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## *Perinatal Loss in Low-Income African American Parents*

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**Objective:** To examine the experience of low-income, African American parents surrounding perinatal loss and to describe how other life stressors influenced the parents' responses and caring needs.

**Design:** Descriptive, using a phenomenologic approach.

**Setting:** All data were collected in person. Interviews were held in parents' homes or, at the request of three parents, in an office in the university between 5 and 21 weeks after the loss.

**Participants:** A total of 23 parents (17 mothers and 6 of their partners) were interviewed after a perinatal loss (16 weeks gestation or later) or a neonatal death (first 28 days of life). Follow-up interviews were held with 21 of these parents.

**Results:** Four themes were revealed: (a) recognizing problems and responding to the loss, (b) dealing with stressful life events, (c) creating and cherishing memories of the baby, and (d) living with the loss.

**Conclusions:** The results of this study reveal experiences not previously reported and provide initial insight on the loss experience in this group of parents. Health care professionals should be aware of the presence of additional stressful events that parents may be experiencing and intervene appropriately to provide culturally competent care in a sensitive manner. *JOGNN*, 34, 595-605; 2005. DOI: 10.1177/0884217505280000

**Keywords:** African Americans—Parental grief—Perinatal loss—Phenomenological research

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Numerous studies have been conducted on perinatal loss in an exclusively (Crowther, 1995; deMontigny, Beaudet, & Dumas, 1999; Madden, 1994; Theut et al., 1989) or primarily middle-class White population of parents (DiMarco, Menke, & McNamara, 2001; Swanson, 1999; Thomas & Striegel, 1994-1995). Only a few investigations included parents with a wide range of socioeconomic levels, and the majority of these were White (Lang & Gottlieb, 1993; Mekosh-Rosenbaum & Lasker, 1995; Stinson, Lasker, Lohmann, & Toedter, 1992). However, these investigators did not report differences due to economic variables. The experiences of African American parents during loss were recently examined (Van, 2001; Van & Meleis, 2003), but these studies included only mothers with primarily middle to upper income. Therefore, little attention has been given to the experience of perinatal loss in low-income African Americans.

Studying the responses of African American parents is critical because of the high incidence of perinatal loss among Blacks and the other stressful life situations that African Americans often experience concurrently. Perinatal data for Blacks demonstrate that the incidence of perinatal loss in Blacks is more than twice as high as in Whites (Arias, MacDorman, Strobino, & Guyer, 2003). Furthermore, a recent study of African American and White women in the Detroit area demonstrated that African American women who lived in the city had significantly more acute life events, such as the death of someone close, than did White women (Schulz et al., 2000). In that

study, socioeconomic status made a significant contribution to variations in health status. Also, in clinical observations of mourning in low-income families, one third of whom were Black, Fulmer (1987) reported frequent and intense negative environmental pressures that gave the families more occasion to mourn but depleted their capacity to do so. Because of the lack of research in this area, the purpose of this study was to examine the experience of low-income African American parents surrounding perinatal loss due to stillbirth (fetal death of at least 16 weeks gestation) or neonatal death (death of a live-born neonate younger than 28 days) and to describe how other life stressors influence the parents' responses and caring needs.

### Low-Income, Childbearing African American Women and Stress

In a study of urban, African American, single mothers, Brodsky (1999) described both protective and risk factors. "Making it" was the overall process used by mothers to respond to stress, which was brought on by their neighborhood, relationships with family and friends, and lack of money. An essential characteristic of making it was cultivating a sense of appreciation for even small successes.

Natality and mortality data for Blacks demonstrate that Black women have worse pregnancy outcomes compared to White women (Arias et al., 2003). Poor pregnancy outcome, as defined by a high percentage of low-birth-weight and preterm neonates and high neonatal mortality, has been attributed to a number of factors, including stress and poor prenatal care. Although the percentage of Black women who began prenatal care in their 1st trimester of pregnancy has increased in recent years, racial disparities still exist (88.7% for White women, 75.2% for Black women; Arias et al., 2003). Morgan (1996) asserted that decreased use of prenatal care by African American women was related to care that was not culturally congruent. In this study, professional prenatal care was seen as necessary, but there was a distrust of noncaring professionals and barriers to such care. Culturally congruent care meant protection, presence, and sharing. Social structural factors that greatly influenced health were spirituality, kinship, and economics.

