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Fathers' Experiences in the Neonatal Intensive Care Unit: A Search for Control

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ABSTRACT

OBJECTIVE. This qualitative study aimed at understanding the experiences of fathers of very ill neonates in the NICU.

METHODS. Sixteen fathers of very ill and/or very preterm infants who had been in the NICU for >30 days were interviewed by a male physician. Fathers were asked about their level of comfort with or concerns about staff communication regarding their infant, about accessing information, and about more general perceptions of their experience in the neonatal intensive care unit. Interviews were audiotaped and transcribed for analysis. Coding used content analysis with construction of themes by 3 researchers.

RESULTS. The overarching theme for fathers was a sense of lack of control. Their world view, as a "backdrop" theme, provided context for all of the themes. Four other interrelated subthemes were identified, including information; communication, particularly with the health care team; fathers' various roles; and external activities. Fathers reported that relationships with friends/family/health care team, receiving information consistently, and receiving short written materials on common conditions were ways of giving them support. The fathers said that speaking to a male physician was a positive and useful experience.

CONCLUSIONS. Fathers experience a sense of lack of control when they have an extremely ill infant in the NICU. Specific activities help fathers regain a sense of control and help them fulfill their various roles of protectors, fathers, partners, and breadwinners. Understanding these experiences helps the health care team offer targeted supports for fathers in the NICU.

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BECAUSE OF NEW reproductive technologies, advancing maternal age, and advances in antenatal and postdelivery neonatal care, preterm birth rates and the birth of infants with previously considered lethal abnormalities continue to rise in many industrialized countries, including Canada.¹⁻⁴ Parents are rarely prepared for the shock, stress, and anxiety that occurs when their infant is born extremely early or sick enough to require critical care in a NICU.⁵ Indeed, the birth of a preterm or critically ill infant can alter transitions to parenting and has long-term implications for both parents.⁶⁻⁸ In recent years, qualitative research methods have been used to document in more detail the experiences of mothers of critically ill neonates (for examples see⁹⁻¹¹). Mothers have been interviewed more commonly not only because of their unique perspectives, but also because they are more likely to be in the NICU during the daytime.

Although fathers are acknowledged as being very important participants in the care of their infants, little is known about their experiences in the NICU.^{6,8,12,13} In fact, in the NICU, fathers often have the earliest contact with their infant and with the health care team because the mother is postdelivery or may be very ill or in another hospital. Few studies have reported the ways in which fathers experience having a critically ill newborn.¹⁴ No studies have reported exclusively from the fathers' perspective their ideas regarding support mechanisms that would assist these fathers during their time in the NICU.

The little that we do know indicates that fathers of infants in the NICU face unique challenges.¹⁵ Fathers strive to strike a balance between work and family life.^{15,16} Despite these competing demands, ensuring that each infant's

TABLE 1 Father/Infant Demographics

Fathers' Age, y	Ethnicity	Occupation ²⁹	Structured Religious Involvement	Infant Gestational Age at Birth, wk	Infant Primary Medical Diagnosis	Infant Disposition at Time of Interview
35	East Indian	Laborer	Yes	23	Extreme prematurity, NEC	Home
45	White	Professional	No	39	Chromosomal abnormality	Died
48	White	Professional	Yes	23	Prematurity, chylothorax	Died
34	White	General manager	Yes	25	Extreme prematurity	Home
36	White	Professional	No	25	Extreme prematurity	Home
24	White	Trades worker	Yes	25	Prematurity, multiples	Home
39	White	Laborer	Yes	26	Extreme prematurity, severe airway problems	Home
38	East Indian	Professional	Yes	24	Prematurity, multiples, IVH	Home
41	White	General manager	No	24	Extreme prematurity, NEC	Home
39	Asian	General manager	Yes	29	Hydrops fetalis, congenital anomalies	Died
32	White	Graduate student	Yes	37	Tracheoesophageal fistula/tracheostomy	Home
39	White	Associate professional	Yes	40	PPHN, PIE	Home
36	White	Trades worker	Yes	28	Prematurity	Still in hospital
43	East Indian	General manager	Yes	25	Extreme prematurity	Still in hospital
42	White	General manager	No	36	Thromboembolic abnormalities	Home
21	White	Trades worker	Yes	27	Prematurity, vocal cord paralysis	Still in hospital

NEC indicates necrotizing enterocolitis; IVH, intraventricular hemorrhage; PPHN, persistent pulmonary hypertension of the newborn; PIE, pulmonary interstitial emphysema.

father is engaged actively with the infant (and the health care team) is vital for developmental reasons.¹⁷ In addition, the involvement of fathers is crucial when major decisions have to be made regarding the clinical care of the infant, decisions that may include critical life-and-death situations and situations that may present ethical and religious dilemmas for the father and the family. Thus the decision-making process, which is already complex, is made even more difficult for the father if he has not been able to be involved closely in the care of the infant in the NICU.

