Parents’ Perceptions of Helpful vs Unhelpful Types of Support in Managing the Care of Preadolescents With Chronic Conditions

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Objective: To identify parents’ perceptions of helpful vs unhelpful types of social support received in managing the care of preadolescents with chronic conditions.

Design: Multimethod cohort study with 1-year follow-up.

Setting: General community.

Participants: Volunteer, consecutive sample of parents of 124 preadolescents with a variety of chronic conditions.

Methods: In-depth, in-home interviews conducted with parents. Quantitative data from the Social Support Assessment questionnaire was used to assess and compare sources and types of helpful support at baseline and 1 year later. Content analytic methods were used to categorize unsupportive behaviors described by parents during the first interview.

Results: Both mothers and fathers reported that other family members were the primary source of helpful emotional and tangible support, while health care providers were the primary source of helpful informational support. The amount of perceived support from family members, community members, and service providers stayed relatively stable over time, except that fathers reported a significant increase in helpful emotional and informational support from extended family members from baseline to 1 year later. Also, 388 incidents of unsupportive behaviors were identified; the majority of these behaviors were attributed to health professionals and extended family members.

Conclusion: While patterns of perceived support remained relatively stable over a 1-year period, reports of unsupportive behaviors suggest gaps in service and problems that must be addressed to improve the care that children with chronic conditions and their families receive.


The positive, protective effects of social support have been well documented in articles about families who care for children with chronic conditions.¹⁻³ There is ample evidence that social support from social networks buffers the negative effects of stressful events and enhances physical and emotional well-being in adults.⁴ Perceived availability of support, in particular, has been found to buffer the effect of stress on psychological and physical health problems. For example, Kupst and Schulman⁵ found that the perception of the availability of support, rather than the amount of support received, positively influenced psychological functioning in parents of children with leukemia. Moreover, perceived support has consistently been negatively correlated with measures of distress.⁶

Although studies indicate that lack of support negatively affects individual and family adjustment to chronic illness and disability,⁷,⁸ little is known about which behaviors parents perceive as nonsupportive or hurtful. Our goal is to describe parents’ perceptions of helpful as well as unhelpful types of support received in managing the care of preadolescents with chronic conditions.

Since previous research findings indicate that the same type of support can have different meanings for different individuals and families depending on the context, this study focuses on identifying parents’ perceptions of the quality of support received from a variety of sources in their social networks. A social network refers to persons in a social system who could

Editor’s Note: No man (or woman) is an island—even if he (or she) is ocean deep in managing the care of a child with a chronic condition.

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SUBJECTS AND METHODS

PARTICIPANTS

The data were gathered from mothers and fathers representing 124 families who have a preadolescent (between the ages of 8 and 11 years) with a chronic illness or disability. Participants are enrolled in the preadolescent cohort of Project Resilience. The overarching purpose of this longitudinal research project is to increase our understanding of the factors that contribute to the psychosocial development and healthy functioning of children and youth with chronic illnesses and disabilities and their families. No intervention is provided in Project Resilience, which includes separate young child and preadolescent cohorts. By design, children with a variety of chronic conditions were included in this study. This noncategorical approach to studying chronic conditions is based on clinical and empirical data that indicate that most children with chronic conditions and their families have similar experiences and encounter similar problems in adjusting to life with a chronic condition, regardless of their specific diagnoses.18,19

