Web-based Resources for Health Care Providers and Women Following Pregnancy Loss

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Experiencing perinatal loss can leave women and families feeling distressed, overwhelmed, and with many questions, while health care providers often lack time and may not be prepared to provide all the answers. This paper highlights the rationale for use and benefits of the Internet with this population and outlines an effort to review and select reliable Internet resources containing valid and substantial content specific to pregnancy loss. A summary table is included for distribution to women and providers. *JOGNN, 35,* 523-532; 2006. DOI: 10.1111/J.1552-6909.2006.00065.x

The experience of pregnancy loss can leave women and their families feeling distressed, overwhelmed, and wanting answers to their many unanswered questions. At the same time, health care providers often are pressured for time and may not be prepared to provide the support, information, or referrals for community or psychological resources that could be helpful to these patients. These two factors, combined with a lack of societal recognition of pregnancy loss as a loss to be mourned and that can contribute to impaired functioning, may contribute to social isolation and distress.

> It is not advisable for health professionals to simply recommend that women search key words on the internet.

Although high-quality informational and service resources do exist that can help these individuals feel more connected and informed, it can be difficult for women and their families who have experienced loss to locate these resources. As is common today, many may turn to the World Wide Web seeking comfort, information, and answers (Fox & Fallows, 2003). While the Internet can be a valuable tool for gathering information, it can be challenging and time consuming to navigate the multitude of available Web sites, many of which are transient and of poor quality.

The myriad of sites that search engines identify as "hits" is particularly problematic given that most individuals seeking health information go online without a systematic plan. Research suggests that if individuals are unable to readily identify the credibility of the information presented, they will abandon the site (Fox & Rainie, 2002). Therefore, individuals may terminate their search efforts prematurely.

Recognizing the need to provide timely and individualized information to patients, as well as acknowledging that patients are likely to seek information on the Internet, health care professionals are now providing "information prescriptions." The intention is to connect patients with evidence-based medical information specific to their health issue (Kemper & Mettler, 2002; Mettler & Kemper, 2003) that is adjunctive to the verbal instructions provided to patients immediately following treatment. They may not fully comprehend this information in the moments following distressful news or traumatic events. There is also the added benefit of allowing patients to review the information when they are ready to do so.

Consistent with this trend toward giving patients access to the adjunctive information they desire

when they desire it, this paper outlines an effort to review and select, as systematically as possible, reliable Internet resources containing valid and substantial content specific to pregnancy loss. Table 1 highlights key features of selected sites that can serve as a reference for health care providers and also can be distributed directly to patients. The literature that demonstrates a need for and the benefits of providing communication, informational resources, and support in the aftermath of pregnancy loss, as well as barriers that may prevent health care providers from providing adequate information consistently, is reviewed. This is followed by a brief discussion of the selection process for resources included in this article and an overview of the key features specific to each of the eight selected Web sites.

As an important caveat, the term "pregnancy loss" is used to refer to the array of perinatal loss events, including miscarriage, stillbirth, and ectopic pregnancy. While this may not be the preferred term in practice with individuals experiencing such losses, the intent is to convey the information in a concise manner. When referencing material specific to a particular type of loss, the more precise terminology is utilized.

Provision of Information Postloss

Literature that examines women's satisfaction with care following miscarriage indicates that many women receive little information from health care providers following loss, and most desire more (Cecil, 1994; Friedman, 1989; Helstrom & Victor, 1987). Specifically, women wish to know the cause of their miscarriage, when to expect their next menstrual period, when it is safe to attempt another pregnancy, risk of recurrence, and anticipated emotional reactions (Nikcevic, Kuczmierczyk, & Nicolaides, 1998). Standard practice is to conduct diagnostic tests to determine the cause of miscarriage only for those women who have miscarried three or more times. However, research suggests that discussing even general causes of miscarriage has been associated with greater satisfaction with medical care than being given no explanation at all (Nikcevic, Tunkel, Kuczmierczyk, & Nicolaides, 1999). Such information may even result in better health outcomes. For example, Tunaley, Slade, and Duncan (1993) found that women who received an explanation for their loss experienced a decrease in intrusive thoughts as measured by the Profile of Moods States Questionnaire. Explanations that "aid understanding" of the loss may influence psychological adjustment (Dunn, Goldbach, Lasker, & Toedter, 1991), with researchers reporting that an explanation that attributed cause to medical problems versus variables associated with personal responsibility was associated with decreased anxiety (Tunaley et al., 1993). Consistent with this finding, Jind (2003) found that blaming oneself for the loss was related to posttraumatic symptoms such as increased arousal and re-experiencing the loss, as measured by the Harvard Trauma Questionnaire. Thus, a discussion of common causes of miscarriage may confer some benefit in the form of increased emotional adaptation following loss by decreasing women's tendency to engage in behavioral self-blame.

