CE 1.5 ANCC Contact Hours

Support for YOUNG BLACK URBAN WOMEN *After Perinatal Loss*

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Abstract

Purpose: To describe the bereavement support needs of black urban women in late adolescence after perinatal loss.

Study Design and Methods: Eight black women aged 18 to 21 years who had experienced recent perinatal loss were interviewed in person or by telephone at three points in the 12 weeks that followed their loss to describe their perinatal bereavement experience and support needs. Data from the interviews were analyzed using constant comparative analysis.

Results: Black adolescent women need culturally appropriate bereavement support targeted at key transition points along the bereavement trajectory. They need accurate information, compassionate and respectful communication, and support from their mothers, grandmothers, and other women from their community of faith who have experienced perinatal loss. They value mementos, such as photographs and footprints.

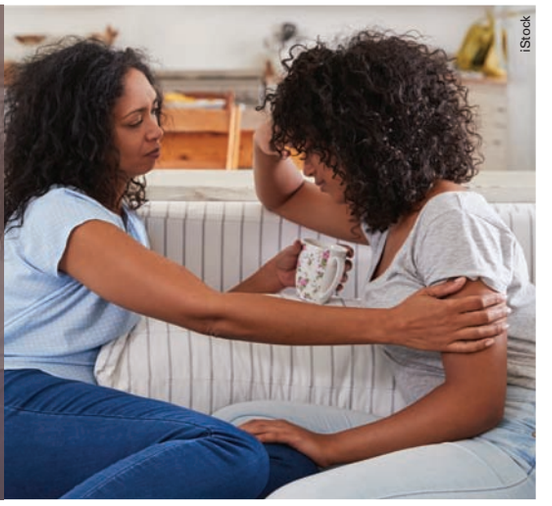
Clinical Implications: Nurses are well-positioned to be consistent caregivers and to provide clear, compassionate communication and anticipatory guidance to young black women experiencing perinatal loss. Attending to spiritual needs, harnessing family support, providing mementos, and encouraging reflection through journaling may help adolescent women find meaning and new perspectives on their bereavement experience.

Key words: African American; Bereavement; Perinatal death; Perinatal nursing; Pregnancy in adolescence (defined by MeSH as under the age of 19 years).

Perinatal loss is a profound and often life-altering event for women and their families. Perinatal loss includes stillbirth, miscarriage, or infant death within 28 days of birth (Barfield, 2016). In spite of the overall slow decline in perinatal mortality rates in the United States, disparity exists across categories of race, ethnicity, and age, with young women and non-Hispanic black women experiencing the highest rates of perinatal loss (MacDorman & Gregory, 2015). The perinatal mortality rate in non-Hispanic black women remains more than twice the rate for non-Hispanic white women, with women under the age of 20 experiencing higher rates of fetal mortality than other women of childbearing age (Gregory, Drake, & Martin, 2018).

Although black non-Hispanic adolescents experience a high rate of perinatal loss by virtue of both race and age, few studies have been conducted to explore their perinatal bereavement experience. Response to perinatal loss is variable and influenced by cultural norms, past experience with loss (Fenstermacher & Hupcey, 2013; LeDuff, Bradshaw, & Blake, 2017), and the meaning that is ascribed to the pregnancy (Fenstermacher, 2014). Evidence about the bereavement experience and support needs of adolescent black women and how their needs might differ from needs of other women who experience perinatal loss is lacking. Addressing this gap in knowledge is important to nurses who care for young black women as they traverse the bereavement experience that follows perinatal loss.

Black adolescents who experience perinatal loss need clear information and compassion during their loss event.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Here we describe the perinatal bereavement experience and support needs of black urban women in late adolescence as identified through a grounded theory study that explored the perinatal bereavement experience in this population. The study, with theoretical results previously published, produced a substantive theory of "enduring to gain new perspective" that explicates the phases of the bereavement experience in the first 12 weeks after perinatal loss (Fenstermacher, 2014). We present additional findings from a secondary analysis of the narrative data specifically on the bereavement experience and support needs and offer suggested clinical implications for nurses to facilitate strategically timed bereavement support at critical transition points during the first 12 weeks following perinatal loss.