Initially, fathers report having more concern for their partner than for their infant, a concern that makes early bonding with their infant more difficult.^{6,18} Furthermore, fathers express a need for information and report that timely provision of information allows them to focus on their infant.⁶ Additional unique stressors exist for fathers whose infants are transported a distance from their home community.^{5,19} Finally, although structured support systems are in place for parents, these systems tend to be based on the health care providers' perceptions of what parents might need, rather than based on parent input. In fact, one study has reported that support systems for mothers tend to increase over time, whereas, for fathers, support systems decrease.¹⁶

To the best of our knowledge, no studies have evaluated the experiences of fathers of critically ill/preterm infants in the NICU using a male physician interviewer. In support of our decision, a recent report found that physician students were more attuned to concerns of patients of their own gender²⁰; in addition, in another study, same-gender communication was rated as "more friendly."²¹ Thus, the purpose of this qualitative study was to learn how fathers of neonates who need protracted intensive care in a NICU describe their experiences and their needs for support during this difficult time.

METHODS

Patients

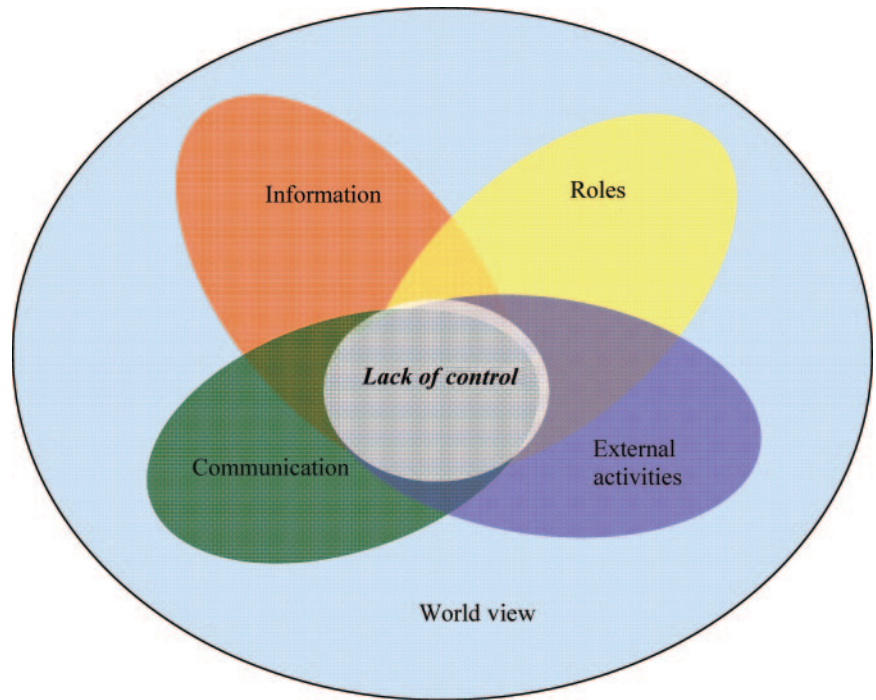
Using purposive sampling, this study included 16 English-speaking fathers whose infants were admitted to and had stayed in the level III NICU in the Women's Hospital in Vancouver, British Columbia, Canada for >30 days. Fathers were enrolled until no new themes were identified by the researchers.²² Written informed consent was obtained from each father according to a protocol approved by the Behavioral Research Ethics Board of the University of British Columbia and the Children's and Women's Hospital Research Review Committee. All fathers who were contacted consented to the study. Table 1 presents the demographic information of the fathers and medical information of the infants whose fathers were interviewed.

Data Collection

Each father was interviewed and audiotaped using a semistructured format with open-ended questions.²³ The interviewer was a male physician who was a fellow in neonatology (Dr Arockiasamy) and who may or may not have been involved directly in the care of these infants. The interview began with questions to obtain information regarding their infant's current condition and the fathers' social and demographic information. Then, fathers were asked to describe their experience in the NICU and were encouraged to speak freely in narrative form. At the end of the narrative part of the interview, specific questions were asked regarding whether issues had not been discussed to ensure that all defined areas had been covered. These areas included questions relating to the following topics:

1. Fathers' expectations of their experiences in the NICU
2. Fathers' level of understanding of their infant's illness

FIGURE 1
Interrelationships between the themes.