> **L**iterature that examines women's satisfaction with care following miscarriage reveals that women desire more information from health care providers following loss.

Written Information

Despite the fact that women report wanting personalized, verbal information in a timely manner (Cuisinier, Kuijpers, Hoogduin, de Graauw, & Janssen, 1993), anecdotal reports suggest that information may be conveyed more often via written materials. Because the provision of written information alone can lead patients to perceive medical staff as uncaring (Paton, Wood, Bor, & Nitsun, 1999), written information seems best used as one component of a multicomponent treatment package. As part of an individualized treatment package, the provision of some written information can help to validate women's loss experience as a significant, important event worthy of their health care provider's attention. Moreover, given that women may not be able to fully attend to and recall information provided by health care providers at the time of loss due to the physical and emotional stress associated with miscarriage (Hamilton, 1989), written information may aid information transfer. A study of patients with cancer documented that written information is perceived to be a useful reference as patients do not always remember details they have discussed with their physician (Hope, Williams, & Lunn, 2000). Still, care needs to be taken with respect to sensitivity surrounding the gravity of pregnancy loss.

The provision of written material can confer additional benefits for women experiencing psychological sequelae following loss. Specifically, health care providers may be unaware of the relatively common incidence of elevated rates of depression and anxiety following miscarriage (Geller, Kerns, & Klier, 2004; Klier, Geller, & Ritsher, 2002), may not be adequately versed or trained in the provision of referral options, or may not know what system-wide resources are available. These factors, coupled with a lack of perceived competency and the assumption that