Study Design and Methods

After institutional review board approval, non-Hispanic black urban women ranging in age from 18 to 21 years (late adolescence) with a recent perinatal loss were recruited with the help of perinatal bereavement coordinators at three inner-city hospitals in Pennsylvania. Participants were interviewed shortly after perinatal loss and at two additional points within the first 12 weeks after their loss to elicit a description of the bereavement experience and support needs in the immediate perinatal loss period. Trustworthiness was assured through an audit trail of field notes and memos as well as peer debriefing. Constant comparative analysis as per with grounded theory methods (Corbin & Strauss, 2008) was used to analyze the data to produce the substantive theory (Fenstermacher, 2014). Data saturation of the theoretical categories for the theory derivation was reached after eight participants were interviewed. Findings presented here are the result of revisiting the data to answer the question; "What are the bereavement experiences and support needs of young black women after perinatal loss?"

Sample

Inclusion criteria stipulated that all of the participants were non-Hispanic urban black women, unmarried, English speaking, and with no prolonged hospital stay after their loss (Fenstermacher, 2014). Six were partnered at the time of loss—two of whom remained so at the end of the 12-week study. None had planned their pregnancies. Average gestational age at the time of loss was 19.8 weeks (range 9–32 weeks). Of the eight, three miscarried, three gave birth to a baby who was stillborn, and two experienced the death shortly after birth—one whose baby died shortly after birth in the newborn intensive care unit, and one whose preterm (18 weeks gestation) twins died in the delivery room. Among the interview questions were "tell me how you are coping with your loss" and "what has helped you (or not helped) during this time?"

Results

Participants described their bereavement experience and specific support needs following their loss. As the interviews were analyzed, transition points along the bereavement trajectory were found to represent opportunities for providing bereavement support: during the loss event, immediately following the loss event, during the hospi-

tal stay, at hospital discharge, and during follow-up. The transitions illustrate changing perinatal bereavement support needs over time.

Support During the Loss Event

The loss event was described as a time of uncertainty, chaos, and fear. Participants recalled the event in detail, reporting that they felt alone and scared. When the cramping and spotting started, many of them described feeling confused about what was happening to their bodies, particularly if they had not yet had a prenatal visit where they may have been advised about the signs of preterm labor. One participant said, *I was on my way to school and I started having back pains. I really didn't pay attention . . . and then my water just broke and there was blood everywhere.* These young women had unspoken questions—"What is happening to me?" and "Will my baby make it?"—and they wanted honest, direct answers. One participant recalled, *I was emotional because I didn't know what was going on. The whole time I was there, I still didn't like believe it.* Thus, to the extent possible, compassionate and accurate information about what is happening should be offered during the loss event. When the gestational age of the baby is known to be incompatible with life (e.g., by ultrasonography completed in the ambulatory clinic), it is important to avoid implying that the baby "might still make it."

Support Immediately Following the Loss

Immediately after the loss, decisions must be made about whether to hold the baby, disposition of the baby's remains, and what type of funeral or memorial (if any) should be planned. Several women in this study chose to hold their baby, although they reported that they needed encouragement from the nurses to feel brave enough to do so. Some reported being too scared to hold the baby, but all who did were grateful for the opportunity. Many did not initially understand that their extremely preterm infant would still look like a baby, just much smaller. One mother described her feelings about holding her stillborn daughter: *It's like I want to spend as much time as I can, because I thought I'll probably never see her again. I couldn't even sleep that night. I was just up the whole night.*

Alternatively, those who miscarry early (e.g., at 9 weeks) may see clots and tissue rather than a formed fetus, which was true for two study participants. The nurse who offers a description of what the mother is likely to see in an empathetic, compassionate way helps with the mother's fears and uncertainty.

