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Social Support Following Perinatal Loss

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Abstract

The purpose of this project was to examine parents' descriptions of the ways family and friends supported them after they had experienced a perinatal loss. For this project, a secondary analysis of data from two phenomenological studies on perinatal loss was performed. A combined total of 62 interview transcripts from 22 mothers and 9 fathers were examined. Data analysis included identifying all statements in the interview transcripts that pertained to the ways that family and friends supported parents. The modes of supportive behavior (emotional, advice/feedback, practical, financial, and socializing) in Vaux's theory of social support served as a useful framework for presenting the findings. Parents received emotional support most frequently. Findings from the current study provide data for health care professionals to use to provide guidance to family and friends of bereaved parents.

Keywords

perinatal loss; family support; social support; parent support

Parents who experience a perinatal loss (death of a baby during pregnancy or in the newborn period) often seek the support of family and friends immediately after and during the months following their loss to assist them during this difficult time. Yet friends and family are often unsure how to provide support to bereaved parents. The way in which families and friends support parents can have lasting effects. If parents perceive that they are not supported, they may feel isolated and misunderstood in their grief (Clyman, Green, Rowe, Mikkelsen, & Ataide, 1980; Malacrida, 1999). Furthermore, a lack of social support has been linked to complicated or chronic grief (Lasker & Toedter, 1991; Nicol, Tompkins, Campbell, & Syme, 1986).

Despite the importance of knowing the ways that family and friends can support parents after a newborn death, this area has received limited attention in the research literature. However, several investigators have documented the social isolation parents experience after a perinatal loss (Clyman et al., 1980; Helmrath & Steinitz, 1978; Rajan, 1994). Results of studies demonstrate that parents often feel abandoned by their family and friends. In one study (Clyman et al., 1980), a total of 35 parents were interviewed during a follow-up visit 2 to 4 months after

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having experienced a perinatal death. Results of this study demonstrate that encounters with family and friends led to many negative emotions and feelings of isolation. Parents described behaviors such as being avoided, or experiencing sudden silence when they entered a room in which family and friends were conversing. In addition, in this study parents reported anger when they were given unsolicited advice about how to feel or act by individuals who themselves had not lost a baby. Parents also reported that it was difficult when family and friends did not understand or acknowledge their feelings of loss and dismissed their infant's death as insignificant.

Investigators have continued to document parents' reports of a lack of social support and isolation (Cecil, 1994; Malacrida, 1999; Rajan, 1994). The focus of one study (Cecil, 1994) was on the mother's perceptions of support given by family members after she experienced a loss. A sample of 27 women who had experienced a miscarriage in the first trimester were interviewed and followed over a 6-month period. Support from families was found to be inadequate in most cases. Parents were often told by their family how they should feel. Women were told that they should be grateful for their surviving children or that they could try to have more children. Men's feelings were often discounted, and they were told to be supportive and strong for their wives. These types of messages showed little acknowledgement of the parents' feelings and minimized the importance of their loss.

Rajan (1994) also demonstrated the isolation that parents experience. In this study, Rajan assessed the contribution of social support to the process of grieving. Data from a randomized controlled trial of a social support intervention program in high-risk pregnancy were used for the study. A sample of 85 women who had experienced a perinatal loss were interviewed. In this study, women spoke of friends completely ignoring them, afraid to speak to them because they did not know what to say or do. These experiences led women to feel isolated, alone, and abandoned.

Investigators have also documented that parents who experience a perinatal loss do not receive the same type of social support as other bereaved individuals (Helmrich & Steinitz, 1978; Malacrida, 1999). Helmrich and Steinitz (1978) examined the nature and extent of alterations in family and extrafamilial relationships. Semistructured interviews were conducted over 1 year with seven couples who had experienced a newborn death. The investigators found that parents felt extreme isolation after their loss and that this type of loss was treated differently than other types of losses, such as the death of an adult or a child. Many couples expressed feelings of disappointment, resentment, and anger at others' responses to their loss. Malacrida (1999) interviewed 22 parents who experienced a perinatal loss. The results of her study indicated that parents were not provided with the material social support that individuals would receive surrounding a death or a normal birth.

The quality and quantities of ties with a social network have been shown to be affected by perinatal loss (de Montigny, Beaudet, & Dumas, 1999). Twenty parents who had experienced a perinatal loss within the previous 6 years were interviewed. Parents in the study reported that extended family members often felt uncomfortable and unsure of how to react to or support parents who were grieving. This led to unsupportive reactions, such as avoiding talking about the baby and making comments that diminished the magnitude of the loss. To avoid being hurt by these reactions, parents often isolated themselves, alienating themselves from friends and family. As a result, perinatal loss had a significant impact on the family members' quality and quantity of relations within their network. Some family relationships were strengthened after a loss when their families were present to let them express their grief. Others were weakened, ultimately leading to a permanently lost relationship within their social network.

