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RESEARCH PRIORITIES IN PAEDIATRIC HAEMATOLOGY–ONCOLOGY NURSING: A MULTI-ROUND DELPHI STUDY

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Abstract

Clinical nursing research in a pediatric unit of hematology, oncology, immunology, and infectious diseases must be effectively integrated and applied to practice. To achieve this, ownership and identification of priorities must come from those most likely to implement research findings in clinical settings.

The "Nurses' Research Group" initiated this study as a first step toward developing a nursing strategy based on evidence. Four members of the group volunteered to form a working party to conduct the study. This paper describes a four-round Delphi study. The study questionnaire was sent to all nursing staff within the unit. The initial process identified 151 research topics/issues. Through a process of refinement, the priority list was reduced to 89 topics.

Repeated rounds were conducted, culminating in the identification of four top-priority research areas.

Keywords: Symptom management, Negotiation of care between the child and the family, Quality of life issues, Staff retention

INTRODUCTION

A recent focus in nursing is the need to develop evidence-based practice (Department of Health 1993, Sackett et al. 1996, Callery 1997, Cullum 1997, Kitson 1997). However, despite longstanding encouragement, nurses still appear reluctant to use research to support their practice, making the adoption of evidence-based practice a considerable challenge. Hunt (1987) suggested the reasons for this are that nurses do not understand research, do not believe in research ®ndings and do not know how to apply research to practice. This is unsurprising when frequently the social context in which research priorities are decided is academic rather than practice-based (Kuhn 1970, Kirkevold 1997). Walsh (1997) con®rmed that these ®ndings are still in evidence and that, in addition, nurses in his study identi®ed pressures of the workplace and lack of research training as barriers to implementing research.

For research to be successfully integrated and applied to practice, ownership and identi®cation must come from those who are most likely to implement research; that is clinical nurses (Baesler et al. 1994, Walczak et al. 1994, Cavanagh & Tross 1996). Paediatric oncology is not immune from the above problems (Hinds et al. 1990) and it has been suggested that a strategic research framework that is relevant to patient care

must be advocated to improve participation in nursing research (Hinds et al. 1990, Stevens 1997). Such frameworks receive strong support from clinical sta as they identify with the purpose of the research, and therefore ®ndings are more likely to be implemented into patient care (Lindeman 1975, Hubbard & Doneower 1980).

In order to respond to some of the issues surrounding the use of research in practice, a Delphi survey was undertaken with nurses working in a paediatric haematology, oncology, immunology and infectious diseases unit to identify and rank their clinical research priorities. The aim was for the priorities to form the focus of a future research programme within a strategy of evidence-based nursing on the unit. As a means of structuring the study, the working party decided to use the published work of Hinds et al. (1990) as a framework. This was chosen as their enquiry closely re¯ected the patient group within the unit being studied. In addition, the steps of the Delphi survey were clearly documented and thus o ered a guide to researchers who were novices to this method of data collection.

Within Hinds et al.'s (1990) study two groups of nurses were asked to identify their research priorities. One group included nurses at a children's hospital, and the second group included participants at a paediatric oncology nursing conference. All participants provided direct care to children with cancer. Three rounds of questionnaires were completed using the classic Delphi technique. Participation level was high (91% and 81% respectively). The two samples identi®ed similar types of research priorities but rated them di erently. The predominant focus of those identi®ed in the children's hospital was the speciality itself, i.e. of the top ten research priorities identi®ed, nine focused on professional issues with only the tenth related to patient care. The somewhat surprising low priority given to patient care research may be due in part to the hospital in which the survey was undertaken. St. Jude Children's Research Hospital has a strong history of nursing research focused on patient care; for this reason nurses may have chosen areas not adequately addressed in current research but nonetheless important to their role as paediatric oncology nurses. The consensus reached from the Delphi has according to Hinds et al. (1990) some degree of generalizability to other paediatric oncology units. This would appear to be borne out by the ®ndings of this work and other research (Hinds et al. 1994 , Harding 1996, Gould 1996, Bradding & Horstman 1999, Peacock et al. 1999) that appear as published papers in UK and US journals.

