

Measuring the Care Needs of Mothers of Children with Cancer: Development of the FIN-PED

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Menée en deux temps, cette étude visait à évaluer le Family Inventory of Needs-Pediatrics (FIN-PED), un instrument comprenant 52 données réparties selon deux sous-échelles, la première servant à évaluer le poids des besoins en matière de soins et la deuxième, la mesure dans laquelle ces besoins ont été comblés. Au cours de la première étape, un groupe expert formé de mères ayant un enfant atteint de cancer a évalué l'instrument en fonction de critères de clarté, de consistance interne apparente, et de validité du contenu. Tous les éléments correspondaient aux critères pré-établis. Lors de la deuxième étape, 110 mères ont évalué l'instrument selon des critères de consistance interne et de précision, de fiabilité et de catégorisation. Les deux sous-échelles ont atteint une valeur estimée de 0,94 sur le plan de la consistance interne. La fiabilité de l'instrument a également été démontrée. L'analyse factorielle a produit 4 facteurs interprétables, ce qui suggère que l'instrument est multidimensionnel.

This 2-phase study tested the Family Inventory of Needs-Pediatrics (FIN-PED), a 52-item instrument structured to include 2 subscales, the first measuring the importance of care needs and the second measuring the extent to which needs were met. In Phase I, an expert panel of 6 mothers of children with cancer rated the tool for clarity, apparent internal consistency, and content validity. All items met preset criteria for these assessments. In Phase II, 110 mothers rated the instrument for internal consistency reliability, stability over time, and internal construct validity. Both subscales achieved an estimated internal consistency of 0.94. Evidence of the instrument's stability over time was also achieved. Factor analysis resulted in 4 interpretable factors, suggesting that the tool is multidimensional.

Each year in Canada approximately 912 children are diagnosed with cancer (National Cancer Institute of Canada/Statistics Canada, 1998). Despite vast improvements in treatment outcomes, malignant diseases

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remain the second leading cause of pediatric deaths (Aitken & Hathaway, 1993). Approximately 67% of children diagnosed with cancer will survive beyond 5 years (Bleyer, 1993). However, these children will minimally require an annual assessment for recurrence of the original disease and may develop late side effects of treatment, which can include second malignancies and mental and cognitive changes. Parents are continuously challenged in coping with various levels of uncertainty and the demands imposed by different phases of the illness. Family members of a child with cancer face many stressful events over an extended period and experience many needs. A review of the pediatric literature from November 1983 through May 1996 suggests that health-care providers are sensitive to the needs of parents whose children are diagnosed with cancer (Foster, Hunsberger, & Anderson, 1989). The literature describes parental needs as honesty, support, and information about their child's condition; involvement in the care of their child; and participation in decision-making concerning treatment (Shields et al., 1995; Williams, 1992). There are few studies that document the use of a reliable and valid instrument for measuring these parental needs. This study was designed to address this gap.

Both mothers and fathers are affected by and involved in the care of their child. However, the literature indicates that most often mothers are the primary caregiver in cases of pediatric cancer, and that when both parents provide care they may be at different stages of adaptation and have different needs (Hayes & Knox, 1983). Given the lack of research in this area, it was judged useful to focus on one group of parents for the development and testing phase of the research program. Therefore, the purpose of this first study was to develop an instrument to measure the care needs of mothers whose children have been diagnosed with cancer. After further validation of this tool, studies to assess the reliability and validity of the instrument for use with fathers and siblings will be carried out.

Review of the Literature

A review of the empirical pediatric literature prior to the study (November 1983 through May 1996) revealed that few studies addressed the care needs of families of children diagnosed with cancer. Wittrock, Larson, and Sangren (1994) investigated coping strategies and self-reports of psychological adjustment in parents of children with cancer ($N = 17$) using an interview format. This information provided descriptions of the types of needs that might have relevance in the construction of a needs-assessment tool.

Shields et al. (1995) studied the psychosocial needs of pediatric cancer families from the perspective of social workers. The Family Needs Survey (Bailey & Simeonssen, 1988) used in that study had been developed to assess the functional needs of parents of young children with a handicap, a distinctly different group from those with cancer. Therefore, although their results provided information about the types of concerns parents might have, use of the tool for parents of children with cancer was judged to be limiting and unlikely to elicit the range of concerns specific to this population.

