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## Supportive Care Needs of Parents of Children With Cancer: Transition From Diagnosis to Treatment

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**Purpose/Objectives:** To analyze research related to the pediatric oncology population supportive care needs from diagnosis to treatment.

**Data Sources:** Articles published from 1992–2002.

**Data Synthesis:** 49 studies were included. All six categories of the Supportive Care Needs Framework were found, with most studies addressing one to three of the need categories. Informational (88%) and emotional (84%) needs were identified most frequently.

**Conclusions:** No one study examined the entire range and types of supportive care needs from diagnosis to treatment. This knowledge is key to planning appropriate care and services. Future research should be directed at understanding the full constellation of needs encountered by parents during this time. Further refinement of the Supportive Care Needs Framework is required to fully define the categories of need.

**Implications for Nursing:** Although more research is required, supportive care that focuses on informational and emotional support appears to be most important from diagnosis to treatment. Using a conceptual framework such as the Supportive Care Needs Framework provides a methodology for planning care based on needs.

Parents dealing with childhood cancer face many different stressors throughout the course of their child's illness. The use of coping strategies such as social support, communication, and search for meaning has been described (Cayse, 1994; Clarke-Steffen, 1993, 1997; Cornman, 1993; Dahlquist, Czyzewski, & Jones, 1996; Enskar, Carlsson, Golsater, Hamrin, & Kreuger, 1997a; Goldbeck, 2001; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998; LaMontagne, Wells, Hepworth, Johnson, & Manes, 1999; Larson, Wittrock, & Sandgren, 1994; Martinson, Xiao-Yin, & Yi-Hua, 1993; McGrath, 2001b; Mu et al., 2001; Noojin, Causey, Gros, Bertolone, & Carter, 1999; Shapiro, Perez, & Warden, 1998; Shields et al., 1995; Sloper, 1996; Sterken, 1996; Williams, 1992). The ability for parents of children with cancer to deal with these stressors may depend largely on the supportive care available to them (Buckley, 2000; Clarke-Steffen, 1993; Enskar et al., 1997a; Shields et al.; Williams; Yiu & Twinn, 2001). The provision of supportive care is a key component of nursing care for a child and family dealing with

### Key Points . . .

- ▶ This review on supportive care needs provides a detailed synopsis of parental needs identified in the research through 2002.
- ▶ The six categories of supportive care needs identified in the framework are discussed within the literature, but no study was designed to examine the constellation of supportive care needs.
- ▶ A prospective assessment of needs from the perspective of parents and providers would be the next logical step of inquiry to assist in the planning and provision of quality care from diagnosis to treatment.

cancer (Clarke-Steffen, 1993; Enskar et al., 1997b; Hoekstra-Weebers et al., 2001; Martinson et al., 1993; McGrath, 2001a, 2001b; Shields et al.; Williams).

### Supportive Care

Supportive care has been defined as a benefit to patients and their families by encouraging individuals to live as well as possible (Tebbit, 2001). In a comprehensive Canadian model, six categories of need crossing the continuum of care were described. For the purpose of this review, the definition of supportive care within the Supportive Care Needs Framework (SCNF) of the Ontario Cancer Treatment and

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Research Foundation, which now is known as Cancer Care Ontario, was used. This framework characterizes supportive care as the provision of necessary services as defined by those living with or affected by cancer to meet their physical, informational, psychosocial, emotional, practical, and spiritual needs during the prediagnostic, diagnostic, treatment, and follow-up phases, while encompassing issues of survivorship, palliation, and bereavement (Fitch, 1994). The model outlines a taxonomy of supportive care needs and influencing factors (see Figure 1). The six categories of need are outlined in Table 1. The category of informational needs is divided further into subcategories of medical, practical, and emotional information. These needs are thought to vary across this spectrum of experience. Families are faced with a continuum of care that involves many different sectors, including hospitals, community home care, and ambulatory specialty clinics. Frequent hospitalizations, lengthy treatments, and complications affect the daily routine for children with cancer and their parents (McCray, 1997).

The literature on supportive care has evolved from a focus on the dying child to the child and family living with cancer and an uncertain future (Grootenhuis & Last, 1997a). Two supportive care reviews related to families dealing with children with cancer have been published. Peace, O’Keeffe, Faulkner, and Clark (1992) specifically focused on psychosocial needs and assessed needs from the perspective of the disease trajectory, the individual within the family, the family as a single unit, and social and cultural influences. Sixty-four clinical and research articles published from 1978–1990 were included in the review. The time of diagnosis, days immediately after diagnosis, and first relapse after treatment were found to be the most stressful times for parents. Parents wanted information about their child’s illness to be truthful and provided in appropriate verbal and written formats. Peace et al. were unable to recommend when

**Table 1. Definitions of and Percentages Cited for Supportive Care Needs**

Care Need	% <sup>a</sup>	Description
Informational	88	Need for information to reduce confusion, anxiety, and fear; better inform the patient’s or family’s decision making; and assist in skill acquisition
Emotional	84	Need for sense of comfort, belonging, and reassurance in times of stress and understanding
Psychosocial	80	Needs related to one’s sense of self-worth, competence, and being valued; needs related to family relationships and community acceptance
Practical	45	Need for direct assistance to accomplish a task or activity and thereby reduce demands on the person
Spiritual	22	Needs related to the meaning that life holds a sense of purpose and a relationship with a higher being
Physical	10	Physical comfort, freedom from pain, optimum nutrition, and ability to carry out activities of daily living

