

THE NEEDS OF PARENTS OF HOSPITALISED CHILDREN IN AUSTRALIA

by

Linda Shields PhD, FRCNA, FRSA
Professor of Nursing, University of Hull, England
Adjunct Professor, University of Queensland, Australia and University of
Northumbria, Newcastle-upon-Tyne, England; Visiting Fellow: Örebro University,
Sweden and Queensland University of Technology, Brisbane

Jeanine Young, PhD, FRCNA
Nursing Director – Research, Royal Children’s Hospital, Brisbane, Australia
Adjunct Associate Professor, Queensland University of Technology
Adjunct Senior Lecturer, University of Queensland
RGN, EM, Neonatal Nurse, BSc (Hons)-Nursing, Advanced Diploma of Nursing Care

Damhnat McCann MPH, GDip (Paeds), RGN, MRCNA
Lecturer – School of Nursing & Midwifery, University of Tasmania, Australia

Key words: parents, nursing

Correspondence:

Professor Linda Shields
Faculty of Health & Social Care
University of Hull
Cottingham Rd
Hull HU6 7RX
U.K.
Tel: +44 (0)1482 463326
Fax: +44 (0)1482 464588
E-mail L.Shields@hull.ac.uk

ACKNOWLEDGEMENTS

At the beginning of this work, the first author (LS) was supported by the National Health and Medical Research Council of Australia Public Health Postdoctoral Fellowship Number 997096; National Health and Medical Research Council of Australia Travelling Fellowship Grant ID 235610; and the Winston Churchill Memorial Trust. Thanks for statistical support goes to Professor Gail Williams, Australian Centre for International Health and Nutrition, The University of Queensland and Associate Professor Michael O'Callaghan, Department of Paediatrics and Child Health, Mater Children's Hospital, Brisbane. A special thanks must go to Professor Gudrun Kristjánsdóttir, University of Iceland, who kindly allowed us to use her questionnaire, and to the staff and parents of the Royal Children's Hospital, Brisbane who gave of their valuable time to participate.

Abstract

Aim: to compare perceptions of needs held by parents of hospitalised children, with those held by the staff caring for them.

Background: family centred-care is a central tenet of paediatrics and should encompass all aspects of the child and family's experience of hospitalisation.

Important to this are the needs of parents when their children are hospitalised.

Methods: A widely used and validated tool was used with a convenience sample in paediatric facilities in a children's hospital in Australia.

Results: Some differences were found between parents and staff for scores for perceived importance of the 51 needs included in the questionnaire, and whether or not they were being satisfactorily met during children's hospital admission, though there were no consistent patterns. Parents declared themselves more independent than the staff perceived them to be.

Relevance to clinical practice: These findings facilitate improvements in communication between parents and staff and can be included in education programmes for both.

Introduction

The concept of family centred-care is a central tenet of paediatric nursing and should encompass all aspects of the child and family's experience of hospitalisation (Shields et al., 2006). Participation by families in their child's care promotes normality of the family unit, continues the normal routines of the child's life within the limitations of the hospital setting, and reduces the emotional stress for the child (Newton, 2000; Hopia, et al., 2005). Nurses are well informed regarding the concept of family-centred care but fail to consistently incorporate elements of this concept into their daily practice (Callery, 1998; Franck and Callery, 2004). Involvement of parents into the daily planning and assessment is often on an ad-hoc basis, rather than a negotiated plan based on assessment of needs (Franck and Callery, 2004; Hopia et al., 2005).

The study from which this paper is drawn is a cross-cultural examination of needs of parents of hospitalised children in Sweden, England, Australia and Indonesia using the "Needs of Parents Questionnaire" (NPQ) (Kristjánsdóttir, 1986; 1991; 1995). Presented here are the results of analysis of the Australian data. For further literature, and details of the methods used, see the paper published in this journal which presented the English arm of the study (Shields, et al., 2004). Part of the Swedish section has been published (Shields, et al., 2003; Shields and Kristensson-Hallström, 2004).

