

The role of emerging technology in women's response to pregnancy loss

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Evaluation of: Gold KJ, Boggs, ME, Mugisha E, Palladina CL. Internet message boards for pregnancy loss: who's on-line and why? *Womens Health Issues* doi:10.1016/j.whi.2011.07.006 (2011) (Epub ahead of print).

Women who experience pregnancy loss are frequently turning to the internet for information and support, making it critical to understand the impact of online communication forums as emerging technologies, including patterns of utilization, perceived benefits and iatrogenic effects. An anonymous internet survey posted on 18 active US message boards related to pregnancy loss revealed that the 1006 respondents appeared different to the epidemiologic distribution of women with pregnancy loss in that most were white and highly educated. Most reported great satisfaction, stating they had learned new medical information from the boards, felt less isolated and more validated in their loss and grief and valued the unique features of online communication (e.g., privacy, anonymity and convenience). In addition to research assessing usage, utility, functionality and impact of internet resources for pregnancy loss, an examination of racial and cultural differences in coping with pregnancy loss and internet-mediated support, and opportunities for telemental healthcare are warranted.

KEYWORDS: bereavement support • internet • message boards • miscarriage • pregnancy loss • social support • stillbirth • support groups

Pregnancy loss is the most common adverse pregnancy outcome in the USA, with approximately one in six pregnancies ending in miscarriage (fetal loss prior to 20 weeks completed gestation) [1] and one in 160 deliveries involving stillbirth (loss after 20 weeks completed gestation) [2]. Racial disparity also exists. Specifically, black women in the USA have a 2.2-fold increased risk of stillbirth relative to white women, with factors contributing to risk varying by gestational age [2]. There are a variety of psychological responses that often include sadness, distress, grief, guilt, self-blame and fear (for example, see [3]). The severity of symptoms ranges from mild to severe, with some women grieving intensely for extended durations. Evidence from controlled investigations of psychological morbidity demonstrates that pregnancy loss is a risk factor for depressive and anxiety symptoms and disorders (for example, see [4,5]).

In many cases, despite their frequent occurrence, pregnancy losses are often both hidden and 'invisible'. Societal recognition of pregnancy

loss, particularly early miscarriage, as a valid loss to be mourned relative to other deaths is limited, and the potential psychological significance to an individual woman is often minimized. Even medical providers may not legitimize the loss experience or be prepared to provide the needed support, information or referrals, that can contribute to women's dissatisfaction with post-loss care [6]. The lack of recognition of the loss and absence of appropriate post-loss support may confer increased social isolation and further distress.

In recent years, internet technology has emerged to provide a resource for health information-seeking and support, most frequently utilized by women and medical populations [7]. The unique features of the internet offer possibilities for engagement in psychoeducation, bibliotherapy, written emotional expression and group-based formal and informal communication and social support. Opportunities for informational, social and emotional support exist in a number of formats, such as informational websites and

interactive communication forums (e.g., message boards). While in-person support groups successfully provide support [8], they often are not accessed or available. Specific features distinguishing computer-mediated support, such as constant availability and convenient access to similar others from the privacy of one's own home, as well as anonymous and passive engagement in support activities, controlled self-presentation and neutralization of social structures compared with face-to-face interaction (for example, see [9]), may be particularly well-suited and helpful for women who have experienced pregnancy loss and may be socially isolated and even stigmatized. The provision of reputable internet resources also may help promote patient-provider discussion, enhancing adjunctive follow-up care and providing vehicles for ongoing support for these women [10]. Research examining trends and development of internet resources to assess their usage, utility, functionality and impact are sorely needed. The recent investigation by Gold and colleagues contributes to this process [11].

Summary of methods & results

The researchers developed a 57-question, largely quantitative, online survey (using Survey Monkey®) designed to assess preferences and attitudes about the use, structure and experiences with pregnancy loss-related message boards, as well as demographics, general use of the internet, social support and depression. One open-ended question was included (“for you, what do you think is the most helpful thing about internet pregnancy loss support sites?”).

A search for large, active (defined as ‘having multiple postings per day’), pregnancy loss-related (but not exclusive to miscarriage) message boards that were primarily based in the USA identified 62 potential sites, of which 15 (with a total of 18 message boards) agreed to post a link to the survey. Stillbirth sites were intentionally oversampled, and women who had voluntarily terminated their pregnancy were included. The survey, which was anonymous and collected no identifying information, was added as an ongoing post (if permitted) or posted 1 month apart on two occasions. Over the course of 8 months in 2008–2009, 1006 of the 1039 individuals that entered the site provided complete/usable data. The majority of respondents were white (92%), educated above high school (91%), insured, native English speakers (95%), and living in the USA (88%). Approximately half had experienced stillbirth (54%) and half experienced miscarriage (46%). Time since loss ranged from the past year to over 20 years, with half (mostly those who experienced miscarriage) responding within the first year after their loss. Most women (91%) accessed the internet from home and 53% reported posting at least once a week, with 8% never having posted a message.