TABLE 1
Selected Web-Based Resources for Women

	American Pregnancy Association	American Society for Reproductive Medicine	BabyLoss	Hygeia Foundation	Miscarriage Support Auckland Inc.	M.I.S.S.	SHARE	www.pregnancy loss.info
URL	http://www.americanpregnancy.org/pregnancyloss/index.htm	www.asrm.org	www.babyloss.com	www.hygeia.org	www.miscarriagesupport.org.nz	www.missfoundation.org	www.nationalshareoffice.com	www.pregnancyloss.info
Date of origin	1995	1944	2000	1995	1985	1996	1977	1998
Intended audience								
Women	☒ Women	☒ Women	☒ Women	☒ Women	☒ Women	☒ Women	☒ Women	☒ Women
Male partners	☒ Male partners	☐ Male partners	☐ Male partners	☐ Male partners	☒ Male partners	☒ Male partners	☒ Male partners	☐ Male partners
Surviving siblings	☐ Surviving siblings	☐ Surviving siblings	☐ Surviving siblings	☒ Surviving siblings	☐ Surviving siblings	☒ Surviving siblings	☒ Surviving siblings	☐ Surviving siblings
Grandparents	☐ Grandparents	☐ Grandparents	☐ Grandparents	☐ Grandparents	☐ Grandparents	☒ Grandparents	☒ Grandparents	☐ Grandparents
Teen parents	☐ Teen parents	☐ Teen parents	☐ Teen parents	☐ Teen parents	☐ Teen parents	☐ Teen parents	☐ Teen parents	☒ Teen parents
Health professionals	☒ Health professionals	☒ Health professionals	☒ Health professionals	☒ Health professionals	☐ Health professionals	☒ Health professionals	☒ Health professionals	☐ Health professionals
Appropriate for								
Ectopic pregnancy	☒ Ectopic pregnancy	☒ Ectopic pregnancy	☒ Ectopic pregnancy	☒ Ectopic pregnancy	☐ Ectopic pregnancy	☐ Ectopic pregnancy	☐ Ectopic pregnancy	☒ Ectopic pregnancy
Miscarriage	☒ Miscarriage	☒ Miscarriage	☒ Miscarriage	☒ Miscarriage	☒ Miscarriage	☒ Miscarriage	☒ Miscarriage	☒ Miscarriage
Stillbirth	☐ Stillbirth	☒ Stillbirth	☒ Stillbirth	☐ Stillbirth	☐ Stillbirth	☒ Stillbirth	☒ Stillbirth	☒ Stillbirth
Neonatal death	☐ Neonatal death	☐ Neonatal death	☒ Neonatal death	☐ Neonatal death	☐ Neonatal death	☒ Neonatal death	☒ Neonatal death	☒ Neonatal death
Subsequent pregnancies	☒ Subsequent pregnancies	☐ Subsequent pregnancies	☐ Subsequent pregnancies	☐ Subsequent pregnancies	☐ Subsequent pregnancies	☒ Subsequent pregnancies	☒ Subsequent pregnancies	☐ Subsequent pregnancies
Information								
Medical	☒ Medical	☒ Medical	☒ Medical	☒ Medical	☒ Medical	☐ Medical	☐ Medical	☒ Medical
Emotional/Psychological	☒ Emotional/ Psychological	☒ Emotional/ Psychological	☒ Emotional/ Psychological	☒ Emotional/ Psychological	☒ Emotional/ Psychological	☒ Emotional/ Psychological	☒ Emotional/ Psychological	☒ Emotional/ Psychological
Spiritual	☐ Spiritual	☐ Spiritual	☐ Spiritual	☐ Spiritual	☐ Spiritual	☐ Spiritual	☐ Spiritual	☒ Spiritual
Communication resources								
Chat rooms	☐ Chat rooms	☐ Chat rooms	☐ Chat rooms	☒ Chat rooms	☐ Chat rooms	☒ Chat rooms	☒ Chat rooms	☐ Chat rooms
Forums	☒ Forums	☐ Forums	☒ Forums	☐ Forums	☒ Forums	☒ Forums	☒ Forums	☒ Forums
Phone line	☒ Phone line	☐ Phone line	☒ Phone line	☒ Phone line	☒ Phone line	☒ Phone line	☒ Phone line	☐ Phone line
E-mail	☐ E-mail	☐ E-mail	☐ E-mail	☒ E-mail	☒ E-mail	☒ E-mail	☒ E-mail	☐ E-mail

TABLE 1
(Continued)

