Michelle Helliwell, MLIS
Dalhousie University, Halifax Nova Scotia

Building information bridges between parents and health care providers in the neonatal intensive care unit

Abstract: The goal of this study was to investigate the information needs of parents in a neonatal intensive care unit environment (NICU), and to uncover any gaps in the information exchange between parents and health care providers as perceived by parents of NICU patients. Brenda Dervin’s sense-making theory was employed to test the idea that health care providers (HCPs) offered information their clients (parents) actually wanted, not information it is assumed parents needed. The participants included parents and HCPs in a level 3 neonatal intensive care unit. The study was conducted in two phases. The first phase involved parents whose babies were in the NICU for a period of not less than three weeks. Parents completed a brief questionnaire shortly after their baby’s admission to the NICU, and kept journals during the course of their baby’s stay. Before discharge, parents were interviewed. Research documents were analyzed and all of the recurring themes were coded using QSR Nudist v.4 software. The themes were utilized to develop questionnaires, for HCPs and the general NICU parent population, which were completed in the second phase of the research. The study’s findings showed the impact of the parents’ length of stay as an intervening variable in their information search process and as a part of their sense-making. The study also supported the idea that parents’ perception of their parenting role was an extremely important aspect of their information behaviour. This research offers groundwork for future interdisciplinary research in this area.

Résumé: Le but de cette étude était d’investiguer les besoins informationnels des parents dans un service de soins intensifs néonatals (SSIN) et d’identifier les lacunes dans les échanges informationnels entre les parents et les fournisseurs de soin de santé (FSS), tels que perçus par les parents de patients des SSIN. La théorie du « sense-making » de Brenda Dervin a été utilisée pour tester l’hypothèse que les FSS donnaient à leurs clients (les parents) l’information que ceux-ci souhaitaient, et non l’information qu’on peut supposer qu’ils avaient besoin. Ont participé à l’étude des parents et des FSS d’une unité de soins intensifs néonatals de niveau 3. L’étude s’est déroulée en deux phases. La première phase portait sur des parents dont leur enfant était dans le SSIN pour au moins trois semaines. Les parents ont rempli un bref questionnaire peu de temps après l’admission de leur bébé dans le SSIN, et ont tenu un journal durant le séjour de leur enfant. Les parents ont aussi été interviewés peu avant le congé de l’enfant. Les documents de recherche ont été analysés et tous les thèmes récurrents ont été codés avec la version 4 du logiciel QSR Nudist. Les thèmes ont été utilisés pour développer des questionnaires destinés aux FSS et à la population parentale régulière des SSIN. Ceux-ci ont été complétés durant la seconde phase de l’étude. Les résultats de l’étude démontrent l’impact de la durée du séjour comme une variable intermédiaire dans le processus de recherche d’information et à comme faisant partie de leur compréhension (sense-making). L’étude appuie également la thèse que les perceptions des parents quant à leur rôle de parents est un aspect important influençant leurs comportements informationnels. Cette étude offre un travail de base pour de futures recherches interdisciplinaires dans ce domaine.
1. INTRODUCTION

In the preparation to become a new parent, expectant mothers and fathers read pregnancy books, web sites, and talk to family and friends who can offer parenting experiences. When things go wrong in pregnancy or in the birthing process, a baby’s admission into the neonatal intensive care unit (NICU) can render much of that information useless. Babies admitted to the NICU are premature, or have other complex medical and surgical issues. When a mother or father cannot hold, feed or make the primary decision about a child’s wellbeing, other avenues must be sought to fulfill that role. An enormous learning curve faces the new parent in the NICU, and the quest for information takes on a new significance.

How does information help parents? How can health care providers (HCPs), and librarians, help parents to bridge the inevitable information barriers that occur between parents and HCPs in a complex medical setting? Can good information delivery empower parents to be involved in their baby’s medical care? This research focused on these questions. The study results are specific to the Neonatal Intensive Care Unit (NICU) environment, but aspects are relevant to almost any patient context where decision-making and information delivery occurs.