Overall, women expressed satisfaction with the message boards and would recommend them to others with a loss. Bivariate analysis of available quantitative data revealed that 75% thought the boards should have a moderator/leader; 89% felt a professional health worker should monitor the boards; 86% felt a mental health provider should participate; 82% reported that they learned new medical information from the boards; and 34% disclosed personal information on boards.

The authors utilized an iterative coding process to identify key themes (and codes) for the qualitative data characterizing participants' perceptions of message board benefits. Kappa scores demonstrated inter-reviewer agreement for each of 15 reported codes (ranging from 0.7 to ~0.96). The four themes that emerged were:

- “I am not alone” (e.g., close community with others with similar experiences, enjoy sharing/reading others' stories) – identified by 78% of respondents;
- “Validation and safety” (e.g., nonjudgmental, anonymous and private, helped normalize grief);
- “Internet ease and convenience” (e.g., access to individuals not available in everyday life, ease of accessibility);
- “Moving forward” (e.g., learning how to cope and grieve, gaining hope and reassurance for future pregnancies, helping others).

Discussion

Despite the growing popularity of internet-based health-related support and information, particularly among women, usage patterns and outcomes remain largely unstudied. The current investigation is among the first and largest to examine participation and experience with online support in a post-loss population and provides important information about perceptions of benefits for users of pregnancy loss message boards. Overall, participants reported that message boards helped them feel less socially isolated and provided beneficial information on coping skills, normative grief and expectations for the future. Different from face-to-face groups, they also valued the unique aspects of the internet format, such as ready access, convenience, privacy and anonymity, particularly when sharing emotional responses. The majority of women reported that they believed the board should have a professional monitor or moderator/leader and desired the participation of a mental health provider. The involvement of a professional with medical knowledge of pregnancy loss may help ensure that the new medical information many of the users reported receiving is accurate.

The authors note that the sample, although large, does “differ dramatically from the epidemiological distribution of women with pregnancy loss.” The greater level of education among message board users who participated (91% above high school) relative to the level of those in the population who have experienced pregnancy loss (52% above high school) was also noted and attributed to the greater internet use among the better educated in general. More notably, although African-American women demonstrate twice the risk of stillbirth and stillbirth sites were oversampled, there was a surprising lack of participation in virtual support by African-American women (only 2% in this study). This was unexpected given that close to 60% of African-Americans have online access. The few studies that have addressed the experience of African-American women following loss have found that the experience of grief and need for support as well as gaps in support, is similar to that of white women (for example, see [12]). The authors report that other types of online support groups

find low participation among African-Americans and speculate that a greater mistrust of medical research may have contributed to reduced response rates. While it remains unknown whether African-American women do not have a notable presence on these message boards or whether they were merely less likely to participate in this voluntary study, the authors emphasize that it is likely the former since half of respondents reported stillbirths. This issue was identified as a significant concern.

Another issue raised by the authors involves the challenges of surveying existing internet sites in terms of the difficulty gaining permission to post to their sites (only 15 out of 62 potential sites agreed), and that the use of a convenience sample recruited from the sites who granted access is not necessarily representative of the views of all users, let alone all women who experience pregnancy loss. Additionally, there may be respondent bias towards subgroups who use the participating message boards, sites which had continuous (vs intermittent) posting, frequent board users or those with strong opinions about the use of boards.

Time since loss for respondents ranged from the past year to over 20 years. Although half of participants were in their initial year of bereavement, the finding that women with decades since their loss participate on these message boards highlights that pregnancy loss is an enduring issue for many women.

Expert commentary

As indicated above, little quantitative research exists regarding the use of the internet as a support venue for women following pregnancy loss. This is also true for outcomes of health-related internet use in general, although evidence points to several positive psychosocial correlates. For example, a study of individuals with spinal cord injuries found that the frequency of internet use was associated with indicators of health-related quality of life, including social integration, occupation with goal-directed activities, perceived health status, and health compared with the previous year [13]. Consistent with the findings of Gold *et al.*, others have identified several empowering mechanisms of internet-mediated support for those experiencing health concerns, including encountering emotional support, finding recognition and understanding, exchanging information and helping others. These empowering mechanisms were found to predict several outcomes of empowerment, including being better informed and enhanced social well-being [14,15]. Users of computer-mediated support have also reported improvements in health behaviors, understanding of health issues, health-related decision-making and partner relationship quality [7]. Examination of outcomes specific to the experience of pregnancy loss are warranted.

Gold *et al.* state that the addition of online support as a component of structured perinatal bereavement programs evaluated by randomized controlled trials is on the horizon [11]. The fact that 86% of the women in their study reported wanting a mental health provider to be involved in message boards suggests that women are interested in and open to seeking online support for psychological issues. With significant advances in technological platforms, greater possibilities for remote assessment and treatment of specific symptoms, such as depression, exist. Women who

have experienced pregnancy loss who are unable, or reluctant to seek in-person treatment, whether due to symptoms, physical distance or other issues, may obtain telemental health services at a preferred location, such as their home. Such access, including connecting with medical professionals for follow-up, may help decrease dissatisfaction with pregnancy loss aftercare [6].

