Social Support in Children with a Chronic Condition

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This study used a descriptive exploratory design to describe social support in children with a chronic condition and how children use social support in coping with everyday demands and demands related to their condition. Participants comprised 62 school-aged children (16 with diabetes, 16 with cystic fibrosis, 15 with spina bifida, and 15 with no chronic illness). Data were collected about their social-support networks, the support functions provided by the networks, and their satisfaction with support. The children also described the social support they received and their use of social support as a coping strategy in specific stressful situations. The healthy children had the largest support networks overall and the largest peer networks. Children with spina bifida had the smallest networks overall and the smallest number of peers in their networks. Healthy children reported more support overall than the children in the illness groups. Both the healthy children and the children with a chronic condition described academic issues as the main source of everyday stress. Children with a chronic condition identified restriction due to illness as the key illness-related stressor. Children with a chronic condition reported more
stress and more support-seeking in everyday stressful situations than in illness situations. The results will guide the design of a future social-support intervention for children with a chronic condition.

In many ways, life for children with a chronic or handicapping condition is better than it was only a few years ago. Advances in health care have ensured that many children are surviving serious illnesses and living into adulthood (Darrow & Stephens, 1992; Drotar, 1981). Furthermore, the capacity to provide for the needs of even medically fragile children outside hospital has improved. Most children are able to live at home with their families (Horner, Rawlins, & Giles, 1987). The lobbying efforts of families and health professionals have resulted in better school transportation and better accommodation of children with a chronic condition within the school system. Concurrently, however, the impact of chronic childhood conditions is placing demands on children’s psychological health, which pose new challenges to families, health-care providers, and researchers.

In Canada, an estimated 500,000 children under the age of 20 years (7.2% of all children) have a chronic condition (Statistics Canada, 1991). Almost half of those conditions are serious enough to limit or prevent the child’s participation in home, play, or school activities. Children with a chronic condition are considered to be at risk for behavioural and emotional problems (Cadman, Boyle, Szatmari, & Offord, 1987; Wallander, Varni, Babani, Banis, & Wilcox, 1988). Attempts to offset these risks can place heavy demands on family and community resources. There has been some study of the factors associated with psychological and social outcomes in children with chronic conditions (Dorner, 1975; Perrin, Stein, Walker, & Weitzman, 1993). However, the impact of social support on the lives of these children has only begun to be documented, and little is known about their perceptions and use of social support in managing difficult life situations. The purpose of this study was to describe how school-aged children with a variety of chronic conditions view their sources and types of social support, how they appraise the support they receive from their social network, and how they use social support in coping with the developmental and condition-related stress in their lives.

**Literature Review**

The Health Activity Limitation Survey in Canadian Children (Statistics Canada, 1991) examined the effect of disability on children’s lives. Almost 40% of children aged four to 14 years and 50% of older children with a disability were unable to participate in community recreation
programs because of their condition. Older children identified inadequate finances, facilities, and transportation as reasons for their exclusion from leisure activities. Almost 10% of these children believed they lacked the necessary support of family and friends to participate more fully in community activities.

**The Effects of a Chronic Condition on Children's Psychological Health**

Children with a chronic condition are at increased risk for psychological adjustment problems such as anxiety, depression, peer-conflict, hyperactivity, and aggression (Cadman et al., 1987; Gortmaker, Walker, & Sobel, 1990; Lavigne & Faier-Routman, 1992). Mothers of children with a chronic condition report poor social competence in their children that interferes with peer relationships (Wallander, Feldman, & Varni, 1989) and results in social isolation (Spirito, DeLawyer, & Stark, 1991).