Originally designed for parents, the NPQ (Kristjánsdóttir, 1986; 1991; 1995) was adapted for use with staff. Piloting and reliability testing with both parents and staff provided evidence that this tool is a reliable and valid measure of perceptions of parental needs, yielding a Cronbachs' alpha of 0.91 for both parents and staff. The aim of this paper was to investigate, in an Australian setting, parents' perceptions of

their needs when they have a child who is hospitalised, and compare them with staff's perceptions of the parents' needs. Study results highlighted several areas requiring improvement in communication between staff and parents.

METHODS

Parents and staff (nurses, doctors and allied health staff) at a tertiary referral paediatric hospital participated. Parents were recruited either by a nurse researcher or by one of the ward staff, while staff were informed about the project at ward meetings. Packages of the NPQ and collection boxes were left in the wards for distribution or were distributed to staff using the hospital internal mail system. The sample comprised parents of hospitalised children aged from birth to 18 years and staff (nurses, doctors and allied health staff) who cared for them. All units except oncology and intensive care were involved. Power calculations determined that for a power of 80%, a sample size of 102 for staff and parents samples each would be needed to detect a 30% difference with a control proportion of 0.1. Due to unforeseen circumstances during data collection, fewer responses were obtained in the staff sample. While this increased the possibility of a Type II error (Polit and Hungler 1987), the differences found were statistically significant, and may have been greater if the sample was larger. From 139 staff and 188 parent surveys distributed, 79 staff and 130 parent questionnaires were returned, yielding a response rate of 57% and 69% respectively.

The NPQ has been described in detail elsewhere (Kristjánsdóttir, 1986; 1991; 1995; Shields et al., 2003; Shields et al., 2004). In brief, it consists of 51 statements about needs of parents of hospitalised children, and has three scoring systems to ascertain a) importance of each needs statement ("importance score"); b) whether the

needs are being met during that admission (“fulfilment score”); and c) whether the parents would need help from staff to have the needs met (“independence score”). The results from comparisons between parents and staff of the three scores for each individual needs statement are described.

Statistical analyses

Data were normally distributed and Chi-square (or Fisher’s exact test (Siegel and Castellan 1998) if a cell contained less than the expected count) were used to compare staff and parent responses to individual statements in the scoring groups. Because of 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”, indicating whether the respondent gave the statement any importance at all, or no importance whatsoever. The three point fulfilment score was treated similarly to indicate “met” or “unmet”, and the independence score required a “yes” or “no” response.

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 1, 100% of staff and 88% 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 were examined for each needs statement within each group. An α -level of 5 per cent was considered statistically significant for all comparisons.

RESULTS

TABLE 1 about here

Table 1 shows the characteristics of the staff sample. Of the 79 staff who responded, the majority (69%) were nurses, and included doctors (14%) and allied health staff (17%) (physiotherapists, play therapists, dietitians, and occupational therapists). Similarly to the Swedish and English arms of this study, (Shields, et al., 2003; Shields et al., 2004; Shields and Kristensson-Hallström, 2004) age groups reflect the ageing health workforce with 60% of the staff sample aged between 26 and 45 years, and with over a quarter aged 46 years and older. Only 3% had been working in their present occupation for less than two years, while over half (58%) had been working for longer than 10 years. Similar proportions were found in the years they had been working with children, and no-one had been working with children for less than two years. Australia requires a bachelor's degree for registration for health professionals, so it was not surprising to find that 83% held university education. The remainder were enrolled nurses who had technical college education or vocational training. Of the respondents, 39% had children of their own, and 89% were female.

