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Parental Involvement in Neonatal Pain Management: An Empirical and Conceptual Update

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Abstract

Background: New findings are emerging about parental perceptions and desires for involvement in infant pain management in the neonatal intensive care unit (NICU) setting, and the importance of building greater knowledge about this aspect of the patient care is beginning to be appreciated.
Objectives: The study had two aims: (a) to describe perceptions and feelings of parents who participated in a randomized controlled trial of an intervention to increase parent knowledge and involvement in infant pain management; and (b) to further refine the conceptual representation of the parental experience of involvement in infant pain management (or lack thereof) and the influencing factors.
Methods: Thematic analysis was used to explore the content of parents' written comments and to integrate the present and previous research findings.
Results: Parents expressed strong preferences for more information about all aspects of infant pain care, improved timing of information giving, and involvement opportunities. They further desired increased sensitivity and consistency in infant care giving and increased use of specific pain-relieving interventions by NICU staff. Contextual factors such as parents' emotional state and the communication and support from NICU staff influenced parents' ability to achieve their desired level of involvement.
Discussion: The role of parents in infant pain management is a relatively new area of research. The discussion of conceptual models to guide research and practice is an important milestone representing new opportunity for further scientific developments with important clinical implications for the nursing care of critically ill infants and their families.
Clinical Relevance: New data continue to emerge about parental perceptions and desires for involvement in infant pain management. A new empirically based model may be useful to nurses in providing optimal pain management for NICU infants in partnership with parents.

Over the past 10 years, researchers have begun to describe the views of parents regarding the management of infant pain in the neonatal intensive care unit (NICU) setting and to explore the potential for greater parental involvement in nonpharmacological management of infant pain and distress (Franck, Cox, Allen, & Winter, 2004; Franck, Scurr, & Couture, 2001). Greater understanding of parents' perceptions and their desire for information or instrumental support regarding this complex aspect of neonatal care is needed because research suggests that parents' emotional distress related to infant pain may have long-lasting effects on the parent-infant relationship

(Hohmeister, Demirakca, Zohsel, Flor, & Hermann, 2009; Wereszczak, Miles, & Holditch-Davis, 1997).

Only six studies have used qualitative methods to investigate the views of NICU parents about their role in infant pain management, including assessment, decision making, and treatment. In the first two studies, analysis of interviews ($n = 5$) and focus groups ($n = 6$; Gale, Franck, Kools, & Lynch, 2004) or written comments ($n = 257$) (Franck, Allen, Cox, & Winter, 2005) revealed similar themes for British and American parents of NICU infants (23–43 weeks gestation and 1–72 days of age). Infant pain was distressing for parents because they (a) were unprepared for infant pain and its impact; (b) experienced negative interactions with some staff in relation to their concerns for infant pain management; (c) encountered barriers to enacting their parental role; and (d) felt unable to comfort or protect their infant from pain. Parents experienced relief from this distress when they were (a) provided with information about infant pain; (b) actively involved in parenting and giving comfort to their infant; and (c) receiving support and encouragement to be involved in infant comfort from clinical staff (i.e., nurses and doctors). Parents had well-developed concepts about the causes of infant pain and worried about the short and long-term effects of infant pain for both the infant and for the parent-infant relationship. Parents were dissatisfied with the lack of available information about infant pain, and most wanted to be more involved in providing comfort to their infant. Some parents were concerned about being present during painful procedures because they preferred not to observe the procedure itself or felt that their level of involvement should be determined by clinical staff. Some parents were concerned about the way that clinical staff responded to an infant's signs of pain and distress, and they described how clinical staff could better support them to be more involved in their infant's comfort care.

