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# An examination of the needs of parents of hospitalized children: comparing parents' and staff's perceptions

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## An examination of the needs of parents of hospitalized children: comparing parents' and staff's perceptions

The needs of parents of hospitalized children have received some attention in the health literature, but few studies have compared parents' perceptions of needs with staff's ideas about parents' needs. The aim of this study was to examine differences between the perceptions of the needs of parents of hospitalized children held by staff – nurses, doctors and allied health staff, and parents in a 150-bed paediatric hospital in Sweden. The convenience sample comprised 132 staff – nurses, doctors and allied health staff and 115 parents of children admitted to all the wards except intensive care. Kristjánsdóttir's "needs of parents of hospitalized children" questionnaire (NPQ) was the instrument of choice and was modified slightly for use with staff. Results indicated significant differences in

perceptions of the importance of different needs of parents, of how well they were being met in the hospital and how much help the parents needed to have them filled. Differences between parents' and staff's perceptions of the importance of parental needs were found in areas relating to psychosocial needs, but in general, in that hospital, the needs were being adequately met. The main differences between staff's and parents' results were in the degree of independence shown by parents in requiring help to have their needs met. This demonstrates either that parents are much more independent than appraised by staff, or, that parents are sometimes unaware of the level of assistance available.

**Keywords:** hospitalized child, parents, needs, satisfaction, staff.

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## Introduction

When a child is admitted to hospital, the family is always affected. Parents (in this work defined as the primary caregivers to the child) usually accompany their child, and at many hospitals they stay and participate in the care. During recent decades, there has been a shift in paediatric health care towards family-centred care (FCC) based on close and continuous involvement of the child's family. FCC has become a commonly used term in children's hospitals and wards. No one definition of FCC exists, however, widely recognized key elements are those des-

cribed by the Association for the Care of Children's Health (North America) (1) and centre around the concepts that the family is the constant in a child's life, whereas service systems and personnel within those systems fluctuate, and that parent/professional collaboration at all levels of health care enhances the care of children within health facilities. Family-centred care is considered by some to be a cornerstone of modern paediatric practice (1), while others believe it is an ideal that cannot be successfully implemented (2, 3). Darbyshire (4) suggested that the complexities of FCC were minimized in the literature. While a wonderful ideal, it is, in reality, extremely difficult to implement because of the judgmental attitudes of nurses towards parents, resulting in the feeling that they are "parenting in public". Likewise, nurses feel they are "nursing in public". He suggested that for FCC to succeed, understanding, empathetic communication between parents and nurses was necessary. An examination of staff's attitudes to the care of children, and, separately, their parents in four countries indicated that in all places, staff gave a more positive score for working with children than

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with parents (3). While this may not be surprising, given that staff who choose to work in paediatrics do so because they like children, it indicates that truly effective FCC is not being implemented as parents are an equally integral part of this model and working with them should elicit similar positive scores to working with children. We support this argument and the study reported here was based on this assumption. Integral to this, while children's needs during an episode of hospitalization are important, attention should be given to the needs of parents as often they reflect the needs of their child. Parents know their children best and often act as a bridge between the child and staff in order to ensure their child's needs are fulfilled (5). In a descriptive study (6), it was found that if parents' needs were met, they were better able to cope with the child's illness. Other investigators found that parents who cared for a child with chronic illness felt that they could access higher quality care at home than in hospital as nurses were too busy or understaffed to provide optimal care (7).

### *Theoretical framework*

Discussion of needs suggests the requirement for an examination of the independence of people, and the ability of them to meet their needs themselves. According to Orem's model of self-care (8), humans have an innate ability to care for themselves, and the role of nursing is to ensure that this is maximized in time of need. Three constituents comprise Orem's theory – self care, self-care deficit and nursing systems (9). Taylor (10) has described family as an important part of the application of self-care theory, as it is, first, a conditioning factor which influences individual self-care systems; second, it is the setting for dependent-care which becomes relevant when self-care is not possible, for example, with children and infants, and, third, it is a unit with certain functions in relation to both self- and dependent-care. Dependent-care is a corollary to self-care; parenting is described as related to, but more than, dependent-care, and not all dependent-care is done as part of parenting (11). von Wright (12) suggested that people need such things that are bad for them to be without. While such a definition is vague, the author asserts that a more precise definition could lead to a false description. Other authors have defined the concept of needs in different ways, such as a means of reaching a goal (13, 14).

