

Online Health Seeking Behaviours: What Information Is Sought by Women Experiencing Miscarriage?

Patrick Cheong-Iao PANG^{a,1}, Meredith TEMPLE-SMITH^b, Clare BELLHOUSE^b,
 Van-Hau TRIEU^a, Litzia KIROPOULOS^c, Helen WILLIAMS^d, Arri
 COOMARASAMY^d, Jane BREWIN^e, Amanda BOWLES^f, and Jade BILARDI^{b,g}

^a*School of Computing and Information Systems, The University of Melbourne, Australia*

^b*Department of General Practice, The University of Melbourne, Australia*

^c*Melbourne School of Psychological Sciences, The University of Melbourne, Australia*

^d*Tommy's National Centre for Miscarriage Research, The University of Birmingham, UK*

^e*Tommy's Charity, UK*

^f*Bears of Hope Charity, Australia*

^g*Central Clinical School, Monash University, Australia*

Abstract. One in four pregnancies ends in miscarriage, a distressing event which can cause significant psychosocial impacts for many women, and yet often remains unseen and unspoken. Many would-be mothers turn to the internet for information and emotional support, and to share their experiences. In this paper, we present the results from 12 semi-structured interviews with women, investigating how and what online information they searched for at the time of miscarriage. We found that women are passive information seekers, searching for causes and preventive strategies to inform future pregnancies. Women want information presented in an easy to understand manner that is not overly clinical, and informed by credible sources. Women also seek psychological support and emotional relief through reading about others' experiences and sharing their stories online. The findings from this study provide a unique insight into the support and information needs of women, and will be used to guide the content, design and functionality of web-based technologies for women experiencing miscarriage.

Keywords. Miscarriage, pregnancy loss, online, information needs, health information-seeking behaviour

Introduction

Miscarriage, which in Australia refers to a pregnancy loss in the first 20 weeks of gestation [1], is estimated to occur in one in four confirmed pregnancies [2]. While miscarriage is common, few people talk about it. Moreover, women often wait to disclose a pregnancy until after the first trimester when the risk of miscarriage is reduced. If miscarriage occurs before a pregnancy is made public, silence is a common response.

¹Corresponding Author: Patrick Cheong-Iao PANG, School of Computing and Information Systems, The University of Melbourne, Parkville VIC 3010, Australia; E-mail: mail@patrickpang.net.

However, this often leaves women feeling alone and unsupported in their feelings of grief, loss, anger, and guilt [3–6] and can compromise social support following miscarriage. Women repeatedly report a lack of support from their social and health networks, including a lack of sensitivity and acknowledgement of miscarriage, lack of follow-up care, lack of medical information provision, receiving unwanted advice from others and an expectation that they should recover from the grief quickly [7–11]. Consequently, women often turn to the internet to look for information and support for themselves [12–14].

Clinical levels of anxiety and depression in the weeks, months or even years following miscarriage are not uncommon [7,15–18]; information provision and emotional support may reduce the risk of long term psychosocial complications [19]. Understanding women's information-seeking behaviours and needs plays an important role in provisioning information and services. Past research has highlighted the knowledge gaps around the classification of miscarriages, causes and treatment, as well as the experiences of others [13,20]; with additional work citing women's need to interact, share their grief and tell their personal stories, and prepare for a new pregnancy [20,21]. A recent study showed that women are reluctant to share miscarriage stories on public social network sites (SNSs), and desire spaces to disclose their experience without risk of negative responses [22]. As there is only scant work about miscarriage and relevant online health seeking behaviour, there is a need to conduct a study to inform a more comprehensive understanding about the needs of women experiencing miscarriage, and the online support required by them.

Motivated by the importance of filling this gap in the literature, we investigated the online health information-seeking behaviours of women who have experienced miscarriage. The research question was: what online health information is being sought by women who have experienced miscarriage? Understanding the behaviours can help to design web-based services that meet user needs, and thus enhance the effectiveness and the engagement of such services [23,24].

1. Research Design and Method

To address the research question, we adopted qualitative methodology and conducted semi-structured interviews with women either face-to-face or by phone. A purposive sampling technique was used to recruit women aged 18-50 years old, who had a good understanding of written and verbal English, and who had experienced miscarriage more than 3 months ago but less than 10 years ago.

Recruitment initially started with women who had participated in our previous studies about miscarriage and had expressed an interest in our future research studies. Additional participants were also sought through existing networks known to the researchers, industry partners for pregnancy loss support, SNSs and snowball sampling. Participants received a \$50 Coles-Myer gift voucher for the interview. Our study was approved by the Human Research Ethics Committee of the University of Melbourne, No 1750460.1, Approved 17th Nov 2017.