TABLE 2 about here

Table 2 shows the characteristics of the parent group. Most of the respondents were mothers (81%), married or in long term relationships (87%), aged between 20 to 40 years (82%) and almost half had high school education. Of the child admissions, 43% were unplanned and 33% were admitted for treatment of a chronic condition. At the time of questionnaire completion, 27% of parents had been in hospital for one day, 16% longer than a week. Of respondent families, 19% had no other children. Thirty-

six percent of other children in the families were aged between 3 and 10 years, while between were infants (41%), and 24% adolescents. Most families (94%) lived within one day's travelling time from the hospital.

TABLE 3 about here

Figures in Table 3 illustrate the proportion of staff and parents responding to each needs statement. For example, 79 staff (100% of the sample), and 111 parents (88%), indicated that to have a special place in the unit where parents could be by themselves (Statement 1) was important, while only 7 staff (9%) and 12 parents (12%) indicated by the fulfilment score that this need was not being met. Using the independence score, significantly more staff (70, 90%) compared to parents (63, 57%) thought that parents would require help to have that need met ($p < 0.001$). The differing numbers in some cells occur when not all the sample answered that question. All those for which significant differences were found are given for completeness, however, in some instances the cells contained less than five responders, despite Fisher's exact test being used. The results described below relate to the statements for which significant differences were found and in which cells contained five responses or more.

Importance scores

A greater proportion of staff assigned importance to 48 of the 51 needs statements compared to parents (Table 3). For the remaining three statements, 100% of parents and staff thought that these needs were important, including that nurses recognise and understand the feelings of parents, that parents get exact information

about their child's condition, and that parents be told about everything that is being done to/for their child and why.

Although the majority of both parent and staff respondents indicated the following needs were important, a significantly greater proportion of staff compared to parents thought this was so. They were: needs relating to reducing anxiety, access to a social worker to obtain financial assistance, having a nominated person assigned to recognise and assist parents to meet their needs, an opportunity to speak privately with a doctor or nurse about concerns; provision of a sleeping place, discharge follow-up and information; explanations for family and friends, time for other children, and child education and development. Interestingly, more than half the parents (58%), and 27% of staff gave no importance to meeting with other parents to share and discuss the experience of the child's hospitalisation (Statement 2), while 95% of staff and 67% of parents considered that meeting with parents with similar experiences of an ill child (Statement 7) was important.

Fulfilment scores

Twenty statements showed significant differences between parent and staff scores, though only four of these had sufficiently large numbers to make the analysis reliable. Statements 6, 7, 46 and 49 were more likely to be thought to be fully met by staff than parents.

Independence scores

Proportionally more staff than parents indicated that parents would need help in having the need met for each of the 51 statements. These differences between staff and parent independence scores were statistically significant for eleven statements

that also had sufficiently large numbers in each cell for reliable interpretation:

Statements 2, 5, 7, 11, 16, 17, 22, 28, 30, 37, and 44.

DISCUSSION

Similarly to the English and Swedish (Shields et al., 2003; Shields and Kristensson-Hallström, 2004) arms of the project, parents indicated they did not need as much help as the staff supposed, illustrating that parents of hospitalised children are more independent than staff perceive them to be. It has been found that parents use strategies to have their needs met while their children are hospitalised (Kristensson-Hallström and Elander, 1997; Hallstrom and Runeson, 2001), and these findings relate to this. However, these results may mean that parents were not fully cognisant of the level of support available to them, or it may show a paternalistic approach by staff. A qualitative study could examine some of these perspectives. Conversely, in Iceland, the home of the NPQ, Bragadottir (1999) found that most parents perceived that they needed help from hospital staff in order to meet their needs.

This study of a convenience sample of staff and parents in Australian tertiary paediatric hospital settings examined attitudes relating to their perceptions of parent needs. Some needs which were of lesser importance for parents included those related to meeting other parents and to communication with staff, but there was no detectable pattern, consequently differences are difficult to explain. These results differ from those found in the importance scores of the Swedish arm of this study (Shields et al., 2003; Shields and Kristensson-Hallström, 2004), but were similar to the English results (Shields et al., 2004) suggesting the influence of culture.