Kristjánadóttir (15, 16) identified 43 needs of parents in paediatric units in the United States and Iceland. The needs were categorized as the need to trust health care providers, the need to be trusted, the need for information, the need for support and guidance, needs related to human and physical resources, and needs related to other family members. Fisher (17) and Kirschbaum (18) identified parental needs during the child's stay in a paediatric intensive care unit. Many of the identified needs were related to being able to see the child frequently and

receiving adequate information. Most hospitalizations are not serious enough to warrant admission to intensive care, however, parents commonly report that their primary need when seeking advice from health care professionals is for reassurance (5, 19), and information about their child's illness and how to best to care for their child (5, 20–22). Stewart and Mishel (23) suggested that parents' perceptions of uncertainty affect the child's illness experience.

Bragadóttir (24) found that most parents perceived that they needed help from hospital staff in order to meet their needs. Parents have different needs and also different ways of ensuring those needs are fulfilled. Hallström and Runeson (5) identified five different strategies parents used to ensure their needs were satisfied: avoiding being a bother, having a positive attitude towards the staff, asking questions, preparing themselves, and informing the staff about how they wanted things to be. It is important for professionals to identify these differences in parents, otherwise risk exists that the needs of quiet and nondemanding parents will not be met, and this may affect the care their child receives.

Children are major users of health services but are rarely consulted as health care consumers (25) as there are significant difficulties in studying the needs of sick children. Parents are extensively used as proxies for children. Children of all ages are more or less dependent upon their parents, which may make the situation difficult for parents as their parental role changes when they enter the hospital. It is important to remember their accounts may not always accurately reflect children's perceptions (26). Often assumptions are made that staff know how children think and feel about treatment and care. A study (27) which compared nurses' perceptions of parents' needs with parents' ideas about them found that parents and nurses agreed on needs related to support, information and community services, but differed in the prioritization of the needs. The study suggested that partnership in care works well if parents' and staff's perceptions of parents' needs concur.

Hospitalization of a child inherently implies that help is needed for one reason or another. It is evident that hospitalization of a child will affect the parental role (26) and utilizes aspects of the dependent-care model. Hallström and Runeson (5) suggest that nursing theories are often grounded in nurses' definitions of parents' needs. Parents probably have different needs and also different ways of having their needs fulfilled. Understanding this is a prerequisite for professionals that will enable them to meet parents' needs, something, we suggest, that relates to the dependent care aspect of Orem's theory.

Cross-cultural research in paediatric care affords understanding of differences between the way care is delivered, and expectations of care, in different countries. A project investigating models of care of children in hospitals in developed (Australia and Britain) and developing

(Indonesia and Thailand) countries (3) indicated that health staff (nurses, doctors and allied health staff) have significantly different attitudes to the involvement of parents in some aspects of care including presence of parents in anaesthetic and recovery rooms, parental involvement in care such as intravenous therapy and drug administration, and whether parents should stay with their child in hospital. Significantly fewer Australian than British staff indicated a positive response to such concepts.

The study described in this present paper is part of a cross-cultural project which compares parents' and staff's perceptions of needs in three countries – Sweden, England and Australia. It examines differences between the countries, and will be reported at a later date. It is beyond the scope of this article to discuss in detail the cross-cultural results, and the Swedish data are presented here. The aim of this study was to examine differences between the perceptions of the needs of parents of hospitalized children held by staff – nurses, doctors and allied health staff, and parents in a hospital in Sweden. Assumptions include the notion that FCC (2, 3) is the optimal model for delivery of care to children and families, and that this is recognized by all health professionals, regardless of discipline. To that end we concatenated all staff responses in a single category. Further development of the results and subset analyses will be presented in other papers in this series.