Three studies examined parent views following participation in interventions to increase parental involvement in infant pain care. Two of the studies were conducted with mothers of preterm infants in Finland (Axelin, Lehtonen, Pelander, & Salantera, 2010; Axelin, Salantera, & Lehtonen, 2006), and the third study included both mothers and fathers of infants in a British NICU (Skene, 2010). In the Finish studies, mothers were taught facilitated tucking by parent (FTP) so they could comfort their preterm infants during painful or stressful procedures. The written comments from 19 of the 20 mothers in the study were positive about FTP. Although some of the mothers felt uncomfortable being involved in the procedure, they believed they had an important role and wanted to help their infant by providing comfort. They described their infants as calmer, in less pain, more secure, and more easily calmed with FTP. Some mothers commented that their participation helped them cope better with their own stress. In-depth interviews with 23 mothers after 2 to 4 weeks of using FTP also revealed positive views about parental involvement in infant comfort (Axelin et al., 2010). However, three distinct styles of involvement were identified: external, random, and internalized. For mothers with an external style, FTP was performed primarily because nurses encouraged it. These mothers had neutral or unclear emotional responses to their infant's pain. Mothers with a random or internal style were self-motivated to perform FTP once shown by nurses. The mothers with a random style experienced emotional distress because of their infant's pain, whereas mothers with an internal style also expressed great empathy for their infant's pain. The styles of involvement appeared to be related to the degree of maternal attachment, with weak maternal attachment found in mothers with the external involvement style, growing attachment in the mothers with the random involvement style, and strong attachment occurring early in pregnancy in the mothers with an internalized involvement style.

Skene (2010) used an ethnographic approach to explore interaction between parents (10 mothers and 8 fathers), their infants ($n = 11$), and nurses when parents were given specific information about infant pain and comfort and encouraged to become actively involved in their baby's pain management. The findings revealed that parental involvement in providing comfort to infants developed in stages, from passive to more active involvement, and appeared to enhance the process of becoming a parent. Nurses were observed to facilitate a parent's movement along the trajectory toward confident parenting through the transfer of responsibilities for comforting infants to them over time.

The authors of the intervention studies described above organized their findings in two conceptually distinct frameworks. Axelin and colleagues (2010) proposed a typology of three different styles of maternal involvement in FTP: external, random, and internalized. Skene (2010) proposed a developmental process of learning to parent, wherein parents took on greater responsibility over time for providing infant comfort. Despite the distinctions, the conceptual organizing frameworks share a number of common features. Both describe levels of parent participation in infant comfort activities and draw an association between greater parental involvement in infant comfort and increased parental confidence and competence. Both frameworks propose the concurrent increase in attachment to the infant with greater involvement in infant comfort and indicate a dynamic role for nursing.

In a recent randomized controlled trial (RCT) of a nurse-led intervention to increase parent knowledge and

involvement in infant pain management in the NICU, confidence with their parenting role after discharge was increased. However, parental stress during the NICU stay was not reduced, although satisfaction with pain information and preference for involvement were both increased (Franck et al., 2011). As new data emerge, it is important to revisit and refine the preliminary organizing frameworks for the research, with particular attention to the perspective of the research participants. The generation of robust conceptual models moves the level of discourse regarding a particular phenomenon from the empirical to the theoretical, which then serves to underpin future research and clinical practices (Smith & Liehr, 2008). Inductive approaches are particularly useful for developing theory in new areas of research. Therefore, the present study had two aims. The first was to describe perceptions and feelings of parents who participated in the recent RCT (Franck et al., 2011). The second aim was to further refine the conceptual representation of the parental experience of involvement in infant pain management (or lack thereof) and the influencing factors, informed by the new data and previous research.

Methods

Participants and Procedures

Four London regional referral NICUs participated in the RCT, ranging in size from 31 to 44 beds. A family-centered philosophy of care was espoused by the NICUs, and each had nurse champions of developmentally supportive care and a high level of participation by staff in in-service education on these and related topics. The study was approved by an authorized committee of the U.K. National Research Ethics Service, and written informed consent was obtained from all parents. Further details regarding the setting and sample are reported elsewhere (Franck et al., 2011).

Parents in the intervention group ($n = 84$) received a booklet containing evidence-based information about pain and comforting infants in the NICU setting. The "Comforting Your Baby in Intensive Care" booklet contained information in lay language on the following 5 topics: (a) how acute pain occurs and how it may affect infants; (b) how infant pain is assessed and managed in the NICU; (c) the important role parents can play in providing infant comfort; (d) specific instructions on comforting techniques for parents to use with their infants (e.g., skin-to-skin holding or non-nutritive sucking during heel puncture); and (e) advice on how parents can work in partnership with NICU staff to achieve optimal infant comfort. Intervention group parents then received two visits (approximately 45 min each) from a research nurse to show them how to apply the comforting techniques described in the booklet. Parents were encouraged to ask nurses caring for their baby if they required further instruction. Parents in the control group ($n = 85$) also received two visits (approximately 45 min each) from a research nurse to listen to what parents had to say about their NICU experience (attention placebo).