Social and psychological problems associated with chronic conditions may be attributable to generic issues of chronicity rather than particular dimensions of a condition (Stein & Jessop, 1982; Wallander et al., 1988). For instance, chronic illness in children with functional disability has been associated with higher risk for externalizing disorders (Cadman et al., 1987) and chronic conditions affecting the central nervous system have been associated with the highest risk of all for behavioural and emotional problems (Seidel, Chadwick, & Rutter, 1975). Lavigne and Faier-Routman (1992) conclude that children with chronic conditions, regardless of diagnosis, are at greater risk than healthy children for psychological adjustment problems. In contrast, there is some evidence to suggest that children with a chronic condition do not differ greatly from healthy children in their experience of psychological problems (Breslau, 1985; King, Schultz, Steel, Gilpin, & Cathers, 1993; La Greca, 1990).

**Social Support and Stressful Situations**

**Experienced by Children with a Chronic Condition**

Many children with severe disability are socially competent despite their high-risk status (Egeland, Carlson, & Sroufe, 1993; Garmezy & Rutter, 1983). In adults, social support has been linked to improved self-esteem and the ability to resist stress (Alloway & Bebbington, 1987; Cohen & Wills, 1985; Gottlieb, 1988; Sarason, Sarason, & Shearin, 1986). In healthy children, social support has been associated with self-worth and emotional function (Dubow, Tisak, Causey, Hyrshko, & Reid, 1991). Support from parents has been positively associated with children’s
self-esteem and internal locus of control, while support from peers has been associated with less loneliness and higher levels of social competence (Wolchik, Sandler, & Braver, 1987a). In stressful situations such as parental divorce and school transitions, social support for children and psychological adjustment in children have been positively related (Felner, Ginter, & Primavera, 1982; Wolchik et al., 1987a). The few studies of social support in children with a chronic illness substantiate the power of family and peer networks as predictors of adjustment (Holahan & Moos, 1987; Varni, Setoguchi, Rappaport, & Talbot, 1992; Wallander et al., 1989).

Some researchers have found that the most common stressful situations for healthy children are academic challenges, peer relationships, and family events and relationships (Brown, O'Keefe, Sanders, & Baker, 1986; Cowen & Work, 1988; Puskar & Lamb, 1991). Compass, Malcarne, and Fondacara (1988) found that poor grades and peer conflict to be the most commonly identified daily hassles of school-aged children.

Most of the research with children with chronic conditions has focused on their overall stress (e.g., Thompson & Gustafson, 1996), adjustment in response to having a chronic illness (e.g., Lavigne & Faier-Routman, 1992), or coping with painful medical events (e.g., Peterson, Harbeck, Chaney, Farmer, & Thomas, 1990; Ritchie, Caty, Ellerton, & Arklie, 1990) or hospitalizations (e.g., Spirito, Stark, & Tye, 1994). There has been little examination of the stressful events that children with chronic conditions face daily. Gortmaker et al. (1990) and Perrin, Ramsey, and Sandler (1987) point out that children with a chronic condition must also cope with their own reactions to their condition and the reactions of family members and friends. Additional sources of stress may include barriers to their attempts to gain independence and autonomy, limited social opportunities, teasing, restrictions on activity, uncertain employment prospects, medical interventions, and the demands of care (Eiser, 1990; Harper, 1991; Vessey, Swanson, & Hagedorn, 1995).

Bull and Drotar (1991) found that seven- to 17-year-olds with cancer in remission reported having to deal with both general life stressors and cancer-related stress, although they cited general life stressors much more frequently (85.6%) than illness-related stressful situations. The general stressors related to school (23.6%), family (23.6%), and peers (19.3%). The illness-related stressors were restriction due to illness (29.6%), treatment (22.2%), and others (22.2%).
There has been little examination, however, of how stressful situations differ for children with and without a chronic condition, what support they receive for these stressors, and how they view support from their social network. Furthermore, satisfaction of chronically ill children with their support systems has not been studied. Finally, although these children must adjust to a variety of stressful situations, and although social support can help them cope with these situations, little is known about their use of social support, the factors that influence such use, or whether their use of social support as a coping strategy changes with development.