## Methods

### *Site and subjects*

The site for this study was a 150-bed paediatric university hospital in a city in southern Sweden. Questionnaires were distributed in all the units at the hospital except intensive care. Subjects were parents ( $n = 132$ ) of hospitalized children aged from birth to 18 years of age, and staff ( $n = 115$ ) – nurses, doctors and allied health staff who cared for them. The nurses ranged from auxiliary nurses with basic education to nurses with postgraduate university degrees; the doctors were both senior and junior and the allied health staff comprised physiotherapists, occupational and speech therapists and play staff. Two hundred and seventy-four staff questionnaires and 190 parents' questionnaires were distributed by the first two authors, and 132 (48%) and 115 (60%) returned, respectively.

### *Instrument*

The "needs of parents of hospitalized children" questionnaire (NPQ) developed by Kristjánsdóttir (15, 16) was used. The NPQ was first developed to examine parents' perceptions of needs during hospitalization of their 2–6-year-old children (7) and has been used in the USA and Iceland (15, 16, 28) and Canada in both English and

French (29). In further development it was used with parents of 2–12-year-old children (24). The NPQ initially contained 43 statements that had been derived through expert consultation, literature review and questionnaire development. Further statements were appended to create a total of 51. They comprise a panorama of needs which parents might experience during a child's hospital admission including physical and emotional needs, needs for support and information and involvement in the child's care, and the needs of the parent in relation to other family members. The statements were examined from three different perspectives: (i) the parents' perceived importance of each statement in relation to their child's hospital admission (importance score); (ii) fulfilment of the needs statements during admission to hospital (fulfilment score); and (iii) whether or not the parents would need help to have the particular need met (called "independence" score here). The importance score was examined with a five-point Likert scale ranging from "does not concern me" to "very important"; the fulfilment score with a three-point scale of "fully, to some extent, or not at all" and the independence score required a dichotomous "yes–no" response. Kristjánsdóttir's study (16, 28) found a reliability coefficient of  $>0.91$  for each of the three subscales. Further sections of the NPQ ask for comments on ease of use and relevance of the tool, a section for open comments and one for demographic information. For this paper we have compared staff's perceptions of the needs of parents when a child is hospitalized, with parents' perceptions of their own needs.

The NPQ was designed for use with parents only. So staff and parents' attitudes could be compared, it was adapted to create a separate staff questionnaire. To make it relevant to staff, statements were changed slightly, for example, statement number 3 "that staff encourage parents to ask questions and seek answers to them" became for the staff questionnaire "that parents can ask questions and seek answers to them". The statements in parents and staff NPQs corresponded. They were checked by a panel of six staff members (three nurses, two doctors and a dietician) before being trialled by 10 other staff members in Australia.

The English version of the NPQ was translated into Swedish by one of the authors (I. K.-H.), checked by another English-speaking nurse and trialled by asking 10 parents and 10 staff to complete the questionnaire seeking discrepancies and difficulties, which were then corrected. Prior to its translation into Swedish, a similar procedure had been undertaken in Australia. Few corrections were required. Reliability testing on the importance subscale gave a Cronbach's alpha of  $>0.92$ , for the fulfilment subscale 0.94, and for the independence subscale  $>0.96$ , similar to results obtained by both Kristjánsdóttir (16, 28) and Bragadóttir (24). On the staff questionnaires, similar reliability scores were determined (0.96 importance, 0.93 fulfilment, 0.96 independence).

### Procedure

The parents were invited to participate by ward staff, and while this potentially may have compromised the veracity of the responses, the assured confidentiality of the return procedure was designed to ameliorate such difficulties. The first two investigators approached staff members during meetings instigated by I. K.-H. and bundles of the NPQ were left with staff members for distribution amongst themselves. Subsequently, they were reminded to complete the NPQ and place it in collection boxes supplied in the wards. Similar collection points were provided for parents. Few problems were encountered with the NPQ by either parents or staff, with 99% saying that they understood all or most of the questions, 90% confirming relevance of the statements to their current experiences, 92% affirmed the statements met their expectations of care delivery in the hospital and 93% said the statements reflected their satisfaction with services.

### Ethical considerations

Approval was given by all the ethics committees required for a multicountry study, including that at the Swedish hospital (LU 338-00). Information sheets and consent forms met required ethical guidelines, and a return-addressed internal mail envelope accompanied the NPQ. To assure confidentiality, the respondents were told they could decline to sign the consent form if they wished, given that it would accompany the questionnaire on its return, but were asked to date it.