Table 1. Topics Explored in Open-Ended Questions Regarding Infant Pain and Pain Management

Parent information needs
Concerns about pain or pain medication
Confidence and satisfaction in clinical staff care of infant pain and support for parents' involvement
Involvement and role in infant pain management—actual and ideal
Other comments about parents' experiences
Suggestions for improving infant pain management

Within 3 to 7 days of admission, parents in both groups completed a baseline questionnaire. Then they received the intervention or control booklets and the first visit was scheduled. After the second visit (approximately 1 week later), parents completed a second questionnaire. Parents completed a mailed questionnaire approximately 3 months after discharge. For the purposes of this analysis, only the written free-text comments in response to open-ended questions on the Parent Attitudes about Neonatal Pain (PAIN) survey (Franck et al., 2005; Franck et al., 2004) completed following the intervention were examined. **Table 1** summarized the topics explored in the open-ended questions.

Data Analysis

Thematic analysis was used to explore the content of parents' written comments to gain greater understanding of their experiences (Boyatzis, 1998; Neuendorf, 2002; Braun & Clarke, 2006). The units of analysis were the message characteristics of parents' written comments. Data were initially analyzed separately for intervention and control groups, with coders (KO, EB) blinded to group assignment. Open coding was first used without regard for relative importance in order to appreciate the breadth of conceptual possibilities across the data. Conceptual categories that were salient across participants within each group were created. Coding and conceptual categories were defined precisely and illustrated with verbatim quotes to ensure trustworthiness. The findings, process, and products of analysis (e.g., open coding, preliminary categorization schema, and final thematic categories) were independently developed and later compared among all the investigators. Threats to the validity and credibility of the findings were minimized through

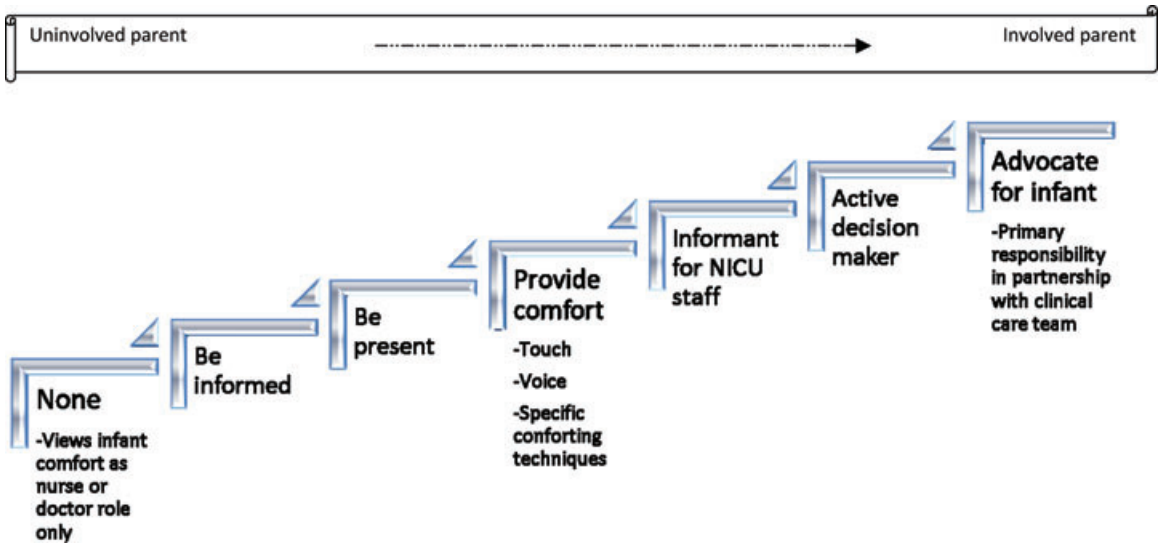

Figure 1. Parental roles in infant pain management.

multiple approaches, including the development of an explicit code, using more than one person to code the raw data, checking reliability between coders, and suspending the analytic framework until coding was completed. The final step was to compare the themes and subthemes between the two groups for commonalities and differences.