	American Pregnancy Association	American Society for Reproductive Medicine	BabyLoss	Hygeia Foundation	Miscarriage Support Auckland Inc.	M.I.S.S.	SHARE	www.pregnancyloss.info
Support group information								
Domestic	☐ Domestic	☐ Domestic	☒ Domestic	☐ Domestic	☒ Domestic	☒ Domestic	☒ Domestic	☐ Domestic
International	☐ International	☐ International	☒ International	☐ International	☒ International	☒ International	☒ International	☐ International
Physician referrals	☒ Physician referrals	☒ Physician referrals	☐ Physician referrals	☒ Physician referrals	☒ Physician referrals	☐ Physician referrals	☐ Physician referrals	☐ Physician referrals
Newsletter								
Printed copy/Mailed	☐ Printed copy/Mailed	☐ Printed copy/Mailed	☐ Printed copy/Mailed	☐ Printed copy/Mailed	☐ Printed copy/Mailed	☒ Printed copy/Mailed	☒ Printed copy/Mailed	☐ Printed copy/Mailed
Electronic	☐ Electronic	☐ Electronic	☐ Electronic	☐ Electronic	☐ Electronic	☒ Electronic	☒ Electronic	☐ Electronic
Other resources								
Glossary of terms	☐ Glossary of terms	☐ Glossary of terms	☐ Glossary of terms	☐ Glossary of terms	☐ Glossary of terms	☐ Glossary of terms	☐ Glossary of terms	☒ Glossary of terms
Pamphlet	☐ Pamphlet	☒ Pamphlet	☐ Pamphlet	☐ Pamphlet	☐ Pamphlet	☒ Pamphlet	☐ Pamphlet	☐ Pamphlet
Suggested reading	☒ Suggested reading	☐ Suggested reading	☒ Suggested reading	☐ Suggested reading	☒ Suggested reading	☒ Suggested reading	☒ Suggested reading	☒ Suggested reading
Audiovisual	☐ Audiovisual	☐ Audiovisual	☐ Audiovisual	☐ Audiovisual	☐ Audiovisual	☒ Audiovisual	☒ Audiovisual	☐ Audiovisual
Links to other Web sites	☒ Links to other Web sites	☒ Links to other Web sites	☒ Links to other Web sites	☐ Links to other Web sites	☒ Links to other Web sites	☒ Links to other Web sites	☒ Links to other Web sites	☒ Links to other Web sites
"Things to Do"								
Advocacy	☐ Advocacy	☐ Advocacy	☐ Advocacy	☐ Advocacy	☐ Advocacy	☒ Advocacy	☐ Advocacy	☐ Advocacy
Membership	☐ Membership	☐ Membership	☐ Membership	☒ Membership	☒ Membership	☐ Membership	☐ Membership	☐ Membership
Research projects	☐ Research projects	☒ Research projects	☐ Research projects	☒ Research projects	☐ Research projects	☒ Research projects	☒ Research projects	☐ Research projects
Volunteer opportunities	☐ Volunteer opportunities	☐ Volunteer opportunities	☒ Volunteer opportunities	☐ Volunteer opportunities	☐ Volunteer opportunities	☐ Volunteer opportunities	☐ Volunteer opportunities	☐ Volunteer opportunities
Memorials								
Keepsakes/Mementos (for sale)	☒ Keepsakes/Mementos (for sale)	☐ Keepsakes/Mementos (for sale)	☐ Keepsakes/Mementos (for sale)	☒ Keepsakes/Mementos (for sale)	☐ Keepsakes/Mementos (for sale)	☐ Keepsakes/Mementos (for sale)	☒ Keepsakes/Mementos (for sale)	☐ Keepsakes/Mementos (for sale)
Virtual/Web posting (free)	☐ Virtual/Web posting (free)	☐ Virtual/Web posting (free)	☒ Virtual/Web posting (free)	☐ Virtual/Web posting (free)	☐ Virtual/Web posting (free)	☒ Virtual/Web posting (free)	☐ Virtual/Web posting (free)	☐ Virtual/Web posting (free)

women's psychological and emotional needs are being met elsewhere may result in women not receiving needed care (Prettyman & Cordle, 1992). Consistently providing every woman who experiences loss with written documentation of informational resources assures that all women have access to appropriate aftercare.

When used as an adjunct to follow-up care, written information, particularly when it has face validity, may help women and families be better informed about physical and psychological symptoms and expectations, increase satisfaction with postloss care, and educate them about options for community resources that can be accessed during appropriate phases in a woman's adjustment. The provision of informational resources in a quick and efficient format increases the likelihood that women will access these resources when needed.

Advantages of Web-Based Informational Resources

Whereas written pamphlets and materials distributed at office visits may have several limitations (they are "static" in that once they are given, rarely is there opportunity to provide updates; they are not personalized in terms of the stage of grief, audience, and type of loss experienced), the distribution of web-based resources has advantages. Similar to printed materials, appropriate Web sites can offer objective medical information that educates patients about potential causes of their loss, symptoms, and expectations for the future (e.g., physical and psychological reactions, risk of miscarriage in subsequent pregnancies) as well as listings for other resources, and Web sites can be regularly updated to provide the most current data available.

Whereas only a limited amount of actual written material can be distributed during medical visits, Web sites contain extensive information that can address the many different aspects of pregnancy loss and patients' concerns. For example, women may have different specific questions and concerns depending on their type of loss, time since loss, and experience of emotional consequences. They also may desire and benefit from information from varied perspectives (e.g., medical, religious or spiritual, psychological). As such, the information accessed through the Internet can be personalized to meet the needs of different women at different stages of loss. Reams of paper and printing costs for lengthy handouts are not required, so the distribution of Internet resources is practical and cost effective.