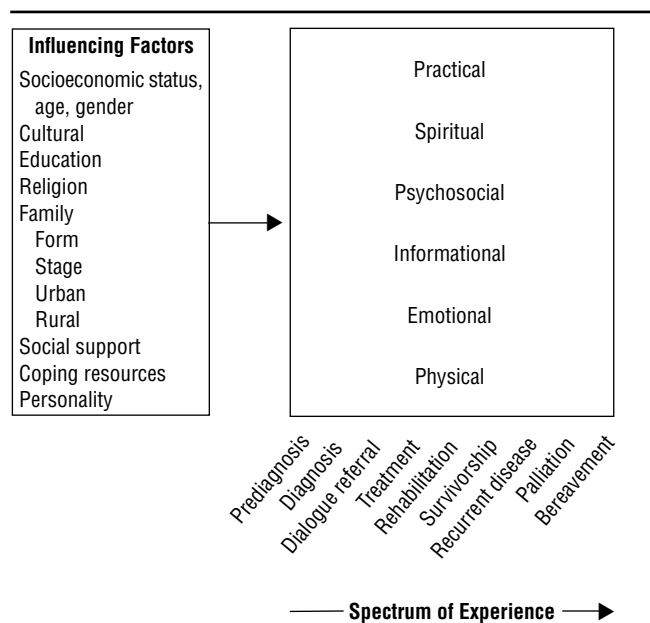
<sup>a</sup> Represents the percentage of instances that supportive care needs were cited in the literature reviewed.

*Note.* Based on information from Fitch, 1994.

psychological support is needed most or the most beneficial format. More stresses may result from medical progress and options as well as societal changes in the intervening years. The authors also noted a preponderance of disease-related research that does not advance knowledge about coping and indicated a major gap in the evaluation of intervention measures.

In their review, Grootenhuis and Last (1997a) cited 84 research articles published from 1980–1995 that specifically examined the literature related to parental adjustment in terms of psychological distress, marital distress, and family functioning. Most of the articles were descriptive studies and focused on three main areas: results recorded (a) only in parents, (b) in families of children with cancer, and (c) in children with cancer with some measurements recorded for their parents. The authors acknowledged difficulty in generalizing the findings from these studies, which were conflicting because of the number of issues. Mothers and fathers had different levels of experience or reports of emotions throughout the course of the child’s illness. Parents may be assessed for coping as a dyad, but assessments more commonly were completed with the mother alone. This was viewed as problematic because mothers and fathers experience situations differently throughout the course of the child’s illness; these differences can contribute to the various levels of stress experienced. Men and women also reported and expressed emotions differently. Parents’ emotional problems declined when their child was no longer in treatment (Grootenhuis & Last, 1997a). The studies reviewed had conceptual and methodologic limitations, including small sample size, nonvalid measures of coping, inclusion of diverse populations of children with cancer (developmental and at different stages of treatment), various methods used in reporting emotional problems by mothers and fathers, challenges in assessing illness-specific problems, and different definitions and measures of coping and adjustment.

No reviews have been published that synthesized the full range of supportive care needs of parents. Peace et al. (1992) and Grootenhuis and Last (1997a) focused on general aspects of supportive care throughout the continuum of care. These



**Figure 1. Conceptual View of Focus for Supportive Care**

*Note.* From *Providing Supportive Care for Individuals Living With Cancer* (p. 10) by M.I. Fitch, 1994, Toronto, Canada: Ontario Cancer Treatment and Research Foundation. Copyright 1994 by M.I. Fitch. Reprinted with permission.

reviews covered literature published through 1995. The current review was undertaken to update the previous work and analyze the research literature related to the pediatric oncology population and the full range of supportive care needs during the diagnostic and treatment phases. Additionally, the review was guided by the concepts outlined within the SCNF and the question: “What are the supportive care needs of parents of children with cancer in transition from diagnosis to treatment?”

## Review Methodology

The search strategy was designed using terms to target the research literature and capture information about physical, psychosocial, emotional, practical, spiritual, and informational needs. The CINAHL<sup>®</sup> and MEDLINE<sup>®</sup> databases were searched for literature published from 1992–2002. Research since 1992 was sought because earlier studies would have limited relevance given the changes in pediatric cancer treatment and healthcare services delivery over this time. The search was limited to English-language articles. Subject headings were searched individually within each database to generate the most relevant results. The literature search generated 158 articles from CINAHL and 187 articles from MEDLINE (34 articles were duplicates). Abstracts of the studies were reviewed further to determine whether they met the review inclusion criteria, including being a quantitative or qualitative study, addressing one or more of six supportive care needs (i.e., informational, emotional, psychosocial, practical, physical, and spiritual), focusing on the parent of a child with cancer, and relating to the diagnosis or treatment phase of cancer. Next, structured abstracts were created for each study that summarized the design, population, methods, and findings. Each study was reviewed using the analytical framework to identify whether needs were addressed or reported and then categorized based on the definitions of the needs provided.

From the structured abstracts, a synthesis table was developed to highlight the themes in the 49 studies reviewed. One reviewer developed the synthesis table, and a second reviewer independently read and validated the content. A third reviewer adjudicated any discrepancies identified by the two independent reviewers.