The sample was recruited from 2 sites: Minneapolis–St Paul, Minn, and Seattle, Wash. Children with chronic conditions were identified from the medical records of 13 hospitals and health maintenance organizations using International Classification of Diseases, Ninth Revision (ICD-9)20 codes that met the following definition of a chronic health condition: a serious on-going physical health condition that (1) has a biological, anatomical, or physiological basis; (2) has lasted, or is expected to last, at least 1 year; and (3) produces, or has the potential of producing, 1 or more long-term sequelae, such as limited functional ability, extra medical care, on-going treatment, or use of medical technology.21 Eligible families were informed about the study through a letter sent from their child's physician, which briefly described the study as follows: "...the research team wants to learn what factors help children with chronic illnesses and disabilities and their families deal with difficult diseases; what helps them succeed in life; and what are the ways to improve their health services, social services, and their relationships with others." Parents were asked to send back a postcard or to call the project coordinator if they were interested in the project. Thirty-one percent of the eligible families chose to participate. Participants were enrolled using informed consent procedures. Reasons for nonparticipation could not be determined by the investigators because, in accordance with Institutional Review Board guidelines, identifying information, such as names, addresses, and phone numbers, that could be used to identify participants was not given to the investigators until after the families replied to the initial letter from physicians, and then only affirmative responses became available. Comparing respondent and nonrespondent data by zip codes provided a crude approximation of socioeconomic status. No statistically significant differences were found between respondents and nonrespondents by geographic residence, type of chronic condition, or sex of the child.

The 124 children had a broad range of chronic health conditions. The following types of conditions were represented in this study: neurologic (26%), pulmonary (15%), endocrine/metabolic (13%), developmental disability with mental retardation (12%), orthopedic (7%), hematologic/oncologic (6%), ophthalmologic/visual impairment (7%), maxillofacial (4%), cardiac (4%), gastroenterologic (3%), and urologic/renal (1%). The children were between 8 and 11 years of age at the time of data collection (mean [SD] age, 9 [0.8] years). Most of these children had been living with a chronic condition for several years (range, 1-11 years; mean [SD], 6.81 [3.05] years). Forty-four percent were girls and 56% were boys. The majority (89%) were white, which is representative of the geographic areas from which participants were recruited.

Participants in this study included the child's parent(s). A parent was defined as a biological or adoptive parent, stepparent, or partner of a parent who lives with the child the majority of the time. Eighty-two percent of the children lived with 2 adult family caregivers, and 18% lived with 1 adult family caregiver. Families ranged in size from 2 to 9 members, with a mean of 4 persons. The modal family income was between $40,000 and $60,000. Eighty-eight percent of the fathers and 32% of the mothers were employed full-time. The majority of parents had technical or college preparation. The average age of mothers at the time of enrollment was 38 years, and 40 years for fathers.

PROCEDURES

In-depth, home interviews were conducted annually with the child's family caregivers. The total protocol lasted about 2 hours. The report focuses on the parents' assessment of support received in managing the child's chronic condition. This portion of the protocol averaged 10 minutes per respondent; each parent responded independently. Data were collected on 2 aspects of social support (sources and types of supportive and unsupportive behaviors) using different methods. The first part of this study involves the comparative analysis of quantitative social support data gathered from 2 yearly administrations of the Social Support Assessment questionnaire. The second part focuses on the qualitative analysis of parents' descriptions of unsupportive behaviors reported during the baseline interviews when the children were between the ages of 8 and 11 years. Ten (8%) of the 124 families dropped out of the study at time 2 for a variety of reasons (eg, 2 children died, 3 could not be located, and 5 chose to drop out of the study).

Assessment of Supportive Behaviors

The Social Support Assessment form is an interviewer-administered structured questionnaire developed for this study based on theoretical literature about social support.4,22 It was designed to assess the family caregivers' perceptions of the type and quality of support they have received in managing the child's chronic condition from 3 major support systems: family, service providers, and community. It simultaneously assesses the family caregivers' perceptions of the quality of emotional, informational, and provide emotional, tangible, and/or informational support. It is important to note that parents of children with chronic conditions exist simultaneously within several social networks or support systems (eg, family, school, community, and health care). Gender is another important variable that can influence the ways in which support recipients view emotional, tangible, and informational types of support.9 When Eisler and Havermans10...
tangible support received from several social networks. This instrument will be used longitudinally to map how patterns of support change as the child grows and the condition changes. The content of the items was reviewed for adequacy and relevance by an interdisciplinary team of 5 clinicians who work with children who have chronic conditions. The instrument was pretested with 8 families, and minor revisions in the wording of instructions were made prior to administration. The α reliabilities for the 9 subscales for the entire sample ranged from .60 to .65 for mothers and .68 to .71 for fathers. Because of the variation in types of chronic conditions and participants’ membership in different social networks, all participants do not have an equal opportunity to receive support from each source listed on the Social Support Assessment form. Thus, the moderate interitem correlations reflect the expected variability in the amount of support individual participants received from different sources within each of the following social network clusters.