The theoretical frameworks for this qualitative study are based on sense-making theory as described by Brenda Dervin (1992), and Carolyn Kulthau’s (1991) information search process (ISP). Sense-making theory has been employed to test the idea that health care providers (HCPs) are giving information their clients (parents) actually want, not information it is assumed parents need. The researcher also wanted to understand if, given the crisis events in the NICU, if parents’ information behaviour was consistent with this model, thus facilitating a means for more effective information delivery.

2. RATIONALE

A cross-discipline literature review revealed that information-based issues such as involvement in decision-making and the reception of consistent and current information are extremely important to parents in the NICU environment. Identifying the information barriers and the behaviours of both parents and health care providers has not yet occurred. Thus, there has been little progress in nursing and medical disciplines to suggest solutions.

This study used information-based theories, such as sense-making theory (Dervin 1992) and information search process theory (Dervin, 1992; Kulthau, 1991), to address information issues that have been identified in nursing/medical literature, but not fully investigated.

Information is an important factor in the reduction of parental stress and as a facilitator of parental involvement in decision-making in the NICU environment. In previous studies to assess parents’ needs or involvement in the decision-making process concerning their baby’s health in the NICU, the parental voice (the user of the health care system), has remained largely silent. This study focuses on that voice in order to find answers to information needs from the client’s point of view, rather than from the health care system perspective. To date, this type of investigation has not occurred.

54
3. LITERATURE REVIEW

There has been an effort, primarily in nursing research, to investigate parents’ stressors as they relate to parenting in the NICU environment. In the past decade numerous studies had addressed this issue. (Affonso, Hurst, Mayberry, Haller, Yost, & Lynch, 1992; Bass, 1991; Lau & Morse, 2001; Miles, Carlson, & Funk, 1996; Miles, Wilson, & Docherty, 1999; Seideman, Watson, Corff, Odle, Haase, & Bowerman, 1997). In almost every study, information issues have been identified as a primary source of parental stress. Specifically, parents are intimidated by medical jargon, overwhelmed with new information, physicians are often unavailable for questions. Parents, fearful of taking nurses away from more important duties, fear of feeling “stupid”, fear of bothering staff, are afraid to ask the myriad of questions that arise daily from the ever changing condition of their baby and his/her environment (Seideman et al., 1997).

The importance of information to parents, and the importance of the communication of information to parents are predominant themes in the literature (Jensen, 1999; Plaas, 1994; Scott, 1998; Seideman et al., 1997). However, there has been little progression and few suggestions of how to find a solution to this information gap. There is still a basic misunderstanding of parents’ motives and actions based on what information nursing researchers believe parents are hearing (Perlman, 1986). Parents who do not ask questions, who ask too many questions, who act as though they do not understand the seriousness of a child’s condition, who overreact to the child’s condition, who do not want to become involved in their child’s care, who become too involved in their child’s care, can all be labeled “difficult” parents, “unaware”, having problems with control, attachment, or simply “not normal” (Lupton & Fenwick, 2001). All of these problems can be linked, in one way or another, with the information issues identified by these same nursing studies.

If any trends in parents’ information seeking behavior can be gleaned from the literature in light of information seeking behaviours of these parents, it is that parents want as much information about their child’s condition as they can possibly be exposed to. Going further, information sought goes beyond the child’s immediate condition to information about prognosis, specific treatments and procedures, support groups, and developmental issues. Much of this information seeking is done by asking questions of neonatologists, nurses, social workers and other parents, relatives and friends. Books, online sources, pamphlets and other hospital-provided literature were also sources of information (Brazy, Anderson, Becker, & Becker, 2001; Dichtelmiller, Meisels, Plunkett, Boyzinski, Clafin, & Mangelsdorf, 1992).