The importance of spirituality and social support has been documented for childbearing and childrearing African American women (Brodsky, 1999; Coffman & Ray, 2002; Wilson & Miles, 2001). Brodsky (1999) described the components and process of resilience among urban, African American, single parents. Spirituality was an important resource for most women. Furthermore, support from friends came largely through church-based friendships. Spirituality has also been

described as a source of support for African Americans who are grieving (Clements et al., 2003) and as a powerful coping strategy for African American mothers of a seriously ill infant (Wilson & Miles, 2001).

### Perinatal Loss and African American Parents

Several early investigators, using structured tools for data collection, found no relationship between race and intensity of grief response (Best, 1981; Lake, Johnson, Murphy, & Knuppel, 1987). However, the conclusions of another investigator (Bradshaw, 1986) raised the possibility that a structured tool may have been an inadequate measure of outcome for the Black participants in the previous studies. In her study of 26 low-income women of various racial backgrounds, Bradshaw (1986) found no differences in the grief response of women who had received an intervention strategy. She recommended further descriptive research with women of low socioeconomic status because of the lack of information on how other stressors could influence their emotional health and affect their perception of the loss. A more recent study of White, African American, and Hispanic American parents (DiMarco et al., 2001) demonstrated ethnic differences in response to perinatal loss. These investigators reported that significantly more Whites attended a support group than other ethnic groups and that White participants had lower detachment scores (defined as being withdrawn and avoiding others) than the ethnic minority participants did.

Experiences of African American mothers after a perinatal loss have been described recently (Van, 2001; Van & Meleis, 2003). In the first study, the healing processes used by 10 African American women after a pregnancy loss were examined. The first strategy was "putting it aside," whereby women avoided thoughts about the loss. The second strategy, "there was a purpose," was an attempt to find meaning in the loss. The third strategy was "heal yourself," actions women used to get better. The final strategy, "he's in a good place," was based on religion and spirituality. The second report examined coping strategies of 20 African American women after a pregnancy loss. These findings were categorized into coping with (a) personal reactions and responses, (b) reactions of others, (c) memories of the baby, and (d) subsequent pregnancies. Personal reactions included "I talked," "I haven't dealt with it," "I prayed," and "going inside myself." Reactions of others, such as coworkers, were often unsupportive, and mothers coped by excusing, praying for, or overlooking these behaviors. Some mothers received mementos of their babies or had planned a funeral service, and these were a source of comfort. Finally, either planning for or experiencing a subsequent pregnancy was a source of fear or anxiety.

The incidence of perinatal loss and other stressful life situations is high among African Americans.

## Method

A phenomenological approach was used in this research. The goal of phenomenology is to describe the meaning of human experience from the individual's perspective (Cohen & Omery, 1994; Giorgi, 1986).

### Participants

For this study, a sample of 23 parents (17 families consisting of 17 mothers and 6 of their partners) was recruited from three hospitals that provide perinatal care to patients at high risk and via an advertisement in a newspaper. The newspaper ad was used to recruit participants from a larger variety of hospitals. However, only 1 mother was recruited by this method. The inclusion criteria were (a) a parent who had recently (within 4 months) experienced a pregnancy loss at 16 weeks gestation or greater or a neonatal death, (b) African American, (c) low-income as defined by the mother being a recipient of Medicaid, and (d) at least 18 years of age. The sample for this proposed study was larger than the typical sample size for a phenomenological study and planned due to potential attrition of participants between the initial and subsequent interviews and the goal to explore the impact of other stressors on the participant's response to the loss.

Eleven parents reported having other living children. Six parents had prior perinatal losses; for 3 parents, the current perinatal loss was their fourth loss, and for 3 parents, the loss was their second loss. Two additional parents had elective abortions because of family pressure. Of the 17 families, 11 experienced pregnancy loss (stillbirths) between 17 and 37 weeks gestation (mean = 26.27), and 6 experienced neonatal deaths weighing between 486 and 3,208 g. These neonatal deaths occurred between 1 and 28 days of age and included one twin. Additional demographic information is provided in Table 1.

### Data Collection

The study was approved by the Institutional Review Boards at the participating institutions. The investigator contacted only those parents who gave their permission through a hospital staff person or who responded to the advertisement. If the parent agreed to participate in the study, an appointment was made for the initial interview. Before the actual interview began, written informed con-

**TABLE 1**  
*Demographic Characteristics of Parents (N = 23)*

<i>Characteristic</i>	<i>n</i>
Age (years)	
Mothers: range = 19–34 ( <i>M</i> = 23.82)	17
Fathers: range = 20–34 ( <i>M</i> = 27.33)	6
Education range = 11–17 years ( <i>M</i> = 13.27)	23
Marital status	
Single, living with partner	13
Single, in a relationship	4
Married	3
Single mother, abandoned by partner	3
Yearly income (dollars)	
<5,000	10
5,000–10,000	8
10,001–15,000	1
20,000 or more	4 <sup>a</sup>
Religion	
Baptist	13
Catholic	2
Other	2
No preference	6