At the time of the interview, participants were asked about their demographic information and their online health information-seeking behaviours at the time of the miscarriage. In particular, women were asked about the information they sought, and the key search terms and websites used. They were also encouraged to express their views

on the websites they used and to highlight information they thought would have been useful but was missing in current online content.

Interviews were conducted by author CB. Then they were recorded, transcribed and analysed using a general inductive approach which provides a systematic set of procedures for analysing qualitative data [25]. Authors CB and PP read each interview manuscript in detail to gain an understanding of the main themes and categories within each theme. CB coded segments of text into the categories and further revised and refined the text within each category to examine similar or differing points of view and ideas.

2. Results

Twelve women participated in the interviews. Their mean age was 36 with a range of 27 to 48. One woman had completed secondary school as her highest level of education, three women had completed TAFE, five women had completed an undergraduate degree, and three women had completed postgraduate studies. The median number of miscarriages women had experienced was two, with a range of one to seven.

Women generally searched passively online for health information: rather than proactively seeking information, their searches were triggered by certain events. They reported that they started to look for online health information when they suspected symptoms of a miscarriage, after clinician visits yielded insufficient information, or when they became aware they were having a miscarriage. They tended to use hospital and government websites because they believed the information was credible and trustworthy. Women sought out information on parenting websites and forums to explore other's women's experiences and to not feel so alone in their concerns.

“(the website) made me feel like there was a whole army of women who'd been through this before” (P4).

The three main themes arising from the interviews centred on the information women sought (information needs), the support women sought (support needs) and the preferred information delivery style (Table 1).

Table 1. Three main themes around health information-seeking of women who have experienced miscarriage

Theme	Sub-themes
Information needs	<ul style="list-style-type: none"> • Causes of miscarriage, e.g. stress / age / diet • Frequency of miscarriage • Symptoms of miscarriage, e.g. spotting / bleeding • Preparing for a new pregnancy, e.g. prevention, exercise, dealing with multiple miscarriages, IVF • Research and breakthroughs on miscarriage
Support needs	<ul style="list-style-type: none"> • Ways to cope with grief • Advice for family, friends and healthcare professionals around things to say/not to say • Preventing blame and normalising the experience • Memorial of the loss
Preferred delivery style of information	<ul style="list-style-type: none"> • Want easy-to-find and immediate answers • Want personalised answers • Learn from other's experience, but not attaching to ideas from others • Prefer reliable information from healthcare professionals • Do not want an overly clinical or medicalised tone • Accessible and relevant for partners and families • Website should not be overly bright or too melancholy

2.1. Information Needs

A wide variety of topics around pregnancy and miscarriage were searched. The main types of information women sought were around the causes, frequency, and symptoms of miscarriages, particularly *“what’s normal and what’s not normal”* (P5). Some women used this information to learn more about miscarriage and try to minimise their risk of miscarriage in a subsequent pregnancy. Women also commonly looked for information on how to increase their chance of successful future pregnancies (e.g. dietary and lifestyle changes, IVF). Many women also expressed a desire to keep updated with the research and breakthroughs in the miscarriage area.

2.2. Support Needs

In addition to seeking information, some women reported searching for support and suggestions of ways to cope with the grief they experienced. Women often reported finding comfort in reading someone else’s story. The support of others was also important, with many women searching for advice for family and friends around things to say and not to say. Others reported searching for information to normalise the miscarriage experience.

“I think because I knew it was a whole group of people who were going to understand the ramblings of the mad woman... everyone is on the page for the same reason” (P5).

Additionally, some women looked for some online memorial spaces for their loss.

“The bears (memorial toy bears provided from Bears of Hope Charity) that they have for each stage... that is such a beautiful gesture” (P8).

2.3. Preferred Delivery Style of Information

Women preferred easy-to-find, immediate answers to their questions around miscarriage and information that was relevant to their specific situation. They also liked to learn from others’ experiences and to read others’ stories, but did not want to receive negative feedback, nor be overwhelmed by ideas that might not be applicable to themselves. Importantly, women wanted information from credible sources, such as healthcare professionals, but without the use of an overly clinical tone or medical terminology. *“You want the health information built in, but in digestible form”* (P6).

Additionally, some women suggested that appropriate and relevant information about miscarriage should be available for their partners and families, so that they could understand more about miscarriage and how best to support women. Lastly, the design and the “look-and-feel” of websites should be sensitive to their audience, i.e. should not be overly bright or vivid, nor too melancholy.