## Results

A total of 49 studies met the inclusion criteria (see Table 2). Studies were not included in the review for a number of reasons, including that they did not address the diagnosis or treatment period (25%), did not focus on childhood cancer (21%), focused on the child or sibling but not the parents (31%), focused on other chronic illnesses (10%), or were not research studies (13%).

The 49 studies were descriptive in design. Twenty-five used quantitative methods, 20 used qualitative methods, and 4 used mixed methods. Questionnaires or surveys ( $n = 25$ ) were used in the quantitative studies; focus groups ( $n = 4$ ) and/or interviews ( $n = 17$ ) were conducted in the qualitative studies. A combination of questionnaires and interviews was used in the four mixed-methods studies.

A review of the 49 studies revealed that needs were cited within all six of the SCNF categories. Most ( $n = 32$ ) of the

studies cited three or more of the supportive care needs identified within the framework. The majority of the studies reported on informational needs (88%) and emotional needs (84%). Within each of the six categories of need, citations of specific needs were noted. Informational needs were cited 132 times compared to 58 citations in the next most common category, emotional needs.

## Informational Needs

Parents most frequently sought general medical information about their child's cancer (Cayse, 1994; Chesler & Parry, 2001; Clarke-Steffen, 1993, 1997; Eden, Black, MacKinlay, & Emery, 1994; Enskar et al., 1997b; Goldbeck, 2001; Han & Belcher, 2001; Martinson et al., 1993; Mercer & Ritchie, 1997; Mu et al., 2001; Mu, Ma, Hwang, & Chao, 2002; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000; Sharan, Mehta, & Chaudhry, 1999; Shields et al., 1995; Sterken, 1996; Williams, 1992; Wills, 1999; Yeh, 2002; Yiu & Twinn, 2001). They wanted written information for reference when healthcare professionals were not available (Aitken & Hathaway, 1993; Buckley, 2000; Eden et al.; Martinson, Liu-Chiang, & Yi-Hua, 1997; Neil-Urban & Jones, 2002; Santacroce, 2002), and they desired detailed and well-defined information about the child's treatment (Levi, Marsick, Drotar, & Kodish, 2000; Shields et al.; Sterken). Parents wanted to be involved in decision making related to their child's treatment and to understand the risks and side effects involved (Pyke-Grimm, Degner, Small, & Mueller, 1999). Specific information that focused on how to care for their sick child also was needed (Mercer & Ritchie; Mu et al., 2002; Pyke-Grimm et al.; Shields et al.; Yeh, Lee, Chen, & Li, 2000; Yiu & Twinn). Having information about their child's condition was essential for parents' peace of mind, allowing them to feel some control over the situation, stay optimistic, and develop strategies that directly could benefit their child (Mercer & Ritchie; Mu et al., 2002; Shields et al.; Yeh et al.; Yiu & Twinn).

Emotional information was the second most frequently cited area of concern for parents of children with cancer. Providing reassurance, as well as coping strategies, to parents at the time of diagnosis was identified as being important (Chesler & Parry, 2001; Clarke-Steffen, 1993). Parents also had a need for positive expectations and a positive outlook (Grootenhuis & Last, 1997b; Yeh et al., 2000). They wanted healthcare professionals to be available to answer questions and to refer them for professional counseling if needed (Brown & Barbarin, 1996; Larson et al., 1994; Wills, 1999; Yiu & Twinn, 2001). The parents' education level, gender, and understanding of the experience influenced the provision of information (Eden et al., 1994; Hoekstra-Weebers et al., 1998; Tarr & Pickler, 1999). Mothers were at an increased risk for distress if they believed that they received less emotional support and were more dissatisfied with care at the time of diagnosis (Hoekstra-Weebers et al., 2001), whereas fathers with a higher education level had the greatest amount of anxiety (Mu et al., 2002).

Practical information focusing on the resources available to parents of children with cancer needs to be available (Han & Belcher, 2001; Mercer & Ritchie, 1997; Mu et al., 2001; Sloper, 1996). The accessibility of general information and availability of practical resources were essential for parents of children with cancer in decreasing their frustration as well as the feeling of inconveniencing the staff (Aitken & Hathaway, 1993; Mercer & Ritchie).