Sloper (1996) investigated parents' satisfaction with services and support and the effect on family life at one specific time, 6 months post-diagnosis. Parents' responses to the diagnosis and treatment of cancer in the early months were evaluated using a non-specified semi-structured interview method. Results confirmed that this early period is extremely stressful, but Sloper did not provide an instrument for subsequent testing.

The literature review uncovered no evidence of a psychometrically sound instrument to measure mothers' needs in a pediatric-care situation. Therefore, the search was widened to include studies describing family needs of adult cancer patients, in the hope of identifying a reasonable tool. Four studies were found.

Tringali (1986) asked 25 family members of adult cancer patients to rate the order of importance of 53 needs statements using a four-point Likert scale. Information needs were found to be most important; however, no psychometric estimates of the tool were reported.

Longman, Atwood, Sherman, Benedict, and Shang (1992) used a descriptive design to measure the needs of home-based adult patients as assessed by both the patients ($N = 30$) and family caregivers ($N = 29$). Needs were measured using the 114-item Patients' Needs Scale and the 90-item Caregivers' Needs Scale. This instrument gave promising psychometric results; however, it was considered too long for use with the present study population and was not specific to pediatric care.

Wingate and Lackey (1989) used an open-ended instrument, the Objects Content Test, to assess the care needs of adult cancer patients and their families. Content analysis of needs statements revealed that psychosocial needs were the most important to both patients and family caregivers. Participants were not asked to report the extent to which their needs had been met. This method required time-consuming qualitative analysis and was not specific to pediatric care.

The 20-item Family Inventory of Needs (FIN) developed by Kristjanson, Atwood, and Degner (1995) measures both the importance of care needs to a family member and the extent to which these needs have been met. This tool has been found to be simple and practical for use with stressed populations. Reasonable internal consistency estimates (0.83, 0.85) and content and construct validity estimates have been reported (Kristjanson et al.). Therefore, a decision was made to use the FIN as the basis for developing a tool to measure the care needs of mothers of children with cancer.

Conceptual Framework of the Instrument

The original Family Inventory of Needs (FIN) was developed based on *Fulfilment Theory* (Schaffer, 1953; Vroom, 1964). According to this theory, satisfaction is a function of the extent to which a person's needs are met (Schaffer). The existence and perception of needs and needs fulfilment are hypothesized to be antecedents to the judgement regarding satisfaction with care.

The FIN was designed to measure two constructs: *Importance of Family Care Needs* and *Fulfilment of Care Needs*. *Importance of Family Care Needs* is defined as the family member's perceived importance of needs for professional care. This is conceptualized as a continuum ranging from "extremely important" to "unimportant." *Fulfilment of Care Needs* is defined as the judgement by a family member of whether his or her perceived needs have been met by health professionals. This is conceptualized as three items: "met," "partly met," and "unmet."

These definitions were refined for the purposes of this study. *Mothers' Care Needs* was defined as the needs that mothers identify related to their child's cancer. *Fulfilment of Care Needs* was defined as the extent to which mothers reported that their needs had been addressed by health professionals.

Content in the original FIN was based on Molter and Leske's (1983) Critical Care Family Needs Inventory (CCFNI) and Tringali's (1986) use of the CCFNI with families of advanced cancer patients. Kristjanson et al. (1995) refined the CCFNI based on qualitative research results to index more precisely the needs of family members of advanced cancer patients. This 20-item tool was augmented and refined based on a review of pediatric literature specific to the care needs of family members of children with cancer. Fifteen of the 20 FIN items were minimally changed and the wording of five items was modified to better reflect the needs of one particular mother of a pediatric cancer patient.

Following a careful literature review, another 20 items were added. This augmented and modified tool was named the FIN-PED, to reflect both the core items in the original FIN and the added items in the adapted FIN. The researchers reasoned that the addition of "PED" would make the tool easily identifiable for use with pediatric populations.

Method

Ethical approval was obtained from the Ethical Review Committee of the University of Manitoba Faculty of Nursing and access approval was obtained from the Manitoba provincial cancer centre. Participants were assured that their names and responses would be kept confidential. Demographic data and instrument responses were identified only by numerical code. Data and codes were stored separately in a locked file accessible only to the researchers and research staff.

Phase I

The testing process used for Phase I was based on Imle and Atwood's (1988) method for assessing the validity and internal consistency of inductively generated instruments. This method involves a three-part psychometric assessment. Each item is rated for clarity, apparent internal consistency, and content validity. This rating sequence ensures appropriate and logical responses to questions. For example, clarity of items must be established before the rater can assess apparent internal consistency. Participants were asked to evaluate the extent to which items in the instrument were clearly worded, belonged together, and actually measured the needs of mothers of children with cancer.