Another level of benefit afforded by Internet resources is the opportunity to reduce social isolation and normalize the experience for many women and their loved ones. As such, Internet resources can help "bridge the gap" between the receipt of static written information and actual support. Many web-based resources facilitate contact between women and families experiencing similar circumstances through "chat rooms" and web-based discussion forums. Several sites have regularly scheduled "chats" related to specific pregnancy loss topics (e.g., "pregnancy after a loss" chat, "grandparent" chat), allowing women and their family members to develop a consistent support resource. This can be particularly valuable for women and families who do not need or desire formal intervention services. Access is also "personalized" as women may go online at any time of day or night and seek the information that is most relevant for them at that time. There may be other communication resources such as staffed phone lines and e-mail addresses for questions. Information and contacts that help link women to support groups locally, nationally, and internationally also can be found. Some sites provide membership opportunities and electronic or printed newsletters. Still others provide tangible ways for women to validate their loss as "real" through personalized keepsakes and memorials. Many sites also provide "suggested reading" lists in a wide range of areas related to pregnancy loss, with direct links to book retailers that carry the suggested items. As women at later stages of adjustment to their pregnancy loss may desire to assist others who are experiencing a loss, some sites offer opportunities to volunteer or participate in research or advocacy projects. Providing women with comprehensive sources of information and support while allowing them to pursue these resources on their own empowers women to tap into their own natural resilience. This process itself may be an adaptive coping strategy, one that gives women a sense of control during a time when they may not feel as if they have control over their bodies or ability to carry a baby to term.

> **W**eb sites contain extensive information and address different aspects of pregnancy loss and patients' concerns.

Because pregnancy loss rarely affects only the woman who has suffered the loss, web-based resources can provide information and guidance for partners, family, and friends of women who have experienced a pregnancy loss. Knowing what to say and do can be difficult for individuals who care for such women. Individuals in a position to provide social support may be more inclined to offer support if they are educated about the topic, learn about options, and feel confident that what they are doing or communicating can be helpful. In addition, there are resources available to help family members address their own responses to the loss. Because family members may also experience distress following the loss, obtaining

support for themselves may make them more available to provide needed support to the woman.

The provision of web-based resources by health care providers demonstrates acknowledgment that individuals are using the Internet as an information source and increases the chance that individuals will be connected with high-quality information. Health care professionals can encourage women to use the Internet appropriately to secure desired information while simultaneously increasing rapport with the women by initiating this conversation. This conversation is an intervention in itself as it validates the woman's loss as "real."

Finally, web-based resources can provide up-to-date information for medical professionals. Since information regarding emotional consequences of loss and education about how to communicate about this sensitive arena of women's health is not always provided in their formal training, medical professionals can use web-based resources to educate themselves. This may be particularly helpful for newly practicing health care professionals, who have more limited patient experience. In addition, these sites may be useful to health care providers who have experienced perinatal loss in their own lives, either directly or through a loved one's experience. Thus, accessing Web sites that are reliable, relevant, and valid is extremely important as they can assist health care providers with their own work, as well as serve as an intervention that providers can "prescribe" to their patients with confidence.

Selection of Sites

Identifying Sites

When entering keywords (miscarriage, pregnancy loss, spontaneous abortion), the sheer number of Web sites found can be daunting. Moreover, there is tremendous variability in the number of "hits" each keyword will generate, not only between different search engines but also from day to day on the same search engine. For example, when entering the keyword "pregnancy loss" on several search engines, the number of hits ranged from 109 to 1,360,000. When entering the keywords identified above in the same search engine at the same time each day for 1 week, the term "pregnancy loss" identified a range of 188,000 to 433,000 hits, the term "miscarriage" identified 668,000 to 1,490,000 hits, and the term "spontaneous abortion" identified 62,900 to 125,000 hits. Five months later, a 1-week search of the same terms on the same search engine identified 615,000 to 842,000 hits (for pregnancy loss), 2,000,000 to 2,600,000 hits (for miscarriage), and 149,000 to 151,000 hits (for spontaneous abortion). While the tremendous variability is largely an artifact of the methodology search engines use to identify sites, and is not specific to sites related to the topic of pregnancy loss,

these findings highlight not only the overwhelming number of sites but also that searches will provide inconsistent results. Therefore, it is not advisable for health professionals to simply recommend that women search keywords on the Internet.

Categorizing Sites

To begin to characterize the types of sites that can be accessed via the Internet, the keyword "pregnancy loss" was entered into the search engine Google. Google was selected because its sole purpose is that of a search engine rather than an e-mail domain or distributor of other types of information (e.g., weather, news, stock reports). While other engines might provide more hits, Google uses the Page Rank System that employs a search algorithm to filter unwanted sites (http://www.google.com/technology/index.html).