### Statistical analysis

Statistical analysis began with frequency analysis to determine distribution of the data, which were found to be not normally distributed, and to give an indication of the respondent's demographic details. Statistical analysis using SPSS for Windows™ software included chi-square to compare staff's and parents' responses to individual statements in all the groups (importance, fulfilment and independence). If a cell contained less than the expected count in a contingency table, Fisher's exact test was used (30), and because of the small numbers in cells in the importance group, cells were concatenated into "important to very important" compared with a combination of "not at all and does not concern me". In this way, whether the respondent gave the statement any importance at all could be compared with an indication that it had no importance whatsoever.

Analysis included ascertaining the percentage of positive responses by staff and parents to each needs statement within each group, for example, in the importance group for statement number 1, 98% of staff and 82% of parents

gave a score indicating that they thought that statement was important. Statistically significant differences were determined between parents and staff, and differences in the percentages between them examined for each needs statement within each group. These differences have been displayed in Table 1. It is important for interpretation of this work that each needs statement is shown, but because of the large Table that this would generate, only the differences between staff's and parents' responses with their *p* values are shown in Table 1.

## Results

### Demographic features of the samples

*Staff.* There were 132 respondents from the staff. Of those 19% were registered nurses, 20% enrolled nurses, 47% doctors (27% residents, 8% registrars and 12% consultants or staff specialists). Allied health staff (physiotherapists, play therapists, dieticians, occupational therapists) comprised 14% of the sample. The age groups reflect the current state of the ageing health workforce in developed countries (31, 32) as 46% of the respondents were over 45 years of age, 52% between 26 and 45 years, and only 2% were younger than 25 years. The respondents had been working in their present occupation for a mean of 17 years (range 0.5–40 years), in their present position for a mean of 11 years, (0.5–38 years) and when asked how many years they had been working with children, responses ranged from 0.5 to 41 years with a mean of 15 years. Most of the respondents were female (90%), and 81% of the sample had children of their own.

*Parents.* Of the 113 parents who returned questionnaires, 83% were mothers, 16% fathers and 1% were related in another way to the admitted child. Ninety percent were married or in a cohabiting relationship, 3% were divorced and 7% single, while 78% of the parents were aged between 20 and 40 years and 22% were older. Twenty-three percent of the respondents had university education, 25% had reached technical college level, 44% had completed high school and 7% had primary school education. The admitted children of the sample parents ranged in age from birth to 16 years, in accordance with the policy of the hospital, and the median age was 1 year. Sixty percent of the admissions were unplanned, 52% were admitted with an acute illness, 12% had been injured, and 36% had a chronic condition. At the time of completion of the questionnaire, 46% of the children had been in 2–7 days, 42% had been in for over a week and 12% were in their first day of admission. Just over half the children (57%) were in hospital for the first time, while 43% had more than one admission to hospital. One-fifth of the parents had no children other than the admitted child, 48% had one other

**Table 1** Percentage points differences between staff and parents who gave a positive score for each needs statement in each scoring domain