Sample and selection criteria. Six mothers were recruited from a Canadian pediatric cancer centre to review the FIN-PED. Participants were 18 years of age or older and were able to read and write English. Excluded were mothers of children diagnosed within the preceding 2 months and mothers whose children had died.

Testing criteria. Criteria developed by Imle and Atwood (1988) were used to assess the responses. Agreement of 83% (i.e., 5 of 6 mothers rating the item acceptable) was preset as the minimum. This criterion is based on calculating the proportion of experts who might agree, out of the total number planned for use, and then setting the standard error of the proportion to identify the cut-off for chance versus real agreement. According to Lynn (1986), this computation allows the researcher to establish a necessary level of percentage agreement at a .05 level of significance.

Clarity of items. Clarity, the first rating procedure, consisted of two parts: rating the clarity of the scale instructions and rating the clarity of the scale items, as either "clear" or "unclear." Raters were asked whether the instructions clearly explained how to complete the scale. They were then asked whether each item in the scale clearly described a need. Space was provided for comments, and time was allotted for discussion of comments. Raters' decisions and comments regarding clarity, format, and reading level were incorporated into the instrument.

Clarity of the instructions and clarity of the items were rated separately. All participants rated the instructions as clear. Five participants rated all items as clear and one participant rated two items as unclear. This level of agreement met the preset criterion of 83% for the directions and all items on the questionnaire. The first item rated as unclear was "be allowed to discuss the terminal stage of my child's illness." The words "terminal stage" concerned one mother because, to her, they suggested that a terminal phase was inevitable and this did not apply to her child's diagnosis. This concern was apparently related to the sensitive nature of the item rather than to its clarity. In the revised version of the FIN-PED, a statement was added to acknowledge the sensitive nature of this question. The second item rated as unclear was "have health care professionals guide me in setting limits for my child." This item was edited by changing the ending to "limits for my child's behaviour." No other items were rated as unclear; however, the participants did suggest a few small wording changes — for example, the phrase "depending on child's age" was added to those items that concerned information-sharing with children.

Apparent internal consistency. Imle and Atwood (1988) define "apparent internal consistency" as the degree to which all scale items group together — that is, homogeneity of content. Respondents were first asked to indicate whether the items in the questionnaire belonged together. All respondents answered affirmatively. Respondents then rated whether each question belonged in the questionnaire. All respondents verified inclusion of each item. This level of agreement met the preset criterion of 83% for the items of the instrument.

Content validity assessment. Content validity assesses how well and how adequately items express the meaning of the conceptual domain without redundancy. Three questions were posed: (1) "In general, does the label and definition of the scale fit the whole set of scale items?" (2) [with respect to each individual item] "Does the item belong to the label and definition?" (3) "Is each item on the question-

naire unique (i.e., not repetitious)?” There was 100% agreement that the label and definition fit all items and no items were judged repetitious.

The last part of the pilot-testing procedure offered participants an opportunity to suggest additional needs. This step resulted in the addition of 12 items (see Table 1). A content analysis of these additional items revealed three general categories of need: needs of the ill child and siblings, needs related to health professionals, and practical needs related to understanding the health-care system. Mothers were firm in their opinion that the additional items should be included. The refined FIN-PED tested in Phase II comprised a total of 52 items (see Appendix).

Table 1 <i>Additional Needs Identified by Mothers</i>	
Needs Category	Item
Needs of the Ill Child and Sibling(s)	<ul style="list-style-type: none">– know how to handle my child’s feelings– have my child participate in decisions about his/her care (appropriate to his/her age)– know how to handle the feelings of my other children– know that health-care professionals accept my child even when he/she is angry– know that where appropriate health care professionals will ask my child’s permission to do things to my child
Needs Related to Health Professionals	<ul style="list-style-type: none">– know that the knowledge of health-care workers fits my child’s needs– know to whom I should direct my questions– know to whom to turn if conflict situations arise
Practical Needs Related to the Health-Care System	<ul style="list-style-type: none">– know where things are in the hospital– know where things are in the city– know where to park at the hospital/clinic– have financial assistance to help cope with the costs of my child’s illness (parking, food, transportation, medicine)

Phase II

Three research questions were addressed in this phase: (1) *To what extent does the FIN-PED evidence internal consistency?* (2) *To what extent does the FIN-PED evidence stability over time?* and (3) *To what extent does the FIN-PED evidence internal construct validity?*

Sample. Mothers were selected from the same pediatric cancer centre used for Phase I, using the same selection criteria. A list of children diagnosed with cancer during the previous 10 years was compiled by clerical staff at the centre. Two mail-outs were made 2 weeks apart: the protocol was mailed to 250 mothers; 44% ($N = 110$) returned the first questionnaire, and 50 mothers who had completed the first questionnaire returned the retest questionnaire.