To date, however, this work has not been replicated in a paediatric oncology unit in the UK. Replication of Hinds et al.'s (1990) work provided an opportunity to examine the transcultural ®ndings of related groups. British paediatric oncology nursing might be found to be experiencing similar professional issues to those identi®ed by Hinds et al. (1990), e.g. changes in the care delivery system and the stress of nursing children with cancer. The question was whether these issues predominate in an area where little nursing research was taking place?

THEDELPHIMETHOD

The Delphi technique is a survey method of research which aims to structure group opinion and discussion using a multistage process. The Rand Corporation in California ®rst developed it in the 1950s. It was

introduced in an attempt to eliminate interpersonal interactions in decisionmaking (Dalkey & Helmer 1963). The technique is now used primarily to reach a consensus in the absence of an acceptable body of knowledge or where there is a desire to gather opinion and initiate debate (Goodman 1987). A useful de®nition is one given by Reid (1988). She believes the Delphi `to be a method for the systematic collection and aggregation of informed judgement from a group of experts on speci®c questions and issues'. This approach is viewed more as an art than a science (Linstone & Turo 1975); the results of a Delphi exercise being beheld more in the nature of what Sackman (1975) called a `structured brainstorming session' and Pill (1971) called `picking the brains of a group' than as a rigid, positivistic and scienti®c exercise (McKenna 1994).

The Delphi survey has become a popular method to identify the research priorities of nurses (Lindeman 1975, Bond & Bond 1982, Hitch & Mugartroyd 1983, Hinds et al. 1990, Broome et al. 1996). Lindeman (1975) was one of the ®rst nurse researchers to determine the research priorities of clinical nurses, using the Delphi survey. Since then, the Delphi survey has been used in a variety of nursing specialities: clinical nursing (Bond & Bond 1982, Fitzpatrick et al. 1991, Daly & Chang 1996), cancer nursing (Western Consortium for Cancer Nursing Research 1987), paediatrics (Broome et al. 1996, Schmidt et al. 1997) and paediatric oncology (Hinds et al. 1990, Hinds et al. 1994).

The Delphi survey is essentially a series of questionnaires. The ®rst questionnaire aims to gain a response to a broad subject and the following rounds are built upon the responses of the preceding questionnaires. Three to ®ve questionnaires may be required before consensus is reached (Beretta 1996). Strauss and Zeigler (1975) have identi®ed six key characteristics that are common to the Delphi process. They are that the survey:

. Will use panels of experts for obtaining information or data
. Is conducted in writing, using sequential questionnaires interspersed with summarized information
. Systematically attempts to produce a consensus of opinion and to identify opinion divergence
. Will guarantee anonymity of both the panel members and their statements
. Will use iteration and controlled feedback
. Is conducted in a series of rounds between

Which a summary of the results of the previous round is communicated to the panel members.

Traditionally, the Delphi survey relies on the judgement of an expert panel (Williams & Webb 1994). However, Pill (1971) de®nes an expert as anyone with relevant input into the discussion of the chosen purpose of the Delphi. The use of a panel of experts increases the content and face validity of the Delphi survey as a tool for data collection, and this is further enhanced when consensus is achieved (Beretta 1996). Both of these factors have been identi®ed as important when identifying knowledge in a speci®c area (Polit & Hungler 1995). However, this may be a ected by panel attrition and fatigue associated with the reducing response rates of each round associated with Delphi surveys. The advantage of this method is that it allows a group of experts to reach consensus without the overt in¯uences of peer pressure and bias that

may be a feature of other consensus methodologies. Within the context of health care the anonymity of the Delphi technique is also an advantage encouraging junior members of sta to respond who might otherwise be reluctant to o er their opinion if it is in con ict with that of senior members of sta . In distinguishing research priorities the strength of the Delphi survey is its ability to provide a systematic approach to data collection where often the alternatives are subjective or anecdotal (Proctor & Hunt 1994). In adopting elements of both quantitative and qualitative approaches the Delphi survey is acceptable to both nurses (who are more accepting of qualitative data) and policy developers (who are more accepting of quantitative data) (Reid 1988). Disadvantages in using the Delphi survey identi®ed by Beretta (1996) are the reliability and validity of results, the in uence of the researcher and ethical issues of consensus methods of research. Each of these issues will be addressed in relation to this study shortly.