A critical qualitative analysis of the present findings in relation to findings from the previous six studies in the field was undertaken by the first author and the integration of the body of qualitative research was represented graphically. Further analysis and comment from the research team and the lead authors of the other studies (Drs. A. Axelin and C. Skene) was sought and used to refine the developing conceptual model.

Results

All parents who participated in the trial (N = 169) contributed one or more written comments for the qualitative analysis. Three major themes were identified and are presented with exemplar quotes below.

The Importance and Desired Level of Parental Involvement in Infant Pain Care

Most parents, regardless of group assignment, saw their involvement in infant pain care as a "vital role" in which they wanted full involvement. Some parents used qualifying phrases such as "as much as possible," whereas others simply wished for more involvement. **Figure 1** shows the range of roles parents wanted to play in infant pain care. One parent eloquently and comprehensively summarized the ideal parental role:

> To be respected as the baby's parent, to be fully informed and given choices and to be aware of what works best for baby in my role of managing baby—be it talking, holding or calming baby and to be supported or told by staff, "Thanks, your help helped your baby." [Control group parent]

Parents expressed some caution and concern about enacting their role. One intervention group parent commented: "I want to be involved as a comforter although I do worry that he might blame me for the pain."

Not all parents identified a role for themselves, with some having the view that it was the role of the nursing and medical staff. After participation in the intervention, more parents in the intervention group wanted "total" or "full" or "100%" involvement and gave examples of how their involvement was important for the infant's comfort and specific techniques they used to provide infant comfort. More parents in the control group mentioned the importance of parental involvement but used phrases such as "don't know" or "just be informed" and gave fewer examples of specific techniques they used to comfort their infant.

Parents in both groups commented similarly on the barriers to involvement in infant pain care. These included emotional difficulties in being present or participating in infant comfort (especially during painful procedures), not wanting to "be in the way," lack of knowledge about how to help, the complications of equipment or health status of the infant, and staff attitudes or behaviors, particularly being told to leave the

Table 2. Barriers to Parental Involvement in Infant Pain Management

Type of barrier	Example quote
Parent emotional state	"[the desire to be present during painful procedures] depended on my emotional state that day and whether I thought I could be strong for my baby" [Intervention group parent]
	"It's easier to leave the room. I'd get too emotional." [Control group parent]
Not wanting to "be in the way"	" . . . Only if helpful and useful . . . " [Intervention group parent]
	"Only if safe, supportive of nurses and doctors . . . " [Control group parent]
	"Only if not interfering, not getting in the way . . . " [Control group parent]
Parental lack of knowledge	"I wish I would have had the skill to help her relieve her pain." [Intervention group parent]
	"I had to ask why my baby had received 'morphine' and other drugs after birth, I have read his drug chart and was pro-active in asking why and what it was for." [Control group parent]
Equipment or health status of the infant	"All I want to do is to be able to comfort my baby when needed. This is not always possible, how can you comfort a baby when you can't hold them due to the fact that they are in an incubator, wired up to different monitors and breathing equipment." [Control group parent]
Staff attitudes and behaviors	"They were dismissive of my fears." [Control group parent]
	"I seem to be a 'spare part' that has been marginalized." [Control group parent]
	"Sometimes [painful procedures] are so routine, doctors and nurses forget they are painful." [Control group parent]
	"When busy, they can sometimes seem unconcerned." [Intervention group parent]
	"Some are just not willing to listen when I'm trying to say that I know my baby better than they do." [Intervention group parent]
	"I wanted to be present when the cannula was being inserted. The doctor asked me to wait outside." [Control group parent]

room during procedures (**Table 2**). Some of the comments indicated an acceptance of the barriers:

> I wish I could have been present every time my baby was having a painful procedure done—however, it was not always possible for me to be at the hospital due to looking after her twin sister, and sometimes I was not allowed to be present. [Control group parent]

More commonly the barriers were a source of distress:

> I wanted to stay when a cannula was being put in my baby's hand but the nurse suggested I leave the room. I left the room feeling upset. [Intervention group parent]