In summary, a large body of literature documents the positive effects of social support on mental and physical health in adults. Family members, adults from outside the family, and peers have been shown to provide complementary support in helping children achieve personal autonomy. Little is known, however, about how children with a chronic condition assess stressful situations associated with daily living and those related to their illness, how children use social support in managing those situations, and the types, sources, and appraisal of support from the perspective of the child.

**Conceptual Framework**

This study is part of a social-support research program that explores social support and its connections to stress, coping, and health outcomes. Social support is defined here as interactions with family, friends, peers, and health professionals that communicate information, esteem, aid, or emotional help (Stewart, 1993). Thus the functions of support are emotional, instrumental (practical), informational, and affirmational (House, Kessler, & Herzog, 1990). These types of support should be specific to stressors encountered (Cutrona, 1990). Furthermore, specific types of support are most helpful when they are provided by specific sources (Dakof & Taylor, 1990). Therefore, the types of support the children received from particular people in the context of specific stressful situations were measured. Support through the network may have negative as well as positive effects (Brenner, Norwell, & Limacher, 1989). Indeed, most social relationships have both supportive and stressful elements (Rook, 1990). Because negative elements may influence health more powerfully than positive ones (House, Umberson, & Landis, 1988; Rook), we assessed the supportive and nonsupportive features of children’s interactions and relationships, in addition to the sources and types of support they receive.
As indicated by the two-way arrow in Figure 1, stress and social support have a reciprocal relationship. Conflicted interactions, miscarried helping, and inadequate support can be stressful (Buunk & Hooorens, 1992), as reflected in the arrow from support to stress. Conversely, support can mediate or moderate the impact of stressful situations on health and functioning (Quittner, Glueckouf, & Jackson, 1990).

![Figure 1 Social Support Research Program](image)

Social support is conceptualized as a coping resource or coping assistance (Thoits, 1986). As illustrated by the arrow from social support to coping, supportive persons, in order to deal with stressful encounters, can alter stress appraisal, sustain coping efforts, influence choice of coping strategies, and augment coping resources. Finally, perceived availability of social support has been linked to coping effectiveness (Bennett, 1993). Conversely, the arrow from coping to support indicates that the ways in which a person copes provide important clues to potential supporters about whether support is needed and, if it is, the types of support that are needed (Silver, Wortman, & Crofton, 1990). People who use avoidance and distancing tend to have fewer support resources, while support-seeking has been linked to greater provision of support (Dunkel-Schetter & Skokan, 1990). Consequently, children’s use of social support as a coping strategy was measured.

The two-way arrow between social support and health depicts a bidirectional relationship (not assessed in this study). The arrow from support to health indicates that integration in a social network, and the ability to draw support resources from the network, can maintain health and facilitate physical recovery (Bloom, 1990; Kaplan & Toshima, 1990). The arrow from health to social support illustrates how health and illness affect availability and quality of social support. The continued need for social support in chronic stressful situations such as illness
can deplete the support (Stewart, 1993) received by children with chronic conditions.

Method

The study used an exploratory cross-sectional, between-groups design to (1) describe and compare the sources, functions, and appraisal of support in children with and without a chronic condition; (2) identify the factors that influence their experiences with support; and (3) describe their use of social support in coping with everyday and condition-related situations, and their satisfaction with support received in those situations.

Sample

The study sample was 62 children between the ages of eight and 16 years. The small sample size limits the power of the study. Detection of a medium effect size at power = .80, \( \alpha = .05 \) would require a sample of 180 (Cohen, 1992). Data were collected during interviews with 47 children who had diabetes \( (n = 16) \), cystic fibrosis \( (n = 16) \), or spina bifida \( (n = 15) \) and with 15 children who did not have a chronic condition.

The children were recruited either through letters to their mothers, who had participated in an earlier study (Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994), or through contact by the hospital clinic staff. The conditions were selected for their representativeness of differences in treatments, restrictions in lifestyle and mobility, and visibility. The children without a chronic condition were nominated by mothers of participants in the three diagnostic groups from among friends of a sibling of the child with a chronic condition. Friends of siblings were recruited because of the possibility that friends of the children with a chronic condition would differ, in some way, in their support from children in the general population.