Supportive relationships have been found to be important to families experiencing a loss. Results of studies demonstrate the importance of women having the opportunity to grieve in an emotionally supportive environment (Cecil, 1994; Rajan, 1994). Women found it helpful when they were able to share their experiences with friends and family who had had a similar experience (Rajan, 1994). Cecil (1994) reported that behaviors such as listening, sympathizing, empathizing, and practical help were most helpful. Parents especially valued the interest and concern of their families and the acknowledgement of the significance of their loss.

Lack of social support has been linked to complicated and intensified grief (Janssen, Cuisinier, de Graauw, & Hoogduin, 1997; Nicol et al., 1986). Nicol et al. (1986) performed a study to investigate the nature and incidence of psychological disturbances and health problems of mothers who experienced a perinatal death and to identify factors that were related to a pathological outcome of bereavement. A sample of 110 women were interviewed 6 to 36 months after they experienced a loss. Results demonstrated that perinatal loss could put families at risk for feelings of isolation, which can lead to abnormal grieving and a decrease in ability for parents to cope. The authors reported that 21% of these women experienced deterioration in their health or experienced social adjustment problems following their loss. These outcomes were more common among women who experienced a crisis during their pregnancy, who perceived their husband or family as unsupportive, or who did not hold their infant.

Grief intensity is affected by the degree to which social support is given to parents (Janssen et al., 1997). A questionnaire that contained the Perinatal Grief scale (PCS) was completed by 227 women who had experienced an involuntary pregnancy loss (Janssen et al., 1997). The women in this study were followed for 18 months and reassessed four times during this period to evaluate their grief over time. Stronger grief reactions were present in women who received less support from their families and social network.

In summary, parents who experience a perinatal loss need support from family and friends to prevent feelings of isolation and potentially complicated grief. However, understanding the nature of positive social support and less helpful forms of social support would be helpful in clinical practice. Based on a secondary analysis of interview data from two phenomenologic studies on perinatal loss, the purpose of the current study was to examine parents' descriptions of the ways family and friends supported them after they had experienced a perinatal loss.

CONCEPTUAL FRAMEWORK

The concept of social support has been defined in a variety of ways (Hupcey, 1998). Vaux (1988) defined social support as a process in which persons manage their social resources to meet social needs. Vaux's theory of social support is composed of three main constructs: support networks (resources), supportive behavior, and appraisal of support (Vaux, 1988). A support network is defined as a person's social network to which she or he routinely turns or could turn for assistance in dealing with life's challenges. Nevertheless, even if the relationship is usually supportive, adequate support for a particular situation may not occur.

Supportive behaviors are defined as specific acts of assistance occurring within a relationship and during incidents in which support is given, that is, intentional efforts to help a person, either spontaneously or on request (Vaux, 1988). Vaux identified five modes of supportive behavior: emotional, advice/guidance, practical, financial/material, and socializing. Supportive behavior is not always perceived as being helpful, and any supportive act may have multiple consequences in the short and long term. The outcomes of supportive behavior depend on the amount given, the timing, and the mode in which a supportive behavior occurs.

Supportive appraisals are a person's subjective evaluation of resources and assistance that have been provided by the supportive network (Vaux, 1988). These are the primary indicators of

how positively support has been perceived by the individual receiving support. These perceptions may include satisfaction, feeling cared for and respected or involved, and having a sense of attachment and belonging.

METHOD

Design

For this project, data were examined from two phenomenological studies on perinatal loss (Kavanaugh, 1997b, 2003). Secondary analysis can be used with qualitative data to analyze data that were previously collected from another study (Thorne, 1994). Through this approach, the investigator is able to further examine questions that were raised, but not thoroughly examined, in the original studies and also combine more than one database for expanded sampling (Thorne, 1994).

The purpose of the first study (Kavanaugh, 1997b) was to examine the experience of perinatal loss surrounding the death of a live-born infant whose birth was at the margin of viability (birth weight of less than 500 grams). A total of 18 open-ended interviews were conducted with five mothers and three of their husbands between 4 and 15 weeks after the loss. A similar methodological approach was used for the second study, which was an examination of perinatal loss in low-income, African American families (Kavanaugh, 2003). For that study, a total of 44 open-ended interviews were held between 1 and 4 months after the loss with 17 families (17 mothers and 6 fathers) who had experienced a perinatal loss due to pregnancy loss (occurring at 16 weeks of gestation or later) or a neonatal death. Therefore, data for this analysis came from a total of 62 interviews that were conducted with 22 mothers and 9 fathers.