**Table 2. Summary of the Literature Reviewed**

Study	Population and Study Design	Pediatric Patients	Variable of Interest	Instruments	Parental Needs
Aitken & Hathaway, 1993	53 parents Descriptive and quantitative	In treatment, most with leukemia	Stress and coping behavior in relation to distance to the hospital	Four of six scales from the Parental Perception Inventory (PPI) were developed from Hymovich Chronicity Impact and Coping Instrument: concerns, beliefs and feelings, coping, and general information.	Informational, psychosocial, emotional, and practical needs
Brown & Barbarin, 1996	68 mothers and 56 fathers Descriptive and quantitative	44% were one-year postdiagnosis; majority had acute lymphocytic leukemia (ALL).	Similarities and differences in perception, emotional response, and performing family- and illness-related tasks between mothers and fathers	Questionnaires (either through the mail or extensive in-home interviews)	Informational, psychosocial, emotional, and practical needs
Buckley, 2000	13 mothers and fathers Descriptive and quantitative	Not identified	Parents' informational needs and views on possible introduction of a written file containing information after child's diagnosis	Survey	Informational, psychosocial, and emotional needs
Cayse, 1994	23 fathers Descriptive and quantitative	61% male; majority had ALL, were 3–6 years old, and were 18 months postdiagnosis.	Stress and coping strategies of fathers with a child with cancer	PPI	Informational, psychosocial, spiritual, emotional, and practical needs
Chesler & Parry, 2001	167 fathers Descriptive and qualitative	Mixed diagnosis	Nature of fathers' experiences and how gender shapes fathers' experiences of parenting a child with cancer	Interview and workshop	Informational, psychosocial, spiritual, emotional, and practical needs
Clarke-Steffen, 1993	40 members of 7 families Descriptive and qualitative	3 males and 4 females aged 2–10 years; 3 with ALL, 3 non-Hodgkin lymphoma, and 1 advanced lymphocytic lymphoma	Strategies used by families in response to childhood cancer	Three semistructured interviews (6–13 days after diagnosis, 5–12 weeks postdiagnosis, and 3 months after remission)	Informational and emotional needs
Clarke-Steffen, 1997	32 family members Descriptive and qualitative	3 males and 4 females with a leukemia or lymphoma diagnosis aged 2–11 years	Strategies used by families in response to childhood cancer	Three semistructured interviews (within a week of diagnosis and remission, and three months after second interview)	Informational, psychosocial, spiritual, emotional, practical, and physical needs
Cornman, 1993	20 families Descriptive and quantitative	80% had ALL and 20% had lymphoma; aged 6–16 years	Individual, dyadic, and family response to cancer experience regarding life stressors, self-esteem, marital satisfaction, and perception of family environment	Three sets of data from each member over six months; parents and children were asked to create drawings and were compared with norms on quantitative measures.	Informational, psychosocial, emotional, and practical needs
Dahlquist et al., 1996	84 parents (42 couples) Descriptive and quantitative	Diagnosed 20 months before evaluation; 48% leukemia, 17% lymphoma, 26% solid tumor, 9% brain tumor; aged 1.9–18 years	Marital adjustment as it related to parents' affective distress and coping style	Spielberger State-Trait Anxiety Inventory, Beck Depression Inventory, Modified Repression-Sensitization Scale, and Dyadic Adjustment Scale were completed 2 and 20 months after diagnosis.	Psychosocial and emotional needs

*(Continued on next page)*

*Note.* Mixed diagnoses included acute lymphocytic leukemia, acute myelocytic leukemia, lymphoma, and solid tumors.

**Table 2. Summary of the Literature Reviewed (Continued)**

Study	Population and Study Design	Pediatric Patients	Variable of Interest	Instruments	Parental Needs
Eden et al., 1994	23 couples Descriptive and qualitative	Aged 5 months–13 years with mixed diagnoses	Receptiveness of parents to information given about child's illness	Structured interview three months after diagnosis	Informational, psychosocial, and emotional needs
Enskar et al., 1997a	5 families Descriptive and qualitative	3 females and 2 males aged 6.5–12.5 years; 4 had ALL, and 1 had sarcoma.	Children's experience of problems related to cancer and the effect of the disease on their life situation	Interview at patients' residence or in hospital (tape recorded and transcribed)	Informational, psychosocial, and emotional needs
Enskar et al., 1997b	16 couples Descriptive and qualitative	10 females and 5 males aged 6–20 years with mixed diagnoses	Identify parents' experience of the changes and challenges of child's disease on life situation.	Semistructured interviews (taped recorded and transcribed)	Informational, psychosocial, emotional, and practical needs
Ferrell et al., 1994	31 families Descriptive and qualitative	10 males and 11 females aged 5–22 years	Describe family factors that influence pain management and measure the knowledge and attitude of family caregivers in managing pediatric pain.	Structured interviews	Psychosocial, spiritual, emotional, practical, and physical needs
Goldbeck, 2001	25 families with child with new cancer diagnosis and 29 with newly diagnosed diabetic child Descriptive and quantitative	16 males and 9 females aged 0.5–15 years; 10 had a solid tumor and 15 had ALL or lymphoma.	Effects of gender and disease on parental coping and parents' and children' quality of life	Coping Health Inventory for Parents, Trier Coping Scales, Ulm Quality of Life, and an inventory for parents of a chronically ill child	Informational, psychosocial, and spiritual needs
Grootenhuis & Last, 1997b	83 parents with a child in remission and 80 parents with a child who relapsed Descriptive and triangulation	43 in remission and 41 relapsed with mixed diagnoses	Determine which variables predict the emotional adjustment of mothers and fathers of children with cancer.	Semistructured interviews, Depression Questionnaire for Children, Control Strategy Scale, Beck Depression Inventory, Trait Anxiety Inventory, and a situation-specific emotional reaction questionnaire	Informational and emotional needs
Han & Belcher, 2001	73 parents Descriptive and quantitative	55 males and 18 females with mixed diagnoses	Describe aspects of computer use as a vehicle for self-help by parents of children with cancer.	Survey created for study was done online; six questions were about use of computers for support.	Informational, psychosocial, and emotional needs
Hoekstra-Weebers et al., 1998	62 couples Descriptive and quantitative	Mixed diagnoses	Investigate differences in psychological distress and coping styles between fathers and mothers of pediatric patients with cancer.	Symptom Checklist focused on presence of psychiatric symptomatology, Goldberg General Health Questionnaire (GHQ) detected nonpsychotic psychiatric disorder, and a questionnaire measured coping at diagnosis, 6 months, and 12 months.	Informational, psychosocial, and emotional needs
Hoekstra-Weebers et al., 2001	128 parents Descriptive and quantitative	41 males and 25 females with mixed diagnoses	Examine the effect of support on psychological functioning of parents of a child with cancer.	GHQ and Social Support List Interactions and Discrepancies were completed within 14 days and 6 and 12 months after diagnosis.	Psychosocial and emotional needs
Jelalian et al., 1997	44 mothers (22 had a child with cancer and 22 had a healthy child) Descriptive and triangulation	Aged 3–10 years and in treatment for ALL and acute myelocytic leukemia	Examine factors influencing the use of discipline and specific discipline strategies.	Discipline Strategies Questionnaire, Eyberg Child Behavior Inventory, and a structured parent interview	Psychosocial and emotional needs