All of the children lived at home with their parent(s) and attended school. Thirty-two of the children were between 8 and 12 years old and 30 were between 13 and 17 years old. The average age was 12.6 years \( (SD = 2.6) \). There were 32 girls and 28 boys. There were no differences among the children in the four groups by gender or age group.

Data Collection

Each child participated in an audiotaped interview conducted by research assistants trained in interviewing techniques. The interview
lasted approximately one hour and took place in the child’s home. In the first part of the interview, the child responded to the Children’s Inventory of Social Support (CISS) (Wolchik et al., 1987a), which elicits children’s general perceptions of sources and types of their social support and their satisfaction with those sources of support.

Many studies of social support have been criticized for their sole reliance on the structural nature of children’s relationships and global assessments of support. Therefore, we also asked about supportive and non-supportive interactions and patterns of support during specific stressful situations. We used an investigator-developed narrative interview guide focusing on the children’s experience of stressful situations and their use of social support in those situations. First, the child was asked to recall and describe a specific “everyday” event of the past two months that had been stressful. The child then rated the stressfulness of that situation on a 10 cm visual analogue scale. Then the interviewer used probe questions to elicit what the child did to manage the situation, who helped him or her, and what that person said or did that was helpful or not helpful. Finally, the child responded on a five-point Likert scale to the seven “Seeking Support” items from the Self-Report Coping Scale (SRCS) (Causey & Dubow, 1992) in relation to the event they described in the narrative part of the interview. The children in the chronic-condition groups repeated the second part of the interview process in relation to a specific stressful event related to the condition. The interview guide was piloted with four children under 12 years – two with a chronic condition and two without. No changes were made to the interview format as a result of the pilot.

Approval for the study was obtained from the Dalhousie University Faculty of Health Professions and the ethical review boards of the Izaak Walton Killam Children’s Hospital and the Grace Health Centre. Children under the age of 12 verbally consented to participate and those 12 and over gave written consent. Parents provided written authorization for their child’s participation.

Instruments

The Children’s Inventory of Social Support (Wolchik, Sandler, & Braver, 1987b) assesses the child’s perception of the source, amount, and type of social support and satisfaction with support received within and outside the family. The interviewer begins by asking the child to select from a list the people (parent, friend, teacher, etc.) to whom the child goes for help or to talk about something (i.e., the source of support). Next, the interviewer explores each of five support func-
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tions (advice/information, goods/services, emotional, positive feedback, and recreation/play [added for its relevance in childhood]) by briefly describing each type of support and asking the child to name all the people in the family and outside the family who provided this kind of support in the last two months. The child also identifies the people who have made him/her feel sad, angry, or bad, and rates his/her satisfaction with each support function provided by family members and others on a 10 cm visual analogue scale (support appraisal). Internal consistency reliabilities between .79 and .90 and test-retest reliabilities between .52 and .85 have been reported for the instrument (Wolchik, Ruehlman, Braver, & Sandler, 1989). In a study of children between the ages of eight and 15 years with divorced parents (Wolchik et al., 1987b), which used the CISS, high levels of support from family adults were found to be negatively related to adjustment problems, and peer support was positively associated with social competence.

The Self-Report Coping Scale (Causey & DuBow, 1992) is a 35-item instrument that measures five dimensions of coping (seeking social support, self-reliance/problem-solving, distancing, internalizing, externalizing) in children eight to 16 years of age. The child responds on a five-point Likert scale to a lead question reflecting specific daily stressors. For this study, we used only the “Seeking Social Support” subscale. Internal consistencies and test-retest reliabilities of the seven-item “Seeking Support” subscale of the SRSC range from .60 to .80. In the present study, Cronbach’s alpha levels for the everyday stressful situation and the condition-related situation for the “Seeking Support” subscale were .71 and .76, respectively.