In the NICU, the problems associated with decision-making are a significant part of the drive parents have for information seeking. There is the fundamental problem of being placed into a foreign situation with no previous knowledge to draw on, and being relied on to give consent to a course of action that could potentially harm or help. Decision-making requires knowledge and confidence, and parents in an NICU, particularly in the most critical moments, have very little of either (Landsman, 1998; Padden & Gladden, 1997; Sims, 2000; Truog, 1999; Wocial, 2000).

Decision-making in NICU settings is a day-to-day occurrence. Parents want to be involved in the decision-making process. In this context, the need for honest, open information, bad or good, is of extreme importance (Jellinek, Catlin, Todres, & Cassem, 1992; Sims, 2000; Ward, 2001;
Wocial, 2000). In this regard they differ little from adult patients making decisions about their own care (Coutler, Entwistle, & Gilbert, 1999). A study of parents whose infants were taken off life support revealed that parents felt that they did not understand much of what was happening in the decision-making process. Instead of being primarily involved in the decisions they felt like “passive observers” (Wocial, 2000). This feeling of not having been fully involved lingered for years after the event, no doubt mixed with feelings of doubt and grief.

A recent press release from a study of Pacific Rim nations into the decision-making process in NICUs clearly stated that parents want more communication from health care providers when treating their children in an intensive care nursery (Trinkl, 2000). Parents need more information and they want it communicated to them in a manner they can understand so they can become fully involved in the decision-making process. Given that health care providers are the main source of information for parents (Padden & Gladden, 1997; Scott, 1998) and that this information is usually delivered verbally, communication of information is an extremely important issue for parents in NICU.

An Australian neonatologist devised a novel way to close the communication gap with parents (Koh & Jarvis, 1998). In the process, he has revealed in stark terms the problems only hinted at in other studies citing communication issues. Dr. Koh has studied the idea of audio taping all communication between neonatologists and parents in the NICU environment. A figure that should give cause for concern to all health care providers is that 85% of parents found that the tapes revealed information they had forgotten in the encounter. Indeed, for several mothers, still recovering from caesarian sections, exhausted, sedated, and traumatized by the entire event, the tapes were a reminder that the initial interview had ever occurred (Koh & Jarvis, 1998). It also lessened the problem of the degradation of information that inevitably occurs when information is passed on ‘second-hand’, or when parents leave the same interview with two entirely different perspectives on what was said.

Patients also have expectations of their health care facility in terms of information giving which go beyond the dissemination of medical information (Audit Commission, 1993). Problems arise when patients assume that the hospital will provide them with support-based information needed to cope with their situation that may not be directly related to their diagnosis. The expectation is that the facility will not only supply them with information about the care of the illness, but all the other information they will need now that illness has impacted their life (Audit Commission, 1993). In the NICU, parents might expect detailed information on raising a child with special needs, frequent updates on their child’s condition or community resources for assistance with child care for other siblings that may be at home. Particularly in medical facility with a family-centred care philosophy, the inference of parents maybe that all these information needs will be dealt with: who else in their community would handle these issues better than the professionals who deal with them routinely?

Recent studies into parental experiences in NICU have explored how stressful the “routine” can be to parents (Redshaw, 1997; Sudia-Robinson & Freeman, 2000). For example, a case study of one family in a non-critical stage decision-making situation by Sudia-Robinson and Freeman found that non-critical procedures could be threatening to a parent because they were still new to their experience and unsure of what was “normal”. This feeling was echoed by another author,
Linda Layne, herself a mother of premature child, who was worried about turns in her child’s condition that the nurses assured her were “normal” (Layne, 1996). When the physician, the nursing unit, or the hospital has internalizes knowledge, makes assumptions or takes for granted what is “normal” or “routine” without communicating this to the patients or parents, communication barriers happen.

Another theme identified by parents is the problem of conflicting information. “The spin” put on information might make the description of the condition of the same child range from optimistic to one health care provider and pessimistic depending on the communicator (Affonso et al., 1992; Bass, 1991; Lau & Morse, 2001; Wocial, 2000). This leaves parents feeling confused and unsure of the “truth”. Of great importance to health care providers, it compromises the trust that parents put in any subsequent information given by particular members of the health care system. In the worst case, the entire system itself is distrusted (Hickson & Clayton, 1995).