From the initial review of the 237,000 sites generated by this original search, it was determined that sites could essentially be categorized into three primary content categories: Informational, defined as sites containing primarily factual information about medical or psychological sequelae; Spiritual/Religious, defined as sites containing primarily religious or spiritual messages; or Personal/Self-help oriented. Many of these latter sites were strictly forums where women could share their individual experiences and were not moderated by a health care provider or other professional or organization. An "Other" category was reserved for sites that focused primarily on a different issue/topic but mentioned pregnancy loss on the site (e.g., nonhuman loss, another medical problem). Web sites that were exclusively commercial in nature (sold books on the subject advertised physician referrals) were also included in this category. An additional category, "Inaccessible links," was identified for sites that could not be accessed after multiple attempts.

To provide a rough estimate of the proportion of sites within each category, the first 500 sites from the list of 237,000 that was initially generated by Google were selected. From this list, 192 (76.8%) Informational sites, 17 (6.8%) Spiritual/Religious sites, 64 (25.6%) Personal/Self-help sites, 209 (83.6%) Other sites, and 18 (7.2%) Inaccessible links were identified.

Procedure and Criteria for Site Selection

With the goal of selecting high-quality sites that present health-related information and emotional support resources for women and health care providers, sites generated by Google searches, as well as sites identified through other sources (e.g., recommendations of providers; listings in books, Web sites), were systematically reviewed. A "short list" of sites employing the following criteria was developed. The aim was to include sites that provide comprehensive coverage of factual material relevant to pregnancy loss that are appropriate to a wide

audience (i.e., not only women experiencing various types of pregnancy loss but also physicians and other health care providers, as well as specific family members). Sites that provide supportive elements as discussed above were searched for. Where multiple sites presented similar information, the site with greater clarity of presentation and those in which the material is presented in a sensitive manner and where the specific source of information is identified (e.g., references to specific research) were selected. Sites with greater longevity and those developed by organizations with more distinguished reputations received priority. Eliminated were sites that were advertisement driven or condoned a specific religious perspective exclusively. Sites that offer some kind of unique and advantageous feature, such as a glossary of terms or opportunities for social advocacy or research, were also searched for. From the initial short list of 18 sites, the list was gradually and systematically reduced to eight sites (following the review of each site by the authors and discussions to finalize the list).

Information Included on Chart

The eight selected sites are discussed below and presented in Table 1 in alphabetical order. In addition to the women themselves, the audience each site targets is identified, including male partners, grandparents, and health care providers. If the site is particularly appropriate for a specific type of perinatal loss or for pregnancies subsequent to a loss, this is identified on the chart. For each site, the type of information presented (medical, emotional/psychological, or spiritual, or all) has been indicated. The types of resources available through each site are identified according to categories: printed or electronic newsletters; "communication resources" such as chat rooms, forums, and contact phone numbers or email addresses; and support group information and contacts. "Other resources" unique to the sites are also identified and include features such as a glossary of terms, pamphlets, suggested readings, and videos. Special opportunities are identified under the heading "Things to do" and include such actions as advocacy, membership, and research and volunteer activities. Opportunities to memorialize the lost child are identified and have been classified as keepsakes and mementos available for purchase and virtual memorials or web postings available at no charge. Finally, it is noted whether sites provide links to other valuable Web sites as well as to physician referrals.

Selected Sites

American Pregnancy Association

While the majority of this site is devoted to providing information about healthy pregnancies, there are sections on both infertility and pregnancy loss. When referring a person who has experienced a loss to this site, it may be best to send them directly to the pages associated with pregnancy loss so that they do not have to sift through information about active pregnancy: http://www.americanpregnancy.org/pregnancyloss/index.htm. The remaining information on the site may be helpful to such women if they become pregnant again.

The information presented on this site is comprehensive and includes information on types of miscarriage, physical and emotional recovery, and subsequent pregnancies. The American Pregnancy Association also provides a toll-free number, allowing women to contact a "reproductive educator," which is a feature unique to this site. A professional from the American Pregnancy Association also moderates discussion forums, although the majority of postings seem to apply to normal pregnancy. Information for family members and friends wishing to support the person experiencing the loss is provided. Last, the American Pregnancy Association offers reading lists for those experiencing loss and provides links to other potentially relevant Web sites.

