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Rural Perinatal Loss: A Needs Assessment

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Abstract

The purpose of this research was to ascertain the availability and depth of services of bereavement care for mothers who live rurally. The specific focus is on those who experienced early losses including pregnancy, stillbirth, neonatal, and young children who were born with fetal anomalies or neonatal disease that resulted in death. The convenience (nonprobability) sample originated from a population of mothers who lived in rural east central Minnesota. Participants were interviewed in a 60-minute interval. All data were coded confidential. Common themes, incidence of resources, or lack of bereavement resources for the participants' lived experiences were considered using a descriptive phenomenological approach. Our appreciation of the continuing bond between mother and child compels us to believe that there is an ethical obligation to reduce and remove these barriers and inequalities in bereavement support services for those who live rurally and have experienced perinatal and infant loss. Results of this study indicate the need for further study and establishment of bereavement resources in rural outreach for perinatal and early childhood loss.

Keywords

perinatal loss, rural, early child loss, bereavement care

Ultrasound, or sonogram, uses high-frequency sound waves to image an embryo/fetus and/or the reproductive organs of the mother. These tests are used throughout pregnancy to evaluate the mother for any malformations or

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problems with the uterus, and so forth and to ensure the embryo or fetus is developing properly. In the majority of pregnancies, routine ultrasounds result in happy moments and sweet images to share with others. By contrast, when serious anomalies are identified, prospective parents are referred to various medical centers for information, diagnostics, and the determination of termination or delivery (Cøté-Arsenault & Denney-Koelsch, 2011). Although medical intervention is difficult even when the parent(s) reside close to the medical facilities, the added stressors of commuting, "living out of a suitcase," or at an extended hospital stay away from family and friends is often traumatic. The mother is commonly separated from her other children and other sources of community support. Visitors are infrequent when the hospital is miles away from their home. Fathers may be tasked with financial or childcare responsibilities that prevent an equal presence at the hospital with the mother or fetus/child and unequal support from hospital staff when they are present (Noergaard et al., 2018).

And what happens upon the death of the baby? In the United States, annual perinatal deaths occur at a high incidence (Limbo et al., 2016). Whether the cause is a fetal anomaly that is incompatible with life or an undiagnosed complication of pregnancy or delivery that results in death, shock and grief are immediate and overwhelming. Research shows that grief following a perinatal loss or a terminal condition upon birth is not only immediate and intense but also disenfranchised (Cacciatore & Bushfield, 2007; Coté-Arsenault & Denney-Koelsch, 2011; Leichtentritt & Mahat-Shamir, 2017; O'Leary & Warland, 2016). Social workers or bereavement coordinators may offer gifts, casts of the baby's feet, handprints, and photos. An invitation is often presented to attend a support group and receive aftercare bereavement services. The bereaved individual or couple might need to arrange for childcare and then drive several hours each way to a hospital setting for a grief support group that lasts for 1 or 2 hours. The burdens of travel, isolation, and challenges of arranging care for other children may add to the intensity during acute grief. Alston and Samuels (2014) note the lack of resources, visibility, and leadership for perinatal care, despite the number of perinatal or neonatal deaths. Further, the U.S. Department of Health and Human Services (HHS), (Centers for Disease Control [CDC], National Center for Health Statistics (NCHS), 2017) found higher incidence of infant mortality in rural areas versus large urban counties and medium urban counties. Overall, infant mortality was 6.55 per 1,000 live births in rural counties compared with large urban counties of 5.44 per 1,000 live births.

Resources in rural areas are commonly limited to a family practitioner or other individuals who have experienced similar losses, assuming those individuals with a prior history of loss have been identified and are willing to offer support to those experiencing recent loss. Rural grief support groups are rare relative to the other types of support groups available, and due to the lower numbers of participants, these groups are usually overinclusive and comprised of individuals who have experienced any type of death loss rather than targeted for a particular type of loss. Therefore, isolation is an even more common theme for these mothers (Cøté-Arsenault & Denney-Koelsch, 2011).