Sample

For both original studies, a convenience sample was selected from three Midwestern hospitals that provide high-risk perinatal care. For the second study, an advertisement was also placed in a newspaper. In addition, for both studies, parents had to be at least 18 years of age and English speaking.

For the first study, the age of the mothers ranged from 24 years to 32 years ($M = 28.3$). The age of the fathers was 25 years to 38 years ($M = 32.2$). All parents were married at the time of data collection. The level of education for both parents ranged from 13 years to 16 years ($M = 14$). Their yearly household income level ranged from U.S.\$5,000 to \$75,000 per year of total family income. All parents reported a Protestant religious background. There were four African American parents and four Caucasian parents. With the exception of one twin who weighed 640 grams, the infant born to these parents weighed between 208 and 485 grams. All infants lived between 30 mins and 13 hrs.

For the second study, the age of the mothers ranged from 19 years to 34 years ($M = 23.82$). The age of fathers was 20 years to 34 years ($M = 27.33$). Of the 17 families, two couples were married, eight couples were living together, and four were in a relationship with each other at the time of data collection. The level of education for the participants ranged from 11 years to 17 years ($M = 13.27$). Parents reported the following yearly incomes: less than U.S.\$5,000 (10), \$5,000 to \$10,000 (8), and \$10,000 to \$15,000 (1). Four parents (two mothers and two fathers) reported incomes of \$20,000 or greater, however these families were kept in the study because the mothers met the sample inclusion criterion of receiving medical assistance because of low income. Parents reported various religious affiliations: Baptist (13), Catholic (2), other (2), and no preference (6). All parents were African American. For the 17 families, 11 experienced intrauterine fetal deaths occurring between 17 and 37 weeks gestation ($M = 27.1$) and six experienced neonatal deaths, including one death of a twin.

Collection Procedures

For both studies, hospital personnel at each referral site identified parents who met the inclusion criteria and obtained parents' permission for the investigator (Kavanaugh) to contact them no sooner than 1 month after their loss to determine their interest in participating in the study. For the second study, one parent responded to the advertisement and similar procedures were followed for that method of recruitment. Before data collection began, informed consent was obtained. Parents were interviewed separately at their convenience. All interviews were audiotaped. With the exception of two parents in the first study and three parents in the second study, data collection occurred in parents' homes. A 2-hr time limit was placed on each interview to control for effects of mental exhaustion on the parent. The first interview had an open-ended format with the beginning question, "Can you tell me about your experience?" Then, probes and specific questions were asked to encourage parents to give further descriptions of their experiences. Two of the probes were "Think about those family and friends who were supportive. What did they do or say?" and "What advice do you have for family and friends of a parent of a baby who has died?" At the end of the interview, each parent completed a family background form for demographic data. A second interview was conducted during each study with all but two mothers. During the second interview, parents had the opportunity to add and/or clarify information obtained during the first interview. For the first study, a third interview was conducted with two mothers for them to complete a description of their experience.

Data Analysis

In the original studies, the researcher's approach was adapted from Colaizzi's (1978) approach for data analysis for a phenomenological study. The interviews were transcribed from the audiotapes onto computer files. Written transcriptions were generated and compared with the original audiotapes for accuracy. Descriptive codes were then developed to identify significant statements and general themes, which were validated by parents.

Vaux's theory was selected as the organizing framework for this secondary analysis after a preliminary determination of adequacy of fit of this theory with the current research. First, concept analyses of social support after a perinatal loss (Korzec, 1999; Trier, 1999) were performed. The literature that was reviewed for the concept analyses included research specific to perinatal loss. The conceptual definitions that are described in Vaux's theory were determined to be congruent with the findings of the concept analyses. Second, relevant themes and subthemes that were generated from the first study (Kavanaugh, 1997b) were re-examined and compared with concepts in Vaux's theory and were also found to be compatible. For example, a subtheme in the first study was accepting a person's feelings (Kavanaugh, 1997b), which is example of a supportive behavior defined by Vaux (Vaux, Reidel, & Stewart, 1987).