Differences in proportions of over 10% in size between staff and parent responses in the importance scores were mainly in communication needs for the parents, such as needing an assigned person to answer queries. These results are consistent with previous studies that have examined parental needs of hospitalised children (Kristjánisdóttir, 1986; 1991; 1995; Fisher, 1994; Graves and Hayes, 1996; Ramritu and Croft, 1999; Shields, 1999; Aitken et al., 2004; Ammentorp et al., 2005). More staff than parents thought these needs were important. Most of the differences between staff and parent responses in the fulfilment scores were small; only seven were more than 10% and these related to parents' need for support. It is apparent that while more staff than parents think that parents' needs are being adequately met in this sample, the differences are small and in general indicate that parents are satisfied with the meeting of their needs.

What is a need? Although several formal definitions are given, it is apparent that the needs investigated here are consistent with von Wright's (1982) definition of something that is bad for a person to be without. It would be bad 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 are cognisant of the needs of parents of hospitalised children and their families. 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, (Kristensson-Hallström I, Elander, 1997), in this study the primary goal was to examine the differences between staff and parent responses rather than investigating how they did this.

The sensitivity of staff to parents' needs contrasts with another study in Australia and Britain (Shields, 1999) which suggested that staff found working with

children more positive than working with their parents. Cultural differences may influence the findings. Because Kristjánsdóttir (1986; 1991; 1995) and Bragadóttir (1999) did not compare staff and parent responses, it is not possible to compare findings. This study was beset with several limitations, however, it can lead to consideration of the interaction between staff and parents, and to further research in this area, thus providing better understanding of changes to the parental role engendered by a child's admission (von Wright, 1999), and informing practice of all health professionals.

Limitations

Because the parents' questionnaires were distributed by ward staff, veracity of the responses may have been compromised. Returns could be assured to remain confidential, minimising potential difficulties in this area. While the rate of return of parents (69%) and staff (57%) were different, they were within acceptable range for this type of study using a cross-sectional survey design (Oppenheim, 2001). However, the difference between the return rates of staff and parents may have biased the results. The sample was drawn from the population of one hospital, which cannot be said to be representative of all health facilities in Australia (or any other country). Fewer questionnaires were obtained than the total required by the power calculations, thus increasing the possibility of a Type II error, but the differences found were true differences and may have been greater if the sample was larger. A larger sample size would have allowed an analysis of subsets.

Kristjánsdóttir's NPQ (1986; 1991; 1995) was found to be as useful in Australia as it was in England and Sweden. However, it is time for a review of this

most tool, as societies around the world have changed since it was last reviewed in 1995.

Implications

This study is being conducted in Indonesia at present, and a study in Iran is under negotiation. Differences and similarities in cross-cultural comparisons will provide a rich source of information on which to base care for people from differing cultural backgrounds. The importance of the need for recognition of the needs of parents, and the role this plays in communication and negotiation between parents and staff cannot be overemphasised, and this is as important in one culture as in any other. Education about effective communication is imperative for doctors, nurses and allied health staff who work with children and their families. While this research adds to knowledge about parents' needs, it would be of interest to see if the needs of children old enough to be involved in such research differ from those of their parents and/or differ from staff perceptions of the children's needs. Such investigation of this topic would broaden our understanding of communication processes within paediatric health care.

What is already known about this topic:

- Parents of hospitalised children have physical and psychosocial needs which must be met to enable them to stay with their children during the child's admission
- Assumptions are made in clinical practice that parents' needs are similar across all countries and cultures

What this study adds:

- This study confirms that the needs of parents in this convenience sample in Australia are similar to those of parents in Sweden and the UK
- Practitioners can use similar concepts to ensure parents' needs are met

No competing interests known.

