

Title: Shrouds of Silence: Three women's stories of prenatal loss

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ABSTRACT

Objective: To give voice to the experiences of women who have suffered a prenatal loss prior to a full term pregnancy.

Design: A descriptive, exploratory qualitative study using mini-biographies was used. In-depth interviews were conducted with women to record their experiences and stories. Interviews were transcribed and the patterns that emerged from the data were identified and themes generated.

Subjects: The mini-biographical stories of three women were gathered. Interviews occurred in the women's homes. The women were recruited through an advertisement in the Stillbirth and Neonatal Death Support (SANDS) newsletter.

Results: The stories revealed the tragedy, pain and silence endured by these women, as they live with loss and grief. Common themes emerged from their stories highlighting grief, isolation, anger and self-blame in the face of their loss and subsequent full term pregnancy.

Conclusions and Implications for Practice: The emergent theme suggests that further research needs to explore how society and the health care community may compound women's grief and isolation and in-turn perpetuate their feelings of anger. In telling their stories, these women give voice to their experiences and offer a number of insights into how current health care practices may be modified to better support the needs of women who have suffered a prenatal loss and also points to the need for further research. Specifically, the study identifies a need for nurses and midwives to offer sensitive care,

acknowledgment of previous loss and supportive counseling strategies for women following prenatal loss and during antenatal care for subsequent pregnancies.

Keywords: prenatal loss, experience, grief

INTRODUCTION

This paper gives voice to three women who experienced prenatal loss prior to a successful pregnancy through the recording and analyzing of their mini-biographies. Although pregnancy is most often associated with joy and happiness for a number of women these feelings are short-lived as their baby dies either through miscarriage, ectopic pregnancy or neonatal fatality. While society relishes birth, there is a silent disregard for the grief and despair that pregnancy loss evokes.

Prior to the late 18th – early 19th centuries birth and death were ostensibly the domain of women (Nolan 1998; Bourne 1984). Traditionally women attended and supported one another, their families, and friends as they passed through these phases. This is particularly true in pregnancy; a time when the tenacity of life and death come together. As a result of technology, modernization and the rationalization of society women no longer have high levels of intimate social connectedness to other women in their local area. This led to women's traditional roles in birth and death becoming encompassed within the domain of health care professional (Nolan 1998; Bourne 1984).

Although previous research has explored the association between prenatal loss and grief and the role of health care professionals, there is a dearth of research focusing on the needs of women who have experienced prenatal loss, specifically in terms of antenatal care for subsequent pregnancies. The term prenatal loss describes varying types and reasons for pregnancy loss and is used in this paper as the overarching descriptor. The focus of this study is not a quantification of prenatal loss to any gestational or underlying

maternal condition nor the influence of loss on a subsequent pregnancy, rather it unfolds three women's responses, experiences and perceptions of prenatal loss, identifies implications for practice, and points to the need for further research.

LITERATURE REVIEW

Prenatal loss is a tragic event that causes physical and emotional trauma (Jacobs & Harvey 2000). Approximately one in five pregnancies end prematurely, with figures in Australia being similar to those of the United Kingdom and the United States of America (Boyce et al 2002; Conway & Russell 2000; Lee & Slade 1998; Beutal et al 1995). Despite these figures, it is only since the late 1960s and the early 1970s has pregnancy loss been recognized as a grief-producing phenomenon, and various studies on prenatal loss did not really appear in the literature until the mid 1980s (Beutal et al 1995; Hutti et al 1998).

Since this time research has been undertaken into the sequelae and other issues associated with prenatal loss (Cote-Arsenault & Mahlangu 1999; Hughes et al 1999; Armstrong & Hutti 1998). Harvey et al (2001) found that silence, isolation and loneliness are common experiences women encounter after a miscarriage. Lindberg (1992) found that despair was significant in the grief response and could be attributed to the lack of mourning behaviours in society and limited awareness that grief after pregnancy loss is a reality. Therefore a subsequent pregnancy can bring about stress, anxiety and reduced prenatal attachment as a result of emotional issues left unresolved from the prior loss. It may be common for women to compare the current pregnancy with the previous one and

perceive their pregnancy as more precarious resulting in guarded emotions about the pregnancy and the baby (Rillstone & Hutchinson, 2001; Cote-Arsenault & Mahlangu, 1999; Hughes et al, 1999; Armstrong and Hutti, 1998).