ISP incorporates into its model the idea that seeking out information can be an extremely fretful experience, incorporating feelings of anxiety and uncertainty about the task at hand (Kuhlthau, 1991). Carol Kuhlthau developed ISP in an academic setting, her primary research group being students. The information this group collected, while crucial to the writing of assignments that were graded for a mark, was not of a traumatic personal nature. An important source for helping to construct idea of information seeking in a threatening situation, or when the information itself might be considered threatening, is George Kelly, a psychologist whose work on personality is based upon the idea of a personal construction of reality (Kelly, 1963).

Kelly postulates that a concept that is incompatible with a person’s current construct of himself and his world is considered a threat. One way people cope with threat is to try and understand the nature of the threat within the context of their personal construct. However, there are times when something is considered so threatening that the impulse is to reject it out of hand. Thus, instead of feeling subject to the threat, a person is a bystander to the events that threaten to change his view of himself and the world around him. “The effect of threat is to compel the client to claw frantically for his basic construct” (Kelly, 1963).

This concept needs to be applied to an information behaviour model, and the application of this theory in its current form could aid in current thinking about parents in an NICU environment. Parents with their shattered expectations of a normal birthing experience, a healthy baby and a “normal” childhood, will have to face a new reality. That reality will be considered a threat by many of those parents. Searching out information, or being given information that drives home that threat will take time to assimilate and might be rejected out of hand. How this complicates the search process, affects preferred information sources and information use, needs further investigation.

Much of the medical/nursing literature currently only acknowledges the issues linking stress and anxiety to information. There are no frameworks in these disciplines from which to suggest a need for mediation or validation of the complex feelings and problems associated with the search process. Parents, feeling overwhelmed and confused by the whole context of their situation are going to find the search process more frustrating. If parents do indeed use information seeking
as a way of finding an adapted role for themselves as mediators and advocates for their babies, then the emotional investment in searching is going to be extremely high. The emotional costs for failing, or running into roadblocks in that search process are likely to mirror that investment. Appropriate mediation and guidance in the search process could lessen the emotional costs and at the same time provide more fruitful results for their efforts (Julien & Michels, 2000). If information seeking is indeed a form of surrogate parenting, then this guidance would be assisting parents in a very meaningful and helpful way.

4. METHODOLOGY

The research setting for this descriptive and exploratory study was a level 3 NICU in a pediatric tertiary care hospital in Halifax, Nova Scotia. A level 3 NICU is capable of handling the most complex of medical/surgical conditions of the newborn.

The study was designed in two phases, with two primary participant groups. The first phase, which focused on parents of longer-stay patients, used qualitative data gathering methods. These methods included surveys, journal keeping and semi-structured interviews. The second phase began after the capture of all the qualitative data from the primary parent group. This second phase, open to all parents and health care practitioners in SCN, gathered data using surveys designed for each group. Questionnaires for health care providers included open-ended questions that gave the participant group the opportunity to express their perspective on the role of information within the context of the NICU environment.

Phase one participants phase were parents of babies who medical condition required a minimum stay in the NICU of three weeks and were followed to a maximum of ten weeks. This length of time was necessary in order to understand the changes that might have occurred in parents’ information behaviour. Parents were generally recruited within 48-72 hours of their child’s admission to the NICU. A total of six parents entered and completed the study.

