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We have needs, too: parental needs during a child's hospitalisation.

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ABSTRACT

The influence of demographic characteristics on the perceived needs of parents in a sample of staff and parents of admitted children in a paediatric hospital in Sweden were examined as part of a project in Sweden, England, Indonesia and Australia. Over 100 parents and 100 staff responded and responses compared, including perceived importance of each of the 51 needs. Few needs were influenced by demography of either staff or parents, except for a) to meet other parents of a child with a similar condition; b) not to feel blamed for a child's illness, and c) to have access to a social worker. The influencing characteristics were a) whether the responding parent was the child's mother or father, b) their education level, and c) if staff held specialist paediatric qualifications. For nine needs all parents and staff agreed that they were important. These findings provide ways to enhance communication between parents and staff and provide evidence about the effects of hospitalisation on children.

Key words: parents, needs, family-centred care, communication

LITERATURE REVIEW

A brief history of the development of paediatric models of care

It is well recognised that during a child's admission to hospital, family life is disrupted. Physical aspects of normal life such as eating, sleeping and hygiene arrangements are altered, and emotional and psychological factors changed. Parents (be they natural parents, step-parents, or any other primary care giver within the family) bear the brunt of re-organising, planning and implementing changes which must occur so the family continues to function as normally as possible. While the needs of the ill child obviously must be met, so must the needs of parents and the other family members.

In the past, hospital admission for a child often meant minimal physical disruption for the family, as the child may have been admitted for long periods and during that time parents often were excluded from visiting the child. Consequently, while the child may have suffered psychological damage, the family continued to function as normal – father (and mothers) continued to go to work and children to school. Some investigators of the time thought that the family was better off this way (Jensen & Colmly, 1948), that mothers were bored if they had to stay beside the bed of a child who would normally be out playing and not in her immediate care (Meadow, 1964). Some felt that the parents' needs were better met if they stayed at home and cared for their other children (Meadow, 1969) and that the hospitalised children developed emotionally from a hospital admission (Blom, 1958).

A change in the knowledge about the emotional needs of hospitalised children occurred with the work of investigators such as Renee Spitz (1945), John Bowlby (1944a, 1944b, 1953, 1958, 1960) and James Robertson (1952, 1953, 1962) and their reports and research which showed that children were psychologically damaged by prolonged hospital stays and their concomitant separation from parents (Alsop-Shields & Mohay, 2001). The first changes in government policy in this area came with publication of the Platt Report (Platt, 1959) in Britain in 1959. With the subsequent development of parent-led consumer groups, the needs of parents began to be acknowledged (Hales-Tooke, 1973; Association for the Welfare of Children in Hospital, 1974; Haris et al., 1974; Chalmers, 1993). Eventually, and in line with recommendations of the Platt Report (1959), parents were encouraged to stay in hospital with their child if possible.

Models of paediatric care

Models of care developed that were mindful of parents' needs as well as those of the child. These included care-by-parent units, where the family moves into a home-like hospital environment so most of the care can be given by the parents (Goodband & Jennings, 1982), partnership-in-care (Casey, 1988; 1995) which involves negotiation to ascertain the level of involvement in the child's care which the parent requires, and family-centred care (FCC), where the whole family is the unit of care rather the individual child (Bruce & Ritchie, 1997; Shields, 1999). While these models may minimise trauma to family and child, they are not always appropriate (Alsop-Shields, 2002). Darbyshire (1994) has found that some parents feel imposed upon because they are expected to provide care for their hospitalised child, and Shields (1999) found that while such models of care meet the needs of some parents, in countries whose societies are built upon cultural constructions such as class, these models may not work.