Conway and Russell (2000) argue that health care professionals can no longer perceive pregnancy loss as a matter of insignificance. Silence is a common response to a woman's loss whilst platitudes trivialize loss and do not legitimize the pain and anguish, thus increasing women's feelings of isolation. Despite the fact that most primary health care professionals view psychological care as important in the aftermath of prenatal loss, dissatisfaction with the care provided is prevalent (Harvey et al 2001; Lee & Slade 1998). The short time spent in hospital following a pregnancy loss may be one of the most mitigating factors in the lack of emotional support provided by health care personnel (Sweet, 2000; Swanson 1999).

Unlike previous research, the present study explores how women experience prenatal loss, the meanings it has for them and how they dealt with the grief and despair. While the literature recognizes that prenatal loss is a grief-producing phenomenon that evokes physical and emotional pain, there is a dearth of research giving voice to women who have lived such tragic events. Listening to women's stories regarding their experiences of prenatal loss recognizes their needs in terms of what they deem as useful, coping, helpful and supportive assistance so as to positively inform health care practice.

THE STUDY

A descriptive, exploratory qualitative framework was used to investigate an under-researched issue for women. The three women chosen for this study had a prenatal loss prior to a successful pregnancy. Participants were over the age of eighteen years and could comprehend and speak English. Although ten women responded by telephone to the advertisement in the Stillbirth and Neonatal Death Support (SANDS) newsletter, most were not appropriate for this study as they had not gone on to have a successful pregnancy. Given the scope, and time limitations of this study, geographical proximity formed the basis for choosing participants. Three women living within a ten-kilometer radius of each other were chosen. Ethics approval from the Griffith University Human Ethics Committee was granted for the study.

Gathering the Stories

The use of unstructured interviews enabled the women to reflect on their experiences, recall events that featured so predominately in their lives and provide a rich and comprehensive understanding of their perspectives (Streubert & Carpenter 2003). The use of unstructured interviews defined the specific context of each participant and focused not only on the women, but also on their individual situation, as context can define and shape behaviour.

Each woman after giving written consent was interviewed in her own home for approximately three hours enabling her story to be told in a setting that facilitated a more comprehensive depiction of her personal viewpoint. To maintain confidentiality the

women were given pseudonyms of Tanya, Connie and Sally. Tanya had lost three children to stillbirth and neonatal fatality prior to the successful birth of her only living child. She lives in the metropolitan area and was cared for under the private health system. Sally experienced a neonatal death and a miscarriage prior to the birth of her two living children. She also lives in the metropolitan area and had her babies under the private health system. Connie had six miscarriages at various stages of pregnancy and neonatal twin deaths. She has successfully given birth to two living children and at the time of her pregnancies was living in a remote rural area and was cared for by the public health system. As the following analysis shows while each woman's background is unique, similarities within their stories were apparent.

The raw data was analysed from the transcripts of the interviews using qualitative content analysis (Lupton 1999; Streubert & Carpenter 2003) to identify patterns and themes emerging from the women's stories. Initially the central focus of this study was on the women's experience of support during a successful pregnancy after suffering a prenatal loss. However during the interviews it became very apparent that the grief following the women's prenatal losses was still very much a mitigating factor and the concept of support could not be investigated without an exploration into the support received after their loss. Content analysis of the women's stories identified two sub-categories 'Being on the outside looking in' and 'Being changed or transformed by loss'. The emergent theme of 'Dealing with the experience of grief, loss, anger, self-blame in a world of silence' conceptualized the essence of these two categories.

RESULTS

Dealing with the experience of grief, loss, anger, self-blame in a world of silence

The women's losses placed them apart from what society deems a 'normal' loss. Brier (1999) believes that often the absence of a person to bury and/or the absence of memories and time together contributes to the feelings of grief. Yet, these women have memories and their loss and sadness is a tragedy.