What Parents Want to Know About Infant Pain

Approximately half of the parents provided comments regarding information they would like to receive about infant pain. The control group parents wanted information on how infants felt pain (and if it differed from adults), what caused pain (which medical procedures in particular), how to recognize signs of pain, what pain prevention and treatment options were available (and the pros and cons of each), and what parents could do to comfort their infants. Some control group parents wanted to know why pain relief wasn't always provided and how the medical staff made decisions to discontinue analgesia. A common topic of interest was the long-term effects of infant pain (e.g., would infants be more sensitive to pain or more tolerant to pain, would it affect their infants emotionally or the parent-infant relationship). Parents also wanted more information on how to recognize and treat pain at home after discharge.

A majority of the intervention group parents wanted further information about long-term effects and pain management at home. Several parents commented that they received sufficient information from the intervention booklet, and others commented that they would like further information to supplement what had already been provided regarding recognition of pain and other comfort measures they could implement. Parents had questions about whether infection or mechanical ventilation caused pain and about how to manage infant discomfort associated with blood-taking procedures or gastrointestinal distress.

Parents' Suggestions for Improving Infant Pain Management

Parents in both groups offered suggestions for improving infant pain management, and the main themes were the same for both groups: (a) providing more information for parents; (b) providing more opportunities for parent involvement; (c) improving the timing of information giving and involvement opportunities for parents; (d) increased sensitivity and consistency in infant care giving by NICU staff; and (e) increased use of specific pain-relieving interventions by NICU staff (**Table 3**). However, parents in the intervention group gave more

Table 3. Parent Suggestions for Improving Infant Pain Management

Theme/subthemes	Control group	Intervention group
Provide parents with more information		
About infant pain, pain management, specific comfort techniques for parents, importance of parental involvement, long-term effects of infant pain	"Explain to parents what we can do to help our babies, tell us what signs to look for that the baby is in pain and perhaps offer on admission a group meeting to help new parents understand the management and policies of pain relief in that hospital." "Talk to parents more, have info freely available in unit, in corridor, in booklets, in parents room. Posters of how to comfort baby etc. (picture format) Internet access on unit for parent to look up procedures, diagnosis info, etc."	"Giving the leaflet on pain is a very good idea as makes you aware of what you can do to help your baby." "Important that staff are providing parents with information as to when painful procedures are to take place and what role we as parents are to play. Make the parents feel more involved and needed."
Providing more opportunities for parent involvement		
Parental involvement in decision making Listening to parents	"Give one of the parents the option to attend when doing pain management." "Keep parents informed about all painful procedures, and administer pain relief to baby with parents permission." "More communication with parents about anything going on that may cause pain, give us the option to be involved with this wherever possible." "Most staff are very good at answering questions, but bad at volunteering information about my babies' treatment."	"Listen to parents! A lot of the time nurses treat you as a nuisance, but doctors and surgeons always ask your opinion and take what you say into account. Why is that? We know our own babies best! Use us. ALL we want is to help our children!" "Sometimes, I have been in hospital and my child underwent a blood test but I wasn't told until after it was done, it would have been nice if I could have been there to comfort her/him while it was being done." "Some more discussion with nurses and doctors about pain and how to help the baby get through it."
Improving the timing of information giving and involvement opportunities for parents		
Importance of advance preparation	"Better preparation of parents before procedures so they can better comfort and support their baby."	"It's very difficult there with associated feelings of powerlessness and helplessness with our babies removed from us—if attention was paid to parents at the start we could practice comforting the baby at the beginning." "Parents should be told in advance of how to relieve pain or calm babies when they feel pain (especially when they undergo procedures, e.g., taking blood). Giving advice during or after procedures is sometimes too late."
Increased sensitivity and consistency in infant care giving by NICU staff		
Nurses working more effectively together Nurses working more effectively with parents	"More comforting time by nurses." "Many nurses have techniques that they are not sharing with each other such as how to reduce the pain of removing Tegaderm or how to avoid using tape (the removal of which cause pain/discomfort). Nurses should routinely share these techniques."	"Put protocols into place so that all nurses manage pain in the same way and pay the same amount of regard to it." "Sometimes they don't listen to me, if they have not looked after [baby] before, they don't know he doesn't like certain positions." "The worst thing for the baby is inconsistent care from staff with perhaps different belief systems about comforting a baby and parental involvement. This is upsetting for me as a parent and I believe this distress is sometimes communicated to my baby—I will stay away more some days when I do not feel comfortable with the nurses' approach—probably when my baby needs me most, ironically. These are very difficult days for us all."
Increased use of specific pain-relieving interventions by NICU staff		
	"If the baby's got nappy rash, change the nappy very often." "It would also be nice to see some proactive treatment, of course, of nappy rash—pain treatment may now be valid but would not have been necessary if steps to avoid continued worsening of nappy rash had been taken."	"Use pacifier, use proper rests, take care when trying on ventilator and CPAP not to injure his face or do it too tight. Improve putting in the long line so it doesn't take so long and so many attempts, he ends up with a lot of cuts/marks all over." "Offering sucrose to babies for heel pricks." "Just continue to be sensitive to the individual needs of my baby and create calm surroundings and as well as administer pain relief when necessary."