*(Continued on next page)*

*Note.* Mixed diagnoses included acute lymphocytic leukemia, acute myelocytic leukemia, lymphoma, and solid tumors.

**Table 2. Summary of the Literature Reviewed (Continued)**

Study	Population and Study Design	Pediatric Patients	Variable of Interest	Instruments	Parental Needs
LaMontagne et al., 1999	20 parents Descriptive and quantitative	11 females aged 3–10 years	Examine what parents identify as a primary stressor before child's invasive procedure, coping strategies used, and level of distress.	Ways of Coping Questionnaire and Observation Scale of Behavioral Distress; parents were observed and scored during invasive events.	Informational, psychosocial, and emotional needs
Larson et al., 1994	17 couples with a child with cancer and 32 couples with a child with flu Descriptive and quantitative	In treatment and follow-up	Examine differences in how mothers and fathers of children with cancer cope and adjust.	Coping Strategies Inventory, Social Support Questionnaire, Dyadic Adjustment Scale, Spielberger State-Trait Anxiety Inventory, and Beck Depression Inventory	Informational, psychosocial, and emotional needs
Levi et al., 2000	22 parents Descriptive and qualitative	Aged 2–18 years	Describe retrospective perceptions of parents of the circumstances of their child's cancer diagnosis and of the informed consent process.	Three focus groups	Informational and psychosocial needs
Manne et al., 1996	55 families Descriptive and quantitative	Aged 3–18 years	Examine the functioning of parents at six months postdiagnosis.	Lansky Play Performance Scale for Children Revised, Family Routines Inventory, Family Adaptability and Cohesion Scales III, Achenbach Child Behavior Checklist, and Beck Depression Inventory	Psychosocial, emotional, and practical needs
Martinson et al., 1993	50 families (25 newly diagnosed and 25 undergoing treatment) Descriptive and qualitative	34 males and 16 females aged 3–16 years; 56% had ALL.	Impact of childhood cancer on 50 Chinese families	Semistructured interview	Informational, psychosocial, and practical needs
Martinson et al., 1997	89 families Descriptive and triangulation	53 males and 36 females aged 0.5–17 years with mixed diagnoses in a variety of stages of cancer experience	Describe the Chinese parental physiologic reactions to their child's cancer treatment and death.	Semistructured interviews, Parent Support Scale, and Parent Stress Rating Scale	Informational, psychosocial, spiritual, emotional, practical, and physical needs
Martinson et al., 1999	18 families Descriptive and triangulation	Aged 1–16 years	Compare caregiving behaviors of Chinese and Caucasian North American families with a child with cancer.	Semistructured interview guide, Functional Status II <sup>®</sup> , Impact on Family Scale, Symptom Checklist 90 Revised, and Care Giving Patterns Inventory; data were collected at diagnosis, after remission or four to six months after diagnosis, and one year after diagnosis.	Informational, emotional, and practical needs
McGrath, 2001a	12 families Descriptive and qualitative	7 males and 5 females with ALL aged 9 months–10 years	Families experience with coping with the initial stage of treatment for childhood ALL	Open-ended interviews (reported at the time of induction remission)	Informational, psychosocial, emotional, and practical needs
McGrath, 2001b	12 families Descriptive and qualitative	7 males and 5 females with ALL aged 9 months–10 years	Experience of accessing support from perspective of parents with a child undergoing treatment for ALL	Open-ended interviews (from end of remission induction to the end of the five-week period)	Psychosocial, emotional, and practical needs
Mercer & Ritchie, 1997	20 parents Descriptive and qualitative	Leukemia or solid tumors	Describe parents' experiences with their resources during the their child's cancer treatment.	Interviews	Informational, psychosocial, spiritual, emotional, and practical needs

*(Continued on next page)*

*Note.* Mixed diagnoses included acute lymphocytic leukemia, acute myelocytic leukemia, lymphoma, and solid tumors.