The American Pregnancy Association site has some industry sponsorship, but advertisements do not dominate the site. Information is presented clearly and simply, making it appropriate for patients at all levels of understanding.

American Society for Reproductive Medicine

Formerly known as The American Fertility Society, The American Society for Reproductive Medicine Web site focuses mainly on infertility. As such, some of the information on pregnancy loss considers loss as it relates to infertility treatments, making this site best suited for a subgroup of women experiencing loss. This site provides reviews on various books and articles written about pregnancy loss and information for both patients and providers. Because some of the information is written at a somewhat advanced level, this site may be best suited for providers. Unique features of the site include information in Spanish and clinical trial opportunities through the National Institute of Child Health and Development.

BabyLoss

BabyLoss is based in the United Kingdom and has been in existence since 2000. The organization is run by a team of volunteers, many of whom have personal experience with pregnancy loss. While many features of this site were under construction at the time of this writing, the site offers an extensive reading list and some basic information on ectopic pregnancy, miscarriage, and placental abruption. Perhaps the greatest strength of the site is the vast array of support resources listed, which include organizations in the U.K. as well as the United States. Links to other Web sites are included as are phone numbers for

24-hour nurse helplines. Virtual memorials can be posted on the site by those affected by a loss.

Hygeia Foundation

The Hygeia Foundation is maintained by Michael Berman, MD, of Yale University. It is a comprehensive site covering all aspect of perinatal loss and bereavement, including miscarriage. There is information for providers, women experiencing loss, and their families. Much of the information is also provided in Spanish.

Noteworthy is the site's focus on siblings affected by loss. The site provides children-mediated discussion opportunities as well as poetry, blackboards, and e-mail exchanges. The poetry blackboards are meant to provide siblings affected by loss with an artistic forum to express their feelings surrounding the loss, while the e-mail exchange puts siblings who have been affected by a loss in contact with each other via e-mail.

The site offers information on finding quality health care, research opportunities, and memorial services. A unique feature of Hygeia is an e-mail service, whereby those experiencing a loss can obtain a Hygeia e-mail account for their Hygeia- and loss-related e-mail correspondence. Individuals are required to register with Hygeia in order to access opportunities and information provided by the site, with no fee associated with registration.

Miscarriage Support Auckland Inc.

Based in New Zealand, this site has existed as an organization since 1985. While the site is updated and maintained by a team of volunteers who have experienced loss themselves, all medical information is provided by physicians. The site is devoted to the experience of pregnancy loss and is quite comprehensive. Information is provided on subsequent pregnancies, grief, and potential causes of miscarriage. There is also a "Frequently Asked Questions" section, information for men, and electronic bulletin boards, allowing women to share their experiences. The society allows for membership, and benefits include access to library materials, voting rights to participate in the direction and focus of the organization, and participation in society-sponsored functions. A great deal of information on support groups is provided, including how to set up support groups in areas where none exist. The information on the site is easy to access and presented in clear, sensitive language, making it ideal for persons at all levels of comprehension.

M.I.S.S. Foundation

This Web site is maintained by the M.I.S.S. Foundation, a nonprofit, volunteer organization founded by Joanne Cacciatore-Garard in 1996 in response to the loss of her infant daughter. The M.I.S.S. Foundation is overseen by a board of directors of both professionals and individuals who have experienced perinatal loss. The foundation was created to support families experiencing perinatal loss and educate the public about infant mortality. Families experiencing the full spectrum of loss, including infertility, miscarriage, stillbirth, neonatal loss, and early infant death, have access to a bimonthly newsletter, domestic and international M.I.S.S. support groups, forums to post messages (each one overseen by a volunteer moderator), scheduled online chats, funeral/memorial planning information, and suggested reading through a partnership with Amazon.com, with a portion of the proceeds going to support the M.I.S.S. Foundation. There are also opportunities to memorialize the loss through Net Pals, an online posting of individual loss experiences. There is a specific link providing grief information and programming for children who have experienced the loss of a loved one, including "Camp Paz," a camp designed to help children experiencing the loss of a sibling. Families experiencing loss can take part in the "Kindness Project," which involves committing an act in memory of the lost child.