In addition, there are distinctive features of grief that are often overlooked or dismissed by a community and even by other family members. These features include the assumption that a pregnancy loss or perinatal loss does not indicate a relationship, and the death of a baby or a pregnancy loss is frequently not recognized and validated by society. Worden (2018) addresses this dismissal of loss as a *socially negated loss*, leaving the parent with what Doka (1989) refers to as *disenfranchised loss or grief*. Perinatal loss is a death; hence, any traditional parameters for ambiguous loss are not appropriate for grief following these deaths. Instead, the grief is frequently disenfranchised grief, as the loss is often dismissed or hidden. Inati et al. (2018) noted high incidence of posttraumatic stress disorder and complicated grief in perinatal loss in an Australian population. In addition, research suggests the presence of *continuing bonds* indicative of relationship between the mother with the developing embryo or fetus (Leichtentritt & Mahat-Shamir, 2017; O'Leary & Warland, 2016; Robinson et al., 1999). The bond of a baby in utero with mother begins very early in the pregnancy (O'Leary & Warland, 2016), and those continuing bonds are present throughout the pregnancy, thus resulting in grief upon death.

These early losses can lead to a lifetime of yearning and *what-ifs*. The grief is the loss of future, an absence of precious memories. There are no picture boards at the funeral, *if* there is a funeral or memorial. General grief support groups often use the inclusion of memory sharing activities. For parents grieving perinatal, infant, or early child loss, the memories are scarce, and there are very few memories that others outside of the parents can share. Due to the overlap in lack of time spent with the living child, there is commonality in some of the parents' experience of the loss. For example, when a 45-year-old dies, there are stories and memories from others that, if shared, may offer comfort and balm to the bereaved. However, when a pregnancy ends in miscarriage or stillbirth, parents have little or no memories or stories, and those memories were future-oriented (dreams of bringing the infant home, rocking them in the nursery, and so forth). Similarly, if the infant or child dies young, the parents have a limited repertoire of memories from themselves, or others, from which to draw comfort. Commonly, death rituals are dismissed for perinatal loss, infant, and early childhood deaths; the grief often becomes a private time of bereavement, held in isolation. The death is an actual loss for the parents, not just of the living being but of the potential legacy of who the child would have become.

The relational nature of continuing bonds of mother and baby in utero should not be dismissed. The evidence of early bonds between mother and child was established by Bowlby (1969) in his seminal work on attachment theory. Others have contributed to the research affirming the bond that is formed in pregnancy and continues as a lifelong bond (O'Leary & Warland, 2016; Robinson et al., 1999). Stroebe et al. (2005) posit preexisting relational bonds. Robinson et al. (1999) suggest that the relational (or continuing) bond exists as early as the planning of the pregnancy. Further, we argue this research could assert that the bond continues, with parents who suffer an intense grief reaction upon milestones that would have been reached if the child had survived. O'Leary & Henke (2017) address the presence of the continuing bond and attachment and its influence and effect on a subsequent pregnancy after a perinatal loss. Through education and clinical therapy, O'Leary and Henke present the effectiveness of adjustment and bonding as the parents work on their relationships with both the baby who has died and the promise of the bond inherent in the new life.

The primary focus of research in perinatal care and loss examines the hospital experience (Cacciatore & Bushfield, 2007; Kendall & Guo, 2008; Kobler et al., 2012) and has studied populations within major medical centers or specialized health-care services, such as children's hospitals. Emphasis on infant palliative care is supported by perinatal education and training for health-care professionals, including building relationships with the parents, guidance in the medical changes, and providing compassionate care, which are not outcome-dependent.

The literature on rural health care has noted a dearth of specialized programs or interventions in rural areas (Lawhorne et al., 1990; Nesbitt et al., 1989). Lawhorne et al. (1990) noted four specific challenges in addressing rural obstetric care, including (a) the impact of perinatal loss, (b) distance to care and cost of that barrier, (c) the overall effect of loss of health-care services for women and children, and (d) the regionalized effects of perinatal care. Nesbitt et al. (1989) found that, compared with urban residents, those in rural areas experience inadequate health care and resources coupled with social and economic factors that hinder access to care.