<sup>a</sup>These parents (3 fathers and 1 mother) were kept in the study because the mothers met the sample inclusion criterion of being a recipient of Medicaid.

sents were obtained. The investigator (first author) used her expertise with interviewing bereaved parents to assess for psychological distress. She then used strategies throughout the data collection process to minimize psychological risk to participants (Kavanaugh & Ayres, 1998). For example, the investigator began each data collection session by establishing a relationship with the parent. One very successful strategy was to look at the baby's mementos before starting the interview.

All interviews were tape recorded and conducted separately with each parent, privately and in person by the investigator. With the exception of 3 parents who requested to be interviewed in an office in the university, data collection occurred in parents' homes. During the initial interview, the interviewer elicited the parent's description of the experience using an open-ended format and began with the broad question, "What has it been like for you to lose your baby?" Then, attentive listening, which is critical for intuiting in a phenomenologic study (Swanson-Kauffman & Schonwald, 1988), and probes were used to assist parents to talk freely about their experience. Each interview concluded with the question, "What was it like for you to participate in this interview today?" At the end of the initial interview, each parent completed a sociode-

mographic questionnaire. Initial interviews were conducted with all 23 parents between 5 and 17 weeks after the loss, and follow-up interviews were conducted with 21 parents who could be reached. Therefore, a total of 44 interviews were conducted. The follow-up interview was conducted to add or clarify any information obtained during the initial interview. The follow-up interview was held as soon as the investigator reviewed the initial interview and was able to schedule the follow-up with the participant. The time between the initial and follow-up interview ranged from 2 to 5 weeks.

Each parent received \$25 for participating in each interview, a personalized thank you letter and sympathy card, and either a memory/memento box for displaying their baby pictures and storing mementos or, if they already had a container for mementoes, several perinatal loss books, which they selected from a catalog. Without exception, parents immediately placed their baby's pictures and other mementos in the box. Parents appreciated these incentives but also valued the experience of being able to talk to an attentive listener who was knowledgeable about perinatal loss. Therefore, parents reported that participating in the study was beneficial. Parents identified the following benefits: emotional relief (4 fathers, 7 mothers), a unique opportunity to talk (3 fathers, 12 mothers), an opportunity to help others (2 fathers, 1 mother), a better understanding of their experience (2 fathers), and evidence that someone cared about them (2 fathers). Although some interviews were only 30 to 40 minutes in length, parents explained that they had talked more than they ever did about their loss. One mother whose interview was the shortest at 30 minutes said, "It was really nice because I've been holding a lot of things in. . . . So it was kind of easy to get a lot of stuff off my chest. . . . Because I had just had so much bottled up because there was nobody really to talk to."

### *Data Analysis*

The interviews were transcribed, typed verbatim, and then checked against the original taped interviews for accuracy. The approach for data analysis was adapted from the steps described by Colaizzi (1978). Initially, all transcripts were read to develop an overall understanding of the experience. Then, significant statements were identified, coded, and grouped into broad topical areas. Next, case summaries were created for each parent participant using the coded data and the demographic forms. Codes were then clustered into themes that were common to all participants. This step was accomplished by a process called "free writing," which captures the investigator's intuited experience. Then, the themes were validated with the original interviews. A description of each theme and subtheme was generated; finally, the exhaustive description of the phenomenon was formulated.

A number of measures that address issues of trustworthiness of qualitative data, as described by Lincoln and Guba (1985) and applied to phenomenological research (Beck, 1994), were performed. First, peer debriefing, which is interaction of the investigator with other professionals, was used. Consultants, which included nurse researchers and perinatal nurse specialists with clinical expertise with the population of parents, were used during all phases of data collection and analysis. Second, thick descriptive data were collected, which is the process of providing a detailed description of the participants to allow for transferability of findings. Third, the investigators established an audit trail, which is a mechanism of maintaining extensive notes that reflect the investigators' analytical thought process during the course of the study. Finally, member check was performed by validating the essential structure of the phenomenon (the summative description of the themes) as experienced by all participants with the participants (Colaizzi, 1978). For this study, a limited member check was performed with 1 participant after data were collected from the first 6 families. The intention was to perform a member check with each participant. However, it was not possible to do so because it was difficult to maintain contact with the participants either by telephone or written communication due to the long duration of the recruitment phase of this study (5 years) secondary to uncontrollable delays in recruitment. For the member check, the participant read a several-page summary of a description of the preliminary themes that had been developed from the first 6 cases. This participant responded that the summary "was really good."

