

Women's perceptions of Nurse-Midwives' caring behaviours during perinatal loss in Lilongwe, Malawi: An exploratory study

A N.K. Simwaka^{1*}, B de Kok², W Chilemba¹

1. Kamuzu College of Nursing, University of Malawi

2. Institute for International Health and Development, Queen Margaret University, United Kingdom

*Corresponding Author: anksimwaka@kcn.unima.mw

Abstract

Objective

The objective for this study was to explore women's perceptions of and satisfaction with nursing care they received following stillbirth and neonatal death in villages around a community hospital in Lilongwe.

Methods

This qualitative, exploratory study through a mixture of purposive and snowball sampling, recruited 20 women who had lost a child through stillbirth or neonatal death in the past 2 years. Data were collected through semi-structured interviews in the privacy of the homes of the women. All interviews were tape-recorded and transcribed verbatim and were analyzed using thematic analysis.

Results

Almost half of the respondents expressed satisfaction with the way nurses cared for them after experiencing perinatal loss, although some felt unable to comment on the quality of care received. However, several bereaved women were dissatisfied with how nurses handled their loss. They noted nurses not providing attention or explanations and some even attributed the death of their child to nurses' neglect.

Conclusions

Interventions are needed which foster awareness where nurses become more sensitive to the mothers' emotional needs in an equally sensitive health care system. There is also need for more research into care provided following perinatal deaths in resource-poor settings to increase the evidence-base for informed and improved care for women who have experienced child loss.

Introduction

Perinatal loss, is a devastating but common experience. Approximately 4 million neonatal deaths occur each year, accounting for 36% of deaths worldwide in children under five¹. Malawi's perinatal mortality rate is among the highest in the world; it was 36 in 2004, down from 46 in 2000². Regardless of national rates, for the woman who has lost a pregnancy or a newborn, the experience is always a devastating event, perhaps especially in a society like Malawi where childbearing is greatly valued.^{3,4}

Perinatal loss involves the loss of the hoped for, planned for, and anticipated child, and a sense of failure to become a parent.^{5,6,7} This makes perinatal loss particularly traumatic because the (anticipated) child is so much a part of the parental identity⁵.

Few qualitative studies have explored women's experiences of nursing care following perinatal death in Africa, but a number of studies have examined women's experiences of antenatal and obstetric services^{8,9,10} including Malawi.^{11,12,13} While some studies show that women were generally satisfied with the care they received from health care providers¹³, a number of other studies show that women frequently received

suboptimal maternal care, with women reporting clinical neglect, insufficient explanation, strained relationships, verbal and sometimes even physical abuse from nursing staff. Given the increased care needs of women following stillbirth and neonatal death, it is pertinent to examine their experiences and perceptions of maternal care received from nurse-midwives.

Methods

A qualitative research design was chosen for this exploratory study because it was important to hear the views and experiences of the women in their own words. Twenty women from 10 villages around a community hospital who had experienced stillbirth or neonatal death in the last two years and had been cared for by a nurse at the hospital were selected. Initially, 12 participants who met this inclusion criteria were selected from perinatal loss records of the hospital. However, because some women's whereabouts could not be traced we changed to snowball-sampling. We contacted potential participants through two primary health care workers.

The investigators were aware of the possibility of recall bias after 2 years for some women and therefore follow-up interviews with the women to clarify any issues were considered but not feasible due to limitations of time and financial resources. However, this was counter-balanced by the fact that most of the women recruited into the study had experienced child loss in the past one and a half weeks to four months preceding the interview. It was assumed that they could still remember how nurse-midwives had cared for them during their hospital stay. While 20 is a small sample size it is typical for qualitative studies because there was saturation of data as no new information was being gathered after interviewing 20 women. The 20 interviews enabled us to identify patterns across individual interviews and obtain initial insights into care experienced. The first (AS) and third (WC) authors conducted semi-structured interviews where the main question was "Tell me your general feelings about the nursing care you received at the health facility following stillbirth or the death of your newborn". Women were interviewed in the privacy of their homes in their vernacular language Chichewa. Interviews were tape-recorded, translated into English and transcribed verbatim.