Financial resources and a maternal grandmother's input were two factors that informed the women's decisions about whether to have an autopsy, to hold a funeral, or to cremate the baby. Only one of the participants had a funeral service, and one had a service of remembrance in her grandmother's home. One woman buried her baby's ashes with her grandfather, a practice allowed by some cemeteries. Others opted for hospital cremation, primarily because of cost:

No, they said we can't keep the ashes. The ashes went to the hospital and like at a burial site for the baby. And I thought it was okay because the funeral costs like a whole lot of money. So that [cremation] was the best decision to do. As young women consider the options available to them regarding the disposition of their baby's remains, nurses can provide guidance to educate them about the choices and urge them to also consider counsel from their family members. Final disposition decisions can be fraught with emotion and confusion about what is the "right choice," but the process must be undertaken with respect and compassion in such a way as to honor the meaning that a woman has given to her pregnancy (Levang, Limbo, & Ziegler, 2018; Limbo, Kobler, & Levang, 2010).

Support During the Hospital Stay

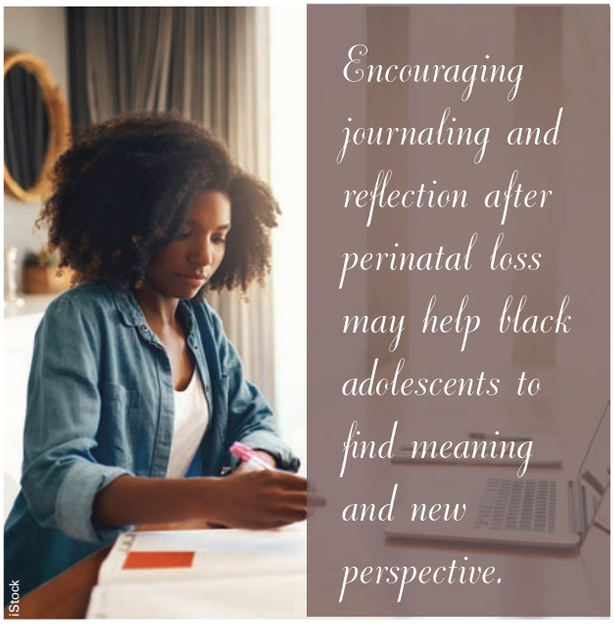
During the hospital stay, nurses and other healthcare providers and support staff, such as chaplains, play an important role in offering bereavement support. It is imperative that bereaved mothers receive affirmation that what they are feeling is "normal" and that they be cared for with a kind, caring, and respectful attitude. Compassionate care from hospital staff was helpful, as one participant stated: *The people in the hospital were all very generous and helpful. They were very sympathetic. They expressed their condolences and everything. So that's another part that helped. The nurses were very helpful and generous . . . very sympathetic.* According to another participant, *The nurses, they talked to me and were there when I needed them. There was a nurse that came in here and talked. Some of the nurses said they didn't know how I was doing it, but it was going to be okay.*

And another: *I don't know, some people might have looked down at them and made it seem like it was their fault. They [the nurses] just treated me real nice.*

The young women in this study all professed a strong faith in God, believing that God was in control, had a reason for their loss, and would see them through their grief. *I have God on my side. He's brought me through things before. He'll bring me through this,* said one. Attention to spiritual needs was an important part of the grief experience, with many of the participants reporting on the helpfulness of a visit from a church member and the power of prayer to give them comfort. One who received a visit from a woman from her church remarked, *She has been wonderful. When she was 18, she was like 8 months when she had her miscarriage. She knows the experience of it. She knows the words to say…*

Several participants reported that the loss of their baby was not the first time they had experienced a loss. Many reported recent losses, such as loss of a grandparent, a father, or friend. Assessing for prior losses may reveal opportunities for better understanding of the grief they are experiencing at the loss of their baby. One participant revealed, *But losing my dad, and then two months later losing my daughter, that was like a deep hole I couldn't escape.*

Participants were also clear that having consistent providers over the course of their hospital stay was preferable to retelling their story to each new physician or nurse: *I just want the same person to check on me every time.*



Support at Hospital Discharge

All of the participants delivered in a hospital with a perinatal bereavement support program, so each experienced some level of standardized bereavement support, which varied by gestational age of the baby and the resources of the individual hospital programs. Typically, support included tangible items, such as a memory box, footprints, hat, blanket, photographs, and bereavement pamphlets, as well as follow-up telephone calls after discharge. Participants reported that they were happy to have mementos to help them remember their baby, responding with such comments as *I'm glad I have it* and *it's helped a lot*.