Data Analysis

We scored the instruments according to their developers’ instructions (the “Seeking Social Support” scale was scored as the total of the Likert responses for each of the seven items [possible range = 7-35]), and calculated descriptive statistics for the demographic variables and for the size and functions of the children’s support networks, their appraisal of support, and their use of social support as a coping strategy. We conducted one-way ANOVAs to explore the relationships between the study variables and the factors of age group, gender, and study group. Post-hoc analyses were done using Tukey’s B multiple-range test to examine where the differences lay. T-tests were used to examine, by age group and gender, differences in number of support functions and appraisal of support. Chi square was used to determine differences in type of helpers identified in different types of stressful situations.
Two of the investigators conducted a content analysis of the children's responses to the narrative interview questions about type of stressful situation, type of helper, type of support, and appraisal of support. The child's complete response to each interview question constituted a unit of analysis and was coded according to a defined category system. The investigators coded the responses independently and achieved consensus in all but five responses. Those five responses were discarded from the data set.

Results

Sources, Functions, and Appraisal of Support (CISS)

The children reported an overall average of 21.3 supporters ($SD = 10.1$) in their networks. Peers formed the largest component of the networks for children in all groups. The composition of the major components of the networks is presented in Table 1. The social networks ranged in size from 26.5 ($SD = 10.3$) persons for the healthy children, to 15.9 ($SD = 9.2$) persons for the children with spina bifida. The scoring of the CISS required that people whom the children identified as providing negative support were not included in the support networks. Typically these negative supporters were siblings and classmates. The number of support functions (i.e., the total number of people providing each type of support – play, advice, goods/services, emotional, positive feedback) reported by the children ranged from a high of 61 ($SD = 26.5$) for the children without a chronic condition, to 33 ($SD = 21.0$) for the children with spina bifida. Overall, the children indicated that they had high levels of satisfaction with their support ($M = 8.5$, $SD = 1.1$).

Factors Influencing Support

Sources of Social Support (CISS). There was a significant between-group difference in the size of support networks ($F(3, 58) = 3.35$, $p = .02$). The children without a chronic condition had the largest support networks (see Table 2), and the post-hoc analysis showed the most significant difference was that between the children without a chronic condition ($M = 26.5$) and the children with spina bifida ($M = 15.9$). There was also a significant between-group difference in size of peer network ($F(3, 58) = 6.39$, $p = .001$). Once again, the children with spina bifida had the smallest peer networks ($M = 3.4$, $SD = 2.4$) – significantly smaller than those of the children without a chronic condition ($M = 11.4$, $SD = 7.3$). There were no differences in network size by age group or gender.
Table 1  Composition of Social Networks by Type of Supporter

<table>
<thead>
<tr>
<th>Type of Supporter</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Adults</td>
<td>5.7</td>
<td>2.2</td>
<td>2-11</td>
</tr>
<tr>
<td>Non-Family Adults</td>
<td>6.4</td>
<td>4.9</td>
<td>1-22</td>
</tr>
<tr>
<td>Peers</td>
<td>7.1</td>
<td>5.7</td>
<td>0-28</td>
</tr>
</tbody>
</table>

Table 2  Overall Network Size by Study Group

<table>
<thead>
<tr>
<th>Study Group</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children with Diabetes</td>
<td>19.5</td>
<td>7.4</td>
<td>11-43</td>
</tr>
<tr>
<td>Children with Cystic Fibrosis</td>
<td>23.4</td>
<td>7.7</td>
<td>11-37</td>
</tr>
<tr>
<td>Children with Spina Bifida</td>
<td>15.9</td>
<td>9.2</td>
<td>4-40</td>
</tr>
<tr>
<td>Children without a Chronic Condition</td>
<td>26.5</td>
<td>10.3</td>
<td>11-56*</td>
</tr>
</tbody>
</table>

*(F(3, 58) = 3.35, p = .02) Children without a Chronic Condition > Children with Spina Bifida