Theoretical background

This study uses the principles of FCC as a theoretical framework. At present, no one definition of FCC exists, and its principles are variously described (Galvin, 2000; Zwelling & Philips, 2001; Eckle & McLean, 2001; Gilmer, 2002). In an attempt to address this issue and to provide a single definition, a Cochrane systematic review of the literature on FCC is underway (Shields et al., 2004). In essence, though, FCC means that when a child comes into a health service, it is always accompanied by a family – be it parent or primary caregiver, siblings and others. The "parent" can range from the biological parent though to the state in the case of an orphan in state care. Consequently, any care of that child must be planned around the whole family rather than the individual child as the family is equally, though perhaps differently affected by the child's admission as the child itself. Fundamental to FCC is the presence of parents and parents have needs of many kinds when their child is in a health service. To make FCC work, staff in the health service must recognise and meet the needs of the parents. In this section of this three-part analysis of FCC and parents' needs (Shields et al., 2002) we describe the characteristics of the samples of parents and staff (nurses, doctors and allied health staff) used in the study.

Kristjánsdóttir (1986) examined parents' perceptions of their needs while their child was in hospital. Initially, using the literature and focus group interviews, she developed 43 statements of needs of parents. These covered many aspects of life for the parent during a hospitalisation episode with an ill child, including physical needs such as food and hygiene, psychological needs such as support, needs relating directly to the child's admission, for example involvement in decision-making about the child's care, and the needs of other family members. Kristjánsdóttir (1991) further developed a questionnaire based on this research, and used it with parents in Iceland and America (Kristjánsdóttir, 1995). It has been used extensively in Canada in both English and French (Bournaki, 1987). Kristjánsdóttir devised six categories of parents' needs – need to be able to trust doctors and nurses, need for information, needs of other family members, need to feel they are trusted, need for support and guidance and physical needs. Kristjánsdóttir (1991) compared responses from mothers and fathers for each of the categories and found significant differences in the responses in the need to feel trusted category, with mothers giving those needs more importance than fathers. In the physical needs category, similar differences were found.

Using Kristjánsdóttir's questionnaire, Bragadóttir (1999) found that most parents perceived they needed assistance from hospital staff in order to meet their needs. Although she reported gaps in her data, where possible she used Spearman's rank correlation co-efficient to examine relationships between demographic characteristics and responses to the needs statements. She found no significant correlations of importance scores with needs statements. However, when she examined the extent to which needs were met, she found that parents' age and education level, length of hospital stay, distance of hospital from home and severity of the child's illness were significantly positively correlated with many of the needs statements. As noted by Bragadóttir (1999), a larger sample size in this study may have given different results.

Disquisition about parents' physical needs such as food, rest and facilities for hygiene has been scant, perhaps because it is surmised that these needs are self-evident. Consumer groups have ensured these needs are regarded

(Association for the Welfare of Children in Hospital Association for the Welfare of Child Health, 1998; Hogg & Rodin, 1993, Audit Commission 1993) though Kristjánsdóttir (1991) included them in her investigations and found that parents rated them as less important than psychological needs. Shields et al. (2002) established that staff considered meeting of physical needs of parents more important than did parents. When investigators have examined parents' physical needs they have been more likely to examine the needs of parents in relation to their employment and how it is affected by a child's admission. In the 1980s, Knafl et. al (1987) found that fathers' work lives were less likely to be affected by a child's hospitalisation than the mothers, though with changes over the last two decades in work practices in developed countries, research in this area now may reveal that mothers' employment is equally affected. In developing countries, Shields and King (2001a, 2001b) found that parents sometimes lost their jobs when caring for a child in hospital, so the needs of the whole family were drastically affected. Callery (1997) examined the cost to parents of a child's hospital admission and found that mothers (the main participants) lost income and/or holiday allowances, and that food and drink, child care for other children and transport were needs that incurred financial losses.

Most of the research in this area has examined parents' psychosocial needs. Kristjánsdóttir (1991, 1995) found that these were more important for parents than physical needs, while others (Hoekstra-Webers et al., 2001) found that parents need emotional support during their child's admission. Scott (1998) found that parents of critically ill children needed to be given adequate information freely, to be able to be present as they required, and to know that the child was receiving optimum care. Parents of infants in neonatal intensive care units ranked assurance and information higher in importance than physical needs, though fathers thought them less important than did mothers.