“It isn’t covered in flowers and brightness and all that crap...” (P3).

“(The website should be) compassionate without being sappy.” (P12).

3. Discussion

3.1. Primary Findings

The findings of our study demonstrate the online health information-seeking needs and behaviour of women who have experienced miscarriage. Women want factual information about miscarriage, miscarriage prevention and current research advances, delivered by credible sources in an easy to understand manner. Women are also seeking online support through other people's shared experiences and for their family and friends. Inspired from the recent successful user-centred design paradigms in health [23,26,27], these insights into the types of information women need will be of value to those designing web-based miscarriage support services.

Even though there has been a dramatic growth of mobile health (m-Health) and SNSs, websites still have their roles in terms of disseminating health information. There is still a tendency to search for health related information with "Dr Google" and by browsing through websites, which offer variable quality and large volumes of information [28]. People search multiple places and go through different websites [29,30], but this is not the optimum method of managing an unfamiliar health issue. Given this, websites can provide a unique, broad reaching and cost-effective way to better inform and improve support for women who have experienced miscarriage.

3.2. Design Considerations of Websites

Based on the feedback from our participants, we propose several design considerations when developing a website aimed at supporting women who have experienced miscarriage. These include: (1) providing story sharing and memorial functions; (2) being mindful of the design and the tone of voice; (3) making use of marketing; and (4) keeping users informed about latest research.

In addition to the abovementioned basic facts that women look for, this study highlights the importance of experience sharing and memorial functions in a miscarriage website. These functions provide an outlet for women to share their feelings of grief and loss, and not feel alone in their experience, within a supportive community. An online commemoration allows a distributed audience to participate, to remember the loss and to show their support [31]. To address privacy concerns, anonymous sharing could be employed. Moderation could also be used to filter confronting, inappropriate or overwhelmingly sad content. These techniques are used in similar digital interventions for sensitive mental health issues [32,33].

Consideration for design and branding is also required to ensure the tone of voice, "look-and-feel" and wording aligns with women's needs and is sensitive to the topic. A warning before any confronting content could be useful to alert users before viewing content. Overall, a participatory design methodology could be employed to include women who have experienced miscarriage to address these issues and ensure the website designs meet the needs of the target population.

Our results showed women search passively online for health information. Passive searchers do not proactively look for information but rely on external factors (e.g. receiving a notification on the phone) to trigger them to start searching [29,34]. As such, to optimise the usability of websites, consideration will need to be given to various

marketing approaches including social media campaigns and promotion by healthcare professionals and clinicians.

Given women want to keep updated with the latest miscarriage research and breakthroughs, websites may also be useful as a platform for miscarriage studies in the field. For instance, a register of women who have experienced miscarriage and indicated their interest in research could be established to maintain a list of active participants for relevant research projects. Researchers could also use these platforms to broadcast and promote their investigations. These strategies have been applied to other populations and obtained satisfactory outcomes [35].

3.3. Limitations

We acknowledge that there are limitations in this study. Our study sample was small and may not be representative of the wider population of women who have experienced miscarriage. Additionally, women may not have remembered the details of their information-seeking behaviours in the interviews, as we interviewed women who had experienced miscarriages within the previous 10 years. Nevertheless, women provided valuable insights into their online health seeking behaviours and needs at the time of, and following miscarriage. Importantly, this is the first Australian study that we are aware of to explore this topic.

4. Conclusion

In this study, we investigated the online information-seeking needs and behaviours of women experiencing miscarriage. Women reported that they commonly searched for causes and prevention strategies to inform future pregnancies. Importantly, they observed that they found psychological support and emotional relief in reading others' experiences and in sharing their own stories. The findings from this study provide a unique insight into women's support needs and will be used to guide the content, design and functionality of web-based support for women experiencing miscarriage.

4.1 Recommendations for Future Research

Future work includes building a test version of the website which will be evaluated and further refined through focus groups with women who have experienced miscarriage. We also intend to use online analytical tools (e.g. Google Analytics) to gain a deeper insight into women's information-seeking behaviours. Such work will complement and validate the findings of this qualitative study.

Acknowledgements

We would like to thank the women who kindly agreed to participate in this study and gave up their time to speak with us. This study was undertaken with funding granted by the Networked Society Institute, University of Melbourne, Australia. Dr Jade Bilardi is in receipt of a National Health and Medical Research Council Early Career Fellowship No 1035135.

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