### **Results**

Analysis of the data revealed four themes common to all parents. These were: (a) recognizing problems and responding to the loss, (b) dealing with stressful life events, (c) creating and cherishing memories of their baby, and (d) living with the loss.

#### *Recognizing Problems and Responding to the Loss*

Parents experienced intense feelings surrounding their loss and were often unprepared for the baby's death, even in those situations in which the mother had experienced serious problems during her pregnancy. To parents, events unfolded very rapidly. Parents clearly recalled the events that occurred before, especially on the day of, their baby's death. One father said, "I can remember the entire day vividly." Parents who had experienced other perinatal losses were in disbelief that they were experiencing another loss and compared their current experience to previous ones.

*Misreading symptoms of pregnancy complications.* Most mothers who were diagnosed with preterm labor or

prolonged rupture of the membranes were not aware of the symptoms accompanying these conditions and misread their symptoms as something else, such as urinary incontinence (for ruptured membranes) or gas pains (preterm labor pains). One father said,

Not even with the water being broken, I guess for a week prior, you know, we thought the baby was just sitting on her bladder and that she had no control of that, but, you know, that's the kind of stuff that comes with being first-time parents and really not knowing what happens.

Although some of these mothers had prior labor experience, they could not believe that labor could begin as early as it was occurring. Several parents questioned their own mothers about their symptoms and were reassured that they were normal symptoms of pregnancy. Other mothers knew that something was wrong during the pregnancy and verbalized their concerns, such as abdominal pressure, to health care professionals. However, they felt that the health care professional minimized their physical complaints or offered conflicting advice.

*Maintaining hope during medical treatment.* Although parents experienced prenatal complications, they maintained hope for their neonate. Even those parents who were told of their baby's death in utero were hoping that there would be a miracle and they would hear their baby's cries at the time of birth. One mother recalled, "I held her and I kissed her and I was just praying for a miracle. 'Please open your eyes. Please open your eyes.'"

Parents were also hopeful because of their expectations for aggressive treatment for their infants. They were familiar with advances that have been made in perinatal care through their own prior experiences, those of family members, or those publicized in the media. One parent made the comparison to knowing people "who were shot in the head and lived." Only those parents whose neonates lived for more than 1 week and had the opportunity to participate in treatment decisions realized that their neonate might die. One of these mothers said,

They said there was no guarantee that she would live, not unless there was a miracle. I was believing in a miracle because I do believe in God and I had faith. . . . But then there was really nothing else more they could do for her because she wasn't getting better. . . . The next day when I went to see her, she was real blowed [*sic*] up. I couldn't see that was her. So I told them, I guess it's time to take her off the machines because they said that her organs were so damaged, and there was nothing else they could do for her.

*Feeling intense emotions after the death.* Parents used words such as *shocked* to describe how they felt when their babies died. One mother who gave birth to a still-

born baby said, "That was the worst moment in my life, the worst moment in my life." Mothers described themselves as being "very emotional" and even feeling like they were "going crazy." A number of mothers recalled suicidal thoughts because of their desire to be with their baby. They cried very often, had insomnia, and initially did not want to talk about the loss. Mothers appreciated nurses who could just sit and hold their hand, especially if the mother was alone. One mother said,

When she found out I lost the baby, she just held me like I was a baby, rubbed my back and everything. She just was real helpful. I don't know if I would have made it. I will never forget her name. I know their job is to be a nurse, but she didn't have to be that nice. She was really nice. She stayed there until my mother came. She sat in the room until my mother came. I felt much better.

Both mothers and fathers recognized the "special attention" that most nurses gave them regarding their physical, emotional, and spiritual needs, and they found this attention very helpful. One mother shared that she was moved when she found out that one physician came in from home to tell her of her baby's death.

A number of mothers also described themselves as being very irritable and "ready to fight" with others, especially with those health care professionals whom mothers perceived as uncaring. Most mothers were themselves hospitalized at the time of their baby's death, and they wanted to be discharged as soon as possible. Guilt was prevalent in mothers of stillborn babies and those mothers who had been treated for pregnancy complications. One mother recalled how she felt when she heard of her baby's in utero death. She said, "Its like my heart stopped and I kept saying, 'I killed my baby. I killed my baby.'" These mothers questioned whether they should have sought health care in a timelier manner.