Recent studies have confirmed these earlier findings. Hung et al. (2017) conducted a 10-year study of availability of obstetric care in rural communities, noting a 9% loss in rural health-care services over the years 2004–2014. An associated study presented findings of the lack of access to rural care for pregnant mothers and the link to negative birth outcomes detailing the increased incidence of out-of-hospital and preterm births in rural areas without obstetric services (Kozhimannil et al., 2018).

Kozhumannil et al., (2018) found, there was a 24% absence of obstetrical care in rural counties of the United States in 1985, and that number has increased to a current absence of obstetrical care in 44% of rural counties. The Minnesota county used as the setting for this study had an absence of obstetrical services for a period of more than 10 years. The lack of accessible obstetrical care in rural areas is closely linked with an absence of bereavement care for losses associated with obstetrics.

In general, continued bereavement care after the loss of an infant has been available primarily at major medical centers. Outreach from major medical centers to rural services has typically been through one or two telephone calls, with no additional follow-up or referral to other resources. There are often many bereavement services at hospitals and urban centers, yet the continuity of care for the bereaved is not as accessible to those who live in rural areas. Resolve Through Sharing® (Wilke & Limbo, 2012) is unique in offering training for health-care professionals, and their training in bereavement care equips health-care professionals to provide compassionate care and relationship with the parents of perinatal and young child death and dying. The organization encourages the establishment of parent support groups and offers training in grief support facilitation. Other interventions created to address perinatal losses over an expansive geographic area including online grief support groups have found some success (O'Leary & Warland, 2016). These groups do not specifically address rural areas. These efforts are commonly offered with live video and audio conversation online. The internet bandwidth in rural areas often fails to have the capacity for participation in these outreach groups.

Purpose of the Study

The purpose of this pilot study was to identify the resources or lack of resources for bereaved mothers who live rurally. To be eligible to participate, participants were to have been mothers who had experienced a pregnancy loss, sudden infant death syndrome (SIDS) death, stillbirth, infant loss younger than 1 year of age, or the death of a young child (younger than the age of 5) who was diagnosed with significant health concerns noted at the child's birth. The sample included a scope beyond perinatal loss as several mothers had experienced multiple losses, and question parameters were used to capture all pregnancy, infant, and early child losses. The study sample participants are from a rural setting where there are limited, or no grief support resources. The research was conducted to assess the need for additional services and highlighted what interventions have been helpful and what still remains a significant need for resources for the rural area. We acknowledge the immediate family (spouse, children) and their roles in grief and loss; however, this was beyond the scope of our research.

Methods

Recruitment

Following institutional review board approval, 15 women were contacted by email and invited to participate. An appointment was made with each of the 10 women who chose to participate. The principle researcher read the informed consent to the participant prior to the interview, and both signed the consent form. A copy was given to the participant, and an additional copy was retained by the researcher. The principle researcher conducted each personal interview that was recorded on a digital recorder, transcribed, and coded to protect confidentiality. The responses of the participants were examined to determine common themes using phenomenological theory to explore and attempt to understand their lived experiences with grief and loss.

Sample

This study was a qualitative descriptive phenomenological study with a convenience (nonprobability) sample, using grand-tour questions and probes. To be eligible for participation, participants had to be mothers who had experienced a pregnancy loss, SIDS death, stillbirth, infant loss younger than 1 year of age, or the death of a young child (younger than the age of 5) who was diagnosed with significant or terminal health concerns noted at the child's birth. The principle investigator has been providing peer grief support, informally and free of charge, to women who had suffered perinatal, infant, or small child loss and who had been referred to her by community members and pastors. The specific region is a sparsely populated, wooded area. Socioeconomic challenges are often the norm for this area, with a lack of full-time positions and underemployment. This small group ($N = 15$) of women comprised a potential sample for the study, and each woman was invited to participate. Participants were contacted by electronic requests on the internet. The participants were not compensated for their time and participation. All participants signed an informed consent form, giving permission for digital audio-recording of the interview.