For this secondary analysis, the following definitions were used: *support resources* were family, friends, coworkers, and church members; *support behaviors* were the specific acts of assistance occurring within a relationship and during incidents where support is given. Specific examples of support behaviors (Table 1) were drawn from the Social Support Behaviors (SS-B) Scale (Vaux et al., 1987) and expanded for this secondary analysis to incorporate the results of the concept analyses (Korzec, 1999; Trier, 1999) and the themes from the first study (Kavanaugh, 1997b). Specifically, under the category of "emotional support," the behavior of "being physically present" was added. Under the category of "advice/guidance," the specific behaviors of "sharing grief," and "giving suggestions from a personal experience" were added. Under the category of "financial/material," the specific behavior of "sending cards, flowers, letters, or gifts" was added. Finally, under the category of "practical," the specific example of "helping with everyday life" was added.

Supportive appraisals were those perceptions of satisfaction, feeling cared for and respected or involved, and having a sense of attachment and belonging. Appraisals that were not positive were those in which parents felt that they were not cared for.

Data analysis was guided by Knafl and Webster (1988) and consisted of (a) reading all interview transcripts; (b) identifying all statements in the interview transcripts that pertain to the ways that the support resources provided supportive or nonsupportive behaviors based on supportive appraisals of parents, including advice that parents had for the support resources; (c) coding the significant statements into categories (emotional, advice/guidance, financial/material, practical, socializing, or other); (d) creating subcodes for emotional support; and (e) integrating the results into a description of each category. Supportive behaviors were used as the organizing framework for results, and support resources and supportive appraisals were integrated within the framework.

Trustworthiness

For secondary analyses, it is critical for the investigators to document the trustworthiness of the original studies and the secondary analysis (Thorne, 1994). During the original studies, the researcher addressed trustworthiness as described by Guba (1981) that included (a) peer debriefing, which is the process of consulting with methodological and context experts; (b) collecting thick descriptive data, or detailed descriptions of contextual factors; (c) establishing an audit trail, which is a record of how data are recorded and analyzed; and (d) performing a member check, which involves confirming the results with the study participants.

For this secondary analysis, trustworthiness issues in the current study have been addressed by the careful use of a theoretical framework, a concept analysis, and peer reviews. Vaux's theoretical framework was used to organize data analysis; concept analyses on perinatal loss and social support validated the use of Vaux's framework. Data analysis was done in collaboration with a team of investigators.

Ethical Issues

The Institutional Review Board (IRB) at the University of Illinois at Chicago granted approval for the original studies after a full review. For both studies, the researcher only contacted those parents who had originally given permission through the hospital where the loss took place. Written informed consent was obtained at the start of the study, and process consent was utilized throughout. Further measures to minimize harm to study participants were used and are described elsewhere (Kavanaugh & Ayres, 1998). IRB approval was also obtained for this secondary analysis, which contained only deidentified data.

RESULTS

Parents described support behaviors for all of the categories that are described by Vaux. These included (a) emotional support, (b) advice/guidance, (c) financial/material, (d) practical assistance, and (e) socializing. There were no descriptions of social support that did not fit in Vaux's categories.

Emotional Support

During the interviews, all parents discussed many subcategories of emotional support, including (a) being physically present, (b) listening/giving an opportunity to express their feelings, (c) encouraging, and (d) accepting their feelings and sympathizing. Within these descriptions, parents discussed forms of emotional support that they wished they had received and nonsupportive emotional support that they did not find helpful.

Being physically present.—Nearly all parents mentioned the importance of having family or friends physically present to give support. One mother stated:

When they found out that she had stopped breathing, there was a couple of nurses that came in and talked to me, but really I didn't want to talk to anyone. And when they told me, before they told my sisters who were there, but after they left, that's when they told me because that's when I found out the heart beat wasn't beating. So I had to call my sisters to come back, and they came. But I really didn't want to talk to anybody else. I just wanted somebody there.

Mothers, in particular, expressed not wanting to be alone after losing their baby. A number of parents noted that they especially appreciated when family members “dropped what they were doing” and came to the hospital immediately. Often, many family members came to the hospital to be with the parents, and in many cases, parents explained that family bonds were strengthened after the loss because of their family's presence. One mother explained that visits were important even after the mother's discharge from the hospital even if the parents had the support of each other, and advised others not to mistakenly think that the parents want to be alone. When the parents were asked for examples of advice for family and friends regarding providing support, several mothers recommended physical presence. One mother stated, “Be there when the person needs you even if you can't bring back that person that died. Just let them know that you are there for them.”