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Table 1. Demographic details of staff sample

Characteristic		n	%
Occupation	Nurse	54	69
	Doctor	11	14
	Allied health	13	17
Age group	< 25 years	9	12
	25-45 years	45	60
	> 45 years	22	28
Education level	High school	9	12
	Technical college	4	5
	University	62	83
Paediatric qualification	Yes	10	13
	No	65	87
Years in present occupation	< 2 years	2	3
	2-5 years	14	19
	6-10 years	18	24
	>10 years	41	58
Years working with children	< 2 years	0	
	2-5 years	18	24
	6-10 years	18	24
	>10 years	39	52
Have own children	Yes	30	39
	No	46	61
Sex	Male	8	11
	Female	68	89

Table 2. Demographic details of parent sample

Characteristic		N	%
Relationship to child	Mothers	98	81
	Fathers	21	17
	Other	2	2
Marital status	Married/long term partners	103	87
	Single parent	16	13
Age	< 19 years	1	1
	20-40 years	98	82
	> 40 years	21	17
Education	School only	53	46
	Technical college	36	32
	University	75	22
Type of admission	Planned	68	57
	Unplanned	51	43
Type of condition	Acute/injury	78	67
	Chronic condition	34	33
Length of stay*	1 day	32	27
	2-7 days	69	57
	> 7 days	19	16
Other children in family	No	23	19
	Other children	96	81
Age of admitted child	0-2 years	49	41
	3-5 years	21	18
	6-10 years	21	18
	11-16 years	27	23
	>16 years	1	1
Home	< 1 day's travel#	46	94
	> 1 day's travel	3	6

* time at which questionnaire was completed

from hospital

Table 3. Comparisons between staff and parents responses for each needs statement for each scoring system: importance, fulfilment and independence. Figures show number and proportion (n, %) of total responses for each section (S = staff, P = parents)

NEEDS STATEMENTS		Importance score			Fulfilment score			Independence score		
		import	not import.	p	not met	met	p	yes	no	p
1 To have a special place in the unit where parents can be by themselves	S	79 (100)	0	<0.001	7 (9)	69 (91)	NS	70 (97)	2 (3)	<0.001
	P	111 (88)	15 (12)		12 (12)	106 (88)		63 (57)	48 (43)	1
2. To have a planned meeting with other parents to share and discuss the experience of my child's hospitalisation	S	55 (73)	20 (27)	<0.001	38 (52)	35 (48)	NS	55 (77)	16 (23)	<0.001
	P	54 (42)	73 (58)		61 (59)	43 (42)		53 (51)	51 (49)	
3. That staff encourage parents to ask questions and seek answers to them	S	79 (100)	0	NS	2 (3)	74 (98)	NS	72 (96)	3 (4)	<0.001
	P	127 (99)	1 (1)		0	114 (100)		82 (77)	25 (23)	
4 To be sure that though I am not present my child will get the best available <u>nursing</u> care	S	78 (100)	0	NS	0	77 (100)	0.04	71 (97)	2 (3)	0.014
	P	123 (98)	2 (2)		4 (4)	108 (96)		86 (87)	13 (13)	
5 That I get sufficient rest or adequate sleep	S	77 (97)	2 (3)	NS	9 (12)	69 (88)	NS	68 (89)	8 (10)	0.001
	P	119 (94)	8 (6)		10 (9)	101 (91)		72 (69)	32 (31)	
6 To be able to see a social worker to get information about financial assistance to help ease problems	S	77 (97)	2 (3)	<0.001	4 (5)	73 (95)	<0.001	76 (100)	0	<0.001
	P	103 (80)	25 (20)		29 (30)	67 (70)		74 (81)	17 (19)	
7 To be able to meet with parents with similar experiences of an ill child	S	73 (95)	4 (5)	<0.001	18 (24)	58 (76)	<0.001	68 (91)	7 (9)	0.003
	P	86 (67)	42 (23)		50 (52)	47 (48)		67 (73)	25 (27)	
8. That I receive written information about my child's health status so I can review it later	S	75 (97)	2 (3)	NS	23 (30)	44 (70)	NS	72 (97)	2 (3)	NS
	P	125 (97)	4 (3)		43 (41)	63 (60)		93 (94)	6 (6)	
9 To be able to ask nurses and doctors about how to explain the illness and/or tests to my child	S	77 (100)	0	NS	7 (9)	71 (91)	NS	75 (99)	1 (1)	0.002
	P	121 (95)	6 (5)		6 (5)	103 (95)		85 (86)	14 (14)	
10 That there is flexibility in the work of the unit according to parents' needs	S	76 (96)	3 (4)	NS	7 (9)	71 (91)	NS	64 (85)	11 (15)	NS
	P	114 (90)	13 (10)		8 (7)	104 (93)		77 (75)	25 (25)	
11 To have a person in the unit (a nurse or a doctor)	S	65 (84)	12 (16)	0.015	32 (42)	44 (58)	NS	63 (85)	11 (15)	0.02