The Malawi College of Medicine Research and Ethics Committee approved this study. Before giving verbal informed consent, participants were told about aims of the study, the inclusion criteria, the confidential and voluntary nature of their participation and that they were free to withdraw from the study at any time or refuse to answer any questions if it caused them any distress. The interviews were tape-recorded with their permission. To ensure anonymity, each participant was given a code number. It was anticipated and indeed noticed that for some women the interview brought back painful memories. To minimize the psychological distress and offer a coping-mechanism, participants were assured that WC, a qualified community nurse, would from time

to time be available in the community with students on clinical practice should they need professional support as they grieve their loss. The participants were told of this free service at the end of each interview to avoid the possibility of their being coerced to participate in the study. After each interview, the researcher left her mobile telephone number with the participant to call her should any need arise. No participant withdrew from the study.

The data were analyzed using thematic analysis. AS and WC read all transcriptions and checked them against the recordings for accuracy. Data analysis was based on an adapted procedure as described by Colaizzi¹⁴. Initially, all transcripts were read to develop an overall understanding of the experience. Then, statements which appeared significant in the light of the research questions were coded and subjected to further, in-depth analysis. Field notes aided the analysis process by providing a reminder of key statements made by participants during the interviews. Finally, a description of each theme and sub theme was generated. AS and WC analyzed the transcripts separately then compared and revised findings until consensus on themes and interpretation was reached. This, together with the checking of the accuracy of transcripts and translations based on the original recordings will have enhanced the study's dependability and credibility.¹⁵

Findings

Characteristics of women

The 20 participants, ranged in age from 17 to 33 years (Mean = 20.4 years) and had educational levels from standard 2 (primary) to form 3 (n=2). Most women were engaged in petty trade like selling small scale farm produce such as vegetables, tomatoes, and maize. 19 were married and one was single. Six had unplanned pregnancies. Parity was from one to nine (Mean = 3.5, Mode = 3).

Prior to the interview, 16 women had experienced perinatal loss from one and a half weeks to four months with one woman at 19 months as the longest period. Therefore the participants had experienced perinatal loss relatively recently. This will have facilitated recall but also meant that for some respondents talking about their experience may have been particularly sensitive. However, as mentioned earlier, we were able to ensure that ongoing professional support was available from a community nurse interviewer also trained in providing psychosocial support.

Women's accounts of care

The women described the experiences they went through soon after stillbirth or the death of their newborn child while being attended to by a nurse-midwife. Analysis focuses on four themes: (1) women's response to the loss, (2) women's experiences of care received, (3) women's expectations of nursing care, and (4) women's coping strategies in dealing with their loss.

Responding to the Loss

Expectation for something positive

All the women, said that they were looking forward to having a baby and expressed grief at the loss. Women used words such as kusweka-mtima (broken-hearted) to describe how they felt when they miscarried or their neonates died.

I was filled with sorrow because I was expecting something, I was eagerly waiting, and I was also happy that I would have a baby. I was heart-broken... I become depressed especially when I see other peoples' children,

but I try to encourage myself to think that it happens (Interview 3)

Respondent three's reaction suggests that perinatal loss is a traumatic experience because it thwarts expectations; the hoped for, planned for, and anticipated child.

A few women related their emotional distress to the work involved in a pregnancy, and this work having been in vain:

I was depressed because ndinapitapachabe (I went in vain) (Interview 6)

'Kupitapachabe' which is literally translated as 'to go in vain' has the connotation of doing work for nothing when a woman miscarries.

I felt very sorry for myself because it was as if I had worked for nothing (Interview 18)

Womens' explanations of the possible causes of perinatal loss

A few interviewees attributed their (unborn) baby's death to external factors, including blaming other people for the loss. Thus, two women suspected that their husbands were promiscuous and that their behaviour had significantly contributed to their perinatal loss.