A number of parents had arranged for a private burial for their baby, and several of those parents specifically mentioned the importance of family being present at the baby's funeral. However, several mothers recalled how hurt they felt when friends and family members did not attend their babies' funerals. These mothers shared their pain and disappointment that their friends and families did not take time to see them and be supportive. One of these mothers said:

Most of them [family] just don't care. Like my grandmother. I've gone to see them as I recall. I haven't seen my aunt or anything. She was out the week before I had him. I haven't heard from her since. I think it's ignorance, and it hurts. When you say you have somebody and you are calling them and they are turning you down, it kind of hurts.

These mothers explained that they were there for others at their time of need but then felt abandoned when they needed support after losing their babies.

Listening/giving an opportunity to express their feelings.—Many parents shared their need to talk about their experience and to have someone listen to them. One mother talked about how her friend just sat and listened to her talk for a few hours. One father said, “The only thing that was helpful was that they listened, that they acknowledged it.”

Parents mentioned that when family members and friends called to check on them and show concern, this was viewed as helpful and supportive in most cases. However, one father thought that it had not been helpful when family and friends called initially. He felt that calls were an interruption that made it difficult to mourn in your own way. In contrast, most of the mothers stressed the importance of having someone to talk to and having someone listen to them. One mother recalled her experience and gave the following advice for other family members and friends:

I got more calls in the hospital than I did at home. I don't basically know why. Maybe they just don't know what to say. . . I guess I really wished they called even if they just called to say, I'm thinking about you. . . I would tell them, “If you don't know what to say, just call and say I'm thinking about you. Don't just not call. That makes

it seem like you don't care." Like I said, I would just really recommend that they call. An occasional visit would be nice also.

Mothers spoke of the importance of providing love and support to the bereaved parent and that family and friends needed to wait until they were ready to talk. Moreover, one mother, who was hurt when she did not receive any more phone calls from her sisters after 3 months, stressed the importance of continuing to call bereaved parents in the months after the loss.

Encouraging.—Only three parents described encouraging words that they received. One mother described the encouragement that her aunt, herself a bereaved parent, told her. This mother said, "She knew what I was going through. She would tell me, 'You are going to make it. Its just going to seem hard. You are going to make it.'" This aunt also advised other family members to give the mother time to grieve. Another mother reported that she wished she would have received encouraging words. In fact, she said, "If they can't say anything that would encourage me or anything, then don't say anything to me at all."

Accepting their feelings and sympathizing.—Many parents described the importance of having their family and friends accept their feelings and sympathize with them. Several mothers talked about their own mothers who were "always there for me." One father recommended that family members should not be hesitant to share their feelings. Another father explained the support he received despite his perceived gender differences in response to loss. He said, "Men are not into grief per say like women are, you know, and there were a few men more sensitive or more open than other men are. And I had a few come and say they were really sorry about your loss and this and that and whatever."

All mothers felt it was very important that people accepted their loss as a real loss. They wanted people to understand that they had lost a child, and that that child was real. Some mothers mentioned how important it was to show pictures of their infants, to let people know and understand that their baby was real. One mother expressed how much it meant to her when her father-in-law asked to see pictures of her twin girls. She stated:

"I do want to see the babies' picture." He had told me that. He hadn't wanted to before. And I showed them to him and he goes, "These were my grandchildren." He said, "These are my only girls, my only granddaughters." And he picked up the book and looked at them, and he cried. But it was a positive, it wasn't a difficult thing.

Negative emotional support.—Many parents described behaviors of family and friends that did not portray an acceptance of their feelings or allow them to grieve. One mother talked about the difficulty of being around her sister who was pregnant, and that her sister told her that she was evil for feeling that way. Another mother spoke of how hard it was to live with her boyfriend in his mother's house because his mother was not showing her any support. One mother did not feel her family's words of support were very comforting. She said, "My parents say, 'She's in a better world, she's more happy, she probably knows how this world is.' I don't want to hear that." Another mother reported that her own mother hid the Memory Box she had received from the hospital to hold her baby's picture and mementoes. These mothers perceived that these behaviors did not validate their feelings or provide them an opportunity to grieve in their individual way.

Many parents felt it was unsupportive when family or friends asked "stupid" questions, blamed the parent for the loss, or said inappropriate comments. One mother was upset when someone asked her if she had had a formed baby and referred to the loss of her twins, who were born at 23 weeks gestation, as miscarriages. Another mother explained that her friend was surprised that the mother would have the normal bodily changes (such as lactation) after her loss. Mothers

explained that these comments minimized their experience of losing a baby. One mother summarized what not to say to a bereaved parent:

Don't say it was God's will. . . . Don't tell me that it was good that I lost him while he was little instead of him being 2 or 3 months because it doesn't matter. It was still a baby. It was still my baby who came from me. . . . Especially that you are young, you can have another baby. That ticks me off. . . . Don't tell me it was God's way of dealing with a pregnancy that wasn't normal.