Interview Guide and Procedures

The principal investigator conducted individual in-person interviews that were recorded on a digital audio-recorder (with consent), and a transcript of each interview was created and secured. Interviews were conducted primarily in the homes of the participants, with a few exceptions using public places with private rooms. Every effort was taken to provide privacy and confidentiality. All transcripts were coded, and no names were included in the transcripts.

The interview guide consisted of grand-tour questions or open-ended questions, allowing room for follow-on probes. Every effort was made to keep the experience conversational. The participants were initially asked about their age and marital status at the time of the loss, what kind of loss they had experienced, the age of the child at death, whether the death was gestational or after birth, and whether the participant had experienced the death of another young child or infant. They were asked to identify any barriers that existed with respect to seeking out professional grief support services.

Losses were delineated as shown in Table 1.

Table 1. Definition of Loss Parameters.

M = Miscarriage	Loss <20-week gestation
PL = Perinatal loss	Loss at 20-week gestation <1 month old
IL = Infant loss	Loss >1 month old and <1 year
Child = Child loss	Loss > 1 year <5 years, diagnoses with anomaly or disease at time of birth or in utero

The interview proceeded with questions about the experience of care the participants had in the hospital following the death/pregnancy loss, whether resources or information about grief and loss were offered, and if these resources were perceived to be helpful. Participants were asked if they were provided with information about grief support services located in their rural areas. If yes, they were asked what resources were available and whether they were perceived to be helpful. Participants were then asked what, if any, local resources (i.e., support groups, counseling, church/spiritual support) in their rural area were helpful in their grief journey. Next, participants were asked if they could identify what types of resources might have been more helpful, and was there anything about that time period, particularly with respect to the grieving process, they would like to share.

Demographics

This study included 10 participants, as 5 women elected to not participate in the research. All of the women in the sample had experienced early child losses when the mother was between the ages of 18 and 42. Half of the participants experienced multiple losses including miscarriages, stillbirth, and complicated pregnancy. The majority of the participants were married at the time of the loss or losses, with only one stating she was single. Only one woman went to private counseling. Barriers to their attendance in bereavement care included cost, inconvenient location (too far to drive), inconvenient time, no knowledge of available services, and the lack of childcare for their other children. Losses in this sample included 13 miscarriages, 1 SIDS, 4 perinatal losses, an infant loss, and 3 children who died from fetal anomalies or diseases diagnosed at birth.

Results

With respect to their experiences in the hospital after the death/pregnancy loss, participants who experienced pregnancy loss/miscarriages noted a lack of psycho-social-spiritual support for their well-being. Most women felt the procedures or examinations were clinical in nature and failed to acknowledge the life and death of the moment. Participants commented that they were basically "just a patient," and one participant was told, by a nurse, that "it wasn't really a baby yet." This same participant regretted not looking at her baby, but the nurse told her that the baby "didn't look right" and discouraged her from looking. Another participant said that no one offered her the opportunity to hold or see her baby and now wonders what it would have been like to hold the baby, even wrapped in a blanket.

These experiences contrast significantly with participants who experienced live births or young children's deaths. The prevalent themes for mothers who experienced live births were a memory of compassionate care for both the baby and the mother. The practice of taking photos, making handprints and footprints, clipping a lock of hair, and creating memory boxes were very helpful to these bereaved mothers. The SIDS mother received clinical care in attempting to resuscitate the infant, yet there was no continued care from the rural hospital. Each of the other losses happened at specialty hospitals to the north or south of the area, a drive of 70 to 100 miles each way. It is evident that the specialty hospitals were prepared and trained in caring for perinatal and infant losses, and the care these participants received was better. These participants overwhelmingly noted both the care for the child as well as the care for the mother.

