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Exploring Preterm Mothers' Personal Narratives: Influences and Meanings

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Preterm birth, regardless of the cause, is a birth that occurs too early. As the word suggests, a “preterm” human birth takes place before a pregnancy is deemed full term, that is, at least 37 weeks gestation. Worldwide approximately 15 million infants are born preterm annually, a leading cause of mortality in children under 5 years old.¹ According to 2010 data, preterm birth rates are on the increase globally, even in regions with access to modern obstetric care and technologically advanced neonatal care.^{1,2} Despite a steady decline in the U.S. preterm birth rate from 12.18% in 2009³ to 9.57% in 2014,⁴ preterm birth remains all too common in the United States. Data such as these have prompted various social support and healthcare initiatives designed to prevent and mitigate the consequences of preterm birth.^{5,6}

In every preterm birth, vast human, clinical, and technological resources are required to maintain the life of the uniquely vulnerable preterm infant, to compensate for their physiologic instability and developmental immaturity. The typically unexpected and often urgent nature of a preterm birth only serves to compound the situation. Time to fully prepare for a preterm birth is a luxury many women facing such an experience are not afforded. For both mother and infant, potentially significant life changes enter the realm of possibility, whether the mother is ready for them or not. Therefore, in this environment of uncertainty, the mother experiencing a preterm birth is in her unique way, also vulnerable.

Scientific literature consistently depicts the preterm neonatal period, including the birth, as a trauma or crisis.^{7–13} Extant literature suggests the traumatic nature of a preterm neonatal experience and the associated maternal psychological stress stem from the abrupt nature of the birth event,^{7,11} infant characteristics,^{8,12,14,15} the neonatal intensive care unit (NICU) environment,⁹ the NICU nurses' specialized knowledge in caring for preterm infants,¹⁶ or parental role alteration.^{11,17} These factors often thwart successful maternal role attainment for preterm mothers,¹⁸ thus compounding maternal psychological stress. Contextual features may also influence a preterm mother's experience and appraisal of associated stressors including her childbirth and mothering reality compared to her expectations,^{11,18} her

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perceptions of support given during and after birth,^{11,17,19,20} her cultural orientation,^{21,22} having a history of prior trauma,¹² and socioeconomic factors.²³

Most studies conducted on the experiences of mothers of preterm-born children focus on the first two years of the child's life and highlight specific, identified issues.^{15,16,24–28} Few studies have provided preterm mothers the opportunity to share what they believe to be the most salient aspects of their personal experience and the meaning they attribute to it over time. This is surprising given the widespread depiction of maternal trauma or crisis related to the preterm experience. Therefore, the purpose of this study was to explore the personal narratives of mothers of former preterm infants now at preschool age.

Method

Narrative inquiry was the primary research method used for this study. Each participant's personal story of being the mother of a preschooler born preterm was elicited in order to discover how each participant depicted her own experience and the meaning attributed to it.^{29,30} Eliciting participants' narratives when their preterm-born child was preschool age not only served to address the gap in the literature regarding preterm mothers' experiences but also captured a time of simultaneous change: for the child in terms of developmental-stage and for the mother with regard to her evolving maternal identity.³¹

The sampling frame for this study was composed of 37 adult mothers, known to the second author, who had participated in her previous research (2004–2007) exploring their preterm infants' stress responses to standard care-giving in a level IV NICU at a mid-Atlantic children's hospital in the United States. To be eligible to participate in the previous studies these mothers' infants had to be relatively healthy preterms between 28–34 weeks gestational age, without congenital anomalies or known intra- or peri-ventricular hemorrhage greater than grade II. Infants experienced common morbidities associated with prematurity including hyperbilirubinemia, respiratory distress syndrome, chronic lung disease, neutropenia, apnea, sepsis, intra- or peri-ventricular hemorrhage (developed post-enrollment in the previous study), patent ductus arteriosus, renal failure, gastrointestinal reflux, retinopathy of prematurity, and post-hemorrhage hydrocephalus. Demographic characteristics of the infants whose mothers participated in the current study were as follows: born at a mean $\pm$ (standard error) gestational age of $32.4 \pm (.7)$ weeks, weighed $1857.6 \pm (193.8)$ grams and required hospitalization for $29 \pm (5.4)$ days.

After approval was granted from the associated university's Institutional Review Board, the first author (the primary investigator [PI]) sent a letter introducing the study to the mothers. While the PI had no prior relationship to the mothers, the introduction letter acknowledged the mother and her former preterm baby(-ies) had participated in a study in the NICU with the second author as well as the association between the second author and the PI. Mothers who were interested in participating were asked to complete and return a brief form (in a provided SASE) at the bottom of the letter noting their telephone number(s). Interested mothers were telephoned by the PI to discuss the study and to arrange a time for them to meet, give written consent, and tell their story.