Demographic information about the mothers was obtained from 106 of the 110 respondents (see Table 2). The typical mother was under

Table 2 *Demographic Profile of Mothers (N = 106)*

Characteristic	Frequency	Percentage
Age		
< 40 years	69	65
≥ 40 years	37	35
Marital Status		
Single	12	11
Not single	94	89
Education Level^a		
Less than high school	26	25
High school	27	26
College/vocational training	26	25
Undergraduate degree	12	11
Graduate degree	13	12
Occupation^a		
Teacher	10	9
Nurse	8	8
Other profession	9	9
Clerical	14	13
Other job	31	29
Not working	33	31
Distance from Urban Centre		
> 240 km	24	23
100–240 km	15	14
< 100 km	14	12
Urban residence	53	51

^aTotals for education ($n = 104$) and occupation ($n = 103$) are less than 106 due to missing data.

40 years of age (65%), either married or living in a common-law relationship (89%) in an urban dwelling (51%). Approximately 51% had not been educated beyond high school; 69% were employed outside the home.

Demographic and medical information about the children was provided by 109 mothers (see Table 3). The two most frequent disease categories represented were malignant solid tumours (37.4%) and leukemias (36.4%). The mean age of the children at the time of the survey was 11 years. Gender distribution was almost even. Most children had a history of hospital admissions related to cancer treatment or complications (e.g., fever, neutropenia, infections).

Table 3 *Frequency and Percentage Distribution of Children's Illness Characteristics*

Characteristic	Frequency	Percentage
Diagnosis		
Malignant solid tumours ^a	40	37.4
Leukemia	39	36.4
Brain tumour	10	9.3
Other	18	16.8
Gender		
Female	55	50.0
Male	54	50.0
Age		
1-5 years	25	22.9
6-10 years	29	26.6
11-15 years	32	29.6
> 15 years	23	21.1
Number of Hospital Admissions		
1-4	44	45.8
5-19	36	37.5
> 20	16	16.7
Reason for Hospital Admission		
Original diagnosis	41	6.4
Treatment	300	56.0
Relapse	5	0.8
Other	237	36.9

^aexcludes brain tumours.

Testing criteria. Internal consistency reliability was assessed using Cronbach's standardized alpha coefficient. A criterion of 0.70 was preset as the minimum for internal consistency, which is considered acceptable for a newly developed instrument (Nunnally & Bernstein, 1994). As well, Carmines and Zeller (1989) suggest that 50% of item-to-total correlations should be between 0.40 and 0.70. Scores above 0.70 indicate redundancy and scores below 0.40 indicate that the item may not contribute information about needs parallel with other scale items. Test-retest reliability was also assessed. A correlation of at least 0.70 was preset as the criterion for satisfactory test-retest reliability (Nunnally & Bernstein).

Determination of the number of scale factors obtained from the factor analysis involved examination of the scree plot (graph of eigenvalues) and an expectation that interpretable factors would have eigenvalues of at least 1.0 (Kim & Mueller, 1988; Wood, Tataryn, & Gorosuch, 1996). Criteria for deciding which items to include in each factor were item loadings of greater than 0.40 on the factor, with a difference of at least 0.15 between loadings on different factors (Kim & Mueller).

Results

The possible range for the needs items was 1 to 5 (1 = not at all important; 5 = very important). The range of means for the needs statements was 2.94 to 4.94 with standard deviations between 30 and 1.72. For most items, the scores were slightly negatively skewed. The possible range for the Needs-Met subscale was 1 to 3 (1 = met; 2 = partly met; 3 = unmet). The range of means for the Needs-Met subscale was 1.07 to 1.85 with standard deviations between 0.26 and 0.81. Needs-Met items had slightly positively skewed distributions, indicating that most needs had been met or partly met.