PURPOSEOF THESTUDY

The purpose of this study was to provide an opportunity for all nursing sta on the unit to identify and rate their priorities for nursing research. By using a Delphi survey the intention of the researchers was to encompass all grades of nursing sta , and thus hopefully radiate the message that the views of everyone were important and valued. It also aimed to place future research undertaken as a result of the Delphi in the social context of the unit. The Delphi was part of a wider (and ongoing) project to develop a clinical research strategy and culture within the unit. According to Street (1995), such a culture of ownership and placing importance on setting research priorities are key factors in its success.

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METHODS

Sampleanddemographicdata

The initial sample included all quali®ed nurses working within the Host Defence Directorate, which includes four in-patient wards and an outpatient area. These areas encompass the specialties described in Table 1. To encourage grassroots involvement and to bestow ward level credibility and acceptability of the results (McKenna 1989), all nurses working in the clinical areas were invited to participate (n=101). These included Clinical Nurse Specialists (CNS) working within the specialities of palliative care, haematology, oncology, immunology, hepatitis C, haemophillia, bone marrow transplant, HIV and intravenous therapy and senior nurses working within management. The initial invitation to participate also encompassed 10 nurses undertaking the Paediatric Oncology Nursing Course who were allocated to wards throughout the unit at the time of the survey.

Methodology

Table1 AreaofspecialtywithintheHostDefenceDirectorate,numbero fbeds,totalnumbersofnursingsta¡ andresponses atthe time ofthe f|nalround

Specialty	No. of beds	Totalno. ofnurses	Number whoresponded
Bone MarrowTransplant	8	20	5 senior 1junior 30% of total
Haematology/Oncology(area1)	8	19	5 senior 5 junior 52% of total
Haematology/Oncology(area 2)	16	20	3 senior 15% of total
Immunology	7	14	3 senior 1junior 28% of total
Unit Day Care and Out-patients	N/A	7	3 senior 42% of total
CNSs and others	N/A	11	11 100% of total
Paediatric OncologyNursing Coursemembers	N/A	10	0 0% total

In summary, the Delphi technique is a method of structuring group communication in a series of rounds (Du?eld 1989). It consists of questioning a known group of experts about a speci®c issue, either in the form of an initial question or statements. In the ®rst round participants are asked to make judgements or comment on the items presented. The individual responses are then collated for re-submission to the group of experts. In the second and subsequent rounds, participants receive statistical feedback on the group's responses and are asked to reconsider their judgement. Repeat rounds are carried out until consensus of opinion, or a point of diminishing returns, is reached (Williams & Webb 1994).

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Procedure

Data collection was undertaken in four rounds and spanned a period from May 1998± June 1999. An overview of the procedure and response rate for each round can be found in Figure 1.

Firstround

For the ®rst round respondents were asked to identify three areas related to patient care that they felt should be subjects for nursing research within the unit. Using the o-duty rotas from the in-patient and out-patient area to identify all sta members, 98 questionnaires were distributed.

This initial process identi®ed 151 priorities. Following the steps identi®ed by Hinds et al. (1990), areas of overlap were addressed. Three of the researchers independently reviewed the list of priorities, clarifying areas of overlap and reducing the list to 89. The fourth researcher collated the work from this re®ning process, noting any lack of consensus. This combined list was con®rmed as the ®nal list of priorities by one of the researchers, ensuring that any merged priorities still accurately re¯ected the initial priority described.

The next step was to group the list of priorities using category headings identi®ed by Hinds et al. (1990) in order to provide structure and a user friendly format to the second-round questionnaire (see Table 2). Clari®cation of the term team care delivery systems was felt to be necessary by the researchers for a UK audience. The researchers independently categorized the identi®ed priorities under these headings; this categorization was discussed and agreed by the researchers.