Data collection, which took place in 2009, began with a digital, audio-recorded interview conducted by the PI in a private office at a school of nursing adjacent to the children's hospital campus. Interviews were in-depth, unstructured, and averaged one hour in length. In order to initiate each narrative, a global request for information was posed to each participant regarding her preterm mothering experience: "Tell me about a time that stands out for you, a time you'll never forget, that will help me understand your experience of being the mother of a child who was born preterm and is now preschool age." Probes were used to elicit additional information and enhance clarity as needed. Each audio-recorded interview was transcribed verbatim. Participants also completed a brief questionnaire regarding current obstetric history and demographic data regarding their age, marital and employment status. The PI also maintained field notes and a journal throughout the data collection period. One participant who had moved out of state just prior to the start of data collection communicated her narrative via two email exchanges; the second email exchange provided the PI an opportunity to pose follow-up questions to enhance clarity. Each participant was given a \$25 gas or gift card after they shared their story.

In contrast to other qualitative research methods, narrative inquiry does not seek to reduce data, develop theory, or interpret the shared meaning of those within an identified cultural or social group. The purpose of narrative inquiry is to discover a participant's personal experience and the meaning they attribute to it.³⁰ The primary unit of analysis in narrative inquiry is the cohesive narrative or story offered by a participant.^{29,30}

Using multiple approaches to narrative data analysis can occur with narrative research, an approach which serves to deepen one's understanding of the data.³² Each narrative and its attributed meaning for this study were considered unique, therefore neither data saturation nor the discovery of collective themes or a meta-narrative were methodological goals.³³ The PI analyzed and interpreted the data one narrative at a time to allow for focused, concentrated immersion and incubation.³² With these factors in mind, data analysis began with a naïve reading of a given interview transcript followed by multiple re-readings of the same.³⁴ Simultaneous to this hermeneutic process, data from each interview were analyzed noting characters, relationships among characters, facets of time, shifts in location in relation to actions and events, gaps in a participant's narrative,³³ patterns of thinking, memories, identity and situated contexts.^{29,33}

Data interpretation was guided by the meanings disclosed in the narrative texts³⁴ including an examination of that which was not explicitly expressed or obvious.³² Each participant's story was carefully deconstructed and interpreted without fracturing or dismantling its coherent structure.³² A metaphorical theme that captured the over-arching message in, and meaning attributed to, each narrative was identified.³⁵ Each participant was given the opportunity to review and respond to the written analysis and interpretation of their respective narrative for trustworthiness and credibility; none communicated disapproval or disagreement. This form of member-checks supported the analysis and interpretation of the narratives; the re-telling of the narratives was found to be trustworthy and credible.^{36,37} In addition, the second author (a psychobiologist and neonatal nurse practitioner with expertise in family counseling) and another experienced researcher (an expert on narrative inquiry) also found the analysis and interpretation of the narratives credible.

Results

Thirty-seven mothers were invited to take part in the study. One of the mothers replied to the invitation letter stating she was not interested in participating. During the course of recruitment it was discovered that one of the mothers from the sampling frame had died. Of the remaining 35 eligible mothers, 9 replied positively to the invitation, and 8 of them scheduled interviews. Two of the mothers repeatedly canceled scheduled interviews or did not keep their interview appointments. The remaining 6 mothers consented to participate. At the time of the study the former preterm infants born to these women were children between two and five years old. Five mothers met with the primary investigator for an in-person, audio-recorded interview and one mother who had moved out-of-state provided written narrative data via email. Mothers' ages ranged from 26–38 years, all but one was married, and four of the mothers were employed outside the home.

The personal and contextual elements revealed in the narratives were diverse and significantly informed the participants' preterm mothering experience. Exemplar excerpts from participants' narrative data (italicized) with the accompanying interpretation are noted here. Participants were asked to identify a word or phrase that described their experience of being the mother of a former preterm infant now at preschool age; that word or phrase along with the participant's pseudonym introduce each section. Each section concludes noting the metaphorical theme that encapsulates the results of that narrative's analysis.

Judy: "A Willing Sacrifice"

Judy is the mother of two children; her first child, a son, was born preterm. At the time of her interview, Judy's son was 5 years old; since his delivery she had had a full term daughter who was 2 ½ years old. Judy revealed she felt compelled to be the ideal mother, an effort fueled by a variety of ongoing personal sacrifices. While Judy made it clear she was willing to make needed sacrifices for her children, in particular her preterm-born son, the years of ongoing self-denial and neglect of her own needs, without meaningful support from her husband, had taken a toll. Her narrative was strongly informed by her experience of post-partum depression.