After consent was gained, parents were administered a brief questionnaire. Parents were then given a brochure detailing how to keep a journal, and the journal itself. Journals were A5 sized, coil bound and lined. Parents were asked to record information events. Information events included such things as a question parents asked or wanted to ask, an answer parents received, information sources parents approached, and information that was volunteered or found serendipitously. They were also asked to record feelings and/or problems associated with those events. The brochure recommended writing on a daily basis if possible, although the exact structure of the entries was not dictated. Weekly check-ins allowed the researchers to ask about any problems parents encountered, as well as to provide gentle encouragement to continue journaling. Before their baby’s discharge or at the end of ten weeks, parents were interviewed. The interviews were semi-structured, and took place in a private location in hospital. Interviews were recorded and transcribed. Notes were also taken. Journal and Interview data was analyzed using QSR Nudist qualitative software. Data was analyzed for themes such as information sources, barriers, use and different types of information (i.e., baby’s progress, prognostic information, unit environment).
Phase two study participants were health care providers (HCPs) in the NICU. For the purposes of this study HCPs includes neonatologists, staff nurses, and neonatal nurse practitioners. This group was given a questionnaire. Major themes from the qualitative parent data were used in the formulation of the questionnaires directed at HCPs and the general parent population. Specifically, HCPs were asked about the value of certain information types to parents, and what information sources (other than themselves) they were comfortable recommending to parents. Questionnaires were colour-coded by profession in order assess if there was any differences in the answers. Each of these professions has a different kind of contact with parents. The response rate for doctors was five out of six replies for a response rate of 83%, three out of three of the NNP’s for a return rate of 100%, and 40 surveys of a total of 100 handed out to nursing for a total return of 40%.

A general parent survey was also administered to parents who did not necessarily fit the study criteria in phase one. The response rate to this survey was 31.25% (ten of thirty-five). This questionnaire was added to the study to garner a fuller understanding about the importance of information types, sources and barriers and whether these were impacted by demographic variables.

Qualitative data from the HCP questionnaire was coded for themes such as communication barriers and roles of information providers. A descriptive statistical approach was used for the quantitative data of both phase two questionnaires.

5. FINDINGS

The data revealed that most important variable in parents’ information behaviour was their baby’s length of stay (LOS) in the NICU. The analysis below will take that structure and interpose themes from the HCP and parent data that impact upon the different aspects of parent information behaviour at those intervals.

Length Of Stay 0-6 days: Parents at this time were in a state of crisis. Suffering from physical fatigue and emotionally distraught, they were unable to fully comprehend, internalize and remember information. To compensate for this, parents may have focused on what may have seemed like inappropriate issues given the current situation at hand. They were suffering from memory problems. Hence, they might ask questions over and over, or try to verify what they are learning by asking several different sources. The information pipeline parents could accommodate at this time was extremely narrow. Parents used few sources and the information types that were most important were related to the baby’s survivability, and to his/her daily well-being.

HCPs were asked about obstacles to communication of information. Among nurses, answers that described “parent behaviours” was the second as the most identified obstacle. (See Table 1 below) Parent behaviours cited by nurses included parents repeatedly asking the same questions, asking several people for the same information, or focusing on non-medical issues when the child was very unstable medically. What these nurses viewed as an obstacle was in fact a normal part of the information process for someone in a crisis situation. Understanding this might
mitigate information delivery by viewing these behaviours as normal, and thus accommodating them more reasonably, rather than as simply problematic. One way to address these problems is to have HCPs repeat key information for parents several times during this first week. In addition, parents might be provided with a written report at the end of the week that “sums up” what has transpired thus far.

**Table 1 - A comparison of HCP identified parent related obstacles and parent experiences**

<table>
<thead>
<tr>
<th>Parent Behaviour</th>
<th>Parent Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>have found you need to repeat the information frequently for parents to take it in</td>
<td>I spoke to the nurses in charge of each baby...only half understanding, at the time, what they were saying. (J003)</td>
</tr>
<tr>
<td>when parents are very upset relaying information can sometimes be misunderstood</td>
<td>After a bad week, the baby was starting to get better. The nurse who came on that day started in on the 'long road' conversation, while mom was concentrating (as always) on getting him home. Mom does this with little goals, such as weight, gestation, etc. The nurse called him sick, tiny - focused on the negative... Instantly created bad feelings. (I005, interview notes)</td>
</tr>
<tr>
<td>They don’t seem to hear and understand the first or second explanation and/or misinterpret what you tell them...</td>
<td>I don't remember going in to see them for the very first time...because everything's a blur and there's so many people and everything like that and so all the information... so you're just floating through it and on top of that you've just had them so you're still on that whole little high of having them as well. Not sleeping and everything, so I really do think that, you know, if the nurses and the doctors were to kind of go back over things it would be really helpful. (I003)</td>
</tr>
<tr>
<td>Many parents ask the same questions to each person they encounter</td>
<td>This is all so overwhelming and I feel like I'm having a hard time getting and understanding straight answers regarding my child's condition. (J004)</td>
</tr>
</tbody>
</table>

