From Seed to Tree: Developing Community Support for Perinatally Bereaved Mothers

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ABSTRACT

Despite burgeoning evidence on the positive effects of perinatal loss support groups, some communities still lack such services. Those wishing to begin a support group may find the task daunting, especially if there is little support for their efforts. In this article, the authors discuss the development of a pregnancy loss support group, which included a community assessment, launching a pilot program, and providing training for facilitators. Other practical considerations will also be reviewed, such as finding a location for the group and securing funding for advertising.

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BACKGROUND

Every year in the United States, nearly 1 million women experience pregnancy loss (Ventura, Abma, Mosher, & Henshaw, 2009). Some women experience depression, anxiety, altered family and social relationships (Van den Akker, 2011), and emotional and physical symptoms of grief (Hsu, Tseng, Banks, & Kuo, 2004; St. John, Cooke, & Goopy, 2006). Those who experience such distressing symptoms often reach out to others for support and comfort (Wright, 2010). However, many perinatally bereaved women have reported that their grief was not adequately recognized by friends or family members (Gold, Boggs, Mugisha, & Palladino, 2012), which left them feeling emotionally abandoned.

Perinatal bereavement is a unique mourning situation because parents' expectation and joy at the

prospect of a new life change into despair and grief. To facilitate a normal grieving process among bereaved families, the nurse should be equipped with adequate knowledge, a positive attitude, and skill in rendering such care (Raddi, Samson, & Kharde, 2009). Unanticipated perinatal losses and fertility barriers challenge emotional well-being (Price & Mcleod, 2012).

One way for women who are experiencing perinatal grief to find support is to attend a pregnancy loss support group where they can express their grief in a safe and supportive environment (Coté-Arsenault & Freije, 2004). This type of social support is crucial in reducing the rawness of the grief experience (Cacciatore, 2007). Specifically, pregnancy loss support groups provide support, education, and resources and encourage "positive resolution of grief" (Carlson et al., 2012, p. 278).

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Online pregnancy loss support groups and message boards are also beneficial to bereaved women in that they help bereaved women feel less alone in their grief. Women who use online message boards to connect with others who share their experience report different benefits from those gained through face-to-face groups. In some cases, women felt freer to talk without becoming visibly emotional and without having to deal with the “pitying stares one can get face to face” (Gold et al., 2012, p. 70). The flexibility of accessing support anywhere at any time was also seen as an advantage to online message boards (Gold et al., 2012).

Although many types of support groups exist to provide a mechanism for connecting with others who have a shared experience, perinatal loss support groups are unique in that the types of losses that are discussed are “invisible losses,” meaning that they are not generally shared or recognized by others (Paul et al., 2010). Because the benefits of support groups is well documented, the authors set out to develop structured support for perinatally bereaved women. After determining whether a community need existed, it was important to determine whether women in the community were interested in attending a group face-to-face or online.

Community Assessment

The community assessment was conducted to examine the scope of perinatal loss in our area and to help us gain a deeper understanding of the number of families in our community who have been affected by pregnancy loss. Perinatal and infant mortality statistics were reviewed for the two counties that would be served by the support group as well as vital statistics of the population. The birth rate in the two counties is lower than the statewide average, but the infant mortality rate is higher than the national average (March of Dimes, 2010). Both counties are urban and have a combined total population of more than 500,000 residents with a median household income of \$44,240. Approximately, 14.5% of families

are living below poverty level in both counties, which is higher than the state average (U.S. Census Bureau, 2010a, 2010b). Because low-income women have poorer pregnancy outcomes and less access to care than women in higher income households, a free support group would be a crucial service for women in our community, particularly for those who did not have the resources to seek private counseling.

Pilot Wellness Program

The data indicated that a great number of families had been affected by pregnancy loss and that a free perinatal support group might be helpful. However, we needed to determine whether there was an interest in such a group within the community. To this end, we developed a pilot project offering a six-session wellness program for women who had experienced pregnancy loss. The topics of the sessions were nutrition, stress management, art therapy, time management, body image, and mindful meditation. Grant funding supported speakers and refreshments. The attendees indicated on their evaluations of the program that they would like to attend a perinatal loss support group. Such a forum, they said, would help them to form connections with other women who had suffered similar life events and would help them to normalize their grief. With the community need established and an interested group of women identified, we developed a plan to launch the perinatal loss support group.

Components to Consider When Developing a Support Group

Several decisions were made regarding the structure of the group. First, we decided that the group would run independently of the local health-care systems. This decision was made because there are two large health-care organizations in the area and neither organization could lend adequate financial support in terms of advertising because the group would not generate any revenue. However, one organization allowed the group to hold the monthly meetings in its facility without charge. The meeting place is not within the hospital that provides women’s and children’s services, the facility where most women would have sought care after a loss or experienced a loss during labor or shortly after birth. This decision was made purposefully so that women would not have to revisit the facility where their losses occurred to attend the group meetings.