This site also includes a link to the "Missing Angels Bill," a legislative bill that provides for the provision of a "Certificate of Birth Resulting in Stillbirth" to individuals who lose a child to stillbirth. Prior to the introduction of this bill, parents losing an infant to stillbirth were only able to obtain a "Certificate of Fetal Death," which many thought denied recognition of the fact that parents lost a "child." The site includes information about the history of the bill, the political issues related to stillbirth, hints for parents meeting with their legislator, and a chart of states that issue a "Certificate of Birth Resulting in Stillbirth." Additionally, there are links to news articles about this issue, information about how individuals can locate their elected officials, access to a nationwide petition for the bill, and sample letters to send to legislators.

Information for professionals, including articles such as the "Dos and Don'ts of Grief Support," workshop and conference information, and information about the "Baby's Breath-Healthy Baby Campaign" is available. The Web site is extremely easy to navigate, with information presented in a clear, empathetic manner, making it appropriate for women and families experiencing all types of perinatal and neonatal loss.

SHARE

This Web site is maintained by SHARE, a not-for-profit nondenominational organization founded in 1977 to support families experiencing miscarriage, stillbirth, and neonatal death. There are currently 130 SHARE chapters, including international chapters. This is a comprehensive site for families experiencing perinatal loss, with a variety of resources. Families experiencing perinatal loss can obtain a packet containing information regarding the emotional experience of this type of loss; a list of support groups in the United States, Bermuda, Canada, and

England; a "Bereavement Resources" catalog; and a copy of the SHARE newsletter, *Sharing Newsletter,* published bimonthly. The information packet is available in both English and Spanish. Individuals may also register to post messages on an online message board and participate in two regularly scheduled online chats. There is a link for "News and Updates," which provides information about events related to perinatal loss, as well as legislation regarding pregnancy loss. The SHARE Web site also provides a resource catalog of materials related to perinatal loss, including books, audio and video resources, specialty items (e.g., "Recognition of Life Certificates," embroidered blankets), Spanish-language resources, and subsequent pregnancy resources. There are links to other Web sites related to perinatal loss, although these sites are not maintained by SHARE. A unique feature of the site is the opportunity to purchase a "memorial brick" in remembrance of the loss, which is placed at the base of an "Angel of Hope" statue located at the SHARE national headquarters in Missouri during brick dedication ceremonies held twice a year. Also, a toll-free number is provided for individuals who "need to talk" about their loss.

Professionals have access to a quarterly newsletter, *Caring News*, providing information about working with individuals experiencing early perinatal loss and research being conducted on perinatal and neonatal loss. SHARE conducts "SHARE Group Leader Certification" workshops twice a year that focus on bereavement issues specific to perinatal loss and provide information about starting a SHARE support group. Professionals can join the SHARE network, which includes a discount on all items in the "Bereavement Resources" catalog, five copies of the *Sharing Newsletter,* a copy of *Caring News,* listing of all SHARE support groups, and permission to reprint all SHARE copyrighted materials. Professionals can also obtain perinatal loss statistics and a report on a stillbirth research project. The longevity of the SHARE organization is evident in the organization and breadth of information provided on the Web site. The Web site provides comprehensive information in a clear, sensitive manner.

www.pregnancyloss.info

This site is maintained by an individual rather than an association who was prompted by her own loss. The site provides information on various pregnancy loss groups, including a special section for teens experiencing their own pregnancy loss. There is a "frequently asked questions" section that covers unique topics such as how to explain a loss to children, spiritual explanations and coping strategies, and ways to honor the lost child.

This site also provides stories of others who have experienced loss, a glossary of relevant terms, a virtual memorial wall, and e-cards for those who have experienced a loss. While there is a spiritual overtone to this site, the information provided is comprehensive and nondenomina-

tional. The women's stories section adds a personal touch, and many women experiencing loss may appreciate the spiritual aspect of this site.

Conclusions

Woman and families typically have many questions following a pregnancy loss and may turn to the Internet for answers. Health care providers may need to access current and comprehensive information about pregnancy loss for themselves and also may wish to provide relevant resources to their patients as an adjunct to medical treatment. To address these needs, Internet sites relevant to pregnancy loss were systematically reviewed and those about which women and providers can feel confident have been selected. The significant features of these eight sites are highlighted on Table 1. The table is meant to "stand alone" and be distributed to all women experiencing pregnancy loss regardless of their apparent level of distress or concern.

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