*Length Of Stay 7-28 days:* This is a critical period in parents’ information behaviour. The change was often dramatic. Information needs widened; in a short period of time, parents’ need to know about their baby’s condition became extremely important. Some parents were more proactive in their seeking. However, all parents’ ability to understand their circumstances and the information surrounding it increased. The parenting instinct awakened, and the need to take responsibility for their child’s well being seemed to drive this change in behaviour. In the journal data, there seems to be a singular event that often triggers this change, and it involved a parent feeling disassociated from their parenting role. For two parents, this involved an invasive
procedure. For another, it was the revelation that preferred feeding methods might be introduced earlier that she was made aware. This one event left parents feeling an information barrier had occurred, and proactive information seeking begins shortly after this event.

When asked to rate helpfulness of information types, HCPs rated test and procedure information last or next to last. However, at this time in the parents’ length of stay, this type of information was extremely important. The stress caused by the lack of this information was out of all proportion to its occurrence. This maybe confusing to the HCP facing the displeasure of a parent in this instances, when several days before much more invasive procedures were done with little question or comment. HCPs need to be aware that their information delivery must take into account where parents are in their stage of information behaviour.

Another aspect of parents’ information behaviour was their tendency to move beyond human sources to secondary sources, such as books or the Internet. Many attempted to turn to secondary information sources to fill in gaps of information they were not receiving from primary information sources. Parents recorded searching out a more complete concept of their child’s illness. However, these secondary sources were often difficult to come by and none of the parents in this study mentioned the facilitation of searches by HCPs.

Nurses were the least comfortable with books as a secondary source. This may have impacted on parents’ search for these sources. Some parents recorded being cautioned when seeking them out, and they may not have received recommendations of sources that might have been helpful. However, helping parents find good source materials could not only assist parents in gaining a greater understanding of their child’s illness, but could also help parents to understand associated information such as tests, procedures and differences in medical approaches to problems, which might alleviate their stress and allow for more open communication about these issues. Parents recorded instances of HCP assistance in finding information as a universally helpful behaviour.

Inconsistency, both in information and information sources, was highlighted by nurses as a barrier to information giving. This was attributed to the inherent problems of a large staff in the NICU. During this Length of Stay period, parents did start to become more sensitive to details. They were learning as much as they could. As a result, all information became more important as they were sorting out what they needed to know to advocate on their child’s behalf. Understanding subtle differences in caring behaviours or treatment routines was recorded as being stressful to some parents.

Parents viewed primary nurses as a valuable remedy to this problem, because of the consistency in care and the relationship between parent and primary nurse. Primary nurses were able to help explain differences in details, or recommend written sources to help parents learn. Some parents found the monthly rotation of medical staff stressful because of the lack of consistency and the need to relearn and renegotiate with information sources.

Length Of Stay +28 days: Parents during this time tended to refocus their information needs. They had become more familiar with their surroundings, their baby and their baby’s medical needs. In the process of learning about the medical condition, they also prioritized their information needs. Parents were goal setting for discharge or for the next stage of their child’s
treatment if the outlook was for long term care. Parents’ information sources were still preferably human. HCPs were still important resources, but other human sources also rose in importance, including other parents, and additional HCPs beyond regular nurses and medical staff. These HCPs were often professionals with a focused interest in aspects of the baby’s care that were particular to the current context of the child’s condition.