Secondround

The second-round questionnaire was distributed to the 51 nurses who had responded to the ®rst round. Respondents were then asked to rate priorities in each category (see Table 3) using a 5-point Likert scale with a rating of one meaning `strongly disagree' and a rating of ®ve meaning `strongly agree'. The **questionnaires** were analysed quantitatively by two researchers using Excel 97 to determine the median score.

At this point concerns were raised about the sample size for the third round. Following the Delphi procedure the third-round questionnaire should have been sent to the 40 nurses who had responded. However, when this number was considered in terms of the total population currently employed on the unit, the sample was very small and unrepresentative. Thus the resulting research strategy would represent the views of a small number, of mainly senior nurses, working on the unit. To address this issue the third-round questionnaire was distributed to the whole of the current nursing team (n=101). Recent recruitment had raised the number of nurses on the unit from 98±101. This process to increase sample size in the third-round of a Delphi survey had been used previously by Broome et al. (1996). The third-round questionnaire was a repeat of the second round, with the addition of the median scores.

Thirdround

For the third round respondents were given the median rating for each priority identi®ed in round 2. Using the same 5-point Likert scale respondents were asked to rate the priorities once again considering the

median and their own score. They were asked to comment where their own response varied from the median.

The median and mean scores were calculated from the data. The mean score was used to rank the priorities identi®ed by respondents. The next step in the procedure was to ask respondents to rank the top 25% statements from each category (highest score the most important and lowest the least important). A percentage rather than number was used to ensure equity within the categories. Each statement was considered on its own merit and in response to `whether nursing should take the lead in researching this area'?

Fourthround

Of the 41 questionnaires returned for round 4 , only 37 had been completed correctly. Some respondents had clearly not understood the principle of ranking, awarding the same number to a number of di erent listed priorities. The ®nal rated priorities for each category can be found in Table 3, 1 being the most important research priority for that category.

FINDINGS

The category `Nursing Procedures' encompassed the highest number of research priorities, 32 in total. The top priorities re ected concerns such as symptom management, assessment of children, preparation for procedures and e ectiveness of care (Table 3). In the category titled `Psychosocial Care Needs' the focus was on helping children and families deal with their disease and treatment throughout their cancer experience, 23 priorities in total. Support, information and the impact on quality of life were the top priorities (Table 3). `Professional Issues' resulted in 21 priorities, with the top priorities re ecting concerns about the role of the nurse in terms of scope of practice, advocacy and stress/burnout (Table 3). The ®nal category, `Care Delivery Systems', encompassed the least number of priorities but still re ected a focus of family care in terms of who gives information to families, negotiation and communication between the di erent service providers. Overall, the ®ndings highlight patient/ family-centred priorities with the top ranking of each category being management of the child's symptoms, negotiation of care with the child and family, quality-of-life issues and the e ects of high sta turnover within the unit respectively.

Although there was also a section for comment within each round of the Delphi survey very few comments were made. Of the 60 respondents in round 3, only 16 took the opportunity to o er further comment. Most comments o ered clari®cation of why they were voting in a certain way, reinforcing the importance of their score, or commenting that some areas were already a focus of research on the unit and elsewhere. Also highlighted was the view that some of the priorities had more of a `medical focus' than nursing. The fact that some of the priorities would be di cult to `research' was also addressed and the use of `expert' opinion was identi®ed as a way forward in some of these areas, e.g. methods available to pre-medicate children.

There was concern expressed in some of the comments regarding the `cancer' focus. The overwhelming number of responses (n=57%) came from the haematology/oncology areas within the unit. This specialty

encompasses the largest area, with more patients and therefore more nursing sta. The working party were concerned that this factor may bias the priorities towards this specialty, with the results of the ®rst round reinforcing this concern with the identi®cation of many haematology/oncology/bone marrow transplant issues. However, when nurses throughout the unit were asked to rank issues in order of importance/relevance, more general issues, applicable across all specialties, were identi®ed as having the highest priorities (Table 3).

DISCUSSION

The use of the Delphi technique has enabled the unit to identify the top research priorities around which to structure a research strategy. Once developed, this strategy will specify research activities for the next 3 years based on the research priorities identi®ed. Alongside other activities introduced to establish a research culture, the research priorities will contribute to an evidence-based approach to nursing care by initiating further research into the areas identi®ed or by identifying areas where further dissemination of research ®ndings are needed.