Statement	% Differences		
	Importance	Fulfilment	Independence
1. To have a special place in the unit where parents can be by themselves	16 (p < 0.0001)	<b>3 (p &lt; 0.0001)</b>	43 (p < 0.0001)
2. To have a planned meeting with other parents to share and discuss the experience of my child's hospitalization	–	–	12 (p < 0.05)
3. That staff encourage parents to ask questions and seek answers to them	–	–	32 (p < 0.0001)
4. To be sure that though I am not present my child will get the best available nursing care	–	–	17 (p < 0.0001)
5. That I get sufficient rest or adequate sleep	7 (p < 0.001)	–	32 (p < 0.0001)
6. To be able to see a social worker to get information about financial assistance to help ease problems caused by my child's hospitalization	21 (p < 0.0001)	11 (p < 0.0001)	24 (p < 0.0001)
7. To be able to meet with parents with similar experiences of an ill child	20 (p < 0.0001)	30 (p < 0.0001)	13 (p < 0.05)
8. That I receive written information about my child's health status so I can review it later (e.g. reason for admission, diagnostic terms, names of medications and tests, and simple explanations of these)	–	11 (p < 0.05)	14 (p < 0.0001)
9. To be able to ask nurses and doctors about how to explain the illness and/or tests to my child	10 (p < 0.001)	–	16 (p < 0.0001)
10. That there is flexibility in the work of the unit according to parents' needs	–	–	12 (p < 0.01)
11. To have a person in the unit (a nurse or a doctor) especially assigned to care about and to respond to parents needs	13 (p < 0.0001)	18 (p < 0.0001)	19 (p < 0.0001)
12. That I get an opportunity to speak privately with a doctor or a nurse about my own feelings/worries	3 (p < 0.05)	5 (p < 0.05)	19 (p < 0.0001)
13. That I get advice about the care of my child in preparation for my child's discharge	–	–	11 (p < 0.01)
14. That I be permitted to make the final decision about the treatment my child will receive, after having been informed about proposed treatments by doctors and nurses	–	–	13 (p < 0.05)
15. That I be informed about all known health outcomes for my child	–	–	3 (p < 0.0001)
16. To be encouraged by staff to come and stay with my child	12 (p < 0.05)	3 (p < 0.05)	35 (p < 0.0001)
17. That a nurse assists me to recognize my own needs, e.g. meals, sleep	7 (p < 0.05)	10 (p < 0.01)	20 (p < 0.0001)
18. To feel that I am trusted to be able to care for my child in hospital	5 (p < 0.01)	–	37 (p < 0.0001)
19. That I be informed about all treatment that my child will receive	–	–	15 (p < 0.0001)
20. To have a person in the unit especially assigned to take care of the needs of my child	4 (p < 0.01)	–	16 (p < 0.0001)
21. That I have a place to sleep in the hospital	–	–	24 (p < 0.0001)
22. That a nurse (e.g. from a community health centre who is aware of possible effects on children from being in hospital) follows up my child after discharge	–	–	–
23. To be able to participate in the nursing care of my child	–	–	27 (p < 0.0001)
24. To learn and be informed about how illness and its treatment affects children's growth and development	–	–	10 (p < 0.01)
25. That I can stay with my child 24 hours a day if I wish	–	–	21 (p < 0.0001)
26. To feel that I am not blamed for my child's illness	11 (p < 0.001)	–	35 (p < 0.0001)
27. To be able to do physical care for my child, e.g. change nappy, bath, feed, etc.	–	–	37 (p < 0.0001)
28. That I be able to explain things in connection with my child's hospitalization to my relations, friends, and to my other child/children	–	–	30 (p < 0.0001)
29. That I be prepared for the expected day of my child's discharge and informed about any change in that date	–	–	12 (p < 0.01)
30. That I have time to be with my other child/children	9 (p < 0.001)	12 (p < 0.001)	36 (p < 0.0001)
31. That I be informed as soon as possible about results from tests done on my child	–	–	14 (p < 0.0001)
32. To be able to trust that though I am not present my child will get the best available medical care	–	–	–

Table 1 (Continued)