Parents want to know that their needs for professional support post-discharge will be met (Lundblad et al., 2001), needed a feeling of security that their child was receiving the necessary care and that staff understood and tried to meet their needs (Sloper,, 2000). Parents used different strategies to ensure they received adequate and appropriate support, including (a) relinquishing all care to the staff; (b) trying to retain a measure of control over their child and (c) insisting that they know what is best for their child (Kristensson-Hallström & Elander, 1997). In another study, parents described five strategies they used to ensure their needs were met. These included avoiding making themselves a nuisance to the nurses, being positive towards the staff, asking questions, ensuring they were as prepared as possible for whatever might happen during the child's admission and informing the staff about their expectations (Hallström & Runeson, 2001).

The study reported here is part of a large study of the needs of parents during a child's hospital admission in three countries – Sweden, England and Australia. We used Kristjánsdóttir's (1985, 1991, 1995) Needs of Parents questionnaire (NPQ) and modified it slightly for use with staff. The aim of this paper is to demonstrate the influence of the demography of the Swedish sample on the responses.

METHODS

Instrument

The NPQ has been used in several countries in three different languages - Icelandic, French and

English, and was designed to examine parents' perceptions of needs during hospitalisation of their two- to six-year-old children (Kristjánsdóttir, 1985; 1991; 1995). The literature provided base data and a panel of parents and nurses confirmed content validity. Trials were conducted and statistical reliability ascertained. Originally, the NPQ contained 43 statements of perceived needs of parents, subsequently eight were added. The needs relate to parents who accompany their child during a hospital admission and include physical and emotional needs, needs for support and information and involvement in the child's care, and the needs of parents in relation to other family members. Originally, the statements were examined from three different perspectives: the "importance score" - the parents' perceived importance of each statement in relation to their child's hospital admission; the "fulfilment score" determined if parents thought each of the needs statements were fulfilled during the admission to hospital, while the "independence score" identified whether or not the parents thought they needed assistance from staff to have the particular need met. 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. Each of the three subscales in Kristjánsdóttir's study (1991, 1995) had a reliability coefficient of 0.91. Further sections of the NPQ elicit comments on ease of use and relevance of the tool and there are sections for open comments and demographic information.

The NPQ was designed for use with parents. For this present study it was adapted for use by staff – nurses, doctors and allied health staff. Some statements were changed slightly, for example, statement Number 3 "that staff encourage parents to ask questions and seek answers to them" became "that parents can ask questions and seek answers to them". The corresponding statements in parents and staff NPQs were checked in Australia by a panel of three nurses, two doctors and a dietitian before being trialed by 10 others. Reliability testing in the current study gave a Cronbach's alpha of 0.91, results similar to Kristjánsdóttir's (1991; 1995).

Translation into Swedish was done on completion of trials on the modified questionnaires in Australia. Specific steps in the translation process ensured accuracy (White & Elander, 1992). The second author (IK-H), translated the questionnaire from English into Swedish, it was then checked by another English-speaking nurse and the translated NPQ trialed by asking 10 Swedish parents and 10 staff to complete it. Errors were corrected and difficulties addressed though few corrections were required.

SUBJECTS

After ethical approval was granted by the relevant agencies in Australia and Sweden (LU 338-00), recruitment began. Health professionals and parents of hospitalised children in a 150-bed paediatric university hospital in a city in southern Sweden formed a convenience sample. The staff sample comprised nurses (from auxiliary nurses with basic education to nurses with postgraduate university degrees), doctors and allied health staff. The doctors were both senior and junior and the allied health staff were physiotherapists, occupational and speech therapists and play staff.

PROCEDURE

Questionnaires were distributed by the first two authors and from the 274 staff questionnaires and 190 parents' questionnaires, 132 (48%) and 113 (60%) respectively were returned. Ward staff invited parents to participate and distributed the questionnaires, information sheets and consent forms and collection boxes were provided in the wards. To recruit staff, the authors attended ward meetings and left copies of the NPQ, and after two weeks reminded them to complete the questionnaire. Few problems were encountered with the NPQ by either parents or staff. Ninety-nine percent reported that they understood all or most of the questions, 90% confirmed the 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.