3. Fathers' views on the timing, the amount, and the way in which information on their infant had been provided.
4. Fathers' expectations and experiences regarding decision-making in the day-to-day care of their infant, as well as during critical life-and-death situations
5. The ways in which fathers thought that we might improve support systems for fathers in the future
6. Fathers' feelings regarding the interview itself, particularly regarding the benefits or difficulties in speaking with a physician.

Data Analysis

Each interview was transcribed, and each transcription was coded by hand using the constant comparative method of content analysis.²⁴ Using this method, each interview was coded line by line by a research assistant who was trained in qualitative research methods, and themes were constructed. In addition, the 3 investigators reviewed each interview independently to code themes. To identify uniformity of themes and/or expansion of themes, the interview codes were compared in iterative steps thereafter. Then codes were analyzed and discussed until consensus was reached by the 3 investigators and the research assistant. To ensure that our analyses were systematic, audiotapes were used; an independent transcriptionist prepared the transcripts; and for all coding discussions, a detailed documented audit trail that included memos on decisions made was maintained.

RESULTS

From the interviews, a single overarching theme was identified: lack of control. Five interrelated subthemes

were also identified. Figure 1 shows the interrelationships between the overarching theme and subthemes. In addition, the fathers provided information regarding who was supportive and the ways the health care team could support their needs. The fathers in this study identified doctors, nurses, or social workers as the "health care team." Finally, the fathers described their experiences of being interviewed by a physician. Three of the fathers interviewed had infants who died as a result of their illnesses. No unique themes were identified from these fathers compared with the fathers whose infants were alive at the time of the interviews.

Themes Related to Having an Infant in the NICU

Sense of Lack of Control

The universal response of the fathers to having an infant in the NICU was their feeling that the situation was "out of my control." As 1 father stated, "There's nothing you can do." For another father, lack of control seemed to ease his stress during his infant's hospitalization stating: "I felt I had no control over him because of the care he was getting. I knew he was getting the proper care and stuff that I couldn't do for him, so it's like, okay, you guys are in control; you know what you're doing. I felt I didn't have to worry about anything."

Alternatively, 2 fathers found that their feelings of lack of control affected them to such an extent that they had to remove themselves from the situation. A father of an infant who was born extremely preterm stated [referring to his infant's care], "It was out of my control . . . it was like so frustrating for me, so I stopped coming to the hospital for a while." Two others expressed their lack of control in terms of their religion: "We try not to worry about it, if we can't do anything

about it; worrying about it is not going to help, so if it's in God's hands, it's in God's hands; if he doesn't want [the infant], you know, if he wants him back well, that's up to him, that's not really up to us."

The fathers' experience of "lack of control" was central to the following 5, interrelated subthemes.

World View

World view, which included issues such as notions of meaning or personal values, seemed to function as a "backdrop" that guided the fathers through their nursery experience (see Fig 1). For example, "being positive" was a way of taking control in the situation: "There was no moping or lamenting or why us; it was just let's be thankful that she's alive and let's work with it. . . . We made a decision to be positive with her at all times 'cause we didn't want her to feel any negativity from us."

Religious belief was also cited as an important influence on their sense of control. One father stated, "God wouldn't put them here to take them away . . . we are guided very, very strongly by . . . moral issues . . . we must keep this body alive no matter what." This statement provided the direction that helped guide the father in decision-making for his infant's care, increasing his sense of control.

Finally, notions of meaning of their experience were expressed eloquently by 2 fathers. One stated that his preterm infant son had brought a lot of people together: "He's influenced a lot of people, he's just 1 [infant]." Another father whose infant died stated that "it makes me feel, feel like her death wasn't in vain . . . if we can build from these mistakes . . . and learn from them . . . then, you know, infants like [my daughter], then it will not be in vain."

Information

The subtheme of information seemed to be related to how much control the fathers believed that they had over their experience. For example, 3 fathers reported coming into the NICU, seeing their infant, and then immediately "going through the numbers" to find out how their infant was doing that day. This activity was a way of obtaining directly information regarding the status of their infant.