Participants were asked to rate the helpfulness and type of support they received from multiple sources of support that were grouped into 3 different social network clusters. The family cluster included 5 sources of support: spouse/partner, children, parents-in-laws, siblings, and other relatives. The service provider cluster included 7 sources of support: physicians, nurses, teachers, hospital chaplains, social workers, therapists, and mental health professionals. The community cluster included 6 sources: close friends, neighbors, coworkers, minister/priest/rabbi, church members, and illness-related support groups. Participants rated the degree of helpfulness (1, a little helpful; 2, moderately helpful; and 3, very helpful) of 3 types of support received from each of the 18 sources of support. The 3 types of support included (1) emotional support, defined as feeling cared about, loved, and/or valued; (2) informational support, defined as receiving advice and information about chronic conditions and managing family life; and (3) practical help, defined as having someone do things for you or give you things. The interviewer recorded each parent’s ratings on a separate matrix that included 3 columns for each type of support and rows for the 18 sources of support. Nine summary scores were created by summing the helpfulness ratings for each of the 3 types of support (emotional, informational, and practical help) received from each of the 3 clusters of sources (family, service provider, and community). The maximum score for family sources was 15; the maximum score for community sources was 18; and the maximum score for service providers was 21.

Assessment of Unsupportive Behaviors

After the participants completed the structured assessment of social support, the interviewer asked each parent the following open-ended question: “This question is about people who have not been supportive to you and your family in managing your child’s care. Can you think of any times when someone—from your family, in your community, or a service provider—has hurt or disappointed you?” When the parent replied affirmatively, he or she was asked to describe the situation and to identify the source of unhelpful support. Each parent could describe as many situations as he or she chose. Interviewers recorded verbatim responses from each respondent on a separate flowchart that included (1) the relationship of the person to the parent and (2) a description of the unsupportive behavior. Flowcharts were used to systematically organize the data and to facilitate the coding process.

Analysis of Supportive Behaviors

Parents’ responses to 2 annual administrations of the Social Support Assessment questionnaire were examined. First, frequencies for the 3 types of support were calculated for data collected at baseline and 1 year later. Then, paired t tests examining differences in types and sources of support between administration times 1 and 2 were conducted separately for fathers and mothers. The Bonferroni multiple comparisons procedure was used to reduce the probability of type I error, treating data from mothers and fathers independently. For the current analysis, an overall type I error rate of α = .10 was used. Therefore, an error rate of α = 1.09 = .01 was used for each of the 9 comparison tests.

Analysis of Unsupportive Behaviors

The analysis of qualitative data from parents’ responses to the open-ended interview question about unsupportive experiences focused on categorizing the types of unsupportive behaviors by source. Verbatim responses were entered into a master data file on the computer organized by case number, source, and type of behavior. These data were organized into 4 separate data subfiles based on the source of the unsupportive behavior: (1) “extended family” (including the child’s grandparents, aunts, uncles, or cousins); (2) “health care providers” (including the child’s physicians, nurses, social workers, therapists, and home health aides); (3) “in-school providers” (including the child’s teachers, principal, and school nurses); and (4) “community members” (work associates, child care providers, acquaintances, friends, neighbors, church members, other parents, other children, and strangers).

Content analysis techniques23 were used to classify the types of nonsupport caregiving families received from extended family members, health care providers, in-school providers, and community members. The family was the unit of analysis, so the same incident reported by both a mother and father was only counted once. Separate coding categories were identified by 1 of the investigators for each of the 4 major sources of nonsupport and listed in a codebook. (Examples of specific coding categories are listed in the tabulations summarizing the findings.) Using the codebook criteria, 2 coders independently categorized each family’s response to the open-ended question by type and source of nonsupport. There were 388 total codable incidents of unsupportive behaviors. The interrater agreement was 91%. For cases in which there was a disagreement between coders, a third coder also evaluated the incident. The final rating was based on a consensual rating between 2 of the 3 coders. The behaviors that families identified as unsupportive were tallied and rank ordered to illustrate the degree of emphasis that parents placed on particular issues.
Contrast, advice from health care providers was viewed as helpful, while advice from family and friends was viewed as unhelpful. These findings suggest that support recipients have differing perceptions of the helpfulness of particular types of support received from various sources.