Advice/Guidance

Many parents received advice and guidance from family and friends. This included providing advice and sharing experiences with other bereaved parents. As they recalled their experiences, parents described positive and negative support.

Several mothers discussed how advice from family, typically a mother or a sister, helped them feel that it was normal to feel the grief that they felt, and gave them strength to go on.

I asked my mother should I feel bad that I never looked at my niece or held her. She said, "No" that my sister should be able to understand what I'm going through right now, that I just needed some time to get over it, that it will take time. That's what she tells me.

Another mother said, "The best advice my sister gave me was, 'If you are going to cry, go ahead and cry. Don't try to keep it inside.'" Mothers appreciated hearing that it would take time before they felt better.

Most of the mothers had the opportunity to talk to another bereaved mother and found this very helpful. One half of the low-income mothers had a close relative who lost a child, and they received great comfort from these relatives. One mother explained that another bereaved parent really knew how she felt:

She [her god sister] was very helpful. She knew how to take it and how it was going to be and stuff like that. It was kind of easy to talk to her, like her and my friends and my mother and other people, they say they understand, but they don't. They don't really understand. They don't understand unless they've been through it. . . . They ask a personal question and then say, "I know how you feel" when they really don't.

Another one of the mothers had a friend from church who had also experienced a newborn death. This woman from church came over to her house to talk to her when she found out about her loss. It was a surprise to this mother that she had never been told about her friend's baby. The father thought that his wife's ability to talk to her friend from church who had also lost a baby was the most important and helpful thing for his wife. He stated:

But I think the ability for Jane to sit and talk with one person that had shared the exact same thing with her helped her deal with it better than all other cards and everything else. Because I saw more of an effect. I think talking to this one woman was more than everything else. That helped her deal with it and come to terms with it more.

Several low-income, African American parents received advice/guidance from family that they felt was not supportive. Most of the advice centered on recommendations for a subsequent pregnancy. Mothers reported that it was inappropriate for family and friends to give advice on planning or delaying a subsequent pregnancy. One mother said:

My grandma, both sides, my mother's mother and my father's mother, calling me and making comments on I don't need to try and have another baby. I don't want to hear all this. It doesn't help me now. My brother made a comment, my mother's mother

made a comment saying next time it might not be the baby. It might be you. I said, "Okay, I don't want to talk to you no more." I just hung up. You know, I don't want to hear that. Not now. Now is not the time to tell me what I really don't need to do.

Another mother advised that family and friends should not mention that other parents have also experienced a death of a child. She said, "Sometimes what people don't understand is when a mother loses her child, we don't care that it happened or that it happens to other people who are going through it. The only things we understand is my pain."

Financial/Material

Financial/material support was received by only approximately one third of the parents in the form of books, cards, and flowers. In addition, one mother talked about how a funeral director had offered her the funeral for no cost. One mother who did not receive this type of support said, "Bring a fruit basket with a card saying I don't have much to say but I'm thinking about you and praying for you. Just call to see how you are doing. Something."

Although parents reported that receiving cards was supportive, some parents explained that receiving plants and flowers was not supportive because they were a sad reminder of their baby's death. One father said:

We got a few cards. But mostly a lot of flowers. . . . A lot of flowers you know, and let's see we got a little plants and stuff, but I didn't want those flowers around because I knew what they were for. All the rest of these flowers or plants got a different story to them. I don't want to look up in the window and see that fern and know where I got it from.

Practical Support

Approximately one half of the mothers mentioned that they received practical assistance from family and friends. The assistance included helping with everyday life, such as child care and meals, and helping to make funeral arrangements. Five of these mothers received assistance with funeral arrangements from family members. One mother talked about how much it helped to have her sister and boyfriend's mother assist her. She stated:

His mother even came back and she helped me look for scriptures because I wasn't a church member and didn't know anything about the Bible or scriptures. And she helped me look for scriptures that talked about babies. . . . She was with me when I made the funeral arrangements, her and my sister, and they went with me to the graveyard. So she was real helpful to me. She did a lot of things that she wouldn't have had to do.

One mother advised that family and friends should anticipate the practical help parents need because parents may not know to ask for help. She said:

There are a lot of physical needs there too. I didn't like asking for help. I hated to. But I had real physical needs that I had that I couldn't take care of. Just trying to keep yourself open, your eyes open to whatever that person is needing right then. Be it somebody to talk to or somebody to listen, somebody to do the laundry if they are not capable.