It's wonderful to see that all that work and all of that anxiety and sacrifice, absolute sacrifice, that you make...is benefiting him now and that's a treasure for me. But it was a true sacrifice. I wish my husband would have sacrificed a little bit more of his life than he did. ...my husband really didn't change his life very much [when our son was born] and still hasn't. I would have liked to have heard more affirming things [from my husband], like, you're doing a good job and wow, you're really a good mom or, thank you for all the work you've done with [our son]. Didn't really hear a lot of that. I was the one that stayed home from work, I went on maternity leave, I hated every minute of it. ...I had to do it, I was a mother, I do the right thing all the time, my whole life. I do the right thing. Whether I want to or not.

I'm a different person as a mother now. ... [W]hen I had my 2nd child...I was very ill, I was mentally ill. I had severe post-partum depression which, um, I was not diagnosed with when I had [my son]. ... I was put on medication for post-partum

depression, I did therapy. And what I realized, and what my doctors realized was, most likely you don't...have post-partum depression with the 2nd child and not have it with your 1st child. ... And I do believe that after going through what I went through [with the birth of my son] I was depressed with [my son] and I never got help. ... So by the time [age] 4...came around, our whole entire household was different because I was different as the mother. I was able to see more clearly, to not be as anxious, and to not be just sad all the time and want to have a little bit of fun and not worry about, ok I have to make sure that [my son] is well-fed, well-dressed, bathed, has a story, like everything has to be perfect because I have to make this better, because look what I did. So...I think...that's where that depression was coming from.

Judy made clear that Judy the woman, the person, not Judy the mother or wife, got lost along the way. As her son grew and became more independent of her, she realized she needed personal renewal, to be re-acquainted with herself, to find fresh purpose in life apart from her son. This realization held both fear and the fulfillment of long deferred, long-awaited self-care and growth. Judy's conflicting feelings about self-care was compounded by the prominent place she gave self-denial in good mothering; for Judy, failure to self-deny was failing to be a successful mother.

I just did what I had to do. And I forgot about myself. ...I don't know what I like anymore 'cause I don't remember. ...I struggle still with...when is it my turn? ...if someone could show me how to do that, that would be great, without sacrificing something from either of my kids. ...I feel very guilty saying that out loud and even thinking it, because that might mean that I'm a failure. If I even want to think that, then, am I failing in being the mother?

In analyzing Judy's narrative, the over-arching message that emerged was "I matter too." Judy's narrative revealed her resentment that despite her self-denial, she was not recognized for what she had done for her son or for the extent of her personal sacrifice that had been needed to meet his needs. Judy acknowledged her ongoing self-denial and lack of attention to meeting her own needs was not therapeutic and verbalized a longing for the day when it would be her turn to once again be a priority in her own life.

Jane: "An Adventure"

Jane is the mother of a preterm-born son who was 5 years old at the time of her interview. Jane's narrative began with her prenatal hospitalization at 23 weeks' gestation. Her mothering experience was strongly informed by the many contextual details of her narrative, particularly with regard to her real versus imagined mother-self. Within the first few minutes of her interview and for its duration, Jane quietly shed tears; the following reveals what informed that emotional response.

I'm done having children. And as much as I feel like I'm ok with having one child, um, there's a part of me that still would like to have more. ...I feel kind of broken. I'm...sad that I can't have any more children. ...I sometimes get a little jealous...of women that...flippantly talk about being pregnant. I never thought about how

difficult it was to be pregnant and have children until I had my first miscarriage and then after I had [my son] then they said...you really shouldn't have any more.

I did not produce very much breast milk. ...[a lady]...in the crib room with us... had triplets. ...she had bags that were like, brimming with breast milk. And my husband goes, "You can get that much milk out of a breast?" And I said, "Yes honey, mine don't work." ...I felt like I was being pressured to pump and to produce breast milk. ...when I told...the nurse that I was not going to be pumping any more they kind of made me feel bad about it. ...I understand how important it is...but...it wasn't working for me.

I love it when I go into the doctor's office and the nurses say, "Hi [my son's name], how are you? We're going to do this today." ...Or, "...Mom, how are you? What's going on?" ...asking me questions or telling me what's going on and saying, "Ok, this is what we're going to do" so I know what's happening so I...can make him feel better. ...those are...things that I think are helpful...when they engage the child and talk to the child as well as the mother and...not like you're another millionth person that they saw that day.