ANALYSIS

Associations between the "importance scores" and the demographic variables were sought for both parents and staff for each of the 51 needs statements. Because of the small numbers in some cells in these scores, the responses on the Likert scales were concatenated into "important to very important" compared with a combination of "not at all and does not concern me". In doing this, if the respondent gave the statement any importance at all could be compared with an indication that they gave it no importance whatsoever. Data from the needs statements were normally distributed but most demographic data were not. Bragadóttir (1999) in her study of the influence of the demographic characteristics of her parents' sample (and using the NPQ), employed Spearman's rank correlation coefficient, but the nominal nature of the structure of our responses precluded us doing likewise. Hence, non-parametric Chi-square was used and if a cell contained less than the expected count in a contingency table, Fisher's exact test (Siegel & Castellan, 1998). Analysis was undertaken with SPSS for Windows™ software. In many cases, "important" responses were given by both groups of respondents, leaving the numbers in the "not important" cells too small for statistical analysis.

RESULTS

Staff sample

Table 1. Demographic details of staff sample

Characteristic		n	%
Occupation (128)	Nurse	50	39
	Doctor	61	48
	Allied health	17	13
Age group (125)	< 25 years	3	2
	25-40 years	65	52
	> 40 years	57	46
Education level (116)	High school	36	31
	Technical college	70	60
	University	10	9

Paediatric qualification (127)	Yes	48	38
	No	79	62
Years in present occupation (121)	< 2 years	2	2
	2-5 years	16	13
	6-10 years	15	12
	>10 years	88	73
Years working with children (113)	< 2 years	6	5
	2-5 years	9	8
	6-10 years	14	12
	>10 years	84	75
Have own children (125)	Yes	101	81
	No	24	19
Sex (126)	Male	13	10
	Female	113	90

Source: authors

Table 1 shows the demographic characteristics of the staff sample. Almost half the staff sample were medical officers, of whom 35 were residents (interns), 10 registrars and 16 consultants or staff specialists. Two-fifths of the staff sample were nurses, including registered nurses and enrolled nurses, while physiotherapists, play therapists, dietitians, occupational therapists constituted the allied health sample. The age groups reflect the current state of the ageing health workforce in developed countries with 46% of the respondents over 45 years of age (Buchan 1999, Anonymous 2000). The respondents had been working in their present occupation for a mean of 18 years (range 0.5 – 40 years), in their present position for a mean of 13 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 17 years. Most of the respondents were female, reflecting the predominance of females in the nursing profession, and most of the staff had children of their own. Thirty-six percent held a paediatric qualification, which included specialist paediatric nursing courses offered at graduate certificate or diploma level, play therapy qualifications, postgraduate diplomas in paediatric nursing and specialist paediatrics for some of the medical staff.

Parents sample

Table 2. Demographic details of parents sample

Characteristic		n	%
Relationship to child (100)	Mothers	83	83
	Fathers	16	16
	Other	1	1
Marital status (100)	Married/long term partners	90	90
	Divorced	3	3
	Single	7	7
Age (100)	20-40 years	78	78
	> 40 years	22	22

Education (100)	High school	52	52
	Technical college	25	25
	University	23	23
Type of admission (90)	Acute/injury	58	64
	Chronic condition	32	36
Length of time in hospital* (92)	1 day	11	12
	2-7 days	42	46
	> 1 week	39	42
Other children in family (99)	No	19	19
	1 other	48	48
	2 or more	33	33
Age of admitted child (98)	0-2 years	46	47
	3-5 years	19	19
	6-10 years	18	18
	11-16 years	15	16
Home (99)	< 1 day's travel#	95	95
	> 1 day's travel	5	5

** time at which questionnaire was completed; # from hospital*

Source: authors

Table 2 shows that most of the parents who responded were mothers (83%), and the majority were married or had long-term partners. About one-fifth of the parents were aged over forty years. Twenty-three percent had university education, 25% had reached technical college level and almost half had secondary school education only. In accordance with hospital policy, the admitted children of the sample parents were aged from birth to 16 years (median age 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 hospital for two to seven days, 42% had been inpatients for over a week; only 12% were in their first day of admission. For 57% of the children this was their first hospital admission, and 30% of the parents had never had a child in hospital before. One-fifth of the parents had no children other than the admitted child, 48% had one other child and 33% had multiple children. Almost all the parents lived within one day's travel of the hospital.