Note. CPAP = continuous positive airway pressure; NICU, neonatal intensive care unit.

suggestions about what NICU staff could do to improve the timing in relation to giving information and involvement opportunities for families, and they provided more detailed and specific recommendations than did parents in the control group. Ten parents in the intervention group and only one parent in the control group commented on dissatisfaction with aspects of NICU care, including poor hand hygiene, errors made, poor communication, and poor care coordination by medical and nursing staff.

Discussion

Interpretation of Present Findings

This analysis confirms and extends the previous findings regarding parents' preferences and involvement in relation to their role in providing comfort to their infants in the NICU setting. As has been suggested by previous research (Axelin et al., 2010; Franck et al., 2005), parents have a range of views regarding their desired level of involvement, with the majority of parents wanting total involvement or "as much as possible." They also varied in their views on what involvement means. To some parents being involved meant understanding the plan of care, whereas for others it meant being able to touch and soothe their infant during or after painful procedures. Parents also expressed a strong desire for more information regarding all aspects of infant pain care and were able to identify a number of aspects where they believed care could be improved. Contextual factors such as the parents' emotional state and the communication and support received from clinical staff influenced parents' ability to achieve their desired level of involvement.

The analysis of parents' written comments revealed some differences between the intervention and control groups that were not seen in the analysis of the quantitative measures. The differences related primarily to the greater depth, breadth, and action orientation of comments provided by intervention group parents.

A New Conceptual Model of Parent Involvement in Infant Pain Management

The previous organizing frameworks for parent involvement in infant comfort in the NICU setting do not provide an adequate representation of the present or past findings, particularly in relation to the contextual facilitators or barriers to parental involvement. A more comprehensive model is needed to depict the state of knowledge about the phenomenon, which can then be used to guide further research and clinical practice. From our critical examination of the findings of the present and previous qualitative research, and with all due credit to James Reason for adaptation of his Swiss Cheese Model illustration of safety system failures (Reason, 2000), we propose a new dynamic model to describe and explain the actual and potential trajectories for parent involvement in infant pain management (**Figure 2**).

In the new model, each disc represents a set of factors that allow or block the desired level of parental involvement. The number of holes in each disc and their sizes represent the degree of opportunity for parental involvement within that domain of factors. The hard surfaces of the discs represent barriers to parents achieving their desired level of involvement. The arrows represent the potential outcomes for parents. Disc 1 includes factors related to parental beliefs. Factors related to parental beliefs include what parental involvement in infant pain management means to them and how much they value it. These beliefs are related to parents' views about their parental role. For example, how strongly do they feel it is their parental role to protect their infant from harm (and can that role be delegated to others)? Or how important is it that they be the primary providers of care and that they provide comforting care, in particular, to their infants? Another related but distinct concept influencing the value and meaning of parental involvement is the degree of parent-infant attachment. As suggested by Axelin and colleagues (2010), mothers who did not see a strong role for themselves in infant comfort were also less attached to the infant. The stronger the parental beliefs about the importance of their involvement in infant pain management and the strength of their sense of parental role and of attachment, the larger the holes in the disc and thus the greater the opportunities for parental involvement.