Internal Consistency

The Importance of Needs subscale achieved an internal consistency estimate of 0.94 (time 1), as measured by Cronbach's standardized alpha coefficient — well above the criterion of 0.70. The total score on the Importance of Needs subscale was also correlated with each item score. Thirty-eight of the 52 items (73%) on the Importance of Needs subscale achieved item-to-total correlations between 0.40 and 0.70. This is well above the preset range of at least 50% of items within this range. No items had item-to-total correlations greater than 0.70.

The Needs-Met subscale of the FIN-PED instrument achieved an internal consistency estimate as measured by Cronbach's standardized alpha coefficient of 0.94 — well above the criterion of 0.70. Sixty-nine percent of the items on the Needs-Met subscale achieved item-to-total correlations between 0.40 and 0.70. This is also above the preset criterion of at least 50% of items between this range. No items had item-to-total correlations greater than 0.70.

Stability over Time

Fifty of the 110 respondents completed and returned the retest questionnaire. Because of this relatively small sample size, a nonparametric correlational statistic was used to assess stability over time. A Spearman's correlation coefficient of 0.78 ($p = 0.008$) was obtained, indicating that the scale was stable over this tested time period.

Internal Construct Validity

Internal construct validity refers to the internal structural validity of the instrument being tested. This type of assessment is used to determine the dimensionality of the instrument and the domains of a construct measured by a particular scale (Waltz & Strickland, 1988). Factor analysis is the usual method of analysis for this type of assessment.

Factor analysis of the Importance of Needs scale using principal axis factoring with varimax rotation was used to assess the internal construct validity of the instrument and identify possible sub-dimensions of the subscale. Varimax orthogonal rotation was deemed appropriate given the exploratory nature of the factor analysis (Kim & Mueller, 1988). Thirteen factors had eigenvalues greater than 1.0, explaining 82% of the variance. The scree plot also suggested that the first 13 factors should be examined as part of a preliminary interpretation of results.

Eigenvalues ranged from 1.13 to 13.94. Percentage of variance ranged from 27 for the first factor extracted to 2 for the 13th factor. Item factor loadings meeting the preset criterion ranged from values of 0.55 to 0.97. Five items loaded on more than one factor and were not interpretable. Nine factors contained only one or two items.

Examination of the items within Factors I to IV identified groups of needs concerning: Positive Involvement in Child's Care, Information Specific to Child's Plan of Care, Other Children's Needs, and Open and Clear Responses to Questions. These four factors accounted for 51% of the variance. Factors, items, and factor loadings are shown in Table 4.

Table 4 *Factor Analysis of FIN-PED (Needs Subscale)*

Item	Factor I: Positive Involvement in Child's Care	Loading
18	– feel there is hope	.92
17	– know <i>when</i> to expect side effects to occur	.82
16	– know <i>what</i> side effects the treatment can cause	.82
25	– have thorough information about how to care for my child at home	.73
30	– know that health-care professionals offer me the opportunity to participate equally in my child's care	.61
40	– have trust in the health-care system	.55
Item	Factor II: Information Specific to Child's Plan of Care	
19	– be informed of changes in my child's condition	.94
12	– know what treatment my child is receiving	.92
26	– feel that the health-care professionals are sincere in caring about my child	.81
6	– have explanations given in terms that are understandable to me	.69
14	– be told when and why changes are being made in my child's treatment plan	.62
Item	Factor III: Needs of Other Children	
51	– know <i>how</i> to give information to my other children (appropriate to his/her age)	.92
50	– know <i>what</i> information to give to my other children (appropriate to his/her age)	.91
52	– know how to handle the feelings of my other children	.78
Item	Factor IV: Open and Clear Response to Questions	
4	– know I can ask questions any time	.86
5	– know to whom I should direct my questions	.84
8	– know the probable outcome of my child's illness	.84

To confirm internal consistency reliability of these sub-dimensions, a correlation matrix was re-examined to assess inter-item correlations for items on each factor. The four-factor solution resulted in inter-item correlations that met the preset criterion of 50% inter-item correlations between 0.30 and 0.70. All inter-item correlations for the first factor