Fathers explained that they also hurt and experienced a loss of control. One father said, "It has been the worst thing that has happened that I have had no control over." Fathers often kept their emotions under control for fear of further upsetting the mother but were also unsure how to support their partners. Mothers wanted fathers to express their emotions. One mother said, "I wish he would open up to me just once, just once to show me he can cry, too. This was your baby. Don't be embarrassed. You can cry, too. You feel the pain, too."

### *Dealing With Stressful Life Events*

During the pregnancy and surrounding the time of the loss, parents were dealing with stressful life events that were not all related to the loss, such as economic hardship and deaths of other close family members. Many mothers described an overall feeling of being stressed out during

their pregnancy. Several of these mothers felt that their stress contributed to their poor pregnancy outcome. Only 1 mother was receiving mental health counseling during her pregnancy, and an additional few had expressed a need to seek professional care.

**P**arents were dealing with stressful life events such as economic hardship and deaths of other family members that were unrelated to the loss.

*Feeling abandoned or unsupported.* Some mothers described feelings of abandonment or not being supported by family, which caused them stress. For several mothers, arguing with their family members was so intense that the mothers relocated to other housing.

Several mothers explained that they were deserted by the father of the baby when they became pregnant. Several other mothers felt abandoned by their own parents who had been separated from them because of the parents' substance abuse or incarceration. As a result, their own parents were not there for them during the pregnancy. One of these mothers had the extra responsibility of raising her three younger siblings because of her mother's substance abuse.

*Suffering economic hardship.* Parents described economic factors that caused them stress; for mothers, the stress was especially prevalent during their pregnancy. Many mothers expressed concerns about their housing or living arrangements, either because they were unhappily living in another relative's home or they were concerned about the safety of their neighborhood. Many parents also described the stress of either not having a job or being employed under adverse working conditions, which the mothers felt contributed to their poor pregnancy outcome. For example, one of these mothers explained that she saved enough money to live on her own and in a safer neighborhood, which was especially important for her son and 14-year-old brother whom she was also raising. Then, she discovered that she could barely pay the bills and feed her family, so she secured a job on the night shift at a fast food restaurant. As her pregnancy progressed, she found it more difficult to work, but she described why she had to keep her job:

I was still stressed out. I wasn't getting any rest. It was 8 long laboring hours. When I would go to the clinic, they were like, "You are doing too much. You have to

stop. You aren't giving the baby enough rest." . . . I didn't really say to them what I was really going through, I had to have this job. It was the only way to support the kids and keep eating. . . . The money I was getting from public aid was barely enough just to pay the rent. . . . So it would be 2 or 3 days I went without eating, just drinking water and eating crackers. One of them days, I felt the baby move. I said, "Oh, you still surviving in there?"

*Experiencing others' serious illnesses or untimely deaths.* Many mothers had close relatives who were seriously ill, admitted to the hospital, or both during the mother's pregnancy. Also, parents had already experienced deaths of other close family members or friends. These included untimely deaths of their other infants, nieces and nephews, siblings, parents, grandparents, young male cousins, or friends. One father, who was a substitute high school teacher, experienced the deaths of three of his students in 1 year. Even if the death had not been recent, the current loss triggered painful memories of the other deaths.

Despite their young age, nearly half of the parents had already lost their own parent or parent substitute, such as a grandparent, who had raised them. These relatives had experienced an untimely death that occurred while the person was in his or her 30s, 40s, or 50s. For several, these deaths occurred during the mother's pregnancy. A woman whose own mother and grandmother died during her pregnancy said, "I can't take this anymore, another death. I don't know how I would take it." A number of parents were survivors of homicidal or suicidal deaths of young male relatives or close friends, which 1 parent described as "devastating." One father explained that his closest friend was murdered 2 weeks after his baby was buried. This father could barely talk during the interview when he recalled "my best friend, my very first friend was killed."

*Receiving unfair treatment.* Parents perceived that they received unfair treatment mostly related to medical treatment. However, 1 mother also reported unfair treatment by a funeral director who buried her son sooner than she was told initially and without her presence. According to the mother, the funeral director said that he did not know she wanted to be present for the burial. She said,

I was mad with them because they buried my son without me being there. . . . How did he not know that I wanted to go. . . . My heart just dropped. . . . Like I didn't even get a chance to say goodbye to him.

Many parents perceived that the mother or the baby received inadequate care. Many attributed this unfair treatment to their insurance status (medical assistance) and therefore perceived a disparity in treatment. One

mother whose baby died after being in the neonatal intensive-care unit said,

I feel they didn't do the best that they could. I think it was because of financial. I was on public aid and so much that certain doctors will only do so much for people on a medical card. . . . But if I had a better insurance, they would have put their heart and soul into it and I feel they didn't.