The second disc represents factors related to parents' access to information and support. The physical and social milieu of the NICU will determine the degree of parental access to information about infant pain and the potential role of parents. For example, does the clinical team routinely provide verbal and written information to parents about infant pain and the potential role that parents can play in providing comfort to their infants? Do they regularly keep parents informed about when procedures will be performed how parents might be able to participate in their infant's comfort? In addition to information availability and direct communication, parents will be influenced by the degree of support and encouragement that they receive from clinical staff, particularly when parents have decreased emotional or physical availability, or do not as yet have strong attachment or sense of their parental role.

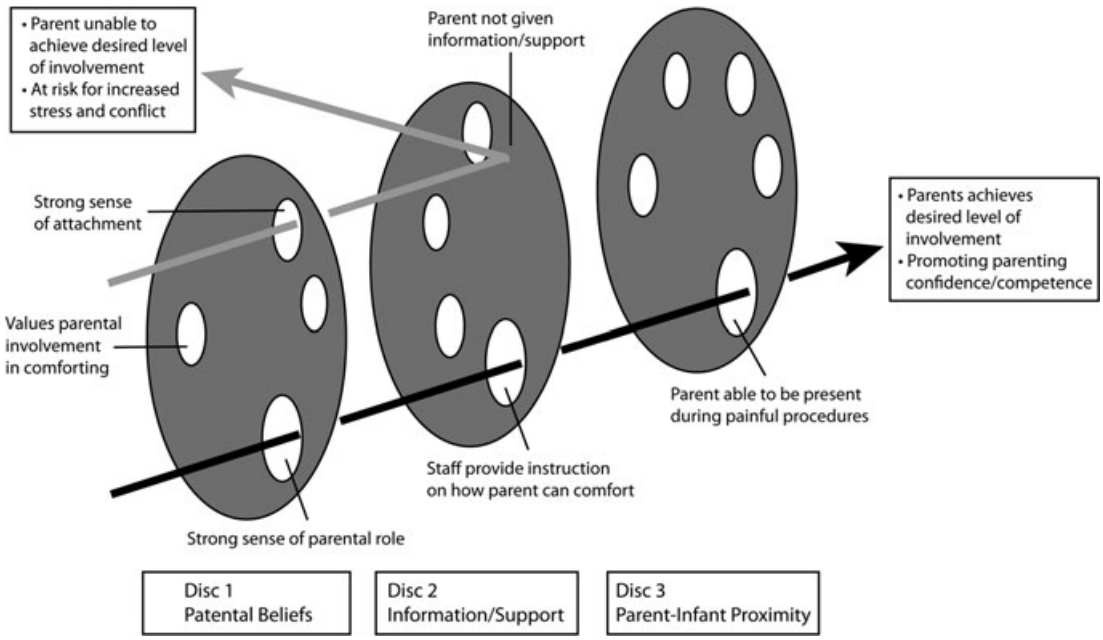

Figure 2. Model of parent involvement in infant pain management with illustrative opportunities, barriers and trajectories. Holes = opportunities for parental involvement; Shaded surfaces = barriers to parental involvement; Arrows = examples of trajectories of parental involvement.

Disc 3 represents factors that facilitate or impede parent-infant proximity and thus the ability of parents to then actualize their intended level of involvement, based on its meaning and value to them. Parents who are unable to visit or who are restricted from visiting will not be able to actualize their desired level of involvement in their infant's pain care. Similarly, parents who are emotionally distressed may not be able to initiate engagement with the infant or clinical team to participate in infant pain management activities, despite the value of this to them. Table 4 shows examples of the opportunities and barriers to parental involvement in infant pain management derived from the current and previous research.

When the holes (representing opportunities for parental involvement) within each disc are lined up, parents are able to achieve their desired level and type of participation in infant pain management. For example, the dark arrow represents a parent who is involved in all aspects of pain management, including being well informed, participating in decision making, and being involved in assessing for pain and providing direct comfort to the infant. This parent desires full involvement, is emotionally and physically able to be near the infant, and receives the necessary information and support from the clinical staff to be fully involved. If the holes are not aligned, then parents will be unable to fully participate, resulting in emotional stress or interpersonal conflict. For example, the light arrow represents parents who desire full involvement but are unable to participate because they are not provided with any information or support from the clinical staff of the NICU and therefore do not know how to participate in their infant's pain management. Clinical staff exclusively provides all aspects of pain management and do not discuss that care with parents. Parents experience emotional distress related to feelings of helplessly watching their infant and not being able to fulfill their desired parental role. The model is not static and each of the discs may rotate, so that the alignment of the holes and thus the penetration of the arrow varies.

