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Australian heterosexual women's experiences of healthcare provision following a pregnancy loss

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ABSTRACT

Background: Despite increased awareness of the psychological impact of pregnancy loss, a lack of recognition continues with regards to women's experiences. Healthcare professionals have an important role to play in supporting women following a pregnancy loss, yet to date only a relatively small body of research has examined women's experiences with healthcare providers.
Aim: This paper seeks to contribute to the literature on women's engagement with healthcare professionals by exploring the experiences of an Australian sample.
Method: Fifteen heterosexual women living in South Australia were interviewed about their experiences of pregnancy loss. A thematic analysis was undertaken, focused on responses to one interview question that explored experiences with healthcare professionals.
Findings: Three themes were identified. The first theme involved negative experiences with healthcare providers, and included four subthemes: (1) 'confusing and inappropriate language and communication', (2) 'the hospital environment', (3) 'lack of emotional care', and (4) 'lack of follow-up care'. Under the second theme of positive experiences, the sub-themes of (1) 'emotionally-engaged and present individual staff', and (2) 'the healthcare system as a whole' were identified. Finally, a third theme was identified, which focused holistically on the importance of healthcare professionals.
Conclusion: The paper concludes by discussing the importance of training for healthcare professionals in supporting women who experience a pregnancy loss, and the need for further research to explore the experiences of other groups of people affected by pregnancy loss.

Statement of significance

Problem or issue

A cultural silence around pregnancy loss continues, and this may be exacerbated by inadequate responses from health-care professionals.

What is already known

Previous research indicates that many women report experiences of poor provider-patient communication, lack of acknowledgement of loss, and lack of specialist services.

What this paper adds

This paper highlights the importance of being present with women who have experienced pregnancy loss, the need for immediate (rather than delayed) support, and the benefits of specialist services.

1. Introduction

The loss of an unborn child is a complex and potentially devastating experience that is often surrounded by silence.[7] To a certain degree such silence is a product of a lack of recognition that pregnancy loss is typically experienced as a loss. This is further compounded by the varying ways that researchers and clinicians divide up the period between conception and 1 month after birth.[33] The terms pregnancy loss, perinatal loss, miscarriage, early miscarriage, stillbirth, fetal death, and spontaneous abortion are all

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used in the literature to refer to losses, according to the period of gestation. While there may be medical and legal distinctions between a 10 week old foetus and a 30 week old foetus (such as in terms of eligibility for abortion), there is no evidence to suggest that a woman's psychological experience of loss is affected by gestational age.[23] However, the literature on the psychological effects of pregnancy loss adheres to the 20 week distinction (in Australia) between miscarriage and stillbirth. Further, the distinction between miscarriage and stillbirth is made at different gestational ages in different countries (24 weeks in Hong Kong for example), and as such, comparison between studies is difficult. In this study, pregnancy loss is defined as any fetal death in utero, and includes miscarriage, ectopic pregnancy, stillbirth, and termination of pregnancy for fetal abnormality, irrespective of gestational age.

In terms of the frequency with which pregnancy losses occur, the Australian Bureau of Statistics[1] publishes data on stillbirths and reports that one in every 170 births in 2011 were stillborn (defined as death of a foetus of at least 20 weeks gestation, or over 400 g in weight). The prevalence of miscarriage (defined in Australia as a loss at less than 20 weeks gestation) is much higher, but more difficult to quantify because losses frequently occur outside a medical setting and are not recorded. However, there is consensus that around 50% of all conceptions end in miscarriage, and that prior to the 7th week of gestation, 15–20% of all recognised pregnancies result in miscarriage.[31],35

Despite the relative cultural silence about pregnancy loss, it has been increasingly acknowledged that the early and often sudden loss of an unborn child is experienced as a complex loss, encompassing not only the physical loss of pregnancy, but the loss of an anticipated future of raising a child, and confusion regarding both the intending parents' resulting identities as parents.[5,7,20,23,29] Adding to the devastation of these multiple losses is the experience of a disenfranchised grief; a lack of socially prescribed norms regarding how to openly mourn an unborn child, leaving many feeling isolated and alone in their grief.[7,20,24] Although the literature suggests that most women do not develop lasting mental health problems following a pregnancy loss, high levels of psychological distress are common immediately following a loss.[12] Further, as noted by Ref. 33, there is inconsistent evidence among the relevant literature regarding the period of time for which this experience of distress will continue for individual women.