In terms of the participants in the survey, a large number of nurses had either over 2 years' experience in the unit or within paediatric oncology nursing and they were con®dent in identifying areas which would bene®t from nursing research. There was a wide range of experience amongst nurses who responded to the ®rst round, `however, in subsequent rounds the number of nurses with less than 2 years' experience that responded dropped signi®cantly, such that in the fourth round the number was 511%. This response may indicate that these nurses felt less able to prioritize issues in a new specialty. On re¯ection, in contrast, the 100 % response rate from CNSs may be due to them knowing the researchers and feeling obliged to complete the Delphi questionnaires.

A concern of researchers at the beginning of the project was that the views of nurses working in immunology would not be represented as fewer nurses work in this area of the unit. However, there is a rotational system in operation for junior members of sta between the oncology and immunology settings resulting in nurses currently working in one specialty having an insight into the needs of other client groups. This was re¯ected in the ®nal top priorities. Still, the problems of reaching a consensus in a unit that encompasses a number of clinical specialties should not be underestimated. Nor are there any easy solutions to this problem.

Several of the top research priorities from the study were similar to those identi®ed by Hinds et al. (1990). Similarities included retention of sta, sta burnout, knowledge of nurses regarding symptom control, sedation/premedication for painful procedures, and communication between tertiary centres and shared-care centres. The existence of these similarities indicates that these issues continue to be important to paediatric oncology nurses, indicating that more research is required in these areas.

It is interesting to note that Hinds et al. (1990) identi®ed sta retention and burnout as a high priority, as do the ®ndings of this work. This appears to be a problem that crosses international boundaries, which may suggest that local/ national policies may not have as large an in¯uence on retention as is commonly

believed and that issues are more related to the nature of the work involved in the specialty. The focus of future research could include identifying stresses in this specialty and recognizing e□ective methods to deal with this stress.

The medical focus of some of the priorities initially identi®ed was commented on by respondents. An example of this is measuring the e□cacy of drug regimens and methods to premedicate children. This does re¯ect the nature of the specialty where nurses clearly do medical work, which is appropriate as it is within the context of nursing and is encompassed into the patient-focused care of a particular child and family. When considering what was important to research, the overlap between the areas of practice in relation to patient care was highlighted. The multidisciplinary focus of care was evident, with some respondents requiring clear guidance to focus on nursing research in the ®nal fourth round. The ability to rank in terms of nursing research may have been complicated from the outset as although the priorities listed were important to nurses, they were not expressed as research questions. Hence what appears in Table 3 is unre®ned and appears in the nurses' own words.

The fact that some respondents identi®ed priorities that were currently part of the research programme on the unit, for example use of painassessment tools and symptom management, was worrying and could be a symptom of trying to communicate with a large team of nurses. Added to which, some respondents were clearly not aware of published research that had already impacted on care. Clearly, if evidence-based nursing is to become a reality then the importance of a culture that facilitates nurse awareness of relevant research to utilize research ®ndings in practice, in addition to undertaking research studies, must be the focus of the research strategy for the unit.

One reason for choosing to use the Delphi technique was its ability to facilitate grassroots involvement while also reducing the e□ect of dominant individuals. As a result, nursing sta□ of all grades were encouraged to participate, ensuring that the focus of research was not in¯uenced by individuals alone and avoiding the potential for unrepresentative individual agendas to dominate. Although the total sample of nurses who participated in the study remained small (n=41) in relation to the population (n=101), the aim of grassroots involvement was still realized as the sample was re¯ective of all levels of nurses involved in direct clinical care.

LIMITATIONS

The limitations of this Delphi survey fall into the three main categories previously identi®ed in the literature: reliability, validity and researcher in¯uence (Goodman 1987, McKenna 1994, Williams & Webb 1994, Beretta 1996).