Finally, one father used the word "comfort" to describe the support he received. He described how important it was for others to do "little things" that provided comfort.

Socializing

Only several parents reported that family and friends had socialized with them as a way of providing support. These parents felt it was important to go out and be with friends. They found

it to be helpful and a necessary part of their healing process. One mother felt that her friends cared about her when they came to visit and encouraged her to go out socially. She said:

My friends, well they came to see me. When I was in the hospital they called, they came. When they heard the baby had died, they rushed over to the hospital and they try and get me to go out and stuff. They are very supportive.

One mother offered the following advice, “Come over and see and take that person out. Do something to cheer them up. They will still be unhappy but go out with them to make them feel a little pressure off them. Call, come over, any little thing.”

DISCUSSION

The results of the research reported here reveal that not all support received by the parents from friends and family is always perceived as helpful. In fact, behaviors that are sometimes perceived as supportive to one person are not always supportive to another. This was observed in the differences between men and women. For example, mothers were more likely than fathers to need to have their loss validated and to want to have someone to talk to about their experience. This finding is consistent with prior perinatal loss research that has documented that women, in contrast to men, are more likely to talk as a way of coping with their loss (Kavanaugh, 1997a).

Emotional support was an important theme throughout the interviews. Parents mentioned the importance of being physically present most often. Parents, especially mothers, expressed their need to talk about their experience and to have someone listen. Mothers especially found it most helpful to talk with someone who truly understood what they were going through, and this person was typically another bereaved mother. Similar findings were found by Rajan (1994) who reported that support from someone who had had a similar experience was helpful and sometimes the preferred source of support for bereaved mothers. Cecil (1994) documented the importance of listening and sympathizing. These findings are not surprising. Perinatal loss can be a devastatingly emotional experience, and parents find comfort in the presence of others. In the current study, some parents also felt that their bonds with their family and friends were strengthened after their loss. The findings of the current study confirm those of prior research that some family relationships are strengthened after a loss when family members were present and let parents talk about and express their grief about their loss (de Montigny et al., 1999).

Only a few parents relayed that they had received comfort or encouraging words. It is possible that family and friends may be able to be present physically with parents but may not know how to provide words of comfort or encouragement. Moreover, a number of the mothers expressed the pain and disappointment they felt when family and friends were not there for them. In some of these cases, family and friends displayed nonsupportive behaviors and made comments that minimized the loss. In these cases, family and friends may think that mentioning the infant would be too painful for the parents. Instead, they may avoid the parents or try to take away the parents' pain and ultimately say phrases that are not perceived as supportive. Some of these remarks may even be “technically” correct, however they diminish the magnitude of their loss. These findings have been documented in other studies surrounding perinatal loss (Clyman et al., 1980; Helmrath & Steinitz, 1978; Rajan, 1994).

In the research reported here, parents described the behavior of advice/guidance as being supportive and nonsupportive. This behavior included sharing grief and giving advice. Sharing grief with another bereaved parent was always seen by the parents as positive. Parents appreciated the care, understanding, and advice that was given to them by someone who had had a similar experience. However, many parents received advice/guidance that they felt was nonsupportive, and the advice usually involved a subsequent pregnancy. Family and friends

may have advised parents to have another baby as a form of encouragement. In contrast, family and friends may have advised the parents to wait before contemplating a subsequent pregnancy because they wanted the parents to heal emotionally and physically. However, parents did not want to hear advice about a subsequent pregnancy, regardless of the nature of the advice. This finding is not surprising because prior research demonstrates that the timing of a subsequent pregnancy is a personal decision for parents, and that parents do not consider professional medical advice either unless it is consistent with their desires (Davis, Stewart, & Harmon, 1989).

In the current research, many parents discussed financial/material support they received but in a more limited way in comparison to other types of support. With the exception of a study by Malacrida (1999) that documented parents' reports of receiving limited financial/material support, there have been limited findings with regard to this type of support. It is possible that because perinatal loss is a very emotional event that emotional support would be most prevalent. In the current study, it was interesting to find that some parents who received flowers did not find them helpful because flowers were a constant reminder of the loss. This finding was unexpected because flowers are typically given to signify a person's sympathy for a bereaved person. However, the reluctance of some parents to want flowers is understandable because of the tragic nature of this event. In addition, in the research reported here, many parents mentioned that they received practical assistance, such as child care, but again in a more limited way. In a prior study, Rajan (1994) reported that women ranked domestic help as the least important of their needs surrounding a perinatal loss. It is possible that this type of support is not seen as a priority.