Statement	% Differences		
	Importance	Fulfilment	Independence
33. That nurses recognize and understand the feelings of parents	7 (p < 0.001)	–	11 (p < 0.0001)
34. That nurses contact and consult me about the care that is needed for the nursing care of my child	–	–	10 (p < 0.0001)
35. To feel that I am important in contributing to my child's well-being	5 (p < 0.05)	4 (p < 0.05)	34 (p < 0.0001)
36. To know that I can contact the ward/unit after my child has been discharged	–	–	23 (p < 0.0001)
37. That I get assistance and support to recognize and understand my own needs, e.g. anxiety, tiredness	–	–	17 (p < 0.0001)
38. That I get exact information about my child's condition	–	–	9 (p < 0.05)
39. That I feel less anxious	–	–	18 (p < 0.001)
40. To feel that I am needed in the ward/unit	12 (p < 0.001)	–	27 (p < 0.0001)
41. To be able to "room in" with my child	–	–	21 (p < 0.0001)
42. That I get assistance to recognize the needs of my child	6 (p < 0.01)	3 (p < 0.05)	24 (p < 0.0001)
43. To be told about everything that is being done to/for my child and why	–	–	4 (p < 0.01)
44. That I can continue to feel hopeful about my child's condition	–	–	15 (p < 0.0001)
45. That I can have meals with my child on the ward/unit	6 (p < 0.0001)	3 (p < 0.0001)	25 (p < 0.0001)
46. That there are bath and shower facilities for parents	5 (p < 0.05)	–	27 (p < 0.0001)
47. To know that my child will get proper schooling (and things to keep occupied) so he/she will not fall behind in development	11 (p < 0.0001)	7 (p < 0.01)	14 (p < 0.001)
48. That the same nurses take care of my child most of the time	–	5 (p < 0.0001)	15 (p < 0.001)
49. That one person (a nurse) coordinates the services and flow of information we get in hospital	17 (p < 0.0001)	–	18 (p < 0.0001)
50. That I do not feel hopeless	2 (p < 0.05)	–	18 (p < 0.0001)
51. That qualified teachers and play leaders are available to ensure that my child's development is maintained	9 (p < 0.01)	–	12 (p < 0.001)

child and 33% had multiple children. Almost all the parents (95%) lived within one day's travel of the hospital.

#### Comparisons of staff's and parents' responses

*Agreement between staff and parents' responses.* Table 1 shows the 51 needs statements and the differences between staff and parents for each statement within each group. Those that were not statistically significantly different, or for which a difference of less than 3% was found are indicated by a dash. In all except statement number 1 in the fulfilment score (given in boldface in the table) more staff than parents gave positive responses for each need.

There were 30 statements for which there was no statistically significant difference within the "importance" scoring group, meaning that staff and parents gave similar responses about the importance of the needs of parents expressed in those statements. In the "fulfilment" scores, there were 34 statements which the staff and parents agreed were being met in the hospital at that time. In the "independence" score, only two statements, 22 and 32 met with agreement, that is, both staff and parents agreed that the parents would require some help

in having these needs met. In all the other needs statements, staff were more likely to think that parents would need help to have those needs met, while the parents were more likely to think they could meet those needs without assistance.

*Differences between staff's and parents' responses. Importance scores:* Table 1 shows comparisons of the importance score statements between staff and parents and indicates those for which statistically significant differences were found. The percentages used indicate the difference between the proportion of the respondents who gave an importance score (as opposed to "no importance") for each statement. In all importance scores the proportion of staff who listed each need as important was higher than the proportion of parents.

*Fulfilment scores:* Table 1 shows the fulfilment scores statements for which differences occurred between the proportion of staff and parents who thought the needs were being met. For all but statement 1, more staff than parents thought the needs were being fulfilled. However, the difference in responses for statement number 1 was only 3%.

*Independence scores:* Table 1 shows the 49 independence scores needs statements for which statistically significant differences were found between staff and parents, and in all, the direction indicates that more staff than parents thought that parents would need help to have the needs met. The proportion of differences in the importance and fulfilment scores were mostly small but in the independence scores many of the differences were large. As an example for comparison, note statement 12 in the importance scores. The difference between the proportion of staff and proportion of parents who thought that staff encourage parents to ask questions was only 3%, while in the independence scores, the difference between the proportion of staff and parents for statement 12 was 19%.

## Discussion

This study of a convenience sample of staff (nurses, doctors and allied health staff) and parents of hospitalized children at a paediatric hospital in Sweden examined attitudes relating to perceptions of needs of parents. We found that, for about half the needs statements, staff and parents agreed about the importance of specific needs of parents, and whether or not they were being met by the hospital during the child's admission. Many differences were found between staff's and parents' perceptions of whether the parents would need help to have those needs met.