One father said, "I know she (his wife) was not in a private room and was not a VIP patient, but, to me she was a VIP patient." This father also perceived unfair treatment regarding paternity establishment. He shared that his name did not appear on his son's birth certificate even though he provided the requested documentation demonstrating that he was married to the mother of his son.

Parents recalled the frustration of seeing many different medical providers at their prenatal visits and thus felt they did not have the continuity of care they would have had with a "personal doctor." Some parents were also very stressed by overhearing health care professionals make negative comments about the mother or argue with each other about the plan of care. One mother who overheard a conversation said, "I could hear the doctor in another room telling him, 'You should have caught this. Why wasn't she given a cerclage right away?' I could hear him fussing down the hall." Another mother was very angry at how she was treated during an evaluation for her pregnancy complications. Because she was worried about child care arrangements for her young daughter at home, she questioned whether being admitted to the hospital was necessary. She said, "'Well, do I have to stay?' The doctor said, 'Well, I don't have a gun to your head.' So I was like, 'You don't have to have a gun to my head to make me stay.'"

Parents expected that health care providers would listen to their concerns and that technology would be applied in their situations. All parents whose infants were born live at the threshold of viability felt that their babies did not receive adequate resuscitative attempts right after birth. One mother said,

When he was born alive, you should have done something. . . . I felt that my son had a chance and they did not give him a chance. . . . When they took him out, they should have rushed him away and said they would see what they could do.

These parents were dismayed and angry when the care they received was not consistent with the care they expected, especially if they were in a hospital that specialized in high-risk perinatal care and the mothers felt they had done everything prescribed during the pregnancy. Several of these parents even made initial inquiries about a medical malpractice lawsuit.

### *Creating and Cherishing Memories of Their Baby*

Parents created memories of their babies by being physically close, noticing family resemblances, and obtaining keepsakes of the baby. Parents cherished these memories. Parents also decided on burial, which typically included a memorial or prayer service and provided another memory for the parents.

*Being with their baby.* Except for 1 father of a neonate born with gastroschisis, all parents saw their babies. Whereas most mothers readily embraced their babies, most fathers were very reluctant to hold their baby but did so with encouragement from nurses or family members. Only 2 mothers had no physical contact with their baby; 1 of these mothers explained that she was too heavily medicated at the time. With the exception of 1 mother, mothers of the live-born infants held them at the time of death. Typically, this time was the only time they had an opportunity to hold their babies. During the interviews, these mothers very tearfully recalled this time and often needed a break from the interview to regain composure and continue. One mother recalled,

And I held him until about 4 hours. I said I loved him. I don't want him to go, but God knows best. Maybe I'm struggling so much that it would be just another burden and He knows best. Well I was just holding him and crying. I said, somewhere you get a chance to see your grandma. I tell him when you get there when you get old enough you think about me.

Parents cherished the time they spent with their babies and were often allowed to keep their baby with them in the mother's room for many hours. Family members were often present and also took turns holding the baby. One mother described the scene as a "room full of love." Most mothers were very averse to having the nurse take the baby away before they were ready, and some even described intense verbal arguments that occurred between them and family members or nurses who were persistent.

*Noticing family resemblances.* Many parents identified family resemblances between their baby and themselves. Family resemblances were of physical or behavioral characteristics. Even the mother of the baby who was born at 17 weeks gestation thought that her son resembled his father. Although parents happily described these resemblances during the interview, they explained that noticing these resemblances initially often made them cry.

*Gathering keepsakes of and remembering their baby.* Parents received many different types of keepsakes from the nurses, including pictures, identification bracelets, blankets, certificates of life, ointment, gowns, and caps. Parents especially treasured any items that had been worn by or come in contact with their baby. Parents reported

that they were grateful for the pictures and especially appreciated nurses who took extra time for carefully arranged photographs. Parents wanted more pictures, especially pictures of their baby after being cleaned up. Parents of live-born neonates wanted pictures of their baby before the baby's death and without any equipment on the baby, particularly on the face. All babies were named, and 1 mother chose to remember her baby by having her baby's name tattooed on her body.