Influence of characteristics on needs statements

Table 3 – Needs statements with statistically significant demographic influences

	Need	Characteristic		+ importance scores	Results
STAFF	To have planned meeting with	Paediatric qualification	yes	43 (45%)	☒2 7.9, df 1,
			no	52 (55%)	

PARENTS	To have planned meeting with other parents	Education level	high school	36 (55%)	χ2 8.2, df 2, p=0.017
			tech college	19 (29%)	
			university	10 (15%)	
	To be able to see social worker		high school	44 (57%)	χ2 8.3, df 2, p=0.016
			tech college	19 (25%)	
			university	14 (18%)	
	To feel I am not blamed for my	Relationship to child	mother	75 (88%)	χ2 9.76, df 1,
			father	10 (12%	

Table 3 shows the needs statements for which statistically significant differences were found. Space considerations preclude the presentation of all the 51 needs statements, but they are available on application to the authors. Few needs were found to be influenced by the demographic characteristics of either the staff or parents. In fact, according to the staff responses, only one need, that parents are able to meet other parents of a child with a similar condition to theirs was found to be affected, and this by one characteristic only – that the staff member held a specialist paediatric qualification. Staff who did not hold a paediatric qualification thought this was more important than did those who were specialist qualified (Chi-square 7.9, df 1, p=0.005). In the parents sample, responses to three needs indicated that parents' characteristics had some influence on the level of importance given to those needs. More mothers than fathers thought that it was important not to feel blamed for the child's illness (Chi-square 9.76, df 1, p=0.002), and parents with only high school education thought it was important to meet other parents whose children had the same condition (Chi-square 8.2, df 1, p=0.017); similarly, parents with high school education thought it important for parents to access a social worker (Chi-square 8.3, df 2, p=0.016).

For nine needs statements parents and staff were in complete agreement that these were important, that is, no one gave these a "no importance" score. These are shown as "all said important" in Figure 1

Figure 1. Needs statements for which all parents and staff gave a positive importance score

- *To be sure that though I am not present my child will get the best available nursing care
- *That I get advice about the care of my child in preparation for my child's discharge
- *That I be informed about all treatment that my child will receive
- *To be able to participate in the nursing care of my child
- *That I can stay with my child 24 hours a day if I wish
- *To be able to trust that though I am not present my child will get the best available medical care
- *That nurses recognise and understand the feelings of parents.
- *To feel that I am important in contributing to my child's well-being.
- *That I get exact information about my child's condition.

DISCUSSION

Our results for importance scores for parents were similar to Bragadóttir's (1999) as she found no influence at all of the demographic characteristics on the importance scores, and we found only four, though we had a much larger sample. She described several characteristics that were positively correlated with parents' perceptions that their needs were being met (fulfilment scores). We briefly explored some of our fulfilment score responses, but found that results were so similar to the importance scores that further examination was redundant.

The nine needs statements which all parents and staff gauged as important are of interest. Five were about communication; two about trust, while the remaining two concern parents' ability to participate in the care of their child. These findings are similar to those of Scott (1998) and Shields (1999) who found that parents wanted information about their ill child's condition and wanted to participate in care. The agreement on trust support findings by Hoekstra-Weeberset al. (2001) and Kristjánsdóttir (1995) who suggested that parents needed emotional support during their child's admission, and others found that staff understood and tried to provide a feeling of security for parents during their child's admission (Sloper, 2000).

It is interesting that only one needs statement evinced responses which were influenced by a demographic factor of both parents and staff samples. "To have a planned meeting with other parents to discuss the child's hospitalisation" was seen to be more important by parents with the lowest levels of education, while staff who did not hold a specialist paediatric qualification thought this more important than staff who did. As these are both educational characteristics, perhaps we can infer that higher and more specialised education gives a more lateral view and that those with a higher education are more likely to give a higher value to self-help without the need to seek support from others. Similarly, the parents responses indicated that those with the lower levels of education would be more likely to think seeking services from a social worker important than their higher-educated fellows.