**Table 2. Summary of the Literature Reviewed (Continued)**

Study	Population and Study Design	Pediatric Patients	Variable of Interest	Instruments	Parental Needs
Mu et al., 2001	100 mothers Descriptive and quantitative	In treatment, mixed diagnoses, 65% male	Examine impact of family stress of caring for child with malignancy as it relates to maternal experience.	Parental Perception of Uncertainty Scale, Sense of Mastery Scale, Spielberger State-Trait Anxiety Inventory, and Boundary Ambiguity Scale	Informational and emotional needs
Mu et al., 2002	80 fathers Descriptive and quantitative	Aged 0.6–19 years, 58 not in remission, mixed diagnoses	Examine the stress impact that caring for a child undergoing chemotherapy or radiation therapy has on a family.	Parental Perception of Uncertainty Scale, Sense of Mastery Scale, and State Form of the Anxiety Scale	Informational and emotional needs
Neil-Urban & Jones, 2002	5 fathers Descriptive and qualitative	In treatment or completed treatment in past four months	Describe the experience of fathers who have a child with cancer.	Two focus groups guided by an open-ended questionnaire	Informational, psychosocial, emotional, and practical needs
Noojin et al., 1999	32 families Descriptive and quantitative	Older than age six with mixed diagnoses, 70% male	Explore role of maternal coping and family functioning in child depression.	Coping Scale of Health and Daily Living Form, Family Relationship Index of the Family Environment Scale, and Child Depression Inventory	Informational and psychosocial needs
Pyke-Grimm et al., 1999	58 parents Descriptive and quantitative	In treatment, younger than age 13, 66% female	Parents' preferred role in treatment decision making and parents' priority information	Sociodemographic Disease and Treatment Questionnaire, Control Preferences Scale for Pediatrics, and Information Needs Questionnaire	Informational needs
Santacroce, 2002	15 parents Descriptive and quantitative	3 males and 9 females with mixed diagnoses	Describe relationships among uncertainty, anxiety, and symptoms of post-traumatic stress (PTS) in parents with a child recently diagnosed with cancer.	Mishel's Parental Perception of Uncertainty Scale, Spielberger State-Trait Anxiety Inventory, and a reaction index used to measure symptoms of PTS	Informational, emotional, and physical needs
Sawyer et al., 2000	88 families (49 were the controls) Descriptive and quantitative	Mixed diagnoses	Assess psychological adjustment of children treated for cancer and their parents.	Child Behavior Checklist, General Health Questionnaire, and General Functioning Scale; assessed immediately after diagnosis and annually for four years	Informational, psychosocial, and emotional needs
Shapiro et al., 1998	29 mothers Descriptive and quantitative	Aged 2–16 years; 22 with leukemia and 7 with a solid tumor (20 in remission, 5 relapsed, and 4 not in remission)	Investigate association among family relationships, personal-psychological caregiver adaptation, and ability to function within healthcare system in mothers.	Centers for Epidemiological Studies–Depression Scale (measures level of depression and sense of burden)	Psychosocial needs
Sharan et al., 1999	30 parents (15 have child with a psychiatric disorder and 15 have a child without) Descriptive and quantitative	ALL	Assess frequency and likely associations of psychiatric disorders in parents of children with cancer.	Comprehensive Psychopathological Rating Scale, Hamilton Depression Rating Scale, and Spielberger State-Trait Anxiety Inventory	Informational, psychosocial, and emotional needs
Shields et al., 1995	77 families Descriptive and quantitative	22 newly diagnosed, 16 more than one year postdiagnosis and in treatment, 35 in remission, 4 died	Assess perceived psychosocial needs of families who have a child with cancer.	Family Needs Survey	Informational, psychosocial, emotional, and practical needs

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Note. Mixed diagnoses included acute lymphocytic leukemia, acute myelocytic leukemia, lymphoma, and solid tumors.

**Table 2. Summary of the Literature Reviewed (Continued)**

Study	Population and Study Design	Pediatric Patients	Variable of Interest	Instruments	Parental Needs
Skolin et al., 2001	11 parents Descriptive and qualitative	46 males and 24 females aged 9 months–18 years with mixed diagnoses	Assess parents' perception of their child's eating patterns after onset of chemotherapy and the strategies they used to cope when eating problems arose.	Semistructured interviews (taped recorded and transcribed)	Informational, emotional, practical, and physical needs
Sloper, 1996	68 mothers and 58 fathers Descriptive and quantitative	4 males and 7 females with mixed diagnoses	Investigate levels of psychological distress in parents of children with cancer.	Questionnaires at 6 and 18 months postdiagnosis	Informational, psychosocial, emotional, practical, and physical needs
Sterken, 1996	31 fathers Descriptive and quantitative	17 males and 14 females, most in treatment	Describe the uncertainty and consequential coping patterns in fathers of children with cancer.	Mishel's Parent Perception of Uncertainty Scale and Jalowiec Coping Scale	Informational, psychosocial, and emotional needs
Tarr & Pickler, 1999	4 families Descriptive and qualitative	Aged 2–6 years with ALL, in maintenance stage of treatment	Explore process by which families of children with ALL "become" patients with cancer.	Semistructured interviews	Informational, psychosocial, spiritual, and emotional needs
Williams, 1992	15 families and 33 healthcare professionals Descriptive and qualitative	9 males and 6 females aged 2–19 years	Describe how parents of children with cancer perceive support and what they found supportive while their child was hospitalized compared to methods of healthcare professionals.	Social Network Inventory, participant observation, and in-depth interviews	Informational, psychosocial, emotional, and practical needs
Wills, 1999	9 mothers and 8 fathers Descriptive and qualitative	5 males and 4 females aged 11 months–13 years with newly diagnosed ALL	Explore experiences of Chinese parents of children diagnosed with ALL.	Semistructured interviews	Informational, psychosocial, and emotional needs
Yeh, 2001	63 parents Descriptive and qualitative	Mixed diagnoses	Increase the understanding of religious beliefs and practices among Taiwanese parents of pediatric patients with cancer.	Three semistructured interviews and focus groups	Informational and spiritual needs
Yeh, 2002	164 couples Descriptive and quantitative	Mixed diagnoses	Investigate gender differences in measures related to stress in parents with a child diagnosed with cancer.	Parenting Stress Index Short Form, Symptom Checklist-35 Revised, and Marital Satisfaction Scale	Informational, psychosocial, emotional, and practical needs
Yeh et al., 2000	26 mothers and 6 fathers Descriptive and qualitative	Aged 0.8–15 years with mixed diagnoses at all stages of illness	Explore adaptational process of Taiwanese parents of pediatric patients with cancer.	Open-ended interviews	Informational, psychosocial, spiritual, and emotional needs
Yiu & Twinn, 2001	5 parents Descriptive and qualitative	Aged 1 month–14 years with mixed diagnoses	Identify needs of Hong Kong Chinese parents with a child with cancer during period of hospitalization following the confirmation of a diagnosis.	Two semistructured interviews (at time of diagnosis and six months later)	Informational, psychosocial, emotional, and practical needs