(Positive Involvement in Child's Care) were between 0.38 and 0.77. Eight of the 10 inter-item correlations for Factor II (Information Specific to Child's Plan of Care) were between 0.39 and 0.73. Items 19 and 12 and items 19 and 26 achieved inter-item correlations of 0.90 and 0.81, respectively, suggesting slight redundancy. Factor III (Other Children's Needs) inter-item correlations fell between 0.72 and 0.91. Factor IV (Open and Clear Response to Questions) inter-item correlations were between 0.49 and 0.75. A Cronbach's alpha coefficient of 0.88 was obtained for the 17-item abbreviated scale based on the four-factor solution. Item-to-total correlations for this abbreviated scale ranged from 0.28 to 0.72, with 12 of the 17 correlations between the preset criterion of 0.40 and 0.70. The Kaiser-Meyer-Olkin measure of sampling adequacy (MSA) was acceptable (0.81), and no item had an individual MSA value below 0.66. Therefore, despite the relatively low observations-to-variables ratio, the results of the factor analysis may be considered relatively stable by this criterion.

According to Carmines and Zeller (1989), if a scale is unidimensional, the first extracted component (factor) should account for at least 40% of the variance in the items. Factor I in this scale accounted for 27% of the variance in the items, suggesting that the FIN-PED is multidimensional. To further assess whether the Importance of Needs scale was multidimensional, a theta coefficient was calculated. According to Carmines and Zeller, if a scale is multidimensional, the theta coefficient should be higher than the Cronbach's alpha coefficient. In this instance the Cronbach's alpha coefficient was 0.94 and the theta coefficient 0.95, providing further evidence that the FIN-PED may be multidimensional.

Posthoc Analysis

Posthoc analysis was used to compare the core items from the original FIN with the modified version of these items included in the FIN-PED. Internal consistency reliability for the revised 20 items from the original FIN was 0.61. Item-to-total correlations ranged from 0.12 to 0.62 with a mean item-to-total correlation of 0.38. Prior testing of the reliability of the original FIN with adult relatives of adult cancer patients resulted in an internal consistency estimate of 0.83, suggesting that the items that form this scale perform less reliably when tested with mothers of children with cancer. This comparison confirmed that the altered FIN-PED instrument is likely more appropriate for use with this population.

Discussion

Both subscales of the FIN-PED demonstrated high internal consistency, as measured by Cronbach's standardized alpha coefficients and item-to-total correlations. Examination of inter-item correlations among items within sub-dimensions (as determined by factor analysis results) revealed acceptable inter-item correlations. Reliability estimates obtained by calculating the theta coefficient, together with these results, suggest that mothers' care needs may be multidimensional.

Although an assessment of internal consistency of the tool is helpful, clinical reasoning suggests that care needs may not be as meaningfully measured using a parallel item reliability model (e.g., Cronbach's alpha). For example, individuals who rate one need as important (e.g., need for information) may not necessarily rate another as important (e.g., need for support from other parents). Therefore, the more appropriate reliability model for further testing of the FIN-PED may be additional assessments of stability of the tool over time.

Further research is needed to confirm the test-retest reliability of the FIN-PED, considering the relatively small number of scores available for testing this type of reliability in the present study. Subsequent testing of the abbreviated four-factor scale is also warranted, to determine whether reliability estimates obtained using the data of this study hold. If reliability estimates remain high, the brevity of this 17-item tool would make it clinically practical. Separate assessment tools for measuring the needs of siblings and fathers could be developed and tested to supplement the FIN-PED. During the pilot study, mothers reported that they believed their needs were different to those of their spouse, providing further support for the need to develop and test a specific tool for fathers.

Although results from this three-phase instrument refinement and testing project appear promising, it would be premature to recommend use of the 17-item abbreviated tool in clinical practice. These results are based on a sample of 110 mothers of children with cancer recruited from one care setting. No claim is made regarding the representativeness of the sample. As well, the tool is still considered immature and warrants further testing. Publication of these results is intended to expedite this process.

The construct validity of the tool might be further assessed by comparing the responses of known groups (e.g., mothers who belong to a parent support group compared to those who do not; mothers of chil-

dren with longstanding diagnosis compared to mothers of children recently diagnosed).

Enskär, Carlsson, von Essen, Kreuger, and Hamrin (1997) have developed and tested a tool in Sweden to measure the life experience of parents of children with cancer. Their report had not yet been published at the time of our study (1994–96). The parallel development of these instruments confirms the international necessity for a needs assessment tool available in different languages. Future concurrent validity assessments of the FIN-PED using Enskar et al.'s tool are recommended.