Parents at this time appreciated when HCPs involved them in decision-making. Facilitation of the parent role continued to be viewed as extremely helpful. An important aspect of this was the honest delivery of information by HCPs that respected the idea that parents were beginning to focus on getting their children healthy enough to leave the hospital, even if that time was many weeks or months away. As well, HCPs might have assisted in helping parents seek out information sources. Some parents recorded persistent questions they were having difficulty finding answers for. For others, complications arose for which parents wanted information to assess the impact on discharge outcomes.

6. SUMMARY

There were many more information issues that parents and HCPs were in agreement with than not. HCPs did relate a sense of the great responsibility they have not only as caregivers but also as information providers and most saw the roles as complementary at the very least. Overall, parents were pleased with HCPs as information sources, and found them to be very valuable. They were aware of the constraints of time, medical uncertainty and their own lack of knowledge, particularly in the beginning of their child’s NICU stay. This research, however, highlights the reality of parents’ information behaviour and how HCPs view on information and their role in giving it impact upon each other.

The parent participants exhibited parenting issues mentioned across the literature. Among them was the stress associated with information seeking, parents’ lack of ability to retain information, a perceived lack of understanding about the seriousness of their child’s behaviour, and feelings of being “outsiders” regarding their child’s care. Many of these parent behaviours were identified by researchers in past studies as problematic. Indeed HCPs in this inquiry felt that parents behaviors were occasionally an obstacle to their communication of information. However, in the context of known LIS frameworks, such as ISP and sense-making, we can to identify these same behaviours as a normal part of the information process or overall information behaviour.

For the parents, information served a central role. In the beginning, when feeding was impossible because of a breathing tube, when cuddles were limited to a touch through an incubator door, parents learned that if they were to parent their child, they had to do something else. They needed to ask questions, read monitors, watch their babies and learn the vocabulary of the medical staff. In other words, they needed information. It provided a way for parents to be surrogate caregivers, or advocates, for their children. This confirms the suggestion in other studies that information seeking is a form of surrogate parenting. The central importance of this role is to the parental identity in the NICU must be made clear to health care providers and information professionals. Unhelpful information events such as being given inconsistent
information, feeling uninformed about a procedure, or not having messages about breastfeeding preferences passed on, impacted upon parent feelings about their lack of involvement in their child’s care. These incidents left parents feeling disassociated from their parental responsibilities and created a negative impression of information sources. In other words, they felt they were left outside the information loop. It is clear from this study that parents’ information seeking is a central aspect of their parenting role.

How does information help parents in the NICU? Given the centrality of information seeking to the parental role, this question takes on a new significance. Parents’ information seeking behaviour seems to hinge upon the cornerstones of sense-making theory. Information’s usefulness is contingent upon the needs of the user, intervening variables play an important role in the information needs of the use, and information is used for problem solving and filling gaps in knowledge in order to make decisions. If one incorporates this with parents’ advocacy role, it is easy to appreciate why information is central to parental stress. From the system (NICU) point of view, it is vital to understand the centrality of information to parents, and the variables that interplay on parents’ use of information. Applying sense-making theory to this study’s findings increases our understanding of this issue. Dervin contended that information is a fluid entity and its use is constrained by external and internal events (Dervin, 1992).

Information helped to ease stress, just as a lack of information appeared to cause stress. This observation has been made often before in the literature, and was exhibited in this study. For example, parents diagnosed prenatally, or in preterm labour, reported feeling relieved that their experience, while extraordinary, was not rare. Fear of the unknown, particularly at this stage, was alleviated by information even if the outcomes associated with that information were not always positive or completely known. Parents in the study found different kinds of information valuable at certain times during their stay. While time (expressed as Length of Stay) was the most obvious variable denoting this, other factors may have been at work. Parental instinct and physiological factors may have as much to do with this as any other variable, which is exhibited in space-time.