The fathers described the theme information in the following 2 ways: the amount of information that they received about their infant and the information that they delivered to others. The fathers varied in their views on the amount of information that they received regarding their infant, but all said that obtaining information was an important factor that contributed to their experience of control. Two of the mothers worked in health care, and another had a family friend who was a nurse in the NICU. These fathers reported that their access to information was excellent and that they believed that they had "an advantage" because someone in their family had medical knowledge. Information was critical to their belief that they could make appropriate decisions regarding their infant's care, increasing their sense of control. One father of an extremely preterm infant reported not

feeling informed, saying repeatedly that he "didn't know what was happening," which contributed to his feelings of lack of control.

In contrast, another father used information-seeking as a way of engaging positively in the NICU experience process and contributing to the care of his infant: "If you're not willing to go out and grab or reach out for some [information], . . . then maybe you're not getting as much out of the experience as you could, right?" His sense of control seemed to be enhanced by participating actively in information-seeking. Medical uncertainty about their infant's condition was also described in relation to decision-making: "It's very difficult for doctors at times to provide you with . . . information . . . because the medical condition of our daughter is very complex, and it changes all the time." Another father stated, "We had to resign ourselves to the fact that [despite getting adequate information] all of the answers weren't clear," a situation that contributed to feelings of lack of control.

At the other end of the spectrum, 1 father perceived that he had not received adequate information and that receiving information related to how much respect he felt from the health care team: "Inform the father what's going on . . . make them feel they're somebody." Three fathers wanted only limited information. One father said that sometimes he did not want to hear information because "point blank, I'm scared." Yet another found that "there was times where it was too much information." Fathers had varying experiences providing information to others; being the "gatekeeper" provided them with control over the amount of contact that they had with others during this difficult time. One father said that providing his extended family with information was a healthy strategy for maintaining contact with the outside world. Alternatively, another father felt ambivalent about talking with people outside his family: "I wanted to tell people because it was so difficult . . . , but I didn't want to talk about it if it was just small talk." Finally, 2 fathers reported not wanting to talk to anyone.

Communication

The consistency (being able to speak to an identified primary communicator) of communication and the communication skills of the NICU staff had an impact on how much control the fathers felt. For example, if the fathers felt "unequal," then they were less likely actively to seek communication with the staff and thus less likely to have access to information.

Uniformly, the fathers expressed their desire for consistency in receiving information. They wanted to have a specific doctor identified as their primary contact and also a primary nurse or nurses with whom they could talk; however, mixed responses were observed regarding the style or abilities of the various health care team members to communicate effectively. For example, 1 father stated, "I think more nurses need to take courses on how to communicate with parents." In referring to respectful communication, 1 father said that "talking down to people because they feel that they're doctors and . . . they know best; they [think they] don't have to

explain themselves . . . some doctors have that point of view, and other doctors talk to you 1 on 1 like you're the same thing as them and tell you exactly how it is." Finally, the importance of communication was summarized by 1 father: "A good doctor is someone who knows the content; a great doctor is how he interacts with the patient and the patient's families."

Roles

Taking on unexpected roles and redefining their role in their family structure was described by the majority of the fathers. In fact, the fathers identified multiple roles, including being overseers, fathers, husbands, primary wage earners, and protectors. One father described his role as the overseer of his family: "Dads look at different things [from the mother] . . . you look at the wife, you look at the children, you look at the whole picture . . . you're taking care of everything."

When describing the alterations in expectations of being a father, 1 father summarized his redefinition of the father role aptly by saying, "I had spent 9 months thinking about what it was going to be like to be a father . . . and what happened was nothing like what I thought it would be like . . . so I sort of re-created the wheel in a way." This same father also stated, "I couldn't feel like a father because it was about survival . . . this fundamental thing of breathing . . . I felt like a nurse . . . I think she needed that more than she needed a father." Feelings of being a father were altered significantly after 1 father held his daughter for the first time: "It was the first time I felt like I was able to be a father rather than a health practitioner; before that, I felt like just another 1 of those doctors and nurses there, just making sure that she is staying alive."

Helping their wives cope was reported spontaneously by half of the fathers. One father described his own controlled feelings as necessary for supporting his wife optimally: "I try not to crack or let the stress get to me around [my wife] . . . because she's putting up with everything. I'm not here; when I do come, it's like I'm the punching bag, she's also overstressed, all frustration, all of the bad things that might be pent up inside of her and she takes it out on me. . . . I don't say anything about it, I just go with the flow, and if that's how she has to relieve her stress, then so be it, I'm good with it."

