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A search for hope and understanding: An analysis of threatened miscarriage internet forums

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ARTICLE INFO

Article history:

Received 21 August 2013
Received in revised form
15 December 2013
Accepted 16 December 2013

Keywords:

Threatened miscarriage
Pregnancy loss
Internet forums
Thematic analysis

ABSTRACT

Objective: threatened miscarriage is a common complication of early pregnancy, which increases the risk of miscarriage or pregnancy complications such as premature birth. Currently there is limited evidence to recommend beneficial medical treatments or lifestyle changes, resulting in a 'watchful waiting' approach. The aim of this study was to describe women's experiences of threatened miscarriage through examining postings to Internet discussion forums.

Design: a Goggle alert for threatened miscarriage was created with emails containing hyperlinks sent to the first author and collected over a seven month period (April to November 2011). Data was analysed using thematic analysis.

Findings: one hundred and twenty one discussion threads were collected. The overarching theme that emerged was one of 'a search for hope and understanding'. Within this there were four sub themes that illustrated this search. 'A reason for hope: stories and real life experiences' illustrated how women sought hope for a viable pregnancy through others. 'Becoming the expert,' captures how women gave advice from their own experiences. 'A safe place to share' and 'connecting to empathic support' illustrates how women used this medium for long distance support.

Key conclusion: internet discussion forums were used by women to seek hope and support they were not receiving from their health professionals. Women urged each other to remain hopeful despite a negative medical prognosis. There was an acceptance of a lay expertise within the forums that was valid enough to challenge medical expertise.

Implications for practice: health practitioners may need education that helps them balance their delivery of medical information with hope in order to increase feelings of trust. With women seeing the Internet as a useful form of support, it may be relevant for practitioners to consider recommending relevant Internet sites and discuss this with women.

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Introduction

Threatened miscarriage involves a history of vaginal bleeding, with or without abdominal pain, a cervical os that remains closed and a presumed viable pregnancy (Swier and Jurkavic, 2011). This is a common complication of early pregnancy, with an estimated 20% of pregnant women experiencing this in the first 12 weeks of their pregnancy (Everett, 1997). Although the risk for miscarriage is reduced following confirmation of cardiac activity on ultrasound, women with light vaginal bleeding have twice the rate of

miscarriage when compared to pregnancies with no vaginal bleeding, and four times the risk with heavy vaginal bleeding (Weiss et al., 2004). These pregnancies are also associated with events such as antepartum haemorrhage, and premature child-birth (van Oppenraaij et al., 2009; Saraswat et al., 2010).

The evidence to date fails to support the use of medications or lifestyle interventions to improve birthing outcomes (Aleman et al., 2005; Empson et al., 2005; Devaseelan et al., 2010; Wahabi et al., 2011), resulting in a 'watching waiting' approach with medical monitoring. Although providing emotional support for these women is mentioned within midwifery and nursing literature, no recommendations are given as to what this advice or support may consist of (Tien and Tan, 2007; Webster-Bain, 2011).

While emotional issues have been explored within the literature around women's experience of miscarriage (Beutel et al., 1996;

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Geller et al., 2004; Lok and Neugebauer, 2007; Brier, 2008; Mann et al., 2008), the care they receive from health professionals (Evans et al., 2002; Rowlands and Lee, 2010), and support received through miscarriage Internet forums (Gold et al., 2012), they remain unexplored for threatened miscarriage.

Although a qualitative study did identify this knowledge gap and aimed to explore the experiences of women presenting for early pregnancy problems (Warner et al., 2012), the majority of women had experienced pregnancy loss at the time of their interviews. This resulted in pregnancy loss reported in all the themes. It may be that women with a viable pregnancy have different experiences and interactions with health professionals. It may also be that there are important emotional considerations for women presenting with threatened miscarriage that have not been adequately identified by health professionals. Social media may be a valuable source of information for health researchers, offering flexibility in terms of time, access to a population not limited by geography, and anonymity which may offer different insights compared to traditional face-to-face encounters (Eastham, 2011; Chen, 2012). Data can be collected from official medical, media and governmental sites, as well as more informal personal blogs and discussion forums. Personal blogs are set up by authors for self-expression, and have been compared to online versions of diary-keeping or letter-writing (Friedman and Calixte, 2009). Discussion forums differ in that they can be seen as a written 'real-time' conversation discussing a specific topic of interest. As such, these responses offer researchers different insights from personal blogs and face to face encounters. Theoretically these forums may be similar to non-participant observation but present unique challenges due to a use of a text medium and the lack of face to face interaction (Bradley and Carter, 2012). There are also challenges relating to consent, privacy and identification verification that are problematic, requiring further debate and ethical guidance to develop the Internet as a credible medium for data collection (Holmes, 2009; Bradley and Carter, 2012).