Importantly, lasting distress has been linked to significant, ongoing repercussions within the wider family sphere. For example, relationship conflict may arise due to conflicting grieving processes between parents,[20] witnessing or experiencing grief may have intergenerational effects on surviving children, and subsequent pregnancies may prove stressful.[3],5 Despite these experiences, some women have also reported improvements in interpersonal relationships following pregnancy loss, building stronger and more intimate connections with partners through mutually engaged grieving processes, or a renewed sense of appreciation and value in close friendships.[5],7 However, support from family and friends is frequently unavailable for many women.[7,23] As such, it is vital for women's healthcare professionals to provide high quality and available support both immediately after, and in the weeks, months or even years following a loss.[29] Yet despite the need for support and the impact that support has on psychological outcomes for women following a loss, there is relatively little research on women's experiences of the healthcare they received after a stillbirth or miscarriage, especially in Australia. Similarly, there is little research which explores the outcomes of support from healthcare service providers on psychological outcomes, with a 2013 Cochrane review highlighting the need for further research in this area.[19] In order to address this gap in the literature, this paper reports on a qualitative interview study concerning heterosexual women's experiences of the healthcare system in Australia and the care they received after a pregnancy loss. Before outlining the current study, we first explore previous literature conducted both internationally and in Australia concerning women's experiences of healthcare following a pregnancy loss.

1.1. Previous international literature on healthcare experiences

The sensitive time following a pregnancy loss for a woman and her family gives healthcare professionals (HCPs) only a brief window of opportunity to provide a sense of genuine care that addresses both physical and psychological needs.[3,10] This is particularly important since a growing number of research studies – from both within Australia and internationally – have demonstrated that women who experience pregnancy loss frequently feel isolated and inadequately supported by the health care system.[15,21–23] Consistent themes of guilt, loss and uncertainty have emerged from this body of work, together with feelings of isolation and an unmet need for sensitivity and emotional support after pregnancy loss.[9,10,13,29] This literature is discussed in detail below.

One of the main findings within the literature concerning women's experiences of healthcare following pregnancy loss is that of inadequate healthcare provider-patient communication, with studies finding that women commonly report a lack of clear and consistent information provision from their HCPs in regards to explanation of their loss, follow-up procedures and implications for future pregnancies.[9,10,18,20,24,25,27,23,29] Research indicates that a lack of explanation or reassurance worsens feelings of self-blame, guilt or 'failure' as a mother.[3,13,24,25,27] Furthermore, a small number of studies indicate that the use of biomedical language and terms by HCPs has been perceived as insensitive and dismissive of families' emotional needs. For example, medical terms including 'spontaneous abortion', 'failed conception' or 'reproductive wastage' can carry particularly negative connotations, and can be perceived by women as disaffirming the reality of losing a child[16], p.126). Such medicalisation of the experience can make women feel confused, anxious or imply a sense of failure, all of which foster further suffering.[20],27 On the other hand, where women and their families have reported positive experiences from HCPs, the literature suggests that such care is frequently related to the work of individual staff members.[10] For example, in research conducted in the UK, Downe et al.[10] comment that such positive experiences frequently rely on staff members who able to provide excellent emotional care by simply being with and sharing in the women's grief when it was needed most, concluding that this was paramount in fostering a positive mental health recovery.

Another recurrent issue seen in previous literature is women's reported dissatisfaction with the hospital environment itself. In many countries, for example the US and UK, women with pregnancy complications often report to the Emergency Department (ED) where many have reported little privacy and competition with other sick patients for immediate priority.[10,18,27] Once admitted, a lack of specialised services mean women who have just experienced a loss are either placed in maternity wards with mothers and their healthy newborns, or in a separate ward where staff are not always familiar with their situation.[10,13,18,24,27] As such, studies suggest that the hospital system itself is typically inadequate to properly deal with women's needs following a pregnancy loss.[24] Indeed, studies investigating the perspectives of HCPs themselves including obstetricians, general practitioners, nurses and midwives, suggest that many feel inadequately trained and ill-equipped to confidently provide appropriate and specialised care for women and their families following a pregnancy

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