This new empirically based model may be useful to guide future research to further understand the interrelationships among the factors and their influence on parental involvement. For example, what factors can be altered to widen opportunities for involvement? Is the order of the discs or the alignment of factors within each disc important to maximize opportunities for optimal involvement? What are the outcomes for infants? Moreover, the model can guide the proposal and testing of interventions to remove barriers and create more opportunities for parental participation in comforting activities. For example, does facilitating parental proximity coupled with increased information allow parents to achieve their desired level of involvement in infant pain management?

Table 4. Examples of the Opportunities and Barriers to Parental Involvement in Infant Pain Management

Disc 1 Parental beliefs	Disc 2 Information/support	Disc 3 Parent-infant proximity	Arrows Potential outcomes
Attachment ● Strong sense of attachment (+) ● Lack or weakly developed sense of attachment (−)	Availability of information ● Parents supplied with information by NICU (+) ○ Multiple formats: verbal, written, visual ○ Explanatory about infant pain ○ Instructional about specific parent-delivered techniques ● Parent only able to access information from external sources (−) ○ Internet, family, friends	Physical proximity ● Parent able to stay at bedside or visits frequently (+) ● Parent unable to be at bedside (−) ○ Distance; other obligations ○ Infant treatments (isolation; ECMO, etc.)	Positive parental involvement trajectories ● Parent achieves desired level of involvement ● Enhanced pre- and post-discharge parental confidence and competence
Parental role ● Protection of infant from harm seen as key component of parental role (+) ● Protection aspect of parental role seen as less important compared with other aspects (e.g., parental love) (−)	Support and encouragement from NICU staff ● Family-centered care climate (+) ○ Parents views as partners in infant pain management ○ Parents provided support and validation for their concerns and desire for participation ● Parents excluded or not encouraged to participate in infant care (−) ○ Dismissive attitude toward parental concerns ○ Parents discouraged from asking questions or participating in comforting activities	Emotional proximity ● Parent has emotional capacity to engage in infant comfort (+) ● High parent stress (−) ● Parent mental health issues (−)	Negative parental involvement trajectories ● Parent desired level of involvement is deflected and not achieved ● Increased parental stress ● Conflict between parents and clinical staff ● Dissatisfaction with NICU infant care
Value of involvement in comforting activities ● Strong belief that parents are the best people to provide infant comfort (+) ● Beliefs that others may be better placed to provide infant comfort (−)			

Note. + = opportunities (holes in Figure 2); − = barriers (shaded surfaces in Figure 2); ECMO = extracorporeal membrane oxygenation; NICU = neonatal intensive care unit.

Conclusions

As new data emerge about parental perceptions and desires for involvement in infant pain management and the importance of the need to understand this aspect of the NICU patient care is appreciated, the new knowledge must be integrated into conceptual models that can then guide further research and clinical practice developments. The utility of the new model of parental involvement in infant pain care will be determined over time as further knowledge is gained in the field. Given the limited research on the topic to date, the findings from the studies and the proposed new model must be considered tentative. Further longitudinal studies and clinical trials are needed to develop a more comprehensive explanatory model. Nevertheless, our understanding of the role of parents in infant pain management has grown dramatically over the past 10 years and the discussion of conceptual models to guide research and practice is an important milestone representing new opportunity for further scientific developments with important clinical

implications for the nursing care of critically ill infants and their families. We encourage our nursing colleagues in research and practice to take an active role in building knowledge and testing the conceptual models to improve the effectiveness of this important area of practice.

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Clinical Resource

- The Child First and Always, http://www.gosh.nhs.uk/research_and_development/centre_nursing_allied_health_research/ http://www.gosh.nhs.uk/research_and_development/centre_nursing_allied_health_research/

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