Online discussion forums are free to access and easy to locate through Internet search engines such as 'Google'. Whereas some discussion forums are structured so that people join as members and carry out private conversations, many are open for public discussion and viewing. Whereas entering the terms 'threatened miscarriage' into a Google search engine demonstrates multiple discussion forums actively receiving postings, to date how women and their partners use these forums has not been examined within nursing, midwifery or medical literature.

The aim of this study was to describe women's experiences of threatened miscarriage through examining postings to Internet discussion forums.

Methods

A qualitative study was undertaken, using internet discussion forum posts as the source of data for this study. A qualitative method was seen as most appropriate as it is ideal when seeking to collect and analyse data where little knowledge is available as it seeks to answer 'what' questions.

Over a seven month period, from April to November 2011, Internet forum discussions were received by the first author. An Internet alert from the search engine Google was created through using the Google search engine; a free service where alerts are posted directly to an email address. To create this alert the Google Alert home page was accessed and the search terms 'threatened miscarriage' and 'threatened abortion' entered. The information type selected was for 'everything', delivery frequency as 'daily' with the option of receiving 'all results'. The contact email address given as belonging to the first author. Daily emails were received

containing hyperlinks corresponding to the search terms specified. These alerts were viewed by the first author, and those relating threatened miscarriage forums were stored in a word document for further analysis. The creation of these word documents followed the initial thread posting and ranged from a single reply to several A4 pages. Quotes were de-identified by using the first two letters of the pseudonym supplied, followed by a number created for each of the discussion threads, and then by the page number for that discussion thread. Thus a comment made by 'worried mumma' collected as the third discussion thread where the comment occurred on the second page of data is represented as (WM/3/2).

Data analysis

Thematic analysis was used to formally analyse and code the data. Thematic analysis was used because it unearths patterns in the data, allowing for the discovery of the true meaning of the data (Boyatzis, 1998; Grbich, 2007). Although thematic analysis is not always acknowledged as a specific method of qualitative analysis, it is a technique widely used as foundation within qualitative analysis (Braun and Clarke, 2006). Indeed Braun and Clarke (2006, p. 80) argue that 'a lot of analysis is essentially thematic but is either claimed as something else or not identified as any particular method at all.' Six phases to performing thematic analysis have been identified by Braun and Clarke (2006) and these were used as a guide as outlined in Table 1.

Seventy-two initial threads were collected over a four-month period (22 April 2011 to 21 August 2011) with these ranging from a few sentences to six A4 pages of data. Following initial coding and analysis for initial themes, data collection continued for another three months, to ensure that saturation had been reached with no new themes identified. A total of 121 threads were collected.

Determining saturation can be complex, and whereas the concept of saturation is often described in literature as the point at which no new information or themes are observed in the data, practical guidelines for determining sample size are virtually non-existent (Guest et al., 2006). For this data collection, saturation was defined as 'the point in data collection and analysis when new information produces little or no change to the codebook' (Guest et al., 2006, p. 65).

To reduce possible researcher bias Nvivo 9 was used to record coding, this allowed coding categories to be sent to the second and third author for comparison and verification. In addition when searching for, reviewing and defining themes a content comparison process was used to provide critical feedback and reflection amongst three authors.

Ethical considerations

Ethical principles concerning informed consent, participant confidentiality and privacy arise when using online data collection (Kralik et al., 2005). Although within discussion forums de-identifying data can be used for confidentiality and privacy, it has been cautioned that within small online communities comments may be easily identified through a Google search and therefore participants should be approached for consent (Eysenbach and Till, 2001). However, within larger online discussion forums people may only comment once or intermittently, making direct contact with participants difficult. It has been argued that although ethical approval is required for data posted as private conversations, this is not considered a requirement for data that is publically posted (Eastham, 2011). The approach for this study mirrors studies where ethical approval was seen as unnecessary when accessing public internet postings (Dahlen and Homer, 2011, 2012) Participants within this study were aware they

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