There was a clear distinction in compassionate care between pregnancy losses and infant losses. Many of the participants had multiple losses and were able to articulate the differences, noting the relative lack compassionate care for the pregnancy losses versus the infant losses. The pregnancy losses, specifically in miscarriage, were dismissed as clinical procedures. In these instances, this experience contributed to the participants' disenfranchised grief and guilt.

With respect to whether participants were offered resources or information on grief and loss, two mothers recalled being given a pamphlet or a folder of information. Neither used the material, and both discarded the paper(s). One mother reported,

> I don't think there was a lot of support . . . there was a support kind of understanding what was going to happen and going through the loss, but once the loss happened I left like 'ok, here you go - you can go home. [I needed more] than just the pamphlet and here you go.

Although it appears health-care professionals have hard copies of available resources that are given to patients being discharged, the resources offered are not geographically reasonable for most rural women who live hours away. Many of the participants could not even recall if they were given a folder of resources, and those who remembered being given resources received them at the time of discharge, which is a moment of significant acute grief. These mothers are leaving the hospital or medical facility without their infant in their arms and will never again be present with, or hold, their infant. Although the parent(s) may have been offered resources (pamphlets, phone numbers, etc.) upon hospital discharge, the juxtaposition of having to prepare to leave the hospital, as though everything is *normal*, versus their affective experience of leaving, renders any offer of information useless, and unhelpful. Many of the mothers reported feeling crippled by grief, in a fog of guilt and shame. The women in our study recommend offering a resource conversation later, not at the moment of discharge from the hospital, and to include resources that are within their geographic area.

Memoirs of similar losses and online blogs were mentioned as helpful, but most participants experienced a strong sense of isolation. Several indicated they would have welcomed a follow-up telephone call or note. The majority of participants expressed an overwhelming need to have continued contact with someone who had a similar experience and emphasized the importance of receiving this kind of initial care while still at the hospital. Most study participants would have appreciated the opportunity for a support group of bereaved mothers with similar losses in an accessible geographical area.

Participants were asked if they used any online grief support resources, and three of them reported they had. Some reported using Facebook or chat rooms to find connections with others who had similar diagnoses or death experiences. One woman made a friend that she talks to casually, yet the others did not find significant connections. Another used grief websites that offered information and blogs. None of the women in the sample were involved in online support groups, and, in fact, most had no knowledge of that option. For this sample, online grief services were not considered particularly helpful.

With respect to resources in their local rural communities, participants noted a lack of local bereavement resources. Only two women went to grief support groups, but only briefly, as it was too far to drive and they did not have childcare for their living children. About half of the respondents noted their church or spiritual home was helpful. Several also mentioned the help of friends and family as a supportive network. One participant shared this:

> . . . I do remember, in particular, it was specifically [two women] that really helped me to push through that time. These women both had experienced losses and I thought, you know, [they] were very strong women and even though I felt lost and hopeless at that time, if you guys could make it, I knew I could make it. So that was huge for me.

Yet not all perinatally bereaved parents experience social support. In contrast, another shared that most of the people she encountered simply dismissed her loss with platitudes and a lack of empathy. She noted one individual who actually acknowledged her loss. “I remember someone who came over and gave me a card saying something about the death of my daughter. It said something like ‘every life matters.’ I kept that and it was so helpful, because at least someone understood.”

There was a consistent and prevalent theme of how important it was to have a supportive relationship with someone who has experienced a similar loss and to have one's grief acknowledged by another person. The theme of isolation and disenfranchised grief was experienced by all participants in this sample. The participants expressed strong needs for both support groups and a resource for face-to-face individual care.

The participants all noted a need for a local support group for mothers who have similar experiences. Further, they were seeking a group with specificity to their type of loss. All participants indicated that a group that addresses pregnancy loss, SIDS, perinatal loss, and early child loss would be most beneficial.