In the current research, several parents reported that family and friends had socialized with them as a way of providing support. Being around people, and getting away from their problems and thoughts, was part of what helped some parents get through their loss. It is possible some family and friends would not consider this type of support to be appropriate for bereaved parents. Moreover, anecdotal reports indicate that mothers, in particular, feel guilty when they think they are having fun socially too soon after their loss. Therefore, this type of support may be beneficial to a limited number of parents.

Finally, some findings in the current research appeared to be more prevalent in or unique to the low-income, African American parents. For example, in contrast to the White parents, a number of the low-income African American women received much support from close relatives who had also experienced the death of a child. At the same time, however, only the low-income African American women reported that they received unwanted, unsolicited advice from family about a subsequent pregnancy. These findings could be related to the large discrepancy in sample size between the African American parents and the White parents. The vast majority of parents in the research reported here were African American parents, and most were low income.

Limitations of Design

There are several identifiable limitations to the current study. As mentioned before, this was a secondary analysis. Data for the current study were collected from other studies that had a different purpose, and only two direct questions related to support by families and friends after a perinatal loss were asked in those original studies. Therefore, the area of social support was not addressed as in depth in the original studies as it would have been had the focus been on social support.

There were also limitations in the original studies. Only several fathers agreed to be interviewed in each study. This gives limited representation of the paternal response. In addition, the sample used in the study was a convenience sample that was selected from

hospitals that have protocols for caring for bereaved families. There could be very different findings if parents were cared for in a hospital without any program of support. Finally, for the combined sample, the majority (27 of 31) were African American parents, and most of these parents were low income (23 of 27 parents). The remaining four parents were middle income and White. Therefore, there is a lack of representative sampling of the demographic groups, and as a result, any differences between these parents can be identified but cannot be accurately accounted for.

Implications for Practice and Research

Nurses and other health care professionals who provide care to women of childbearing age should be knowledgeable about the needs of parents for social support after experiencing a pregnancy loss. These health care professionals are in an ideal position to help family and friends understand what types of support the grieving parents might need.

Results of this secondary analysis indicate that emotional support, especially physical presence and listening, are supportive behaviors. Family and friends need to understand the importance of being with parents and allowing parents, in particular mothers, to talk about the loss. This is important because parents feel that friends and family are minimizing the loss of their baby when they avoid talking about the baby. Family and friends need to be informed that any statement that minimizes the parent's feelings or causes guilt should be avoided. Because many mothers find comfort in hearing words of encouragement from someone who has gone through the same experience, health care professionals should encourage family or friends who have also experienced a loss to share their experiences. Health care professionals should also advise family and friends of the benefits of small gestures of kindness, such as sending a card, bringing over a meal, or assisting with other practical help. Providing family and friends with written bereavement support booklets that include advice to family and friends may provide additional tools for them.

Extensive research is available regarding perinatal loss and the grieving process. However, further research is needed related to social support surrounding perinatal loss, in particular with families of various racial and ethnic backgrounds. Research surrounding the experience of perinatal loss in low-income African American parents is extremely limited, and the findings of this secondary analysis suggest some unique experiences among these parents. Therefore, another study with a larger sample would be very beneficial research. Moreover, parents' reactions to flowers were unexpected, and there were limited data in general on financial/material help, practical help, and socializing. These areas should be investigated further in future studies. The research reported here and analysis of prior research on perinatal loss supports the consideration of Vaux's framework to guide subsequent research.

Summary

During the childbearing years, many parents will experience a perinatal loss. It is therefore essential that health care professionals be aware of the special needs of parents and the friends and family whom they turn to for support. Findings from the current study provide a beginning understanding of the parents' needs for social support after experiencing a perinatal loss.

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Table 1

Operational Definitions for Support Behaviors

<i>Behavior</i>	<i>Operational Definition</i>
Emotional support	Comforting, listening, giving an opportunity to express their feelings, physically being present, being encouraging, holding, hugging, showing affection, loving, being nonjudgmental, accepting of a person's feelings, sympathizing
Advice/guidance	Sharing grief, giving suggestions from a personal experience, giving advice about what to do, assisting someone in thinking through a situation
Financial/Material	Sending cards, flowers, letters or gifts, the lending/giving of money, assisting with purchase/paying bills
Practical	Helping with everyday life (child care, yard work, meal prep, housework, chores), assisting with transportation, lending of material things, helping make plans/arrangements, providing a place to stay
Socializing	Spending time with someone in a social manner to distract someone such as going out to dinner, a concert or a movie, invitation to visit, taking time to take mind off the situation