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# Experience of miscarriage in the UK: Qualitative findings from the National Women's Health Study

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#### Abstract

Miscarriage is the most common adverse outcome in pregnancy. For many women it is a traumatic experience. Previous research has identified shortcomings in the emotional and social support provided for miscarriage sufferers but personal accounts of pregnancy loss remain relatively under-explored. The UK National Women's Health Study (NWHS) is a nationally representative survey of women's reproductive histories. It provided an opportunity to study accounts of miscarriage written in response to an invitation for further comments on the survey questionnaire. In conjunction with quantitative findings from the NWHS, we thematically analysed 172 detailed narratives that facilitated qualitative exploration of a characteristically private event. Analysis of the narratives suggested that few women who had planned their pregnancy were satisfied with fatalistic explanations of miscarriage. Those who were not given medical explanations for their loss engaged in complex searches for meaning, often linked to accounts of their moral deservedness as mothers. The narratives highlighted tensions between biomedical and lay understandings of pregnancy loss. There were reports of inappropriate medicalisation and a perceived lack of emotional support, but also a desire for medical validation of the reality of miscarriage and investigations to identify medical causes. Professionals' reported behaviour played a key role in women's accounts. These findings remind providers that: women do not experience miscarriage as a routine complication; medicalisation is both resisted and desired; and, for some women, more support and information is needed to assist their search for meaning.

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#### Introduction

Miscarriage is the most common adverse outcome in pregnancy; it is estimated that around one in five clinically confirmed pregnancies will end this way (Garcia-Enguidanos, Calle, Valero, Luna, & Dominguez-Rojas, 2002; Savitz, Hertz-Picciotto, Poole, & Olshan, 2002). Research on pregnancy loss tends to focus on risk factors for miscarriage (Maconochie, Doyle, Prior, & Simmons, 2005) and how best

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to manage the event once it has occurred (RCOG, 2000). Very few studies have addressed the lived experience of miscarriage and there is little qualitative research showing how women understand, reconcile and make sense of their loss. Miscarriage is a particularly unusual form of death as there is no obvious dying process and there appears to be nobody to mourn (Lovell, 1997). Lovell (1997) notes that miscarriages are often seen as unfortunate experiences for the mother, described using 'illness' terms, and are not afforded "...the acknowledgement which accompanies the loss of a person who left a mark on the world and occupied a place in the memories of the people who knew him or her". Miscarriage thus tends to lack the emotional and social support provided with other types of bereavement. Recognition that miscarriage is associated with certain negative psychological sequelae (Athey & Spielvogel, 2000; Brier, 2004; Klier, Geller, & Ritsher, 2002) has led to calls to increase the number of Early Pregnancy Assessment Units (EPAUs) in the UK (Logan, Browne, & Bhattacharya, 2002) and provision of follow-up care for miscarriage sufferers (Boyce, Condon, & Ellwood, 2002; Bradley & Hamilton-Fairley, 1998; RCOG, 2000). With this background in mind, we hope to contribute to, and develop, understanding of miscarriage experiences in the UK by using qualitative findings from the National Women's Health Study (NWHS).

The NWHS was a population-based postal survey of the reproductive history of adult women living in the UK in 2001 (Maconochie, Doyle, & Prior, 2004). In addition to questions on reproduction and pregnancy outcome, a section of the survey questionnaire provided space for respondents to add any extra comments (in free text). A significant proportion of women (40%) provided written remarks. While comments on questionnaires have traditionally not been seen as 'good data' (Morse, 2002), preliminary reading of the responses showed a number of rich descriptions or narratives of reproduction. Many of these narratives concerned women's experience of miscarriage and, despite their voluntary nature, several common themes emerged. It was decided to explore the data by conducting a thematic content analysis.

These narratives contribute to an understanding of miscarriage by providing a rare forum for women to discuss what is often seen as a 'silent event' in the sociological literature (Bansen & Stevens, 1992). As the narratives derive from a population-based

survey, they constitute an unusual and valuable resource for examining women's lived experience of miscarriage in the UK. The main objective of the analysis was therefore to describe women's personal experience of miscarriage and to develop future research questions which may contribute to the planning of appropriate treatment and follow-up care.

#### Methods

Data collection

Full details of the study are reported elsewhere (Maconochie et al., 2004). In brief, this was a population-based two-stage postal survey of the reproductive histories of adult women living in the UK in 2001, sampled from the electronic electoral roll. Stage 1 involved a short 'screening' questionnaire sent to over 60,000 randomly selected women to identify those aged 55 and under who had ever been pregnant or attempted to achieve a pregnancy, from whom a brief reproductive history was requested. Stage 2 involved a lengthier questionnaire requesting detailed information on every pregnancy, and any fertility problems. To minimise potential recall bias, questions on socio-demographic, behavioural and other factors were included for the most recent pregnancy only. In total, 26,050 women responded to the first stage of the survey, and 7702 to the more targeted second stage, representing response rates of 46% and 71%, respectively. To increase the number of cases for a risk factor analysis, women whose last pregnancy was not a miscarriage but who had experienced a miscarriage recently (since 1995) were sent a short additional (Stage 3) questionnaire, collecting the same Stage 2 information on biological, sociodemographic and behavioural details related to their most recent miscarriage. Overall 701 women reported that their most recent pregnancy had resulted in a miscarriage, or that they had experienced a miscarriage since 1995. The study received ethical approval from the Trent Multi-Centre Research Ethics Committee and the Ethics Committee of the London School of Hygiene & Tropical Medicine.

The final page of the Stage 2 and 3 questionnaires consisted of a blank A4 page where respondents were asked: "If there is anything else you would like to add, please tell us here". This page gave women the opportunity to expand on previous answers, or

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