Jane noted other examples of how nurses influenced her experience. During her prenatal hospitalization Jane praised a nurse who had arranged for her to get a PICC line, because she hated "*getting stuck*" everyday. The NICU nurses' explanation of the monitors was very helpful to her and her husband "*because you live your life by those (monitors)*." A NICU nurse "*spoiled (the) moment*" by warning Jane's grandmother to stop rocking her son (in one of several rocking chairs in the NICU), suggesting it would give him headaches later in life. Jane noted her grandmother, fearing she had unwittingly done something hurtful, was "*devastated*." Encounters such as these with nurses throughout her mothering experience, both positive and negative, were included in the memories shared in her narrative.

While Jane had begun to revise her perspectives regarding her expectations and hopes of motherhood, exploring various options, there remained a lingering, palpable sense of loss and resignation; the image she held of her imagined mother-self would never be fully realized. Every detail of her experience, what would be her sole opportunity at biological motherhood, was of special import to her; she did not want to miss anything related to her biological mothering experience because she knew it would not come again. As a result, the over-arching message that surfaced in Jane's narrative was "savor the moments."

Ann: "The Best Thing in the World"

Ann has one child, a 2 year old daughter born preterm. At the time of her interview Ann was recovering from a work-related injury, such that she needed help from others to help care for her daughter. Ann's narrative was interwoven with examples of how little she had been supported by family members, including her husband, during her entire preterm mothering experience.

...when I was in the hospital [before delivering he] didn't come see me as much because he works [there]. ...it really hurt me that he didn't come spend some time with me.... ...when [our daughter]...came home...[that] first night I, I was in total

panic. I had to make my husband stay home.... I wish he could just give me a half hour break [once in a while] and...take [our daughter]. ...So how much time does he actually see her? He...gets to see her maybe an hour and half out of the day and then on the weekends.

...before...I hurt myself...whenever I'd asked [my dad and his girlfriend]...to baby-sit, I'd get told, "No," that they always had other stuff to do. ...I try not to get frustrated but...it goes back to when I was a kid. My grandparents...never wanted me. ...And that was a step-grandmother, you know? ...So I guess in the back of my mind maybe that's what I'm feeling [with them]. ...I try not to complain...they're very supportive...they come up every night and put her to bed for me, so, I guess I can't [complain].

In contrast to the attitudes and behavior of her family members, Ann noted affirming support from the nurses and physicians involved in the care she and her daughter received.

I have medical problems...the doctors don't want me to have any more. ...It's disappointing. I, I would have liked to have the second one... I have a genetic disorder...my hematologist said he would have worked with it, and that we could have, you know, tried for another baby. ...But we came to the conclusion...was it worth the risk of losing the mommy[?] ...I asked them about [my preterm labor]... if it was anything I did. They kept telling me it was nothing I did, it was nothing to do with my disorder or anything, it just happens sometimes they said. The doctors...were all great. ...some of the nurses when I was in the hospital [for the delivery], they were the best. They'd do...anything they could for you...they wished they had more patients like me. ...[W]e actually had a, an argument [with the pediatrician] over the, the shots...for her lungs that first winter. Because they were very expensive and we didn't have the money...they finally put it into...a program that would pay for it...I really like her pediatrician, she's really good with her.

The message that surfaced as Ann's narrative unfolded was "affirming my worth." Throughout her narrative Ann recalled events suggesting how significant others, both in her personal life and the healthcare providers she encountered, displayed words and actions reflecting their appraisal of her worth as a person. Her sense of worth was closely tied to her needs and the willingness of others to meet those needs. In order to retain as much affirming support as she could, Ann diminished issues of importance to her, particularly if they represented potential conflicts or problems with others. Instead of freely voicing legitimate complaints or needs, Ann dismissed the true value of her feelings and sought ways to justify the actions of those who did not provide the support she needed. Ann found consistent affirmation of her worth in the support she received from healthcare providers throughout her preterm mothering experience. The quality and quantity of personal, practical, and caring support she received from physicians and nurses was in sharp contrast to the history of unsupportive attitudes and behaviors displayed in her family members.

Kellie: “Blessed”

Kellie is the mother of fraternal preterm-born twins, a boy and a girl, who were 2 ½ years old at the time of this study. Much of the meaning attributed to Kellie’s narrative was related to pre-conception and prenatal challenges to motherhood. Once intra-uterine growth concerns were detected at 26 weeks’ gestation for one of her babies she was put on “*limited bed rest*.” At that point in her pregnancy Kellie realized she had to “*adjust [her] thinking of what [her] birth experience was going to be.*”

...my husband has a chromosomal abnormality. Our only option was...in vitro fertilization. We were able to create 10 embryos, but 8 of them had severe abnormalities. That left us with 2 normal embryos. ...by the absolute grace of God they both attached...I was pregnant with twins. ...The pregnancy progressed wonderfully until around 26 weeks. ...At 34 weeks...[my] baby boy had stopped growing...I needed to deliver as soon as possible.