The reliability of the Delphi survey is at risk of being situational to the time it was undertaken. However, the ®nal identi®ed priorities appear to be consistent with those identi®ed by Hinds et al. (1990), suggesting a level of replicability said to be rare in Delphi surveys (Beretta 1996). In the early rounds areas of current concern and interest to the unit were re¯ected in the responses of nurses. Whilst this is to be expected and potentially unavoidable, the reliability of the consensus may be limited to the length of time

that these issues remain areas of concern. A further threat to the reliability of the ®ndings is a changing workforce in the unit. In common with other teaching hospitals, turnover of sta (particularly junior sta) is high. Hence, the research undertaken in response to the priorities identi®ed from the Delphi survey may not be perceived as a priority by the current sta, a problem identi®ed by Reid (1988).

Although it has been suggested that the content, face and concurrent validity of the Delphi may be high (Beretta 1996), the validity of results will be a ected by response rates. A high level of participant motivation is important to maintain the momentum of the Delphi. The response rate to all stages of the survey was low and waned despite the use of reminder letters. Reasons for this are varied. Firstly, the questionnaires were sent to work rather than home addresses-during a busy shift they were not a priority and once at home other concerns took priority. In both cases the respondents may have rushed when completing the questionnaire, resulting in answers that are not a true re ection of their research priorities. Secondly, in sending the questionnaires to the workplace, this may have encouraged discussion and collaboration in responses, again a potential risk to the reliability of the ®nal outcome. Finally, some nursing sta felt that it was almost impossible to decide which areas were a priority for future research and therefore felt unable to respond. This seemed especially true for nurses with less than 2 years' experience in the unit, leading to potential bias (Du eld 1989) in this case towards meeting the needs of senior sta and the ongoing reliability of the consensus. Response fatigue was also evident. The survey was time-consuming and took place over some months, resulting in loss of motivation re ected in the poor response rates.

A further limitation of the study is the fact that the researchers all worked within the unit. Whilst this may have raised the pro®le of the Delphi and encouraged sta to respond, it may also have in uenced nurses' responses and threatened the anonymity of the respondents. The presence of the researchers within the research setting may have been discerned as silent coercion to complete the questionnaire. Contact with the researchers (and knowing other panellists) had the potential to sway respondents' opinions, leading to a less objective ®nal outcome (Bond & Bond 1982, Goodman 1987).

Finally, the use of category headings identi®ed by Hinds et al. (1990), although providing structure to the questionnaires, may have biased responses, forcing respondents towards a judgement because of the category heading.

CONCLUSION

The purpose of this study was to provide an opportunity for all nursing sta within the unit to identify their priorities for clinical nursing research. Although a long and time-consuming process, it has nonetheless proven to be a valuable experience for all involved. The ®nal step of dissemination to the nursing team, through the unit research newsletter and wardbased teaching sessions, will hopefully result in feedback to the working party on the process (as well as the outcome) that will in uence future project work of the `Nurses Research Group'.

Overall, the ®ndings highlight the continuing patient/child focus of nurses working in increasingly technical/interventionist areas of care. Quality of life and care remain central to the concerns of nurses in these areas, but so too does the impact of working in such areas on their own and their colleagues' lives. The consensus of these areas as a priority for additional researchbased knowledge was also reported in Hinds et al.'s (1990) work. Whether this suggests consensus of priorities within the specialty will become apparent with the completion of a Delphi survey in another UK unit with a similar con®guration to the current research setting.

The four priority areas identi®ed in this survey are directly linked to practice and are well documented in the literature (Hinds et al. 1990, 1994; Broome et al. 1996) as concerns of specialist and general children's nurses. It would be of interest to explore the outcomes of replicating this study with nurses working in a general children's unit in the UK to see if similar in¯uences on the health care of children were identi®ed.

This Delphi survey has recognized the research ideas of only one professional group within the unit. Whilst they may generate and validate knowledge needed by nurses, how can we be sure that it truly re¯ects the areas where nursing research is most needed? In response to this, the researchers propose to seek the opinion of medical sta working within the unit. It is planned also to collect, collate and prioritize the opinions of parents of children (and where possible children themselves) cared for within the three speciality areas (haematology, oncology, immunology). In combining research priorities drawn from four groups an integrative approach to future nursing research on the unit will be undertaken.

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