I think I had a miscarriage because of the sexually transmitted infection my husband passed on to me (Interview 7)

According to local interpretations, affairs can lead to pregnancy problems including miscarriages or stillbirths. One participant attributed the loss to a relative with evil intentions who she suspected bewitched her:

Someone who is my mother's relation did not want me to give a normal birth; she wanted me to die during delivery (Interview 6)

More common was attribution of loss to medical procedures, and blaming health practitioners for the death. Two women mentioned a medical procedure of inserting tubes into their babies' noses during oxygen therapy as having contributed to their neonates' deaths. Three other women blamed it on the nurses' negligence, and in the words of one:

I think it is the nurse's negligence because if she had attended to me a way could have been found to save my baby, either through an operation or widen the way for the baby to come out as it was done for my second born (Interview 9)

However, five participants said that the death of their (unborn) baby was God's wish.

Women's experience of care received

When asked to comment on the quality of care they received from nurse-midwives, women referred to both positive and negative episodes in terms of physical and psychological aspects of care.

Physical aspects of care received

Women's interpretation of the quality of care received depended in part on the kind of physical or medical care received. For instance, one woman was asked what the reaction of the nurse-midwife was after the death of her newborn:

According to me I think she took good care of me as her patient. During labour I was well attended to up to the time I had a stillbirth, and after giving birth to a dead baby, she cleaned me up, pushed me on the wheel chair and laid me on the bed, and I felt that the nurse had really cared for me (Interview 18)

The respondent had a positive perception of care due to a nurse-midwife performing basic (cleaning the patient) nursing tasks. On the other hand, several women described feelings of abandonment or not being supported by nurse-midwives during labour and at the time of their loss.

If only she was close to me at the time I was calling for her, I am sure my child could have been alive now but she went away when the baby was about to come out (Interview 11)

Some women had noticed complications during labour or birth and had felt that their newborns would not live for long without medical intervention. They reported that they verbalized their concerns to nurses on duty but felt that the nurses did not take their complaints seriously and neglected them and their babies.

Psychological aspects of care received

Lack of empathy and attention.

Some nurse-midwives said words of comfort which bereaved women found encouraging:

She said I should not worry too much because that is how God planned it, He gives and takes away so maybe God will give me another gift at a later time (Interview 18)

However, substandard psychological aspects of care were reported as well. Several women found that nurse-midwives lacked warmth and sensitivity and they felt they were cared for in a business-like manner. They reported that the nurses did not show any empathy by saying words of encouragement or counselling them following their stillbirth or neonatal death.

All participants wanted the nurse's attention soon after experiencing perinatal loss and they were disappointed when they were not adequately attended to.

There is nothing that they were doing, when the child died, they were just walking about. (Interview 6)

Some women were themselves hospitalized at the time of their infant's death, and they wanted some nurse's attention and meaningful interaction with them at this crucial time

In the extract below, the respondent points to the absence of a nurse

After delivery she did not come to my bed to attend to me but a different person in a green uniform is the one who came (Interview 19).

Staff wearing green uniform are cleaners who are often called upon by nurse-midwives to assist them carry the baby to the maternity unit after delivery.

Lack of explanations

Women viewed their nurse-midwives positively where they explained to them the possible cause of stillbirth or the child's death. However, twelve women said that the nurses-midwives did not offer any explanation as such these women gave their own explanations as to what may have caused their perinatal loss, such as suffocation, God's will or witchcraft.

Nurse-midwives know better

A few participants expressed difficulty evaluating care; they mentioned that the nurse-midwives knew better and it was up to them to decide what was best for the client.

Discussion

Our findings highlight how problematic a stillbirth or neonatal death can be for Malawian women; women expressed profound grief regardless of the number of earlier pregnancies, number of living children or whether the pregnancy had been planned. The importance women attach to bearing children in Malawi may have aggravated their sense of loss⁴.