> A support group would have been huge. From my experiences of mixed grief groups as soon as you say, I am here 'cause my 2 ½ year old daughter died, it's like people shut down, cause they are comparing. . . .I think [about] . . . how having support would have impacted me.

As stated earlier, participants indicated that it would have been extremely helpful if there had been someone at the hospital who had lived through the experience of perinatal/infant loss. Further, the participants noted that *continued* contact with someone who had a similar loss would be particularly helpful.

> Primarily someone to normalize my grief, whether that were an individual or especially if it were a group of some sort, but that sense of isolation and not feeling like what you were feeling was normal, that's probably the hardest piece to be, to get out.

This mother noted, " . . . you shouldn't have to go and find it. It should just . . . be there or have a counselor come in, you know, that day or even a couple of days later." The prevailing theme of the data centered around normalizing the experience of the loss and the grief that follows. Geographic limitations and distance only serve to exacerbate and magnify the frustration and isolation of grief.

Discussion and Recommendations

A number of themes emerged in this study and will be discussed in turn. Again, seeking common themes through the voices of these mothers, we attempted to share voices from every participant, taking care to include the most salient responses.

Camaraderie and Social Support

First, there is a search for camaraderie, for another person or a group who can speak to these socially negated losses and disenfranchised grief. The burden of bereavement can be lightened if mothers do not have to face the path in isolation and guilt. Especially with respect to miscarriage, it is critical to name and acknowledge the experience as a death and a loss. The dismissal of miscarriage as an act of some deity or a simple negation that it was a life must cease. As one participant noted,

> I wish they would have given me affirmation that it was a loss. If someone, anyone [in the hospital] would have said that I had lost my *baby*, that would have been helpful. Instead it was all about the clinical stuff, the procedure.

The continuing bond between a mother and a baby begins early in the pregnancy, and for some, it begins in the planning of a pregnancy, yet the bond between parent and developing embryo/fetus seems ignored by medical caregivers during or following a miscarriage. Educating medical staff about perinatal loss and grief, and arranging for a peer-to-peer support person in the hospital, could offer women an important level of support.

Clearly, grief within a state of isolation is particularly challenging. Women who live rurally already may have a sense of isolation, especially if they have small children and have elected to be a stay-at-home mom. Compounding isolation with a perinatal or pregnancy loss with the absence of caring adult conversation is deafening. “Oh, just, I did feel very alone because they were my support group, the medical team. So, it was, yeah, of course [it] was gone then. That was hard.” This mother speaks of her children who were born with profound physical anomalies and needed 24-hour care. The support for the mother was the health-care professionals who came to her home. After the children died, the support was gone, and she was isolated in her grief. A local bereavement program that could have addressed her needs would have been helpful in her experience. The physical terrain of wooded areas and sparsely populated region of this rural area further compounds the isolation.

Grief Education

The need for education and options at the time of death can be met by a trained bereavement program team, specifically for these early losses. This participant lives with regret and guilt over her choice:

> The one thing . . . um . . . when it happened they brought her to us. They brought her to us to hold her until she passed away, when she was going to die. I got to a certain point where I was afraid of watching her turn blue and all this and that and I had her taken away. I didn’t want that memory and then I wished that she had been brought back to me. She wasn’t . . . and I live with the regret that I didn’t keep her. . Some nurse did that for me and I didn’t. I feel like I let her down.

It is commendable that the nurse brought the infant to be held by the parents. It is possible that this mother might have made a different decision if she had access to information about what to expect in this type of situation, thus lessening her fear. Instead, this mother harbors guilt, in addition to and compounding her experience of grief.

Grief Support and the Need for Meaning

Finally, these mothers are left without guidance in how to find meaning in their grief, and the life of their child. One participant, whose continuing bond with her son is palpable, shared her quest for meaning after her son's death:

> It's so hard because people . . . nobody met [the baby] so it doesn't, to me I think it's nothing to anyone else, because nobody met [the baby]. I got to see him in the ultrasound every week for twenty weeks. I got to know his personality, that he was a fighter and that he was keeping on, you know, that kind of thing. And nobody else knew him and to treat him as if he was a person . . . that's what I think I needed - that other people acknowledge him and talk about him by [his] name . . . maybe also guidance on how to honor his life more because I feel like what I am doing today is something that is good that's coming out of it and I wished I could have done more of these kind of things; things that kind of bring positivity to the experience.