Current reproductive-related technology offers a number of benefits for many expectant parents, but might also contribute to psychological morbidity in the case of pregnancy loss. For example, historically, a woman who miscarried may not even have known she was pregnant. With the advent of more sensitive at-home pregnancy tests that detect not only human chorionic gonadotrophin but also hyperglycosylated human chorionic gonadotrophin, pregnancies may be detected before the first day of a missed period. This allows greater opportunity to become aware of pregnancies that may end in miscarriage, and thereby more opportunity for a range of psychological responses women may not otherwise have experienced. At the other end of the spectrum, women who have experienced pregnancy loss even decades earlier can experience enduring symptoms of grief and bereavement. Online resources are allowing access to an accepting community when those in everyday life may expect thoughts of the death to be forgotten and grief to be long ago resolved, and remote psychological services may also be helpful for these subgroups. Preliminary research findings of the effectiveness of telemental health services are encouraging, although much more work is needed [16].

In addition to the benefits, concerns about health-related internet use have emerged. For instance, the vast selection of internet resources has led to questions about their quality and accuracy [10], and the fact that 82% of the sample of Gold *et al.* reported learning new medical information from the boards brings into question the credibility of the material they are receiving and who is providing it. Quality standards have been proposed, emphasizing authorship, attribution, disclosure and currency, yet adherence to such standards is poor. For example, an analysis of fertility-related websites found that nearly 50% failed to adhere to any of these quality standards, while only 2% met all standards [17]. Reports of negative social interactions due to increased social disinhibition and anonymity also exist [18]. Additionally, the propensity to become 'addicted' to internet-based support, due to its constant and dynamic availability, has been noted among women with infertility [18].

As discussed above, a representative, unbiased sample of women with pregnancy loss may be difficult to access and engage in research for a variety of reasons, particularly the African-American community. Clearly, research is needed to understand why African-American women do not appear to utilize the internet for support in the aftermath of pregnancy loss. Perhaps they do not feel as if there is a place in the community that represents or reflects their experience, or perhaps their in-person support networks and coping activities override their need to turn to online support. Coping behaviors relevant to social engagement following loss may differ for African-American women, and spirituality and religious behavior may play an important role (for example, see [12]).

Five-year view

The near future may show an increase in research designed to understand the role of social support engendered through the internet. Additional research clearly is needed to understand the varied facets of health-seeking behavior and coping among women with pregnancy loss. Studies should continue to examine mechanisms of support and associated psychosocial and medical outcomes, as well as potential iatrogenic effects of engagement in internet-mediated support. Exploration of telemental health opportunities is likely.

Examination of the potential protective function of religiosity and spirituality for women experiencing pregnancy loss in terms of psychological morbidity, as well as the role of these factors in coping with loss, is likely to expand [19], particularly across cultures.

The near future also may see an increase in the training of professionals about the psychological consequences of pregnancy loss, as well as national certification for providers. Online training programs are available (for example, see [101,102]). The National Board for Certification of Hospice and Palliative Nurses (NBCHPN) is currently in the process of conducting a Role Delineation Study to

determine the state of practice for professionals caring for patients experiencing perinatal loss. Role Delineation Study results will be evaluated to determine the need for and feasibility of creating a national certification examination for all disciplines involved in the care of this patient population.

Recognition of the impact of pregnancy loss on male and female partners, as well as on the couple's relationship, continues to grow (for example, see [20,21]). Greater attention to the unique needs of these groups may also become more evident.

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Key issues

- Miscarriage and stillbirth are the most common adverse pregnancy outcomes in the USA, yet lack of societal recognition of pregnancy loss as a valid loss to be mourned may contribute to feelings of distress, social isolation and stigma.
- Women who experience pregnancy loss are turning to the internet for information and support, making it critical to understand the impact of online communication forums (e.g., message boards) as emerging technologies, including demographics of users, patterns of utilization, perceived benefits and iatrogenic effects.
- Overall, women express satisfaction with pregnancy loss message boards and report feeling less isolated and more validated, more informed about grief and coping skills, more reassured and hopeful about future pregnancies, and appreciate the unique features of internet communication, such as accessible, nonjudgmental, anonymous and private communication with others who share similar experiences.
- Although African-American women demonstrate twice the risk of stillbirth compared with white women, they appear substantially under-represented as users of internet-mediated support.
- Monitoring of pregnancy loss message boards by medical and mental health professionals is desired by users and may be necessary to ensure that accurate information is conveyed.
- Message board users appear open to seeking online support for psychological issues and with significant advances in technological platforms, greater possibilities for remote assessment and treatment of specific symptoms, such as depression, exist.
- High-quality quantitative research examining trends and development of Internet resources to assess their usage, utility, functionality, impact and opportunities for women and couples experiencing pregnancy loss is needed.
- In addition to professional education opportunities, national certification for all disciplines involved in the care of women and families experiencing perinatal loss, may be on the horizon.

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