocation is rarely necessary (Antonucci & Jackson, 1990; Clark & Reis, 1988). In our study mothers reported miscarried helping efforts, conflicted interactions, support that was anticipated but absent, and inadequate reciprocity in relationships with partners and health professionals. Support intervention and intervention research are therefore needed.



### Conclusion

Overall, the mothers in the current study seemed to be isolated in their caregiving roles. The sources and types of support that they received in relation to specific burdens were scattered and inadequate. For example, partners provided some instrumental support but little emotional support. Health professionals provided informational support only in relation to the children's illness episodes or physical care, but not in relation to fostering the children's psychological or social development or meeting the mothers' personal needs. These gaps in support and the stressful interactions experienced by mothers point to the need for support interventions. The mothers most commonly recommended support from individual peers, illness peer groups, and phone buddies. Thus, support is needed from people who have first hand experience with similar stressful situations. Peers can offer informational, affirmational, emotional, and practical support. Furthermore, peers and peer groups can supplement deficient support from partners, family, friends, coworkers, and professionals (Katz, 1993; Stewart, 1990). Nurses need to mobilize support for mothers of children with chronic conditions and test support interventions through research.

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