Limitations

Limitations of this study include a focus on a specific small rural area of east central Minnesota. Further, the study had a narrow focus. Some bias must be considered as the principle investigator had prior knowledge and relationships with the individuals comprising the study sample. The study was conducted after an exhaustive search for studies of perinatal loss in rural U.S. populations. Further research in other rural areas is needed. In addition, a similar study with the father or other parent is also indicated. A replication of this study examining other rural areas across the United States could offer a clearer, detailed understanding of the needs of rural mothers who grieve these early child losses and allow us to determine if these mothers' needs would generalize across demographics.

Conclusion and Implications

This pilot study illustrates a need for rural perinatal bereavement care for mothers who have suffered miscarriage, SIDS, perinatal loss, infant, and young child loss. The women reported primarily positive experiences at the hospital when the loss was of was an infant or child. A very different hospital experience was noted by those in pregnancy loss/miscarriage. Moreover, the women in the study noted isolation, disenfranchised grief, and lack of recognition of their losses. The stories of the women underscore the need for free, local, grief support groups dedicated to these similar losses. Further, we found that childcare for the surviving siblings is also a vital component if we are to remove barriers to their participation in grief support groups or individual counseling/treatment. Resolve Through Sharing® may fit one model of the group; however, there are not enough trained individuals in our rural hospitals. Consistently, in rural areas that have a lack of obstetric services, there appears to be a corresponding absence of bereavement support services. Through this study, we have attempted to capture the bereavement experience for parents, and their ongoing needs, in consideration of the lack of access to care. In summary, it is evident that a professional who has experienced a similar loss could, with appropriate training and education in grief and loss, provide support and education to the grieving mother. The need for specified support groups in rural areas is emphasized.

For example, a rurally based and strategically located program, focused on addressing the anticipatory grief and the inherent loss in a lethal diagnosis for a fetus, or fetal loss, could be established in rural hospitals or in community or county settings, possibly using an extension model. Support might be provided by land-grant universities, urban health-care organizations, or county governments. A single well-educated individual could manage such a program over multiple rural counties, training local volunteers and peer support persons to offer supportive care to families confronting lethal fetal diagnosis or fetal loss. Program staff and volunteers would provide those experiencing pregnancy and neonatal loss with individual support and support groups.

Compared with those who live in resource-richer areas, demographic disparity in bereavement services will continue to complicate healing and recovery for parents who live in rural areas. Our appreciation of the continuing bond between mother and child compels us to believe that there is an ethical obligation on the part of the health-care community to reduce and remove these barriers and inequalities in bereavement support services for those who have experienced perinatal and infant loss. Bereavement programs specific to perinatal loss are imperative to reducing parent distress and increasing psychological functioning and well-being. Education and advocacy for perinatal loss should be part of such a program, and based on the experiential reports of the mothers we interviewed, we strongly recommend inclusion of a multitiered approach of support, referral, education, and advocacy. Advocacy and education for the community and training for others who work in health care should be offered regularly, including hospital staff and administrators. Coordination with funeral homes, hospitals, social services, and places of worship would further support those in the area who are experiencing perinatal and infant loss. Death education in a death-denying society would be helpful for future generations in community or academic settings (Scimecca, 1978); however, our study is focused on women who are actively grieving; thus, this generalized death education is not particularly meaningful or applicable. The goal of this study was to explore and describe the needs of bereaved mothers experiencing pregnancy, perinatal, and early child loss who live rurally to explain the disparity in bereavement services in rural areas and to offer a prediction for programs that would help to reduce disenfranchisement or complications that might inhibit grief processing and, ultimately, psychological healing.

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