One way for women who are experiencing perinatal grief to find support is to attend a pregnancy loss support group where they can express their grief in a safe and supportive environment.

Such sensitivity to factors that trigger or exacerbate perinatal grief is vitally important. Coté-Arsenault and Freije (2004) pointed out that it is especially important for perinatal loss group facilitators to be open, caring, approachable, and sensitive. Educational programs designed to provide cutting-edge information about supporting families through pregnancy loss such as Resolve Through Sharing training have been helpful in sensitizing staff members to the unique needs of bereaved families (Gibson, Finney, & Boilanger, 2011). Thus, all of the facilitators who worked with the support group attendees completed this training.

Another important decision was to determine a name for the group. Because we had already decided to use the Pushing On Theory of Maternal Perinatal Bereavement (Wright, 2010) as a guiding framework, we named the group “Pushing On: Support for Moms After Pregnancy Loss.” With the name and infrastructure established, we applied for and received internal grants offered by two universities to support advertising and training for the facilitators.

Getting the Word Out

Grant money was used to hire a graphic artist to design a logo for the group. Pamphlets and posters bearing the logo were developed and described the purpose of the group, meeting times, and locations. Each facilitator visited local obstetric offices to share information about the group and to deliver pamphlets and posters. Most of the support group attendees learned of the group in this way. The women also visited the group’s website prior to attending meetings to gain more information.

The website (www.pushingon.org) was developed by a webmaster who posted information about the meeting times, locations, how the group was established, and educational resources for perinatally bereaved women. The webmaster also used several free applications to help promote the group. For example, a Facebook page was established for the group, and one of the group moderators posts messages periodically about the group or about dealing with grief, as appropriate. Interestingly, several members of the support group shared that they did not “like” the Facebook page because they did not want their Facebook friends to know that they had suffered a loss. However, they still visited the Facebook page for information and supportive messages.

A Gmail account was established, which was forwarded to one facilitator but could be accessed by all. This allowed us to answer any questions a new member might have. A Google phone number was established so that if facilitators change in the future, the phone number would remain the same. A Google Voice account was linked to the Gmail account so that all facilitators could access voice messages as needed.

Local newspaper coverage provided an excellent venue for informing the community about the bereavement group. We placed an announcement in the “Community Events” section and also submitted an editorial about pregnancy loss in the month of October, which is designated “Pregnancy Loss Awareness Month.” In addition, a facilitator was featured in an article about women’s experiences of pregnancy loss and the development of the support group. Articles about the support group were also submitted to internal publications at the facilitators’ workplaces to raise awareness about the support group among fellow employees. Increases in group numbers were realized from each of these efforts.

DISCUSSION

Preparing, coordinating, and planning are essential components when developing a support group. The location of the meeting, day, time, and who will be facilitating need to be determined. Bereavement training for each facilitator was invaluable. The training provided a rich education experience that enhanced our knowledge, skill level, and personal awareness as we planned for and provided support to mothers who experienced perinatal loss.

Getting the word out in multiple venues is essential. Having a dedicated website offered mothers who were searching for support the ability to find our group. The website was also a centralized place with meeting reminders and resources for mothers to access. Pamphlets enabled offices and hospitals to provide information about the bereavement group to mothers in need. Newspaper articles provided exposure on a large scale to readership in our area, helping to promote discussion about the support group.

Collaboration among the facilitators was important in keeping all parties informed about who was coming to the meetings and the challenges the mothers were facing. The mothers who participated in the group consistently expressed their appreciation for the group.

CONCLUSION

Over the past 2 years, approximately 20 women have attended the support group. Many of the participants have formed social relationships with fellow members and remain in touch between meetings. Meetings are generally viewed as beneficial by the attendees. In addition to attending the group meetings, some women also sought private counseling for additional support. Facilitators were able to make recommendations for counselors as requested.

Development of the support group provided a resource for bereaved mothers who were acutely grieving and who sought the support of other women who truly understood their pain. It is noteworthy that the facilitators noticed that numerous women tended to attend the group meetings for a while, then moved away from the group. We believe that women come to the group in need of support, and as their pain becomes less raw, they stop attending. This pattern is consistent with the Pushing On Theory of Maternal Perinatal Bereavement (Wright, 2010), which was used as a framework in establishing the group. The theory also indicates that like other forms of grief, the pain of the loss reemerges over time in the form of longing, or "regrieving." Thus, women who have moved beyond the initial pain of pregnancy loss still need to work through numerous periods of regrieving and may return to the group for support at any time.

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