The father's role as primary wage earner and "protector of the family" was described by 9 of the fathers as important to their sense of control: "When you have an idea of the role you want to play in providing for your family and providing financially, it makes me feel like you're doing kind of what you should be doing . . . at that moment, me being the breadwinner and shouldering that, I need to be strong . . . I need to show up for my work, you know." In regard to the protective role, 3 fathers described their primary function as being protectors of their infant: "You have to keep track of every medical thing that's happened, or it's like something will get missed."

External Activities

The fathers described a number of other activities that they used during their time in the NICU to help them maintain a sense of control: working, getting away from the NICU, exercising, and attending religious community gatherings were purposeful activities in which they engaged. For 5 fathers, going to work helped shield them from the stress. "I was in denial all the way through it . . . my defenses were working overtime . . . I threw myself into work and concentrated on that." However, for 3 fathers, work added to the stress; 1 father whose infant died stated, "It was very hard to do my work . . . I did more work, felt guilty, trying to block . . . that part of my mind off while I worked . . . I felt a tremendous amount of guilt . . . that I didn't see her enough."

A professional having lost 1 child in a multiple pregnancy was unable to concentrate at work and so had his doctor "deem him unfit" so that he could take time to be with his children. Finally, a father of an infant with congenital anomalies said, "If I could have been there 24 hours, I would have been . . . it was so devastating to leave her [the infant] there, especially if there wasn't someone coming to relieve me."

Being able to get away from the NICU provided relief to 5 of the fathers: "If I wanted to just take off for a few hours and be by myself, which I did many times, [I'd] just drive somewhere and shut the car off." Another father stated, "I saw [met with] the doctor, and I had to go for a walk." Yet another stated that "exercise was my way of dealing with it." For 1 religious father, attending prayer services regularly brought "more tranquility, more calmness . . . just a deeper understanding and basically a release."

Ways of Supporting Fathers

The fathers commented on 2 aspects of their experience that related to supports: their relationships with their partners/family/friends and the health care team and ways in which information about their infant could be delivered. A father whose occupation was selling wood stoves provided perhaps one of the most poignant metaphors of how he and his wife supported each other: "We're like 2 pieces of wood leaning against each other, and that's how you stop falling over." For 5 fathers, being connected to friends provided additional support. One father described it as "really healthy actually . . . because the last thing you want to feel is isolated." However, 3 fathers seemed to rely solely on their wives/partners or themselves for support, 1 father stating that "we just got support from inside ourselves," or, "I got my support from myself."

In reference to the health care team, 1 father stated, "I think the best support that we got was from our primary caregivers." Surprisingly, only a few fathers identified their relationships with other parents with infants in the NICU as being helpful, 1 calling it "our own little underground community," whereas the other 1 qualified it by saying that "when their infant gets sick . . . it's another stress."

When asked what things the fathers thought would provide them with the most support, half of the fathers

commented on their interactions with the staff. These fathers stated that having regularly scheduled meetings with a primary doctor and nurse was important. One father said, "I think doctors or primary nurses should ask the father . . . what they're thinking; they should have an avenue where they can go down and release what they're thinking without any type of intimidation and have a doctor or a nurse that would facilitate that . . . inform the father what's going on, make them feel like that they're somebody." In a similar way but more emphatically, 1 father said that "they [the doctors] should talk with the father . . . most of the fathers [are] giving support to the mother, but nobody [is giving] support to fathers . . . like, fathers are not supposed to cry."

One father expressed his sense that an underlying assumption that the health care team projected was that "fathers are less emotionally involved." His view of support was that the staff should include him equally in the care and nurturing of his infant. Another father stated that "consistency of the message from the health care team" regarding his infant's status provided him with support.

The way in which information was delivered was mentioned by 7 of the fathers. Receiving short written materials describing common medical conditions was suggested by some of the fathers, and 1 father suggested having on-line access to information that they could discuss with their infant's doctor would be helpful. Another father stated that working actively to ensure that when helping services, such as social workers, are offered, fathers are included equally. Importantly, only 1 father suggested that a support group for fathers would be beneficial.

Experience of Speaking with a Physician

All of the fathers stated that talking with the physician had been a positive or useful experience. One father stated that he had never talked with anyone about his whole experience. For another father whose infant died, his interview made him feel that "her death wasn't in vain." The father of a critically ill term infant said that doing the interview was extremely helpful because it is "important what parents think because it's . . . our genetics is lying there so it's hugely important for the parent to believe that the physician values what you think and what you feel." Finally, 1 father stated that "it makes me feel like people care."