Hospital discharge is a critical time of transition as the adolescents prepare to leave their baby for the last time. Most were anxious to put the hospital experience behind them. The discharge transition affords a time for teaching and anticipatory guidance. Nurses can prepare them for what they might experience both emotionally and physically. For example, many participants reported feelings of jealousy, sadness, and anger when they saw other pregnant women, especially their pregnant friends: *To be honest, I'm like why do you get to have a baby and I don't? So, I was slightly jealous*. Another participant remarked, *I just want to be by myself. I don't even want to look at pregnant people*. They should be assured that feelings of jealously and anger are normal.

Only one of the participants reported having to go back to high school after her loss and inform others about what had happened. Having to explain her loss to teachers was awkward, but she thought it was important for them to know. Nurses can assess whether the mother is likely to need to disclose her loss and can offer suggestions for how she might share the information.

Physical symptoms, such as lactation, can be discussed to prepare women to deal with it and perhaps avoid unnecessary discomfort. For example, one participant commented, *My breasts were very engorged and very tender, very sore. I can't even express how really painful it was, but it was like to the tenth degree . . . horrific pain.*

Lastly, anticipatory guidance about gender differences in grieving may be helpful for those young women who are partnered at the time of their loss. Some participants reported feeling confused about the lack of reaction to the loss and the isolation they felt from their boyfriends: *My boyfriend, he never wanted to talk about it. It was like to me- he didn't care . . . he never showed no emotion, never cried*. Another reported, *My boyfriend just blocked me out*. For some, however, their boyfriends were very supportive and caring: *He was there through thick and thin. You know some people's boyfriends they don't be there or they just don't want to deal with the baby, but it felt good to know I wasn't by myself*. Another participant said, *My boyfriend has been my most support. He's been so good throughout this whole thing. He has never left my side…*

Support During Follow-Up

Most of the participants received some type of follow-up support, whether it was a sympathy card or a telephone call from a perinatal bereavement counselor. Participants reported that the calls and cards were helpful. For one, *It made me realize someone really cared*. Another remarked, *At first I thought it [telephone call] was weird and then I thought oh, they actually care and they are trying to understand what's going on and they want to know how I'm doing*.

When asked about other things that helped them in their bereavement journey after they were discharged from the hospital, many of the women reported that journaling was very beneficial. Nurses can encourage journaling and reflection as a way for young women to express their feelings about their loss. One participant revealed, *I cried. I cried a lot. And I've wrote a lot. Well, writing during that period was a big deal cause I really didn't have no one to talk to and when I went out and talked to people they would kind of like listen and they're like okay well I gotta go. Like they didn't want to talk about it with me. So, I just started writing. Writing made me feel better*. Another reported, *I usually write things down sometimes. That's what I usually do. When I keep things to myself I write it out*. Writing out their feelings helped some of the young women to find meaning in their loss experience: *You just get an understanding of how it can change your life. Like this has really changed me*. Still another, in addition to her journaling, read support blogs that were aimed at helping women who had experienced perinatal loss. She reported, *Like I wrote to myself and just reading online blogs. Blogs that other females have wrote and talked about their miscarriages and stuff about their losses. So just reading and writing to myself every day helped me out a lot.*

Participants reported that hearing from other women after they were home—in particular, other black women who had experienced perinatal loss—was very helpful. In some cases, the participants received the support via a visit or call; in other instances, they reached out to other black women who they knew had also experienced a loss. As one participant said, *Yeah, my one best friend, she experienced*

a loss. She was 22 weeks. So whenever I went through it you know I was like wow she went through something like this. So I like texted her like how did you deal with this? Did you feel this, did you feel that? She was really positive about it. She has been there. She was a really good support.