*Deciding on burial.* Parents had to decide on a private or a "hospital" burial for their baby and found it very helpful to receive accurate information about these options from health care professionals. A hospital burial was actually carried out by the county and involved burying the baby in a common burial site, which would be unmarked to the parent. Ten families selected hospital burial, although some of them were advised by family members to arrange for a private burial, and 7 families selected a private burial. Parents explained that they based their decision on what they felt was best for them and their baby. Some parents were concerned about the emotional distress of a private burial, yet others were distressed when they realized what was involved with a hospital burial. One mother was comforted to hear that her baby would be buried with others with a hospital burial, yet another mother thought her baby was "too special" to be buried with others. A few parents were not aware that they could receive financial assistance for a private burial, so economics was a factor in their decision. Even those parents who decided on a hospital burial often selected the burial clothes for their baby and participated in a memorial prayer service that, they very gratefully described, was conducted by the hospital chaplain. Parents found that prayer and reading from scripture were very comforting at the time of the memorial service.

## Living With the Loss

In the weeks and early months after the baby's death, parents had to find ways to live with their loss. Parents encountered difficult situations, relied on their spirituality, sought diversions and support, tried to make sense of the loss, and thought about a subsequent pregnancy.

*Encountering difficult situations.* Most mothers found it very difficult to be in situations that reminded them of "what could have been." Examples of these situations were being around pregnant women or infants, attending baby showers, and celebrating holidays that recognize mothers and involve dressing up children, such as Mother's Day, Christmas, and Easter. For these holidays, mothers explained that they either stayed at home or went out with their partner only late in the evening. Although fathers did not describe any problems with these situa-

tions, 1 father found it difficult to complete job applications that requested information on number of children.

*Relying on their spirituality.* Many parents relied on their spirituality to deal with their loss. For some parents, this was in the form of praying; for others, it was going to church. Parents described "turning their lives over to the Lord." One mother said, "If I hadn't started back praying and had the faith and keeping the faith, I don't think I would have been able to do it." Some mothers were comforted to think that their baby was in heaven surrounded by angels. For these parents, it was very helpful to receive religious books after the loss.

*Seeking diversions and support.* Parents searched for activities to keep busy and divert themselves from dwelling on the loss and also sought social support. Fathers, more so than mothers, found it helpful to keep busy, to "move forward," and to think positively about the future. Mothers with other children explained that having other children to care for helped them. Parents sought support from family and friends and described a number of ways that family and friends supported them. The most common support they received was emotional support, and the various types of support that parents received are described in detail elsewhere (Kavanaugh, Trier, & Korzec, 2004). Although parents were aware of support groups in their area and expressed an interest in attending, none had actually participated. Some parents would consider attending if their partner attended also, and others felt it might be something they would need more of in the future.

*Making sense of the loss.* Parents tried to make sense of their loss and determine why it occurred. Parents who consented for an autopsy were waiting for the final results; a number of them were very frustrated with the delay in receiving the results. Parents also questioned the death from a philosophical or spiritual perspective and explained it within a religious context. Many mothers could not understand why the loss occurred, especially because they believed they had done everything to ensure a healthy pregnancy and had known others who abused drugs and had healthy babies.

*Contemplating future pregnancies.* Parents talked about their plans for a future pregnancy, and several mothers shared that they were possibly pregnant at the time of the second interview. Most parents planned on a future pregnancy, yet those with more than one perinatal loss were very reluctant to plan for another pregnancy. One father explained how a healthy subsequent pregnancy would be part of the healing. He said, "And once it is all right, that will even take away some of the sorrow and pain from the previous times." However, some mothers did not plan on a subsequent pregnancy because of their

concern about their ability to deal with another perinatal loss. Those parents who planned on a subsequent pregnancy described the measures they would take to ensure a healthy outcome. These included delaying a pregnancy until there was less stress in their lives and planning on having one consistent primary care provider.

## Discussion

Several themes and subthemes described in this study are consistent with findings in perinatal loss research. For example, the subtheme that parents experienced intense emotions after the death and the reported gender differences is well supported in other research (Kavanaugh, 1997a; Lin & Lasker, 1996). The gender differences in this research included the tendency for the father to guard his emotions because of his concern for his partner, his inability to talk about his feelings, and his need to move on with his life. Also, the behaviors that parents found helpful, such as physical presence, are similar to the caring behaviors reported in other perinatal loss research (Lemmer, 1991; Sexton & Stephen, 1991) and described in a middle range theory of caring (Swanson, 1991, 1993). However, the subtheme that parents misread symptoms of pregnancy complications has not been well described in the loss research. It is unclear if this finding is unique to this group of parents or, more probably, that this phenomenon has not been examined in other perinatal loss research. The theme of dealing with other stressful life events has also not been reported in the perinatal loss literature. However, it is possible that this finding is related to the parents' race, economic status, or both because of the results of prior research on the prevalence of stress in African Americans (Brodsky, 1999; Schultz et al., 2000).