More mothers than fathers ascribed a higher level of importance to not feeling blamed for the child's illness. Kristjánsdóttir (1995) found similar effects between mothers and fathers in her original studies, while Ward (2001) suggested that fathers thought emotional support less important than did mothers. It is easy to surmise that mothers are more likely to feel less secure in their dealings with health professionals than fathers, and require more emotional support, though reasoning like this borders on stereotyping and should be treated with caution.

The findings of this study substantiate the work done by Bowlby and Robertson (Alsop-Shields & Mohay, 2001) all those years ago. They advocated that parents be a welcome part of the care of children in hospital. Over time, parents have come to expect to be involved in the physical care of their children and the emotional and psychological care, and expect to receive psychosocial care themselves, though Darbyshire's (1994) work suggested that some parents thought that too much was expected of them. Our study found no indication of this, rather, the high level of importance given to almost every need by both parents and staff illustrates how much parents want and expect help, and, pleasingly, how willing staff are to provide it. One question must be asked, though. How much of this is a "chicken and egg" situation? Since Bowlby's and Robertson's time, have parents become so inculcated with the expectation that they will be involved in their child's care that we give them little room for choice? Have we come full circle, and should we be spending more time and effort in finding out just how much pressure we enforce on parents? This will become an increasingly important area for investigation as hospital inpatient times shorten and parents are expected to provide more of the care themselves at home.

The theoretical basis of FCC has been

supported by the findings. The results support the need for the family to be involved in the care of children within health service settings, and the level of involvement can often depend on the demographic characteristics of the parents, who may or may not want to be part of decision-making. Demography, also, influences the way staff are prepared to deliver FCC, and this is similar to other findings (Darbyshire, 1994; Galvin et al., 2000; Eckle & MacLean, 2001; Knafl et al., 1982). Only when FCC is successfully implemented will communication between staff and parents be truly effective (Shields, 1999; Alsop-Shields, 2002) and only then will the care of the children be unequivocally emotionally supportive.

Limitations

The recruitment of parents by ward staff may have compromised the veracity of the responses, though every effort was made to ensure that the confidentiality of the return procedure was designed to alleviate such problems. In the statistical analysis, because of the small numbers in some of the "not important" cells in many of the responses, no meaningful statistics could be calculated, and so no influence was found. This was taken as a positive result as it showed that almost everyone thought the needs important. Only two staff members had been employed for less than two years so statistical comparisons between staff who had been there for a short time compared with long periods were not possible.

The different return rates of parents (60%) and staff (48%) questionnaires may provided bias, though they were within typical range for studies of this type (Oppenheim, 1966). Some sections of the questionnaire were incomplete or not properly done, however these were few and had little influence on the results. The preponderance of doctors may have influenced the results, though it indicates a supportive attitude by the doctors in this particular hospital to nursing research. Also, the percentage of those who held specialist paediatric qualifications was less than the 80% reported by others in a population of Swedish health professionals (Shields, 2001), and this was attributable to the number of younger doctors included in this convenience sample. While the site for this study could be regarded as a "typical" Swedish paediatric hospital, it cannot be said to be representative of all health facilities in Sweden (or any other country).

Respondents found Kristjánsdóttir's (Kristjánsdóttir, 1986; 1991; 1995) NPQ easy to understand and use, and while it was originally designed for use with parents of two-six-year-old children, we found it useful for parents of children of all ages. It was easily adapted to staff. Along with this Swedish site, data are being collected in hospitals in Australia and England and differences and similarities in cross-cultural comparisons will provide information on which to base nursing care for people from differing cultural backgrounds. Children were not asked to describe their perceptions of needs. While this would have been impossible for tiny children, older patients may have provided a rich data set.

Recommendations

Paediatric practice can be informed by this work. Staff education programmes can ensure that attitudes of parents with differing levels of education are recognised, and that communication between staff and parents can take cognisance of this. The work of Bowlby and Robertson should never be considered old fashioned and should be part of any paediatric education, as they are the classic theorists of the psychosocial care of children, and this research bears out the timelessness of their theories. However, more research is needed to explore the ideas first started by them and see if we have gone too far in our expectations of parents' participation in the care of their hospitalised children.

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