After her delivery, several problematic issues surfaced for Kellie, most of which were related to her experience in the NICU. Despite the difficulties of the early days and weeks following the birth of her children, Kellie ultimately revised her attitude about the NICU staff and environment, acknowledging the support she had received there. The NICU had been the means for her babies to have good health outcomes.

I had to adhere to the NICU’s hours. ...The other very difficult issue was that their isolettes were in different locations in the NICU. So I had to balance my time going between them and it was very frustrating to me. ...I wanted so desperately to bond with my babies and it was so awkward to hold them and talk and sing to them in front of nurses and doctors and strangers. I hated that the nurses knew more about my babies than I did. They were all so great at the job and so attentive to them, but it was hard for me to hear them tell me how they were doing and little personality characteristics they saw in them. I wanted to be the one taking care of them and sharing them with others instead of the other way around. ...As difficult as it was to have my babies in the NICU, I [realize] because of [them] being in there how truly blessed and lucky I was. There were very sick babies [there]...some of which did not survive...my babies were healthy. The nurses in the NICU did such a great job of educating me on how to handle and hold tiny babies. They showed my how to bath [sic] them, wrap them tightly into blankets, breastfeeding positions, burping strategies, etc. We had such a positive experience with the nurses. They were a tremendous support...

While her daughter was on target for her age, her son was not in several areas. She indicated she was devoted to her son’s success and expressed gratitude for the practical help and support Early Intervention had provided. While Kellie attributed his behavioral challenges to having been born preterm, she expressed hope that as he makes developmental gains, that will improve.

My son...was behind in several areas. I was told from the doctors in the NICU that it is normal to have developmental delays in the first year. But it was still difficult to hear that your son is behind. We began special instruction and physical and occupational therapy. The support and information the therapists gave me was so

helpful. I felt more empowered as a mother to know how to help my child succeed. My son began having more behavioral issues during his 2nd year...[he] is still receiving early intervention services today. He [has] behavioral issues, eating issues and is behind in other areas. I am hopeful that he will catch up and improve and that there is no serious problem or mental condition. It does worry me...I am grateful for...services to help him be the best he can be.

Kellie noted how being the mother of twins born preterm had influenced her; it had been the means for various kinds of personal growth.

Having my twins has changed me as a person. I am more accepting and less judgemental [sic] of other moms and parenting styles. I am so much less selfish... they are my first priority. I feel more satisfied as a person and I feel so lucky to have them. I am more dedicated to be a better person for them. I am trying to be more active in my church and be an example to them. ...[T]he moment I found out I was pregnant with twins and the doctor told me that this was more than luck...I realized that my conception and birth...was a gift from God. ...This experience has made me aware of the reality of a higher power.

The overarching message that emerged from Kellie's narrative is "against all odds." From the outset the chances for a successful pregnancy were not good, even with the use of in vitro fertilization. Yet, Kellie became pregnant not with just one of the two normal embryos, but both of them. Her son's intra-uterine growth restriction posed another threat to the chances of a successful pregnancy. The remainder of her pregnancy would not be routine; fighting the odds meant Kellie was willing to go along with the changed course of her pregnancy, to change her behavior and her expectations.

Against all odds, Kellie began the processes of bonding with her babies and becoming a mother in the NICU environment. Kellie defied the odds of having a positive attitude about the NICU by ultimately revising her perspective about the nurses. Having this new perspective regarding her babies, who against all odds were healthy, Kellie was determined to do all she could to maintain their good health and to give her son every chance to reach normal developmental milestones.

Even though the odds were stacked against her, Kellie became a mother at last. Her experience made her a better person, confirming the reality and role of a higher power at work in her life. As a mother of former preterm infants, beating the odds had unique meaning for her: *"If I had to say what has been most meaningful to me as a mother of preterm babies it would be that I have [the] chance to be the mother of such special children....I am beyond lucky..."*

Patty: "It's Amazing"

Patty is a mother of preterm-born twin girls who were 2 ½ years old at the time of her interview. She is also the mother of a son, who is 1 year older than her daughters. Patty's narrative contained nothing about her prenatal course, labor or delivery. Patty noted, *"[W]hen [the girls] came home...reality set in. [P]eople can't believe like how, how good*

they are doing. ...I guess it's just um, surprising how, how I dealt with it by myself basically. ...[T]aking care of them by myself all day."

While the twins' father provided practical support, Patty spoke of how little support she received otherwise, even from immediate family members. Being faced with the knowledge that she was more or less on her own most of the time, she approached her mothering and care-giving with a determination to do it without that support and to do it well. With the positive reinforcement from Early Intervention staff that she was doing a good job, Patty concluded she was happy to have done it her way. Patty revealed that underneath her calm, docile exterior is a confident woman with strong opinions about what is right, particularly with regard to her children and how to care for them. She had come to know what works (and what does not) in caring for them and she revealed a low level of toleration for different approaches suggested by others, especially those who presumed to know what her experience had been.