An important finding of this study is the degree of independence shown by parents. The large numbers of independence scores on which staff and parents disagreed could indicate two things: that parents are much more self-sufficient in filling their needs than the staff expect them to be, and that the staff are sensitive to seeing that parents' needs are met. On the other hand, these findings may indicate that parents are not as aware as they might be about the assistance they could access if they knew of the help available. A Swedish study (33) indicated that parents who have a child with a chronic illness need a formal system of nursing support before their child's discharge from hospital as they seldom have a support person available to assist them at home. Orem's theory of self-care and its corollary of dependent-care suggest a framework for these findings. The family, as the setting which conditions the dependent-care system, and the parents within the family (8, 10), may provide a unity (11) which allows its individuals to be more independent than staff in health care settings realize.

Differences over 10% in size between staff's and parents' responses in the importance scores (Table 1) were mainly in psychosocial needs for the parents, such as needing encouragement from the staff to stay with the child, and not to feel blamed for the child's illness. These psychosocial aspects are in line with results from other studies (19–23, 27). More staff than parents thought these were important. Most of the differences between staff's and parents'

responses in the fulfilment scores were small, only five were more than 10% and these were related to parents' need for support. It is apparent that while more staff than parents think parents' needs are being adequately filled in this hospital, the differences are small and in general, indicate that parents are quite satisfied with the meeting of their needs.

The question of what is a need requires some reflection. Although several formal definitions are given, it is apparent that the needs investigated here are more in line with von Wright's (12) definition of something that is bad for a person to be without. It would not be good for parents to be without most of the needs investigated here, and the direction of the differences, that is that more staff than parents are aware of the importance of each need, demonstrates that staff in this particular hospital are well versed in the psychosocial care of hospitalized children and their families. What do we know about parents' individual needs? This question will be more ably answered in the third stage of this analysis by correlating the demographic characteristics of the sample with the staff's and parents' responses (to be reported separately). How do parents act to ensure their needs are satisfied? Conversely to the work of Bragadóttir (24), we have found that parents are more likely to be able to meet their needs themselves rather than rely on staff to assist them. While parents have strategies to ensure their needs are met (5), in this study we were more interested in the differences between staff's and parents' responses than in investigating how they did this.

The sensitivity of staff to parents' needs in this sample may contrast with work in Australia and Britain (3) which showed that staff found working with children more positive than working with their parents, however, this present project using the NPQ is underway in both those countries. Differences between staff and parent responses will again be examined and responses from the countries, including this sample from Sweden, compared. Cultural differences may influence the findings. Because Kristjánsdóttir (15, 16, 28) and Bragadóttir (24) did not compare staff and parent responses, at this stage we cannot draw parallels with Iceland or America. The understanding of the interaction between staff and parents demonstrated in our study will provide better comprehension of changes to the parental role engendered by hospital admission of a child (24), and will inform practice of all health professionals.

## Limitations

The sample for this study was drawn from the population of one hospital, and cannot be said to be representative of all health facilities in Sweden (or any other country). However, it does give an indication of the way staff and parents in paediatric hospitals perceive needs. Children were not asked to describe their perceptions of needs.



While this would have been impossible for tiny children, older patients may have participated.

Kristjánsdóttir (15, 16, 28) categorized each statement given by parents to create a classification for which mean scores could be compared, while Bragadóttir (24) correlated demographic data collected from her sample of parents with their perceptions of needs. We have done this for both the staff and parents' samples, but those analyses will be discussed in later papers.

In the statistical analysis, the numbers in some places were so small that the less sensitive Fisher's exact test had to be used instead of the proposed chi-square (30). In these cases, because of the conglomeration of cells, some power was lost.

Parents of children in the oncology and neonatal wards were used, and may have had different perceptions of parents in the other wards whose children were not so seriously ill. The samples were too small for these to be analysed as a subgroup, and this warrants further, more specific research. However, it is important to remember that parental needs differ according to the child's illness (7), the knowledge and experience of the individual parent and the support they receive from the hospital staff (33). A project with a larger sample size would yield interesting information about influences of factors such as child's diagnosis.

### Recommendations

While this research has highlighted the sensitivity of the staff in this sample towards the needs of parents, education programmes about parents' needs will continue to raise the staff's awareness. Education programmes for parents and parents' involvement in forums, and planning and development committees for the hospital, would ensure that their needs were well known and brought to prominence. Research into children's needs is important and a similar comparison between staff's perceptions and children's perceptions of needs may raise some interesting contrasts.

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