Several methodological weaknesses have been identified in reviews of social support research. Most studies of children with chronic conditions have relied on structured questionnaires to assess social support and have investigated the amount of support without evaluating the recipient’s perception of the quality of that support. Also, information about social support has typically been gathered from only 1 family member, usually the mother, and the focus has been on examining social support in dyadic relationships rather than in a larger social context. Cross-sectional and retrospective research designs have also limited our understanding of the role that social support plays in long-term situations, such as chronic illness and disability, which can change over time. Nestmann and Hurrelmann maintain that longitudinal studies and qualitative methods are needed to investigate the role of social support in the development of children and adolescents.

This multimethod study is based on an ecological approach to assessing social support. Both quantitative and qualitative methods are used to assess parents’ perceptions of the quality of support received from a variety of support systems. Since little research has been done on the sources and characteristics of unhelpful support, an open-ended interview question was designed to elicit parents’ perceptions of unsupportive behaviors. Previous studies indicate that the patterns of support from particular support systems change as children move from middle childhood to preadolescence. The purpose of this project is to describe baseline patterns of support for families of preadolescents with chronic conditions so that we can map changes in patterns as participants in this longitudinal project move into adolescence. Objectives of this report are to identify parents’ perceptions of sources and types of helpful support vs unsupportive behaviors and to determine whether sources and types of helpful support change over a 1-year period.

### Results

#### Helpful Support

Helpful support findings are based on 2 annual administrations of the Social Support Assessment questionnaire. Parents reported receiving helpful emotional, informational, and practical support from a broad range of family members, service providers, and community members. The summary mean helpfulness scores for each type of support are presented in the table for each network cluster.

Although parents reported receiving emotional, informational, and practical help from all 3 types of support, they placed different emphases on the helpfulness of particular types of support they received from these sources. Both mothers and fathers reported receiving more helpful emotional support and practical help than informational support from other family members. In contrast, participants identified service providers as giving more helpful informational and emotional support than practical help. According to both mothers and fathers, community leaders provided more helpful emotional support than practical help or information.

The relative emphasis that family caregivers placed on particular types of support by source was similar from...
time 1 to time 2. Both mothers and fathers reported receiving the most helpful emotional and practical support from family members at baseline as well as 1 year later. On the other hand, service providers were the dominant source of helpful informational support.

Few significant differences in the degree of helpfulness were found between time 1 and time 2 support scores. Only fathers reported significantly more helpful emotional and informational support from family members 1 year later.

**UNSUPPORTIVE BEHAVIORS**

The types and sources of unsupportive behaviors were assessed at baseline using an open-ended interview question. The majority of fathers (63.2%) and mothers (78.6%) reported at least 1 unsupportive incident from extended family members, health care providers, school providers, or community members. Overall, 388 incidents of unsupportive behaviors were documented and categorized by topic and source. Approximately one third (33.5%; n=130) of these behaviors were attributed to health care providers and another third (31.4%; n=122) to extended family members. The remaining incidents were attributed to community members (20.9%; n=81) and school providers (14.2%; n=55). Since there was considerable variability in the types of unsupportive behaviors attributed to particular sources, findings will be reported by source.

**Unsupportive Behaviors From Health Care Providers**

Parents attributed 130 incidents of unsupportive behaviors to a variety of health care providers (physicians, nurses, therapists, social workers, and home health aids); however, the majority (73%) of incidents were attributed to physicians. The 5 most common types of unsupportive behaviors from health care providers, in descending rank order, are as follows:

- Talked to parent or child in an insensitive, dismissive, or rude way
- Conveyed a disrespectful or negative attitude toward the child or family
- Provided inadequate information about the child's condition or care
- Provided inadequate services or referrals
- Provided poor care or treatment

Approximately half of the incidents were related to communication problems between health care providers and families. Parents were especially upset with providers who were rude or disrespectful to them. They also found it difficult when providers did not respond to their concerns or questions.