One of the most important tasks of nurses is to provide client-centred care, which calls for reflective listening, use of empathy and excellent communication skills^{16,17}. Patient-centred care is generally deemed important, but will be especially important when dealing with women who have gone through the traumatic experience of a stillbirth or neonatal death¹⁸. Several women perceived that the care received was of good quality, sometimes on the basis of basic attendance to their physiological and medical needs. On meeting their psychological needs, women who positively described their nurses were pleased with the manner in which nurses empathized with their loss, demonstrated by the nurses talking to them to console them on their loss. Providing explanations to women themselves and their relatives was seen as a positive aspect of care as well. These findings resonate with other studies which identified several supportive nursing care behaviours: provision of social, emotional and physical support, making time to be available, showing compassion, giving information, explaining the cause of death, listening and respecting women's opinions^{19,20}.

However, a number of women point to substandard care during or after birth in terms of physical or psychological aspects. Eight respondents expressed dissatisfaction with the nursing care provided while three commented on the positive aspects of nursing despite their dissatisfaction. Some reported neglect of their emotional needs; nurses did not spend much time with them after the death of the baby or offered no words of encouragement to the would-be mothers. These findings are not specific to Malawi or resource-poor settings; participants in a UK-based study reported that staff were cold, impersonal and felt that they left them alone for too long²¹. Although technical competence is important, physically being with the bereaved woman conveys emotional presence and connectedness and shows that the client matters to the nurse⁷. Moreover, nurses must acknowledge the meaning which women attach to their pregnancies and the significance of the baby to them in a society that highly values childbearing. If nurse-midwives display understanding of women's feelings about losing a wished-for child, this may likely help women cope with their loss⁷.

There is a risk that health professionals view perinatal death from a medical perspective focusing on the physiological factors only. This may lead them to trivialize it, for example, regarding a stillbirth as a failed conception which contrasts with women's perspective of their loss as an emotional and symbolical event²². Instead of empathizing with women's unique grief experiences, nurses often act according to the institutionalized norms of dealing with bereaved women^{23,24}. This can lead to depersonalisation and 'mechanical'

interactions, and grieving women will therefore perceive nurse-midwives as uncaring.

While some respondents expressed disappointment at the nurses' attitudes and professional negligence, some appeared unwilling to comment on their conduct and suggested that nurses were best qualified to know which type of care was best. Other studies found as well that respondents are reluctant to critique health professionals as they think that this may be considered rude and ungrateful.^{8,21} It is argued that women are reluctant to discuss quality of care partially due to institutionalized norms according to which patients are expected to be passive and show subservience to medical authorities and are considered (and consider themselves) too uninformed about healthcare to comment. These expectations and norms seem particularly relevant when patients, like most of our respondents, are relatively uneducated and poor.

Women may attribute their loss to God's will, fate or witchcraft in part because they receive insufficient medical explanations. Medical explanations are desirable because child loss gives rise to feelings of personal helplessness and self-blame, which accurate information about the baby's death may ameliorate.²⁵ In addition, we discussed how some women attributed death of their baby to nursing behaviours. Women's accounts may reflect actual negligence, but this is not necessarily always the case. If alternative explanations for the death of a baby are available, providing these may prevent overly negative perceptions of care. This in turn may well foster future use of maternity care, which is important in order to prevent loss and improve maternal and neonatal health.

Despite the study being small-scale and exploratory in nature, the findings can form a starting point for developing best practice guidelines for application in similar settings. In addition, there is a need for more research into care provided following perinatal deaths in resource-poor settings to increase the evidence-base for informed and improved care for women who have miscarriages, stillbirths or whose baby dies soon after birth.