Parents in this study often were dealing with other stressful events, such as untimely deaths of others close to them and everyday stress, such as that described by Brodsky (1999). These findings are supported in a study of stress and health status among African American and White women (Schulz et al., 2000). In that study, African American women reported more frequent acute life events and unfair treatment than did White women. Mothers in the research reported here also felt that their stress was the cause of their adverse pregnancy outcome. This finding is noteworthy because of the link between perceived stress and preterm birth (Mackey, Williams, & Tiller, 2000; Stancil, Hertz-Picciotto, Schramm, & Watt-Morse, 2000). Also, of particular importance in this study is that nearly 40% of the parents had experienced prior perinatal losses.

Some of these stressful events were clearly related to parents' economic status, such as inadequate housing.

Parents also perceived that some stressors, such as perception of unfair medical treatment, were due to their economic status, but it is not clear if other findings are related to race, economic status, or both. The reports of treatment disparity are parents' perceptions after a very adverse event; no attempt was made to compare their perceptions with the type of treatment that was provided by health care professionals. It is possible that parents did receive unfair treatment, especially because of the prevalence of racial and ethnic treatment disparity in health care (Smedley, Stith, & Nelson, 2003). However, it is also possible that parents had a different understanding of the events than the health care professionals.

The importance of spirituality in the lives of bereaved parents has been established in prior research (Calhoun, 1994; Sexton & Stephen, 1991) and is also supported in this research. Parents relied on their spirituality to cope with and to make sense of their loss. These findings are also similar to other research on African American parents who experienced a perinatal loss (Van, 2001; Van & Meleis, 2003). For parents, their spirituality sustained them through this very difficult time.

## Recommendations for Practice and Research

These findings demonstrate the importance of recognizing the incidence of other life stressors that parents may be experiencing that could affect pregnancy outcome or their response after a loss. Nurses and other health care professionals should assess the presence of stressors in a parent's life, recognize the ways that parents cope, assist

**N**urses should assess the presence of stressors, recognize the ways that parents cope, assist them to mobilize coping strategies, and make appropriate referrals.

them to mobilize coping strategies, and make appropriate referrals as needed.

Specifically, this study illustrates the need for nurses to assess vulnerable pregnant women and their partners for increased instances of life stressors such as the death of a close family member or undesirable employment conditions. The presence of multiple life stressors may have contributed to pregnant women's reported difficulty in identifying or responding to symptoms of pregnancy complications in this study. Nurses should implement addi-

tional measures of empathy, communication, education, and, when appropriate, social support referrals to optimize the health of these women.

This study also explicates the importance of nursing actions and interventions when parents experience a perinatal loss. Foremost, nurses can increase parents' coping abilities during times of perinatal loss by providing a supportive environment for parents. Examples of specific nursing actions include displaying empathy and providing parents with pictures and mementos of their deceased baby. These findings coincide with other research examining perinatal loss (Kavanaugh, 1997b; Lundqvist, Nilstun, & Dykes, 2002). This study also accentuates the need for nurses and other health care professionals to articulate clear and explicit information regarding hospital-based policies, such as autopsy and burial practices, to both mothers and fathers. Significant to this study was the finding that fathers were reluctant to hold their baby without additional encouragement from nursing personnel. This finding underscores the special attention that fathers may need.

It is also noteworthy that in this research, no parents attended parent support groups. This finding suggests that traditional mechanisms for providing follow-up care for parents after a perinatal loss, such as making a referral to a hospital-based parent support group, may not be appropriate for these parents. The results of the research reported here do support the need to find out parents' understanding of events and desire for involvement in treatment plans.

This study provides initial insight to the experiences of low-income African American parents and is not designed to be generalized to a larger population. Further research should be conducted with a larger sample of low-income African American parents. Also, the methodological approach for this study does not allow for inferences to be drawn regarding the influence of race, economic status, or both on the study findings. A larger correlational study could be designed to study those variables. Further research is also needed to compare parent and health care professional perceptions of treatment decisions, including parent desire for involvement in treatment decisions.

## Conclusion

Limited research has been done on the experience of perinatal loss in low-income African American parents. The results of this study provide a beginning understanding of the loss experience in this group of parents and demonstrate some experiences that have not previously been reported in the perinatal loss research literature. Nurses and other health care professionals should be aware of the presence of additional stressful events that parents may be experiencing and intervene appropriately.

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