I will take input but if it's not something that I think is right, then I would still just do things my way.... I'll listen to what anybody says, but...it comes in one ear and right out the other...especially when people think they know...what I'm going through. ...I have to...make sure things go the right way or the way I think it should be. Because I think I know over, over anybody what's right. That's the way I feel.

Patty made it clear that she avoided thinking about her daughters' preterm status. This avoidance was related to the unhappy memories of seeing them in the NICU and was a means of resisting the assumption (and associated stigma) that children born preterm are impaired. Patty's desire was to see and treat her daughters as those without a history of vulnerability, and she hoped others would do the same.

I try not to think about...the girls being preterm...them being...on machines and stuff. ...[W]hen they were in the NICU...it wasn't...a happy time. ...I just...treat them like, just act like they're...regular kids and I don't want to make it like they're disabled or something, just 'cause they were born early. ...I just see them as...regular kids. And I hope that's how people see them, too, not little tiny babies in the NICU.

Patty acknowledged new-found inner ease and overall purpose, both made clear only after the birth of her daughters.

[S]o much has [changed]...I would say more like settled down. ...I feel like more comfortable with my life...it's so hectic and busy but...I just feel like this is what...my life was meant to be. I get to stay home all day with the kids...that's...how my life is supposed to be. And now I'm more, more calm now and I have more patience...a whole lot has changed.

The over-arching message from within Patty's narrative was "honoring new paradigms." The pattern and direction of Patty's life changed with the homecoming of her daughters. Instead of being overwhelmed and paralyzed by the new responsibilities before her, those very responsibilities revealed what her life was supposed to be. She discovered new meaning for her life and her sense of self; her life now made sense. Such revelation was empowering,

promoting an inner locus of control. With this new paradigm in place, she found the inner will and strength to do what she had to do, despite a paucity of outward support. She crafted her own set of care-giving convictions with the determination to carry them out, undeterred by the advice of others.

Declaring her determination to avoid thinking and talking about the NICU in her narrative revealed a second new paradigm, one regarding Patty's daughters' potential. By distancing herself from the unhappy memories of the neonatal period in the NICU and refusing to carry into the future any foregone prospect of ill-health or impairment for her preterm-born daughters, she created a new paradigm of hope for them. This new paradigm was based on the evidence of their well-being and development. Patty had no legitimate reason not to be optimistic about her daughters' future.

Jennifer: "Protect at All Costs"

Jennifer experienced two preterm deliveries. Her first preterm child, a son, died within hours of birth; a year later she delivered a second son, also preterm, who was 2 ½ years old at the time of her interview. Assertive and articulate, Jennifer referenced the influence of her first pregnancy and preterm birth experience on the second one, including the healing effect it had on a cancerous condition. Although her first pregnancy ended tragically, it contributed to her physical healing and the possibility for a second pregnancy.

[W]e were pretty much guaranteed I was going to go early again, which was fine. ...we were taking every precaution possible that we wouldn't go too early. ...my doctors just wanted me to go with a regular doctor; I said no.... They said you had to lose more than two before you go to see a high-risk doctor. ...I pushed because of just everything that happened. [Our second son] was [in the NICU] for 2 weeks. ...I pushed to get him to come home, too. I was there every day for hours and hours. And I tried, 'cause I was trying to breastfeed.

As Jennifer's narrative unfolded, how much her current mothering experience had been influenced by the loss of her first son became evident, captured in the phrase she chose to describe her experience of being the mother of a former preterm infant now at preschool age. It also became clear that the loss of Jennifer's first son triggered significant personal change. The central place her second son occupied in her life as well as her protective stance, both for him and herself, reflected the degree of change she had experienced.

[L]osing that first one changed me forever...it definitely changed me as a person and I am all about my son. ...[A]nybody comes between me and him? I'll kill for him...he's my whole world. ...[T]hat day changed me forever. ...I think after that it just kind of made me strong to the point where I'm not going to let anything like that hurt me like that again, 'cause it still hurts. ...I can only imagine what it would feel like now if something happened to my [second] son; I'd be devastated. ... [T]hat's probably why I am the way I am with my son now, 'cause...I'm afraid, plain and simple. [That experience]...changed me as a person, it changed the way I think about things, it changed everything. I don't want to shelter him but I don't want to see...anything happen to him. ...I'm afraid of losing him because I've already lost one, I don't want to lose another, especially now that I've had 2 ½

years with him. ...That would be something I...couldn't get over. ...I'm not ready to let go yet. ...And I'm sure it has a lot to do with our...first one.