References

- Lawn J, Cousens & Bhutta 2004 Why are 4 million babies dying each year? *Lancet* 364, 399 - 401
- National Statistic Office (NSO) [Malawi] and ORC Macro (2005). *Malawi Demographic and Health Survey 2004*. Calverton, Maryland: NSO and ORC Macro
- Barden-O'Fallon, J. (2005). Associates of self-reported fertility status and infertility treatment-seeking in a rural district of Malawi. *Human Reproduction*, 20, (8) 2229-2236
- Kok, B. C. de & Widdicombe, S. (2008) 'I really tried': Management of normative issues in accounts of responses to infertility. *Social Science and Medicine*, 67, 1083-1093
- Callister L.C. 2006 Perinatal loss: A family perspective. *Journal of Perinatal and Neonatal Nursing*, 20, 227 - 234
- Capitulo, K L 2005 Evidence for intervention with perinatal bereavement. *American Journal of Maternal Child Nursing*. 30, 389 - 396
- Hutti, M.H., 2005 Social and professional support needs of families after perinatal loss. *Journal of Obstetric, Gynecologic, and Neonatal Nursing* 34; 630 - 638.
- Béhague D.P., Kanhonou L, Fillipi V, Legonou S & Ronsmans C (2008) Pierre Bourdieu and transformative agency: a study of how patients in Benin negotiate blame and accountability in the context of severe obstetric events. *Sociology of Health and Illness*. 30, 489 - 510
- Grossmann-Kendall F, Fillipi V, De Koninck M & Kanhonou L 2001. Giving birth in maternity hospitals in Benin: Testimonies of women. *Reproductive Health Matters*. 9: 18. 90 -98
- Jewkes R, Abraham N & Mvo Z (1998) Why do nurses abuse patients? Reflections from South African obstetric services. *Social Science and Medicine*. 47:11, 1781 - 1795
- Ministry of Health (2005). *Emergency Obstetric Care Services in Malawi: Report of a Nationwide Assessment*. Ministry of Health: Lilongwe
- Tolhurst R, Theobald S, Kayira E, Ntonya C, Kafulafula G & Nielson J (2008). 'I don't want all my babies to go to the grave': perceptions of preterm birth in Southern Malawi. *Midwifery*. 24, 83 - 98.
- Changole J., Bandawe C., Makanani D., Nkanaunena K., Taulo F., Kafulafula G., (2010) Patients satisfaction with reproductive health services at Gogo Chatinkha Maternity Unit, Queen Elizabeth Central Hospital, Blantyre, Malawi. *Malawi Medical Journal*; 22 (1) 5-9
- Colaizzi P C (1978) *Reflections and Research in Psychology: A Phenomenological Study of Learning*. Kandall/Hunt, Dubuque, IA
- Koch T (1994). Rigour in qualitative research: the document trial. *Journal of Advanced Nursing* 19, 976 - 986.
- Mead N. & Bower P., 2000 Patient-centredness: a conceptual framework and review of the empirical literature. *Social Science and Medicine* 51, 1087 - 1110,
- Epstein R.M., Franks P., Fiscella K., Shields C.G., Meldrum S.C., & Kravitz R. L. 2005. Measuring patient-centred communication in patient-physician consultations: theoretical and practical issues. *Social Science and Medicine* 61, 1516 - 1528
- Cacciatore, J. 2010 Stillbirth: Patient -centered and psychological care. *Clinical Obstetrics & Gynecology*, 53(3) , 691 - 699
- Homer C, Passant L, Brodie P, Kildea S, Leap N, Pincombe J, Thorogood 2006. The role of the midwife in Australia: views of women and midwives. *Midwifery*. doi:10.1016/j.midw.2007.11.003
- Stamp G, & Crowther C (1994) Women's views of their postnatal care by midwives at an Adelaide women's hospital. *Midwifery*, 10) 148-156
- Smith L, Frost J, Levitas R, Bradley H & Garcia J (2006) Women's experiences of three early miscarriage management options: a qualitative study. *British Journal of General Practice*. 198 - 205
- Frost J, Harriet B, Levitas R, Smith L, & Garcia 2007. The loss of possibility: scientisation of death and the special case of early miscarriage *Sociology of Health & Illness*. 29, 1003 - 1022
- Leon I 1992 A critique of current hospital practices. *Clinical Pediatrics*, 31: 366-374
- Van, P. & Meleis, A. I. (2002). Coping with grief after involuntary pregnancy loss: Perspectives of African American women. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 32, 28-39
- Mander, R. 2006. *Loss and Bereavement in Childbearing*. (2nd ed) Routledge, New York