The women found it helpful to get affirmation that their feelings were normal and to talk to someone who knew the right things to say, as this participant said: *To hear other peoples' stories and understand that I'm not the only one and relating to other people and that people went through the same thing. It's hard to see that and it would make me feel better to hear other people say well this is what I did to make me get through it.*

One of the most notable sources of support came from the women of the family, most often the mother or maternal grandmother. Almost every participant spoke of a strong and faithful maternal figure in her home or extended family who offered emotional, physical, and financial support and guidance through the immediate bereavement experience. One explained, *My mother and my grandmother. They're the biggest support that I've had throughout the whole thing.* Another described how her grandmother looked after her in the days that followed her hospital discharge: *When I came home she wouldn't let me go anywhere, she wouldn't let me even stay in my own room for a couple days, probably for like a week until I got myself together. Cause I couldn't really sleep by myself.*

What Didn't Help?

Participants shared what helped them in their bereavement experience, but they also were asked to describe what did not help. Interestingly, they reported that their friends did not offer much support and understanding after their loss: *'Get over it.' A lot of people would say 'get over it' . . . but when I did hear it, it hurt.* Another said, *My friends weren't there for me at the time I needed them.* Likewise, one participant who was partnered at the time of her loss reported that her boyfriend was not supportive and understanding: *And the hospital gave us a box with all of the baby's things and my boyfriend, he said he never wanted to look at it, he never wanted to talk about it. I just felt like he didn't care.*

Responses of the few participants who attended a hospital-based perinatal bereavement support group revealed that it was not helpful to them, owing to age and marital status differences with other group participants: *Yeah, we went to the support group and they were really good about everything but they were all married and so I kind of felt left out.* Another said, *Like it was good to get it out and it was good to talk, but I felt like I needed like a younger person.*

When asked if they thought a bereavement support group was a good idea and if they believed it would be helpful, one participant replied, *I don't know. I just don't like to re-live and go through some of the things that have already happened. I try to move on and get past it. . . . It's a great idea and I'm not putting or degrading down but I just don't think I could re-live that again or just keep talking about it over and over and over again.* Another replied with ambivalence: *Yeah a support group. Yeah for our age, yeah that would be helpful for some people but I don't think that most because you're like sad and depressed and stuff like that and I don't think that most people would come. Some people, well some people are more open about it so maybe they would come. You know it would be helpful for some people . . . but I tend to keep everything inside.*

Clinical Nursing Implications

Nurses and other healthcare providers play a major role in planning and providing culturally sensitive and developmentally appropriate bereavement support aimed at helping young women through the experience of perinatal loss and the bereavement that follows. Although high-quality evidence about effectiveness of perinatal bereavement support interventions is lacking, many bereavement support practices have been widely adopted as standard of care (Endo, Yonemoto, & Yamada, 2015). DiMarco, Menke, and McNamara (2001) suggest that the best teachers to help nurses learn about the needs of bereaved parents are the parents themselves. Improving our understanding of the factors that affect the perinatal bereavement experience will improve care (Wright, 2011). This study adds evidence about the perinatal bereavement support needs of black adolescents.

In their study of early loss, Limbo, Glasser, and Sundaram (2014) explicated a process of "being sure"—that is, women experiencing a miscarriage want assurance about what is happening to them so that they can make appropriate treatment decisions. The researchers suggest that nurses can play a role in helping women realize the inevitability of their loss. In much the same way, the women in our study needed validation of their loss through clear and compassionate—but direct—communication.

The women in this study who chose to see and hold their baby reported feeling positive about their choice. Limbo and Kobler (2010) suggest that nurses must remain nonjudgmental and open to the preferences of bereaved mothers to offer information without bias. By being sensitive and attentive to the individual needs and wishes of the bereaved adolescent, nurses can prepare mothers for the experience by explaining what the baby will look and feel like, which may facilitate a positive memory of holding the baby.