Table 3  Number of Support Functions by Study Group

<table>
<thead>
<tr>
<th>Study Group</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children with Diabetes</td>
<td>42.5</td>
<td>11.7</td>
<td>17-57</td>
</tr>
<tr>
<td>Children with Cystic Fibrosis</td>
<td>51.2</td>
<td>26.9</td>
<td>28-133</td>
</tr>
<tr>
<td>Children with Spina Bifida</td>
<td>33.3</td>
<td>21.0</td>
<td>10-81</td>
</tr>
<tr>
<td>Children without a Chronic Condition</td>
<td>61.8</td>
<td>26.5</td>
<td>26-113*</td>
</tr>
</tbody>
</table>

*(F(3, 58) = 4.49, p = .006) Children without a Chronic Condition > Children with Spina Bifida

Support Functions (CISS). There were between-group differences in the number of support functions (play, advice, goods/services, emotional, positive feedback) reported (F(3, 58) = 4.49, p = .006) (see Table 3). Post-hoc analysis revealed that the children without a chronic illness reported significantly more support overall than the children in the spina bifida group. While there were no differences in number of family-support functions by study group, the children without a chronic illness and the children with cystic fibrosis reported more non-family support than the children with diabetes and spina bifida (F(3, 58) = 4.98, p = .003). The children without a chronic condition also reported more support functions from peers than the children in any of the diagnostic groups (F(3, 58) = 9.93, p = .000).
The children without a chronic condition reported more providers of all types of support: play ($F(3, 57) = 6.17, p = .001$), information ($F(3, 58) = 4.48, p = .006$), goods ($F(3, 58) = 2.82, p = .04$), emotional support ($F(3, 58) = 2.62, p = .05$), and positive feedback ($F(3, 58) = 3.24, p = .02$). The children with spina bifida had significantly smaller networks (i.e., fewer sources of support), for every type of support, than children in any of the other groups.

The number of overall support functions did not differ by gender. Overall, children over 12 years reported more support functions than the younger children ($t(60) = -2.29, p = .02$, two-tailed). Older children also reported more informational support ($t(60) = -2.27, p = .02$, two-tailed).

**Appraisal of Support (CISS).** Scores for support satisfaction averaged 8.5 ($SD = 1.1$) on a 10-point scale. There were no differences in satisfaction with support overall, or with support from family or non-family, between the healthy children and those in any of the diagnostic groups. Older children were less satisfied with their support than were younger children ($t(60) = 2.22, p = .03$, 2-tailed). In the diabetes group, the girls were more satisfied than the boys ($t(14) = -2.60, p = .02$, 2-tailed).

**Stressful Situations and Related Use of Support (Interview Guide)**

The majority of the children responded tersely to the interview questions; only the older girls gave full descriptions of the stressful situations in their lives and the pertinent support rendered by their networks.

Across all groups, children described major everyday stressful events as including academic issues (30%), such as problems with homework and struggles with parents over completing assignments, and peer relationships (29%), such as arguments with and about friends. Other stressful events included differences with siblings (14%), teasing (13%), and chores (5%). There was more consistency in the children's descriptions of stressful events related to their chronic condition than in their descriptions of everyday situations: nearly half (47%) described stressful events related to restrictions attributable to their condition, followed by situations related to treatments (25%), clinic visits (18%), and hospitalization (9%).

Twelve of the children with spina bifida had mobility problems and all but two used a wheelchair. An adolescent girl who used a wheel-
chair shared the frustration associated with her immobility and a fantasy about dancing: "I would like to be able to dance – and I can, sort of. But I wouldn’t – not in front of anybody. So I just dance in my head." The children's narratives reflected lives of loneliness and physical and social isolation. Most had few close friends. Almost all of the children with spina bifida described struggles to join peer activities. One child talked about the difficulty of manoeuvring a wheelchair through snow to be with friends. Another described injuries sustained trying to participate in a football game. Many children described their frustration at physical barriers such as steps and inclines that led to their exclusion from outings with other children.