Jennifer revealed that she had discovered the value in maintaining a positive attitude despite the painful circumstances she had experienced.

...it's very difficult to keep that positive attitude. ...I have times when I fall back... you just kind of have to pull yourself out of that patch...and just move on...you grow so much faster and broader if you do it that way, by thinking positive, and just pulling whatever you can out of any situation and learning from it. Because if you don't, then you're losing out...on life or out on something. And I don't want to lose out; I lost enough.

The over-arching message from Jennifer's narrative was "lessons from loss." Her current mothering experience was intricately connected to and informed by the death of her first child. That loss also initiated significant personal change in Jennifer, the effects of which were ongoing. Jennifer was a fierce advocate for her second son's safety and well-being; how she demonstrated that had the potential to create misunderstanding and tension with others. As her son invariably encounters a growing variety of people and situations in the upcoming years, Jennifer may face misunderstanding and conflict with others who, without knowledge of her loss, will not know how to interpret her over-protective behavior.

Another lesson from loss was Jennifer's need to protect herself from any situation that might pose a real or perceived risk to her well-being. She readily admitted that while she was very afraid for her son, she was equally afraid for herself. Her experience of loss had taught her to push for the kind of health care that would meet her expectations, thus reducing the risk to her well-being. This behavior may also create negative relationships between Jennifer and unwitting health care providers in the future. Although the full extent of the effects of her loss were not yet clear, Jennifer was determined to keep learning from her experiences and to maintain a positive outlook; she had learned that this perspective was the path to growth, restoration, and prevention of further loss.

Discussion

The purpose of this study was to explore the personal narratives of mothers of former preterm infants. Findings from participants' narratives, including the attributed meanings, reveal that a preterm mother's experience can be significantly informed by contextual, intrapersonal and interpersonal dynamics, some pre-dating a given birth and continuing for years beyond it. The attributed meanings of the preterm mothering experience communicated by the participants in this study were influenced by time, self-reflection, knowledge from other life experiences, and the integration of their experience within their own framework for understanding (e.g., their religious/spiritual stance, available social support, degree of resilience, etc.). As with the findings in this study, Aagaard and Hall³⁸ found that mothering a preterm infant is a process which develops over time whereby mothers move to reclaim primary ownership of their baby and develop their own voice as advocate for their infant. This process is strengthened when health care staff is sensitive to

the individual needs of the baby while also projecting a sense of professionalism and concern for the mother and family.³⁸

Some preterm mothers' depiction of their mothering experience may contrast with what is found in extant literature. For instance, not every mother in this study depicted their preterm child's birth and neonatal period as a trauma or crisis as the literature suggests.⁷⁻¹¹ The birth of Kellie's children was not depicted as traumatic; if anything, it was portrayed as miraculous. This is consistent with research findings that reveal variation in how mothers appraise childbirth.³⁹

Perceived sources of stress/distress for the participants were in contrast to findings in the literature that suggest the stress/distress of preterm mothers is related directly to some facet of the child's health and well-being.^{8,40} Judy's distress was related to her history of post-partum depression and the subsequent feelings of guilt and imposed self-deprivation. Jane's distress was related to her imagined versus real mother-self and the brokenness she felt as a result. Ann's prenatal and neonatal distress was related to what was a chronic paucity of reliable support from family members, including her husband. Kellie's distress was related to the challenges of the NICU environment, including the nurses' familiarity and expertise in caring for her preterm twins. Patty's distress was related to the reality of being on her own in caring for her preterm twins once she brought them home. And Jennifer's distress was strongly influenced by her previous neonatal loss.

Strengths of this study include the use of narrative inquiry as the research method. Narrative inquiry aids in the discovery of rich, vivid, and uniquely personal data, including the meaning attributed to a given experience; this discovery is valuable, even with a small sample size as noted in this study. In the evidence-based practice climate so pervasive in health care, findings from narrative inquiry studies are valuable sources of evidence, distinct from those obtained from studies using quantitative or other qualitative research methods. In fact, the process of exploratory depiction of personal experiences like the event of a preterm birth and transition to motherhood are best suited to narrative inquiry.⁴¹ Purposive sampling is another strength of this study. The participants, known to the second author, were mothers of former preterm infants who had been admitted to a single NICU, who had similar gestational ages at birth, diagnoses, morbidity status and lengths of stay. This makes clear that while the infants were similar medically and were cared for in the same NICU with a consistent standard of nursing care, there was wide variance in the experience of mothering during the neonatal period and thereafter.