...I felt like my heart had been ripped right out of my chest. I don't know how I got over that...you know you hear 'she died of a broken heart'- I'm convinced that's true...that pretty much until the day I die I will be in a state of grief...(Tanya)

...at times I felt that I just couldn't face another day – all I wanted was for the pain to go away – but it never did and it still hasn't (Connie)

The women hid this tragedy, fearing rejection from others. This element is reflected in the work of Morris (1993) who believes that society as a culture rejects the notion of tragedy. For the women the silence began when they were no longer defined by being pregnant, nor by being a mother and felt unable to publicly display their grief.

...in a few weeks you are supposed to pick yourself up and just keep going as though nothing has happened...your feelings and emotions – they just have to stay hidden all the time...(Connie)

This perceived lack of social understanding left these mothers alone and uncomfortable. Added to this, the silence was aggravated by the failure of friends and family to acknowledge the loss and grief as real. They experienced people avoiding them, or treating them as though they had never been a mother.

*...it is too much for most people – if you haven't been in that situation it's too much
– they back away...(Sally)*

Despite the women suffering their losses in different time frames, the amount of anger expressed by each reflected their ongoing grief. The anger experienced was three dimensional and focused on the lack of support particularly after the initial mourning period, the lack of understanding by the general community for their loss, and anger at their loss.

Associated with the anger of their loss was self-blame and guilt. Each woman voiced concerns about their behaviour during the pregnancy, reflecting on things that they could have changed even though they believed that they had not done anything that would have precipitated their prenatal loss. They believed that somehow it was their fault, that they were to blame in some way.

...there is heaps of self-blame – I should have done this and I should have done that...how could I have headed this off...(Sally)

Daiter (2002) notes that women often blame themselves, often harshly and unjustly compounding guilt and adding to an already emotionally volatile situation. These women believed that they had failed at something that “*millions of women in the world do*” successfully.

Being on the outside looking in

It was apparent that the women were seeking a sense of belonging during their pregnancy experiences. They sought this belonging through the culture of pregnancy provided by health care professionals, by attending antenatal classes and by society in general. After their loss however, these women felt that they were no longer able to find that sense of belonging in mainstream health care and society. One woman’s statement that “*you are some kind of freak*” clearly illustrates how the women felt ‘abnormal’. Moules (1998) believes that society’s tolerance of visible grief is limited and resulted in these women feeling alone and isolated. They felt there was “*no place*” where they belonged. This feeling of isolation and of having no clear place in society to be a mother without a child has also been identified by other studies (Harvey et al 2001).

Previous research, although limited suggests that support from health care professionals after a prenatal loss is minimal and not effective. Follow-up visits are rarely organized and there is a failure by health care professionals to validate and recognize women’s experiences resulting in increased fear and vulnerability (Swanson, 1999; Thapar & Thapar, 1992). The women believed they had been left to deal with all the emotional issues brought about by their loss without the support of health care professionals. The

loss of their child placed the women outside the auspices of all mainstream health services. Because the women were no longer pregnant, they did not require antenatal care. They were mothers, but without a child so they did not require Maternal and Child Health services.

The lack of care and support available or offered to the women provided the impetus for these women to seek help outside the realm of health-care professionals. The women sought support through self-help groups and joined at various stages after their loss. The desire to seek support and help from others who have been through similar circumstances was seen by the women as invaluable. Laakso and Paunonen-Ilmonen (2001) believe that discussing difficult issues with those who have had similar experiences is easier and offers positive encouragement. Seeking help from women who have had similar experiences highlights the women's need to belong. For these mothers learning how other mothers coped with grief gave hope and positive encouragement. The common experiences of belonging to a self-help group produced solace, comfort, understanding and hope. This sense of belonging however faded when the women became pregnant again. They believed they no longer fitted into the boundaries of the group; their guilt resurfaced as they felt it was unfair to face women who so far had not been able to successfully become pregnant again, a view that is reflected by Armstrong and Hutti (1998). The anguish, despair and guilt that these women continued to feel over the loss of their babes coupled with the guilt about being pregnant again, left these women isolated and the silence returned.

Being changed or transformed by loss

Each woman struggled with her sense of identity. Although each felt they were a mother, they were a mother without child, and did not have tangible evidence of their motherhood. They had no visible representation for the love, hope and dreams that they felt for their child. Stroebe, Stroebe and Hansson (1993) believe that mothers maintain an attachment to an internal representation of their child and may do so for many years after the child's death. As such, the grief can be a life changing experience that is related to the type of loss and has inescapable elements of suffering and pain (Moules, 1998; Anderson, Besson & Porter, 1994).