especially assigned torespond to parents' needs	P	89 (70)	38 (30)		32 (31)	72 (69)		70 (71)	29 (29)	
12 That I get an opportunity to speak privately with a doctor or a nurse about my own feelings/worries	S P	79 (100) 120 (93)	0 9 (7)	0.01	8 (11) 9 (8)	70 (89) 105 (92)	NS	73 (97) 87 (85)	2 (3) 15 (15)	0.005
13 That I get advice about the care of my child in preparation for my child's discharge	S P	77 (100) 126 (99)	0 1 (1)	NS	0 2 (2)	76 (100) 101 (98)	NS	73 (99) 87 (85)	1 (1) 15 (15)	0.001
14 That I be permitted to make the final decision about the treatment my child will receive	S P	77 (100) 125 (98)	0 3 (2)	NS	2 (3) 6 (5)	75 (97) 109 (95)	NS	73(99) 83 (84)	1 (1) 16 (16)	0.001
15 That I be informed about all known health outcomes for my child	S P	76 (100) 127 (99)	0 1 (1)	NS	2 (3) 6 (5)	75 (97) 110 (95)	NS	75 (99) 88 (88)	1 (1) 12 (12)	0.005
16 To be encouraged by staff to come and stay with my child	S P	76 (100) 123 (97)	0 4 (3)	NS	0 5 (4)	75 (100) 110 (96)	0.03	69 (93) 81 (80)	5 (7) 20 (20)	0.01
17 That a nurse assists me to recognise my own needs eg meals, sleep	S P	76 (97) 94 (73)	2 (3) 34 (27)	<0.001	3 (4) 27 (24)	74 (96) 85 (75)	<0.001	68 (92) 63 (66)	6 (8) 33 (34)	<0.001
18 To feel that I am trusted to be able to care for my child in hospital	S P	79 (100) 124 (96)	0 5 (6)	NS	3 (4) 27 (24)	74 (96) 85 (76)	<0.001	72 (95) 74 (74)	4 (5) 26 (87)	<0.001
19 That I be informed about all treatment that my child will receive	S P	79 (100) 127 (99)	0 1 (1)	NS	2 (3) 1 (1)	76 (97) 115 (99)	NS	75 (99) 89 (83)	1 (1) 18 (17)	<0.001
20 To have a person in the unit especially assigned to take care of the needs of my child	S P	75 (99) 118 (92)	1 (1) 10 (8)	0.04	4 (5) 15 (13)	71 (66) 101 (87)	NS	68 (97) 82 (83)	2 (3) 17 (17)	0.002
21 That I have a place to sleep in the hospital	S P	78 (100) 118 (94)	0 7 (6)	0.03	1 (1) 7 (6)	76 (99) 102 (94)	<0.001	75 (100) 84 (82)	0 18 (18)	<0.001
22 That a nurse follows up my child after discharge	S P	72 (95) 102 (80)	4 (5) 25 (20)	0.003	34 (46) 46 (51)	40 (54) 44 (50)	NS	65 (90) 70 (73)	7 (10) 28 (29)	0.002
23 To be able to participate in the nursing care of my child	S P	79 (100) 121 (95)	0 6 (5)	NS	0 3 (3)	78 (100) 108 (97)	NS	73 (97) 76 (77)	2 (3) 22 (22)	<0.001
24 To learn and be informed about how illness ... affects children's growth and development.	S P	78 (99) 125 (98)	1 (1) 2 (2)	NS	6 (8) 14 (12)	71 (92) 98 (88)	NS	66 (90) 89 (89)	7 (10) 1 (11)	NS
25 That I can stay with my child 24 hours a day if I	S	76 (98)	2 (2)	NS	0	76 (100)	NS	71 (96)	3 (4)	<0.001