Given the unique characteristics of the participants' personal narratives in this study, findings may not be transferable to other mothers of former preterm infants. However, the attributed meanings of the narratives and the implications of the study's findings have relevance for a variety of nurses (including NICU nursing staff) and other health care providers. A potential limitation of this study is the lack of multiple interviews with each participant. Additional interviews or email communication may have enhanced participant reflection regarding their personal narrative and unique journey. Nevertheless, what the participants chose to reveal in their stories and the attributed meanings that emerged from each narrative were varied and rich.

While existing research evidence provides insight into some of the factors that inform a woman's experience surrounding a preterm birth, findings from this study reveal that contextual elements have the potential to significantly influence how that experience is perceived and depicted. These findings also reveal that those contextual elements may not be obvious and therefore require the establishment of a relationship and resulting rapport with the preterm mother to learn what they are. Nurses are uniquely positioned to develop such rapport and to help mothers identify their struggles in the transition to motherhood. Given the potential for influence on a woman's mothering experience, contextual elements such as those expressed in the narratives in this study, should be addressed in perinatal assessments for those at risk for preterm birth, during neonatal assessments, and in follow-up health care appointments of all preterm mothers. While mothers often feel concern about expressing their vulnerabilities in motherhood, establishing trust is germane to the psychodynamic process of disclosure and uncovering opportunities for developing healthy relationships. In situations where nurses are too busy to engage mothers regarding serious parenting concerns or situational struggles, a critical opportunity for support may be lost. In this case, nurses should utilize services by clinical psychologists and social workers to offer vital psychological and/or social support or referrals to additional counseling services when appropriate.⁴²

Exploring the personal narratives of mothers whose preterm-born children have serious, ongoing medical issues stemming from their preterm status and those of mothers living in regions with little or no access to NICU support would be of interest. In addition, research designed to enhance relational presence between preterm mothers and nurses is warranted. Studies focused on engaging mothers and their social support network using tailored communication strategies, with a mother's contextual issues in mind, are needed. These strategies can foster trust and a sense of care for the preterm mother's well-being and provide an opportunity for open dialogue on health promotion issues for women and their families. Such strategies can also facilitate the process of becoming a mother for women with a preterm infant^{43,44} and/or identify when situational stress and role conflict are severe and require psychological referral.

Whether in the prenatal, neonatal or other care settings beyond the neonatal period, nurses and other health care providers need to recognize a preterm mother's evolving role identity and that as a preterm mother, she, like the mothers in this study, may be dealing with a variety of contextual issues and challenges.⁴⁵ Maternal role and identity are highly impacted by an infant's preterm birth and hospitalization, and those experiences shape a woman's view of herself as a mother.⁴⁶ Supporting new mothers in their transition to motherhood, through discussion of the contextual issues surrounding the birth experience and their role as mother, provides not only a means to develop rapport but also to identify and help resolve issues of concern regarding family conflict or lack of support.^{42,47}

In addition, some preterm mothers may go through profound change as a result of their experience, to the extent of personal transformation.^{48,49} Transformative Learning Theory offers surprising utility in helping nurses and other health care providers to better understand the immediate and long-term maternal responses to preterm birth. Prominent in adult education, this theory is centered on the life experiences of adults, one's interpretation of

those experiences, and the potential for new or revised meaning derived from them.⁴⁹ According to this theory, transformation is preceded by a disorienting event, often perceived as a life crisis.⁴⁸ A disorienting event for an expectant mother could be circumstances that alter her anticipated trajectory of motherhood such as preterm labor, a preterm birth, or the realities of being a preterm mother during the neonatal period and beyond. The disorienting event identified in Transformative Learning Theory leaves one unable to cope or problem-solve as usual and sets in motion the process of reflecting on and then questioning held beliefs, assumptions, or perspectives; significant personal change (or transformation) results as one's perspectives are revised.⁴⁸ Navigating through such a process could compound the challenges a preterm mother experiences, in turn heightening her vulnerabilities and need for informed, sensitive support from health care providers and those in her social circle willing to consistently engage her in meaningful relationship.

The personal narratives of mothers of former preterm infants now at preschool age are unique and often complex. While extant literature reveals many of the issues preterm mothers face, those findings reveal only in part what may inform the preterm mothering experience and the meaning attributed to it. Understanding the preterm mothering experience requires taking the time to ask and listen to what makes it unique for each woman. By doing so, nurses can discover new insights, including how they can positively shape that experience and enhance the well-being of preterm mothers and families in their care. Further, when nurses identify that role struggles or family conflicts continue without resolution, or if a preterm mother is in the process of a personal transformation, there is opportunity to link those women to family counseling services and/or community networks to provide additional support. These strategies will not only enhance patient-nurse trust, but also will promote healthy family relationships.

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