Information is used to fill gaps and solve problems, and the problems parents encounter also vary over time. Parents’ initial problem is to learn about their child’s viability and adapting to an unexpected birthing experience. The next problem is contending with the considerable knowledge gap between parents and their child’s caregivers about the medical condition. The key issue here is that in order to be the child’s advocate that is central to their role as parents, they must “learn what they need learn”. In other words, in order to sort out what information is important, they require all of it before they have the ability to know what information is pertinent to them. Once this is achieved, and once parents achieve a certain knowledge and comfort level, the problem then becomes how to get their baby home, or, if there are chronic care issues, to the next level of their care. Goal setting, and how to achieve those goals, can begin at this stage.

The theory of sense-making provides a framework for understanding parents’ information behaviour. The theory can help to isolate the centrality of information to the parental role, and the how parents use information to solve the problems that arise from their baby’s hospitalization. How that behaviour exhibits itself to health care providers and others can be found in the models of ISP.
Overall, this parent group does fit the model of ISP. The emotional involvement parents have in context with the information they seek is no doubt greater than the groups on which this was first tested, but the model does not put a measure on emotional involvement in this way. The significant difference for parents as information seekers in the NICU context is the initial crisis stage. The barriers – physical, emotional and cognitive – are so great that they can make any information seeking extremely difficult.

When information seeking does occur by parents, after the initial crisis, there is an extra urgency to it that seems to reflect a strong emotive response. This period of information gathering, from 7-28 days, is the most critical in the parent’s stay. In order to “learn what they need to learn”, all information becomes important, and it is easy for parents to be overwhelmed. It is during this time that gaps between parents’ information needs and information received becomes evident. The most visible gap of this kind that occurred in this study was the importance of test and procedure information to parents. Parents are taking in information from many sources, human and otherwise, and constantly trying to assess what information is relevant. In the study, offers of information mediation, including the consistency of the primary nurse and anything else that helps parents to learn was viewed as very valuable assistance to them. Returning to the basic theoretical construct, these behaviours helped parents more fully advocate on their child’s behalf. Parents also learned to negotiate “the system” within the NICU as best possible to find information sources they were comfortable with, or how to contend with barriers.

Communication barriers are a much discussed topic in various disciplines, particularly in medical and nursing literature. Communication issues were largely not seen as a problem in this study. While they existed, they were relatively scarce. Other issues where much more important and they pertained largely to personal barriers of the parents as well as role related barriers. Many of the personal barriers, such as knowledge gaps, were addressed by studying sense-making and ISP. It maybe that issues identified by the literature are more information than communication based, and therefore not fully addressed using appropriate research methods or theories.

Parent involvement in decision-making was considered in this research (Coutler et al., 1999; Entwistle, Snowden, & Watt, 1998; Truog, 1999). Of particular interest is that parents in this study were always keenly aware of their lack of expertise regarding caring for their children. For example, they acknowledged that they did not, nor would they ever have, the ability to make decisions about acute care issues. For parents, being a part of the decision-making process did not always mean making the treatment decisions. Rather, parents wanted to be a part of the process. This meant involvement in the discussion, being kept up to date when changes were happening that were necessary, and feeling that they had the right to discuss changes that were not of an emergency nature. Again, these parental feelings are integral to their role as advocates. In order to be their child’s advocate, parents needed information from appropriate sources, in a timely fashion.
7. CONCLUSION

Information is the means by which parents, in the beginning, assume parenting responsibilities. It is the conduit for their advocacy. Previous research has touched on these themes but they have been underdeveloped. A multidisciplinary approach, which includes LIS frameworks, can provide a better understanding of the issues surrounding information and parents in the health care environment, and can find ways to help facilitate the parental role by providing more effective health information delivery.

ENDNOTES


REFERENCES


Lupton, D., & Fenwick, J. (2001). 'They've forgotten that I'm the mum': Constructing and practicing motherhood in special care nurseries. Social Science and Medicine, 53(10), 1011-1021.


Truog, R. D. (1999). ‘Doctor, if this was your child, what would you do?’ *Pediatrics, 103*(1), 153-154.