wish.	P	127 (99)	1 (1)		1 (1)	114 (99)		71 (74)	25 (26)	
26 To feel that I am not blamed for my child's illness.	S	77 (99)	1 (1)	NS	0	76 (100)	0.02	71 (96)	3 (4)	<0.001
	P	117 (94)	8 (6)		5 (5)	101 (95)		60 (66)	31 (34)	
27 To be able to do physical care for my child eg change nappy, bath, feed etc	S	77 (100)	0	NS	0	77 (100)	0.002	71 (96)	3 (4)	<0.001
	P	123 (97)	4 (3)		2 (2)	112 (98)		65 (66)	34 (34)	
28 That I be able to explain things... to my relations, friends, and to my other child/children	S	79 (100)	0	0.02	2 (3)	76 (97)	NS	59 (79)	16 (21)	<0.001
	P	121 (94)	8 (6)		7 (6)	103 (94)		52 (53)	47 (47)	
29 That I be prepared for the day of discharge and any change in that date.	S	79 (100)	0	NS	5 (6)	71 (94)	NS	73 (99)	1 (1)	<0.001
	P	126 (98)	3 (2)		7 (7)	106 (93_)		83 (83)	17 (17)	
30 That I have time to be with my other child/children.	S	79 (100)	0	0.001	4 (5)	74 (95)	0.04	62 (83)	13 (17)	0.001
	P	113 (90)	13 (10)		14 (14)	87 (86)		53 (58)	38 (42)	
31 That I be informed as soon as possible about results from tests done on my child.	S	79 (100)	0	NS	1 (1)	77 (99)	0.04	74 (99)	1 (1)	0.02
	P	126 (99)	2 (1)		9 (8)	103 (82)		90 (90)	10 (10)	
32 To be able to trust that though I am not present my child will get the best available <u>medical</u> care.	SP	79 (100)	0	NS	0	78 (100)	NS	74 (100)	0	0.003
		128 (99)	1 (1)		2 (2)	109 (98)		88 (90)	10 (10)	
33 That nurses recognise and understand the feelings of parents.	S	78 (100)	0	NS	0	78 (100)	0.03	71 (96)	3 (4)	0.03
	P	129 (100)			5 (4)	109 (96)		84 (87)	13 (13)	
34 That nurses contact and consult me about the care that is needed for the nursing care of my child.	S	79 (100)	0	NS	1 (1)	76 (99)	NS	72 (95)	4 (5)	NS
	P	126 (99)	2 (1)		5 (4)	107 (96)		83 (86)	13 (14)	
35 To feel that I am important in contributing to my child's well-being.	S	79 (100)	0	NS	0	77 (100)	0.03	72 (96)	3 (4)	<0.001
	P	125 (99)	2 (1)		5 (4)	106 (96)		74 (77)	22 (23)	
36 To know that I can contact the ward/unit after my child has been discharged.	S	79 (100)	0	0.02	2 (3)	76 (97)	0.001	70 (92)	6 (8)	NS
	P	119 (94)	8 (6)		18 (17)	86 (83)		80 (84)	15 (16)	
37 That I get assistance and support to recognise and understand my own needs eg anxiety, tiredness.	S	77 (100)	0	NS	4 (5)	72 (95)	NS	66 (93)	5 (7)	0.002
	P	121 (95)	6 (5)		15 (13)	97 (87)		75 (76)	24 (24)	
38 That I get exact information about my child's condition.	S	79 (100)	0	NS	0	76 (100)	0.03	73 (100)	0	0.002
	P	126 (100)			5 (4)	108 (96)		90 (89)	11 (11)	