Lack of information about the child's condition and care was another theme that families emphasized. In most cases, parents believed they did not receive adequate information about the child's condition. A few families were upset by misinformation they received. Still others were concerned about the inadequate knowledge or experience that professionals had in caring for children with chronic conditions.

A number of parents described problems with the access and delivery of services from health care provid-

**Unsupportive Behaviors From Community Members**

The majority of unsupportive behaviors by community members were attributed to acquaintances (43.2%), which included neighbors, friends, church members, and other parents. The remaining unsupportive behaviors were attributed to strangers (27.1%). work associates (18.5%), and children (11.1%).

Acquaintances were described as unsupportive by their insensitive comments and questions, lack of understanding, and inadequate support. The withdrawal of contact or friendship was particularly painful for parents. They also found it difficult when acquaintances avoided talking about the situation or minimized the child's condition.

Strangers primarily made insensitive or invasive comments that were hurtful to parents. Staring at the child was the most common nonverbal source of non-support. Parents were also aware of strangers who were fearful of their child or uncertain about how to interact with them.

In work settings, a few families encountered inflexible work policies that did not accommodate their needs. More frequently, parents described bosses or coworkers

**Unsupportive Behaviors From Extended Family Members**

Inadequate emotional and tangible support (not visiting the child at the hospital, not helping with babysitting or cooking, etc.) were common problems reported by parents. Although parents did not emphasize a lack of informational support from extended family members (grandparents, aunts, uncles, and cousins), several did report receiving unsolicited advice or information from relatives that was not helpful. Furthermore, parents found it difficult when relatives did not understand the child's condition or treatment. The 5 most common types of unsupportive behaviors from extended family members, in descending rank order, are as follows:

- Had inadequate contact or involvement with the child or child's family
- Provided inadequate emotional support
- Lacked understanding about the child's condition or treatment
- Made insensitive or invasive comments
- Blamed the parents for the child's condition

A number of communication problems were noted in parents' reports of unsupportive behaviors. Some relatives blamed the parents for the child's condition, while others disagreed about how to care for the child. Parents also found the absence of talking about the child's condition to be problematic. Parents found it particularly painful when relatives ridiculed or treated the child with the condition differently from other children or when they lacked interest in the child, although this type of behavior was less commonly reported.
who either made insensitive remarks or avoided talking about the situation altogether. One father described his boss as insensitive to everyone’s needs and problems. “His attitude was ‘I don’t care what’s wrong with you, don’t bring it to work.’”

Other children were another source of unsupportive behavior. Parents found it particularly distressing when their children were treated in a cruel or mean manner. For example, one mother reported that she gets upset when other children pick on her son and call him “diabetes breath,” because her son has a hard time dealing with the teasing.

Unsupportive Behaviors From School Providers

Parents attributed 58 incidents of unsupportive behaviors to a variety of personnel in the school system (administrators, principals, teachers, counselors, and school nurses). The 5 most common types of unsupportive behaviors from school providers, in descending rank order, are as follows:

- Provided inadequate services
- Were insensitive to the child’s needs
- Lacked understanding about the child’s condition
- Had inadequate professional knowledge or training
- Did not recognize the child’s problems or needs

A number of parents had difficulty accessing school-based services, while other parents reported that existing services were inadequate. Parents also expressed frustration about school providers who did not recognize their children’s needs or problems and providers who had inadequate professional knowledge or training about the child’s condition. In some cases, parents described school providers as insensitive to the needs of the child or family. Differential treatment was also a problem. Parents were concerned not only about school personnel who treated their child unfairly, but also about those who were overly protective.

Comments about poor verbal or nonverbal communication were similar to those attributed to health care providers. For example, a negative or pessimistic attitude about the child’s condition and insensitive or intrusive comments were identified as unsupportive behaviors in both health care and school settings.