Koopmans, Wilson, Cacciatore, and Flenady (2013) describe the standard perinatal bereavement support interventions, such as photographs, footprints, and blankets or clothing that the baby wore. LeDuff et al. (2017) suggest that in spite of controversial evidence, memory items should be offered to help grieving parents. All of the participants in this study reported that the keepsakes that they received were comforting and meaningful to them. Nurses can facilitate collection of such items as photographs, a lock of hair, a baby blanket, and footprints or handprints in anticipation that the bereaved mother may have a desire to have them.

DiMarco et al. (2001) report that perinatal bereavement support groups may not be helpful for everyone, and this was the case for the women in our study, who reported feeling out of place amidst married couples.

Clinical Implications: Perinatal Bereavement Support for Young Black Women

Timing of Support	Type of Support Needed
During the loss event	• Offer clear, compassionate information to avoid misconception about the outcome.
Immediately following the loss	• Provide accurate information about choices for disposition of the body and ways to memorialize the baby. • Encourage mother to seek guidance from her family, particularly the mother's grandmother and mother. • Provide encouragement if mother wishes to see and hold the baby. • Explain what the baby will look and feel like.
During the hospital stay	• Affirm the mother's feelings of sadness, anger, and grief. • Assess and attend to spiritual needs through harnessing the support of the mother's local congregation. • Don't assume that the mother's friends and partner will be supportive. • Encourage the support of other women in the mother's family. • Provide consistent caregivers.
At discharge	• Offer mementos as applicable and available: lock of hair, footprint, clothing, blanket, hat, photo. • Provide anticipatory guidance about potential for lactation, what to expect with emotions (jealousy, sadness, isolation), and gender differences in grieving. • Support groups may not be helpful for young black women. • Reading perinatal bereavement support blogs may help.
At follow-up	• Check in with mothers via phone calls and cards to let them know that you care. • Encourage journaling to stay in touch with their feelings. • Encourage the mothers to make connections with other peers or women from their church who have experienced perinatal loss. • Encourage reflection toward gaining new perspective: Ask, "how has this experience changed you?"

Given that the women in our study voiced that they felt supported by their mothers, grandmothers, and other black women who had experienced a perinatal loss, it may be helpful for hospitals who serve an urban population to offer a perinatal bereavement support group for young women and their family members. Participants also found comfort in their faith in God. Thus, it may be helpful for nurses to assess the spiritual needs and preferences of young black women experiencing perinatal loss and to encourage them to reach out to their immediate families and to their community of faith for support. Nurses can offer anticipatory guidance to warn young women that well-meaning people may say things that are hurtful, not with intention, simply because they do not know what to say. Many of the women in this study chose to journal their feelings about their loss and, in so doing, found meaning and came to terms with how the experience of perinatal loss had changed them. Black and Wright (2012) report that helping women reflect after their loss may facilitate their ability to make meaning of the bereavement experience. Given this finding, hospitals may wish to offer a memory journal to mothers who experience perinatal loss.

Bereavement support should be provided through the continuum of the experience beyond the hospital to avoid complex grief responses (Donovan, Wakefield, Russell, & Cohn, 2015; Inati et al., 2018). Follow-up after hospital discharge is another opportunity to provide bereavement support. Nurses can suggest that young women read blogs that offer perinatal bereavement support. A critical transition may take place within the time that support is offered during follow-up as young women find meaning in the experience and gain new perspective about their loss experience (Fenstermacher, 2014). For some women, the experience of pregnancy loss may result in posttraumatic growth, expressed as having greater compassion toward others who have had a loss along with a feeling of appreciation for life in general (Black & Wright, 2012). During the follow-up telephone calls, nurses can ask, *How has this experience changed you?* The bereavement experience that follows perinatal loss is a time when adolescents seem ripe for encouragement from nurses, parents, teachers, or mentors to follow their dreams and recognize how they have changed in a positive way through the process of enduring to gain new perspective. ✣

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Disclosure Statement:

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