The joy of being pregnant again for these women was overshadowed and marred by their previous experiences. Each woman stated that they were happy to be pregnant again, but that the happiness did not last long.

Oh gee petrified – but over the moon, absolutely petrified and not really hopeful ... - its happened this month and I'm pregnant, but then...the over the moon feeling disappears about half an hour after you read the little urine stick...you hold back on any other feelings...(Sally)

The reoccurrence of similar circumstances, such as pregnancy, can involve comparison of past experiences to current ones and as such feelings of apprehension can occur. For these women it was the threat of another miscarriage. Cote-Arsenault and Mahlangu (1999) found that women are far less confident during a subsequent pregnancy for fear of a recurrence of past events.

For these women, their previous pregnancy experience taught them that not all pregnancies result in a live baby. They were aware that what had gone wrong in their previous pregnancies could occur again. Each woman reflected on how they felt that they had lost the bliss and enjoyment that can be associated with pregnancy. They held back from making an emotional attachment to their unborn child in what could be viewed as a protective self-defense measure.

Undertaking steps that would increase the chances of the safe arrival of their child were exhibited through other practices by the women. Reading and researching into pregnancy loss and stillbirth featured strongly as a measure that would enhance the safe arrival of their child. The concern for these women was how to get through this pregnancy, even though the pregnancy was dominated with fear of another loss, each woman wanted to maximize their chance of having a baby.

The women revealed that they did not attend antenatal or prebirthing classes during subsequent pregnancies. Their non-attendance hinged on a number of factors. Firstly, the women did not wish to minimise the joy of pregnancy that other women may feel if their maternal history was revealed during the natural progression of the classes. Also the women were envious of the joy of others. Indeed, Brier (1999) found that most pregnant women are naive and not prepared for the possibility of adverse pregnancy outcomes. Finally, fear, initiated by the previous prenatal losses, also prevented these women from attending antenatal classes. All the women raised fear as an issue; they

viewed the knowledge that they had gained from their previous antenatal care as inadequate for their needs in their subsequent pregnancy. Fear also included upsetting the other women in the class and a fear of being shunned by other members of the group.

In a way I feel that I missed out on some of the pregnancy experience not being able to attend, like normal people, but a very large part of me was glad that I did not have to go and face all those happy mothers who did not have the foggiest idea what I was going through...but you can't ruin their pregnancy just because yours has gone wrong. (Connie)

Women with special needs often fail to attend antenatal classes which they associate with only positive outcomes (Rossiter & Fowler, 2000; Lumley & Brown, 1993). The women in this study noted that their previous experience of antenatal or pre-birthing classes did not include any reference to pregnancy loss; so again these women felt that they were outside the boundaries of normalcy.

CONCLUSION AND RECOMMENDATIONS

Each woman was asked about what could have helped them in dealing with their loss and their subsequent pregnancy. All the women unhesitatingly replied that they would have liked someone to talk to. They felt isolated and lacked support. These women recognised that because of their experiences they would never be able to recapture the joy associated with pregnancy. Having someone to talk to who understood their situation would have been beneficial in reducing anxiety during pregnancy that was brought about by their previous experiences.

The women also identified the need for improvements in antenatal care. These women believed that provision of classes/groups that address their needs is a major issue. The women openly expressed a desire for knowledge, and to a degree attained some knowledge through literature, but felt that the current agenda for antenatal classes, only addressed positive outcomes and had little to offer them. These women see antenatal care specifically designed for women who have suffered a prenatal loss as an avenue that could be undertaken by the health care profession in alleviating some of the emotional burden that accompanies women in a subsequent pregnancy after a loss. In the future, this antenatal care may allow other women who suffer the tragedy of prenatal loss to find joy in pregnancy instead of fear.

Grief as a sequel to prenatal loss has been well documented through the recent literature and the impact of prenatal loss on a subsequent pregnancy has also been explored. It is, however, important to continue research in this area. Given the perspectives raised by these three women although the study is limited by its size and scope it does point towards the need for further research to examine the effectiveness of strategies and interventions in supporting and assisting women who have experienced a prenatal loss is needed.

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