39 That I feel less anxious	S	79 (100)	0	0.03	1 (1)	76 (99)	NS	71 (99)	1 (1)	<0.001
	P	115 (94)	7 (6)		7 (7)	96 (93)		68 (72)	25 (28)	
40 To feel that I am needed in the ward/unit.	S	76 (99)	1 (1)	0.006	3 (4)	72 (96)	NS	67 (96)	3 (4)	<0.001
	P	110 (89)	14 (11)		8 (8)	93 (92)		64 (72)	25 (28)	
41 To be able to “room in” with my child.	S	78 (99)	1 (1)	NS	0	77 (100)	NS	73 (99)	1 (1)	<0.001
	P	121 (97)	4 (3)		3 (3)	106 (97)		77 (80)	19 (20)	
42 That I get assistance to recognise the needs of my child.	S	78 (100)	0	NS	1 (1)	75 (99)	NS	73 (100)	0	<0.001
	P	121 (96)	5 (4)		6 (5)	105 (95)		80 (83)	16 (17)	
43 To be told about everything that is being done to/for my child and why	S	78 (100)	0	NS	0	77 (100)	0.05	74 (100)	0	<0.001
	P	127 (100)			4 (3)	111 (97)		84 (85)	15 (15)	
44 That I can continue to feel hopeful about my child’s condition	S	79 (100)	0	NS	0	76 (100)	<0.001	69 (93)	5 (7)	0.02
	P	121 (96)	5 (4)		7 (6)	102 (94)		78 (81)	18 (19)	
45 That I can have meals with my child on the ward/unit	S	72 (92)	6 (8)	NS	15 (19)	62 (81)	NS	59 (79)	16 (21)	NS
	P	114 (90)	13 (10)		34 (31)	77 (70)		68 (72)	27 (28)	
46 That there are bath and shower facilities for parents	S	78 (100)	0	NS	5 (7)	68 (93)	0.05	71 (97)	2 (3)	<0.001
	P	118 (94)	8 (6)		18 (16)	93 (84)		69 (75)	23 (25)	
47 To know that my child will get proper schooling ... so he/she will not fall behind in development	S	78 (100)	0	<0.001	0	73 (100)	0.04	69 (97)	2 (3)	<0.001
	P	108 (88)	15 (12)		4 (4)	92 (96)		64 (77)	19 (23)	
48 That the same nurses take care of my child most of the time	S	73 (92)	6 (8)	NS	6 (8)	70 (92)	NS	62 (89)	8 (11)	NS
	P	118 (94)	8 (6)		12 (11)	98 (89)		77 (83)	16 (17)	
49 That one person (a nurse) co-ordinates the services and flow of information we get in hospital	S	73 (92)	6 (8)	NS	21 (29)	52 (71)	0.05	65 (94)	4 (6)	0.04
	P	114 (90)	13 (10)		18 (17)	88 (82)		75 (84)	14 (16)	
50 That I do not feel hopeless	S	78 (99)	1 (99)	NS	6 (8)	67 (92)	NS	69 (96)	3 (4)	<0.001
	P	115 (95)	6 (5)		11 (11)	91 (89)		62 (74)	22 (26)	
51 That qualified teachers ... are available to ensure that my child’s development is maintained	S	79 (100)	0	0.006	3 (4)	73 (96)	NS	73 (99)	1 (1)	<0.001
	P	115 (92)	10 (8)		9 (9)	95 (91)		69 (78)	19 (22)	

* all staff (100%) scored each needs statement as important