During the interviews, the children rated the stressfulness of the two types of stressful situations. The children with a chronic condition reported higher stress levels in everyday situations ($M = 7.92, SD = 1.9$) than in condition-related situations ($M = 6.66, SD = 2.7$) ($t(44) = 2.96$, $p = .02$, two-tailed). There were no between-group differences in stress ratings for everyday situations. Stress scores did not differ by age group or gender.

**Support Received in Stressful Situations (Interview Guide)**

When the children with a chronic condition were asked who helped them manage stressful situations, they identified family members as major supporters in both condition-related and everyday situations. The children without a chronic condition reported that they relied equally on family and friends for support. Children with a chronic condition reported receiving help from non-family members, including peers, in everyday situations more often than in illness-related stressful situations. In non-illness situations, they described receiving advice, material support, and emotional support with equal frequency (31%). In condition-related situations, they described more than a third of their support as emotional (36.2%), followed by material goods (practical support) (31.8%) and advice (informational support) (16.4%).

Children in all the study groups reported being very satisfied with the help they received. The mean rating for satisfaction with support for children without a chronic illness was 8.04. The average satisfaction rating for children with a chronic condition was greater than 8.5 for both condition-related and everyday stressful situations. When the children were asked to describe what was helpful or not helpful in stressful situations, most did not describe interactions that were non-supportive.
Support-Seeking as a Coping Strategy (SRCS)

Total seeking-support scores (out of a possible score of 35) were modes for both condition-related situations ($M = 20.3, SD = 5.28$) and everyday situations ($M = 18.2, SD = 5.6$). The children with a chronic condition used more support-seeking in everyday situations than in illness situations ($t(42) = -3.03, p = .004$, two-tailed). No differences in support-seeking scores were found for everyday stressful situations between the children with a chronic condition and those without a chronic condition.

Summary

The study revealed that children in all the study groups considered family members to be major sources of support. The healthy children reported the largest social networks, the largest number of peer supporters, and the largest amount of support. Children with spina bifida had smaller networks, for every type of support, than the healthy children and the children in the other illness groups, and they reported less support from non-family members, including peers. Older children reported more support than younger children, but less satisfaction with their support. Both the healthy children and the children with a chronic condition described academic and peer issues as major sources of everyday stress; restrictions due to illness accounted for most of the illness-related stress. The children with a chronic condition reported more stressfulness in everyday situations and more support-seeking strategies in everyday situations. Family members provided the majority of support in both types of situation.

Discussion

Consistent with other research on support providers (e.g., Dakof & Taylor, 1990), this study reveals that most support was provided to the children with chronic conditions by family members and within close relationships. The healthy children reported more support overall and in particular, stronger peer support, than the children with a chronic condition. This finding is consistent with those of other researchers (Belle, 1989; Lyons, 1989) that children with disabilities have weak social networks, which can result in loneliness (Taylor, 1988). The significantly smaller networks of the children with spina bifida, particularly networks of peer supporters, may illuminate the social consequences of childhood conditions that limit physical activity and/or visibility.
The children with spina bifida found themselves socially isolated from peers at school because of their limited mobility, and they had few opportunities to interact with other children because most lived in rural communities. The loneliness of emotional isolation (absence of a close emotional-attachment figure) has been distinguished from social isolation (absence of an assessible social network) (Weiss, 1974). These children seemed to experience loneliness from social isolation. Social support can redress different forms of loneliness and isolation (Rook, 1990).

The children with a chronic condition found situations related to everyday life more stressful than situations associated with their condition. These children shared with their healthy peers normal developmental concerns about schoolwork and about social relationships with teachers, peers, and siblings. The everyday stressful situations they identified were the same as those reported by Causey and Dubow (1992) in their study of healthy schoolchildren and by Bull and Droitier (1991) in their study of school-aged children and adolescents in remission from cancer. The findings may demonstrate the essential normality of life for these children despite their chronic condition. Conversely, it may be that a chronic condition has an indirect impact on a child's life; for these children, everyday activities are not really “non-illness” situations. Although the stressful situations in everyday life are the same as those for healthy children, the child with a chronic condition must manage the additional stressful situations associated with the condition.