*Note.* Mixed diagnoses included acute lymphocytic leukemia, acute myelocytic leukemia, lymphoma, and solid tumors.



In addition to the informational needs identified, caregivers' communication skills were seen as very important by parents. Parents reported that the clarity of the information and the manner in which the information was communicated influenced their trust of healthcare professionals (Clarke-Steffen, 1997; Eden et al., 1994; Levi et al., 2000). Identified barriers to communication between families and healthcare professionals were the use of complex language and terms, a reluctance by healthcare professionals to disclose information, attitudes of the person providing the information, lack of trust in the information source, and not having both parents present (Clarke-Steffen, 1997; Eden et al.; Levi et al.; Sterken, 1996). Some parents experienced difficulty in communicating with the physician and, as a result, used other sources of information such as the Internet (Levi et al.). Individuals with lower levels of education required assistance in processing and making sense of the information given to them (Santacroce, 2002). Retaining information in a crisis or stressful situation was challenging; therefore, good communication skills and repetition of information were important (Buckley, 2000; Eden et al.; Enskar et al., 1997b; Santacroce; Shields et al., 1995). Communication of information in a trusting, timely manner was crucial because waiting to hear test results was very distressing (Buckley; Clarke-Steffen, 1993; Levi et al.).

### **Emotional Needs**

Emotional needs were the second most common category of needs cited. Although the percentage of emotional needs was higher than that of psychosocial needs, the number of citations of each need within the literature differed. Emotional needs were cited 58 times in the literature, whereas psychosocial needs were identified in 95 citations.

The most important emotional need was the feeling of uncertainty about the child's cancer, cure, diagnosis, treatment, symptom management, and future (Buckley, 2000; Cayse, 1994; Clarke-Steffen, 1993, 1997; Enskar et al., 1997b; Ferrell, Rhiner, Shapiro, & Dierkes, 1994; Santacroce, 2002; Shields et al., 1995; Sterken, 1996; Tarr & Pickler, 1999). Many different emotions were cited by parents of children with cancer such as fear, powerlessness, denial, stress, guilt, sadness, terror, anticipatory loss, anger, devastation, shock, and confusion (Brown & Barbarin, 1996; Cornman, 1993; Han & Belcher, 2001; Hoekstra-Weebers et al., 1998; Neil-Urban & Jones, 2002; Santacroce; Yeh et al., 2000; Yiu & Twinn, 2001). Parents also described high levels of anxiety regarding their child's diagnosis, palliative care, and death (Hoekstra-Weebers et al., 2001; Martinson et al., 1997, 1999; Santacroce; Sawyer et al., 2000; Shields et al.). Parents rated having a child diagnosed with cancer as the second highest level of distress, which was superceded only by the death of their child (Martinson et al., 1997).

### **Psychosocial Needs**

The main psychosocial need cited was for social support (Brown & Barbarin, 1996; Chesler & Parry, 2001; Clarke-Steffen, 1997; Cornman, 1993; Dahlquist et al., 1996; Enskar et al., 1997b; Hoekstra-Weebers et al., 1998, 2001; Levi et al., 2000; Martinson et al., 1993, 1997; Neil-Urban & Jones, 2002; Shields et al., 1995; Tarr & Pickler, 1999; Yeh et al., 2000). Support from friends as well as support groups for parents provided an opportunity for parents to talk with individuals who were not directly attached to the child. Being able to