Summary

The FIN-PED has been developed to identify the needs of mothers of children diagnosed with cancer. This instrument may eventually be used to assist in planning care for children with cancer. Further reliability and validity testing is required to confirm the initial results obtained in this study. Multi-site testing is also recommended, to determine the needs of mothers of children with cancer irrespective of treatment location.

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Appendix Family Inventory of Needs — Paediatrics

Below is a list of needs identified by some family members who have a child with cancer. Please rate how important each item is from 1 to 5 as it relates to your present situation. If an item is not at all important to you, give it a 1. If it is very important to you, give it a 5. If it is somewhere in between, give it a score between 1 and 5 which reflects how important it is for you. If you rated a need greater than (1) then check whether each need is currently met, partially met, or unmet.

I need to:	Ratings from 1-5	If you rated an item higher than 1, check if need was:		
		MET	PARTLY MET	UNMET
1. have my questions answered honestly.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. believe that the health-care professionals caring for my child are competent.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. know that the knowledge of health-care workers fits my child's needs.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. know I can ask questions any time.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. know to whom I should direct my questions.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. have explanations given in terms that are understandable to me.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. where appropriate, have explanations given to my child in terms that are understandable to him/her.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. know the probable outcome of my child's illness.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. know what my child's stay in the hospital will be like.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. know how to handle my child's feelings.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. know why things are done to my child.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. know what treatment my child is receiving.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. know what situations I can and cannot control while my child is in hospital.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. be told when and why changes are being made in my child's treatment plans.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. be assured that the best possible care is being given to my child.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. know <i>what</i> side effects the treatment can cause.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		If you rated an item higher than 1, check if need was:		
	Ratings from 1-5	MET	PARTLY MET	UNMET
17. know <i>when</i> to expect side effects to occur.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. feel there is hope.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. be informed of changes in my child's condition.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. be involved in decisions about my child's care.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. where possible, know how much time I can take in making my decisions.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. know how I can help care for my child in the hospital.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. know <i>what</i> information to give to my child with cancer (appropriate to his/her age).	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. know <i>how</i> to give information to my child with cancer (appropriate to his/her age).	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. have thorough information about how to care for my child at home.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. feel that the health-care professionals are sincere in caring about my child.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. know that health-care professionals accept my child even when he/she is angry or upset.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. know the names of the health-care professionals involved in my child's care.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. know how to contact the health-care professionals involved in my child's care.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. know that health-care professionals offer me the opportunity to participate equally in my child's care.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. have a respectful relationship with the health-care professionals caring for my child.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. know to whom to turn if conflict situations arise.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Measuring the Care Needs of Mothers of Children with Cancer

		If you rated an item higher than 1, check if need was:		
	Ratings from 1-5	MET	PARTLY MET	UNMET
33. have my child feel trust in the health-care professionals caring for him/her.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. have my child participate in decisions about his/her care (appropriate to his/her age).	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. know that where appropriate health-care professionals will ask my child's permission to do things to my child.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. have health-care professionals guide me in setting limits for my child's behaviour.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. know health-care professionals will respect my family values regarding my child's behaviour.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. feel that health-care professionals accept me even if I am angry or upset.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. feel encouraged by health-care professionals to maintain a normal lifestyle.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. have trust in the health-care system.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. meet with other mothers/parents dealing with similar issues.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. be involved with a support group.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. have someone be concerned with my health.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. be told about people who could help with my concerns.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. know where to park when at the hospital/clinic.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. know where things are in the hospital.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. know where things are in the city.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. have financial assistance to help cope with the costs of my child's illness (e.g., parking, food, transportation, medicine).	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The following question is sensitive in nature,
but your response would be helpful to us.

I need to:	Ratings from 1-5	If you rated an item higher than 1, check if need was:		
		MET	PARTLY MET	UNMET
49. be allowed to discuss the terminal stage of my child's illness, if necessary.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you *have* children in addition to your child with cancer please answer
the following three questions (50, 51 and 52). If you do *not have other children*,
please put an X in this space _____.

I need to:	Ratings from 1-5	If you rated an item higher than 1, check if need was:		
		MET	PARTLY MET	UNMET
50. know <i>what</i> information to give to my other children (appropriate to his/her age).	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. know <i>how</i> to give information to my other children (appropriate to his/her age).	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. know how to handle the feelings of my other children.	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please tell me anything else health-care providers could do to improve the care
for you and your child:

Please tell me anything you would like to about the questions I have asked
you. If you need more pages for your responses, please feel free to add them.

Thank you for your participation.
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