Both mothers and fathers received helpful emotional, informational, and practical help from a broad range of sources. Like Dunkel-Schetter11 and Bryant,9 we found that parents had different perceptions of the type of support received from various sources. Participants identified service providers as the major source of helpful informational support, while family members provided the most helpful emotional support and practical help.

Overall, patterns of perceived support remained relatively stable over a 1-year period in this study of preadolescents with chronic conditions. Only a few gender differences were noted in parents’ perceptions of social support from time 1 to time 2. Fathers reported a significant increase in the emotional and informational support that was provided by family members. This finding may reflect differences in gender role socialization and/or increased involvement in caregiving roles and responsibilities.

Although the amount of perceived support stayed relatively stable in the preadolescent cohort, we found significant increases in the amount of perceived support from families, communities, and service providers for parents in the young child cohort of Project Resilience in a companion study using the same methodology.24 This difference is likely attributable to the fact that families in the young child cohort had been living with the condition for several years (mean [SD], 6.81 [3.05] years). Families in the young child cohort were adjusting to the diagnosis and searching for informational, emotional, and practical support to meet the demands of the illness, while families in the preadolescent cohort were already linked to resources. These findings suggest that perceived social support differs in relationship to the time of diagnosis, which is an indicator of the length of time the family has had to adjust to the chronic condition. Since participants in both the young child and preadolescent cohorts are enrolled in a longitudinal project, our plan is to continue to investigate how social support patterns change over time as these children grow and the course of the condition changes.

Findings from this study suggest the importance of assessing social support within a social context. Extended family, school, health care, and community systems were important sources of social support for families of preadolescents. By contrast, family caregivers in the young child cohort of Project Resilience did not identify schools as a major source of support. Parents of preadolescents received different types of support from various systems. Also, there was relatively little overlap in the categories of unsupportive behaviors across systems, which suggests that support persons in different systems play different roles in families’ lives. Furthermore, the relative emphasis that parents placed on particular types of helpful emotional, informational, and tangible support from specific sources was reflected in the similar emphasis they placed on particular types of unsupportive behaviors. Generally, participants received the most emotional support and practical help from family sources. On the other hand, the absence of emotional support and inadequate practical help were common problems that parents attributed to extended family members. Similarly, parents reported receiving the most informational support from health care providers. Their reliance on health care providers for information about chronic conditions was also evident in their reports of inadequate information and poorly informed providers. In contrast, parents did not talk about receiving inadequate information from family members. Instead, they viewed unsolicited advice or information from extended family members as intrusive.

The emphasis that parents placed on particular unsupportive incidents reflected their expectations of certain types of support from specific sources. For ex-
ample, participants who expected emotional and tangible support from extended family members viewed the absence or withdrawal of needed support as hurtful. Parents who expected health care providers to be informed and knowledgeable about their child's condition were particularly upset when professionals provided misinformation or inadequate care.

Reports of unsupportive behaviors were not isolated to one particular source of support. Instead, nonsupport was encountered in a variety of contexts—family, community, health care, and school. Furthermore, patterns of unsupportive behaviors varied by source. This variability highlights the importance of evaluating the quality of support families receive in different settings. Incidents of nonsupport also suggest changes that need to be made in each social system to improve relationships and services to children with chronic conditions and their families.

The low participation rate and the homogeneous nature of the sample limit the generalizability of findings to other populations. Given the longitudinal, psychosocial, and family-focused nature of this study, this volunteer sample is probably biased toward including families who are functioning well. Families in distress are less likely to volunteer for a study that involves a long-term commitment and focuses on child and family functioning. Also, this sample primarily comprised 2-parent, middle-class, white families. Further investigations are needed with samples that are more ethnically and economically diverse. Meanwhile, perceived support is a variable that needs to be evaluated at an individual level in clinical settings. Thus, these findings are relevant to health care professionals who care for preadolescents with chronic conditions and their families. The issues that participants emphasized suggest topics that clinicians can address when assessing the adequacy of support. The findings also underscore the importance of using an ecological approach to assess the parents' perceptions of the quality of support.

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