connect with other parents whose child had cancer also was an important source of support (Aitken & Hathaway, 1993; Brown & Barbarin; Han & Belcher, 2001; McGrath, 2001a, 2001b; Mercer & Ritchie, 1997; Shields et al.; Williams, 1992; Wills, 1999; Yeh et al.). Support of other children and of the ill child was a significant factor that needed consideration by parents of children with cancer (Brown & Barbarin; Clarke-Steffen, 1997; Enskar et al., 1997b; Mercer & Ritchie; Sawyer et al., 2000; Sloper, 1996; Wills; Yeh et al.; Yiu & Twinn, 2001). Husbands and wives who were sensitive to one another's needs and were able to communicate openly and honestly felt more support from each other and were able to positively cope with the experience of their child's illness (Dahlquist et al.; Enskar et al., 1997b; Ferrell et al., 1994; McGrath, 2001a; Sharan et al., 1999; Tarr & Pickler; Yeh et al.). The support of healthcare professionals, specifically nurses, was recognized as a major influencing factor in parents' ability to cope positively with their child's illness (Enskar et al., 1997b; McGrath, 2001b; Shields et al.; Wills; Yiu & Twinn). Positive relationships with professionals were important because parents often looked to them for support. Parental support was needed at the time of diagnosis because more psychological problems were thought to be experienced at this time of the cancer journey (Sawyer et al.; Shields et al.).

### **Practical Needs**

Support with finances was a highly recognized practical need (Aitken & Hathaway, 1993; Brown & Barbarin, 1996; Cayse, 1994; Enskar et al., 1997b; Martinson et al., 1993, 1997, 1999; Mercer & Ritchie, 1997; Shields et al., 1995; Sloper, 1996; Yiu & Twinn, 2001). Families believed that they were being governed by their child's disease, and most mothers believed that they needed to take time away from work to care for their sick child, thereby decreasing the amount of money coming into the household (Brown & Barbarin; Enskar et al., 1997b). The child's illness affected the normal day-to-day routines, creating stress for both parents who were trying to manage work, family, and home issues (Brown & Barbarin; Chesler & Parry, 2001; Enskar et al., 1997b; Ferrell et al., 1994; Neil-Urban & Jones, 2002; Yeh, 2002). Healthcare professionals needed to assess how families were managing daily activities and consider practical help that might be needed with cooking, picking up the mail, caring for siblings, offering respite from caregiving, and achieving a sense of normalcy (Brown & Barbarin; Cornman, 1993; Manne et al., 1996; Martinson et al., 1993; McGrath, 2001a; Mercer & Ritchie; Shields et al.; Skolin, Hursti, & Wahlin, 2001; Williams, 1992).

### **Spiritual and Physical Needs**

Spiritual and physical needs were cited in less detail than the other needs. Regardless of their previous beliefs, parents sought meaning for their experience and possible explanations for their child's disease from religious activities or practices (Chesler & Parry, 2001; Clarke-Steffen, 1997; Ferrell et al., 1994; Yeh, 2001; Yeh et al., 2000). Spiritual support throughout the cancer journey should be offered to parents because they appear to search for help from religious figures (Martinson et al., 1997; Mercer & Ritchie, 1997; Yeh, 2001). The physical needs cited in the literature describe the needs of the parents as well as the child with cancer. Parents needed support related to understanding and managing the

physical symptoms of their child's illness (Clarke-Steffen, 1997; Skolin et al., 2001). Parents reported that their child's pain was not taken seriously and that they could "feel" their child's physical pain continuously (Ferrell et al.). Parents looked for support for their own physical symptoms of difficulty sleeping, upsetting dreams, fatigue, loss of appetite, loss of weight, dizziness, headaches, and cold (Martinson et al., 1997; Santacroce, 2002).

## Discussion

The SCNF provides useful information in an adult population. However, its use with pediatric populations has been challenging. The framework's definition of needs did not appear to directly relate to a pediatric population and their families. The definition of the word "need" often has various meanings and can create confusion when used in different contexts. Difficulties were encountered in categorizing some of the needs, and some needs could be categorized in more than one place. Definitions of each need, as they relate directly to the children, would facilitate categorization and perhaps development of strategies to meet needs. If needs are not well defined, they cannot be met satisfactorily.

With increasing specialization and a proliferating number of services available, parents often are faced with a complex and overwhelming array of professionals in various care settings. The lack of communication and collaboration between professionals within these various care settings has been cited as a contributor to unmet needs (Buckley, 2000; Clarke-Steffen, 1993; Enskar et al., 1997b; Shields et al., 1995; Williams, 1992; Yiu & Twinn, 2001). When supportive care needs are not met, ultimately, how the child with cancer and family

cope with the disease are affected. Although supportive care is essential for enhancing the quality of care for the patient and family, achieving integration among all of these services, caregivers, and care settings is a formidable challenge (Pyke-Grimm et al., 1999).

Research is required to elucidate the needs of families during the period of transition from diagnosis to treatment. This is a difficult time for children and their families because, for most, the experience is new and presents many challenges. The continuum of care involves numerous sectors and providers in hospital, community, and ambulatory care settings. Questions arise that may not have any definite answers. As the diagnosis of cancer is made and treatment begins, the needs of the child and the family shift. Supportive care is required during this time within the illness continuum because parents can feel insecure and unsure about how to care for their child's needs in relation to side effects as well as come to the realization of and try to live with cancer (McCray, 1997).

This review provides a detailed synopsis of parental needs identified in the research to 2002. The six categories of supportive care needs identified in the SCNF are cited in the literature, but no study was designed to examine the entire constellation of supportive care needs. A prospective assessment of needs from the perspective of parents and providers would be the next logical step of inquiry to assist in the planning and provision of quality care from diagnosis to treatment.

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