DISCUSSION

This qualitative study is one of only a few to examine fathers' experiences with having a critically ill infant in the NICU, particularly after the initial admission period, and is the first to use a male physician to interview the fathers. Studying fathers separately from mothers is important both for elucidating the unique aspects of their experience and for helping us move away from the assumption that mothers' experiences provide us with a "gold standard."^{25,26} On the basis of previous work related to parental views of ethical decision-making, mothers identified the theme "relationships with the

health care staff" as being most important²⁷; however, because the questions posed in this study were different, determining similarities or differences in themes between mothers and fathers given similar interview questions is an important direction for future research.

The data extracted from the interviews revealed complex interactions between themes, with "lack of control" being the universal theme identified by all fathers. Fathers reported that the amount, timing, and method of providing information to the fathers contributed to their feelings of needing to take on additional roles (eg, protector). That is, if the father believed that he did not receive adequate information, then he described a need to monitor his infant's progress more carefully. Indeed, actively seeking out and obtaining information is considered part of "planful problem-solving," an adaptive strategy that has been shown to be used more frequently by fathers than by mothers.^{25,28} Moreover, others have shown that in uncertain situations, stress is reduced by gaining information about the stressor.²⁹

Fathers varied as to whether they shared information about their infant with people external to the immediate family, and their decisions affected their relationships with others both in and outside the NICU. Importantly, no father judged his decision about whether to communicate outside the family as being detrimental to his managing the situation. This finding suggests that health care providers need to be nonprescriptive in allowing fathers to choose the method of information sharing that they believe would be most helpful.

The style and the frequency with which the health care team communicated with the fathers was related to their feelings about the information that they received, their relationships with the NICU staff, and the roles that the fathers altered or adopted. More specifically, fathers who were present more often had more contact with the NICU staff and seemed to feel more positively about their relationships with their infant and to feel supported by the health care team. When work represented the father's primary method of contributing positively to the support of his family, this role strengthened the father's sense of control but affected his availability to obtain information. Despite changing societal norms for what constitutes a "good father,"³⁰ providing financially for one's family seems to remain a central role for most fathers interviewed. An important area to be examined in the future is whether the fathers' views of being a provider conflicts with health care professionals' views about fathers' availability.

In addition, like others, we found that the fathers in this study were concerned for their partners' well-being; the role of "overseer" or "protector" seemed to apply to both the mothers and the infants.⁶ To the best of our knowledge, ours is the first study to report a kind of "hyper-vigilance response" whereby the father monitors carefully actions of the staff. We speculate that this response may be related in part to the increasingly consumer-based health care system in which medical errors are more openly discussed in the media.

As others have found, for a few fathers in this study, physical contact with their preterm infant shifted the fa-

ther's role from that of being one of the health care team to one of being a "father."^{6,8} For fathers who find infant caregiving as a way of gaining control and managing the stresses associated with the NICU, the staff can facilitate fathers' engaging in a parental rather than in a health care professional's role by providing information on how the fathers' interactions can aid in their infants' development.

Specific relationships and strategies to support the fathers were identified. In particular, asking the fathers whether they preferred detailed information or an overview of their infant's status would address individual differences in the amount of information that the fathers might want at any given time. It is interesting that, contrary to the findings of others, only 1 father suggested that a support group with other parents would be important.³¹ Indeed, if the clinical status of the infants worsens in families who form relationships, then a "ripple" effect may be felt, increasing the father's stress. This finding highlights the importance of asking directly how each individual father can be best supported to target resources appropriately. Finally, although possibly representing a bias of fathers who agreed to participate in our study, all stated that speaking to a physician was a positive and validating experience, which suggests that exit interviews would be beneficial.

Several potential limitations of our study should be mentioned. Although it was one of our study's unique features, one of its limitations may have been that our interviewer was a physician. Having one of the most central figures in the care of their infant be interested in hearing about their experience may have allowed us to obtain unique information; however, the perceived differences in power may have influenced the fathers' responses. Fathers may also have responded differently had the interviewer been female; however, the fathers were given the choice to speak to either a male or a female physician interviewer or a female occupational therapist who was not working clinically in the NICU, and none asked to speak to the female. Finally, although a number of strategies were used to ensure reliability and validity of the data, member checking was not completed; therefore, alternative valid explanations of our data may exist.³²

CONCLUSIONS

Fathers reported primarily experiencing a lack of control when they had an extremely ill/preterm infant in the NICU. Specific activities help fathers to regain a sense of control and help them to fulfill their various roles of protectors, fathers, partners, and breadwinners. Understanding these experiences assists members of the NICU team to provide targeted supports to fathers.

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