The children with a chronic condition used support-seeking more as a way of coping with stressful situations in everyday life than in illness-related situations. Support-seeking, as a coping strategy, has been linked to receiving greater social support (Dunkel-Schetter & Skokan, 1990).

The older children reported more overall support than the younger children. The social skills necessary for forming and maintaining relationships (Ford & Procidano, 1990) increase as children develop. However, the older children expressed less satisfaction with their support. This finding is consistent with the challenges of early adolescence, including the acquisition of new cognitive abilities, the transition to junior high school, the need to develop new friends, the decreasing impact of parental attitudes, and the increasing importance of peer influence. For the older children with a chronic condition, these issues were found to be as stressful as those related directly to their illness.
In a study, preceding this present investigation, of the support needs of mothers of children with these three chronic conditions (Stewart et al., 1994), the mothers described extraordinary efforts to provide supportive environments for their children. Yet they worried that life was difficult for their children and that they lacked the support necessary for healthy development. Clearly, parents were the main providers of support for the children with a chronic condition. Regardless of risk conditions for children, such as chronic illness (O’Dougherty & Wright, 1990), the importance of supportive caregiving as a protective factor has been highlighted (Egeland et al., 1993; Rutter, 1990). The results of the study suggest that children recognize and value the support they receive from their families.

Many of the stressors described by the children developed in the context of coping with peer relationships and the social consequences of illness. The expressed needs for peer friendships suggest the value of helping children develop relationships with peers, in which they learn to cooperate, appreciate others’ ideas, and develop skills around consensus-building and reciprocity. These experiences were lacking in the lives of the children with spina bifida. In spite of the differences in support for the children with spina bifida, the results suggest that these children were similar to their healthy peers in their assessment of stressors and their need to develop the social skills to cope with both development and their chronic condition. Research has demonstrated that when children with disabilities have friends and are integrated in schools they have improved self-confidence, communication skills, academic performance, participation in social life and extracurricular activities, social skills, and sense of belonging (Bradley, 1994; Giangreco, Dennis, Cloninger, Edelman, & Schattman, 1993).

The findings of this study have implications for the theoretical interpretation of social support, for nursing practice and for intervention research. Conceptually, two sources of support are particularly important from the perspective of children – parents and peers. The children with limited mobility got most of their support from their parents, and they had less support from peers than children without a chronic condition. Furthermore, support was specific to stressful situations, and support-seeking as a coping strategy was used more by the children with a chronic condition in stressful situations, suggesting conceptual links among stress, coping, and support. A key contribution of this investigation to the study of children’s social support was its assessment of sources, types, and appraisal of support, and specificity of support for stressful situations from the perspective of the children themselves – rather than from the perspective of parents and teachers.
These results can inform the development of support interventions in nursing practice, and they have helped to shape our thinking around the kind of support intervention that should make up the next phase of this research. The intervention should provide the opportunity for children who are isolated, because of their geographical location and/or their physical status, to interact with other children. The similarity of the issues raised by children across groups suggests that the intervention could include healthy children as well as those with various chronic conditions. The inclusion of young children could provide them the opportunity to develop social skills in a representative peer group before they are confronted with the complex social issues of adolescence.

The protective factor – social support – has been linked to resilience in children with chronic conditions (Brown, Doepke, & Kaslow, 1993). The effects of vulnerability and protective factors in childhood should be considered when strategies are developed to help children manage stressful situations. The results of this study provide a more extensive picture of the pattern of social support and the use of social support as a coping strategy by children with a chronic condition, and suggest that, for some children, there is considerable social isolation that may contribute to the previously reported differences in social competence.

References


Acknowledgement

This study was funded by Izaak Walton Killam Children’s Hospital Research.
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Date accepted: January 198