

PERINATAL LOSS: A QUALITATIVE STUDY IN NORTHERN IRELAND

BERNADETTE SUSAN MCCREIGHT, PH.D., B.Sc. (HONS) SOCIOLOGY
University of Ulster, Northern Ireland

ABSTRACT

This article describes the experiences of women in Northern Ireland who have experienced a miscarriage or stillbirth. Pregnancy loss encompasses several dimensions of loss for women, loss of the future, loss of self-identity, and the loss of anticipated parenthood. The study explored how women emotionally responded to loss and the care they received from medical staff. Burial arrangements for the remains of the baby are also explored. The methodology adopted a narrative approach based upon in-depth interviews with 23 women who attended pregnancy loss self-help groups. The women's narratives highlight their emotional responses to loss, the medicalization of perinatal grief, and burial arrangements. Women felt that their experience was emotionally negative in that they had been subjected to a rationalizing process of medicalization. The primary focus for the women was on the need to recover space for their emotions and seek acceptance and recognition of the validity of their grief. The study demonstrated that the women's response to being marginalized led them to make sense of their experiences and to create spaces of resistance to medicalization. The way in which women placed emotion at the center of their narratives is taken to be a powerful indicator that the support they require from professionals should take account of the meanings they have constructed from their experience of loss.

INTRODUCTION

The loss of a baby through stillbirth or miscarriage can be traumatic for parents, grandparents, siblings, the wider family, and health professionals. Set within a

Northern Ireland context, this article reports on one aspect of grief within a larger study exploring the impact of pregnancy loss on parents and health professionals (McCreight, 2004, 2005, 2007). It has been claimed (Moulder, 1999) that in clinical practice, many health professionals treat miscarriage, as distinct from stillbirth or neonatal death, as an insignificant routine event. In contrast, a more sympathetic understanding of grief is afforded to women whose baby is stillborn (Hertz, 1984). There is a substantial body of evidence, however, which suggests that for some women miscarriage may be the most traumatic event of their lives (Brier, 2004; Engelhard, van den Hout, & Arntz, 2001; Hutchon, 1998).

Where a baby is stillborn after 23 weeks gestation, a stillbirth certificate is required and the baby's remains must be buried according to law. In the case of miscarriage there is ambivalence concerning whether a human life has been formed, and death has actually taken place, so that no formal record of death is required, and many parents are not given an opportunity to bury the remains (where remains exist) of their baby. Miscarriage is termed spontaneous abortion by some medical staff, a term which can be upsetting, or at least confusing. For some women the term abortion also carries a disturbing connotation of planned termination.

The starting point for reviewing the women's narratives was acceptance of their feelings and perceptions as valid for them, irrespective of whether they accorded with particular ideological or professional viewpoints. Discussion of pregnancy loss tends to be avoided prior to its occurrence. This 'silence,' for women, continues after the loss of the baby, its recognition expressed in their reported feelings of isolation and separation. This may often be attributable to a failure by medical staff to communicate (Trulsson & Rådestad, 2004) and provide support in a form which might bridge the different life-worlds of bereaved women and medical professionals.

The concept of the life-world relates to the 'the intuitively present, familiar and transparent, and at the same time vast and incalculable web of presuppositions that have to be satisfied if a proposition is to be meaningful' (Habermas, 1987, p. 131). The more thoroughly rationalized and information-rich web of knowledge, that 'reservoir of implicitly known traditions' (Habermas, 1984, p. 12) shared by medical professionals, will have little in common with the communicative repertoire and understandings of bereaved women. Greenhalgh (1999) asserts that conventional medical training teaches students to view medicine as a science, and the doctor as an impartial investigator who constructs diagnoses as if they were scientific theories. According to Foucault (1991) medical symptoms are taken as objective facts, observable under the authority of the 'medical gaze.' Whereas the 'medical gaze' of the 'doctor' is focused on what is physically presented to them by patients, the bodily experience of women in these circumstances is mediated by life-world experiences and the meanings attached to a pregnancy loss. Life-worlds are built recursively out of shared, as well as private experiences. But the private grief of women, who have not articulated discourses

in which to express their feelings, inhabits separate and fragmentary worlds. It is apparent that the experience of many women, following pregnancy loss, remains largely invisible, their voices and life-world experiences often ignored and their condition portrayed in terms of symptoms. This article, using a narrative research approach, will present women's voices as they articulated the emotional impact of their pregnancy loss and the care they received from medical staff. Implications of burial arrangements for the baby's remains are also explored.

REVIEW OF THE LITERATURE

Previous academic research on pregnancy loss has tended to be based on quantitative studies using standardized measures (Barr, 2004; Cuisinier, Keijpers, Hoogduin, de Graauw, & Janssen, 1993; Hughes & Riches, 2003; Säflund & Wredling, 2006; Serrano & Lima, 2006; Stirtzinger, Robinson, Stewart, & Ralevski, 1999; Tsartsara & Johnson, 2006). These have included cross-sectional and longitudinal studies charting the occurrence of emotional distress following pregnancy loss (Swanson, Connor, Jolley, Pettinato, & Wang, 2007). Studies have also shown (Hale, 2007; Hutti, 2005) that many women feel a sense of responsibility and guilt following pregnancy loss, which can lead to unpleasant emotions, suicide and post-traumatic stress disorder. A mixed method approach has also been used in which women were asked to provide written accounts of their loss, following a survey questionnaire (see Simmons, Singh, Maconochie, Doyle, & Green, 2006). Few studies, with the exception of the small scale study carried out by St John, Cooke, and Goopy (2006), have explored women's personal meanings of pregnancy loss and how they have dealt with their grief and despair.

The loss of a baby during pregnancy almost always involves the loss of hopes, dreams, and expectations invested in the expected child (Rubin & Malkinson, 2004). The grieving process following such loss may be long-lasting and traumatic resulting in significant anxiety for women. In their study of Swedish women who experienced a stillbirth, Rådestad et al. (1996), noted high anxiety levels in women who had no token of remembrance of their baby. The authors also found that more women reported anxiety related symptoms when they did not see their baby for as long as they wished. Similarly, Säflund et al. (2004) found that time spent with the deceased baby helped to facilitate recovery. In contrast, Hughes and Riches (2003) suggest that rituals which encourage parents to hold their deceased baby may force parents to confront intense feelings of sadness, grief, and shock, and may be counter-therapeutic. Decision-making in this regard raises ethical considerations, with the potential conflict between the principles of autonomy and beneficence. The principle of patient autonomy is vital, but weakened by the reduced capacity of parents to make decisions at a time when they are shocked and distressed (Badenhorst & Hughes, 2007, p. 249). Health professionals should therefore be sensitive to parents' personal understandings of pregnancy loss, especially concerning how the baby may be mourned within particular cultural and

historical contexts. Trulsson and Rådestad (2004) recommend that health professionals improve the long-term well-being of women after stillbirth by giving more regard to women's intuitive beliefs and diagnoses, thus avoiding further psychological trauma and strengthening their power to cope with loss.

A study conducted in the Netherlands (Cuisinier et al., 1993) found that women who experienced miscarriage show significant, but less intense grief reactions than women who give birth to a stillborn baby. In contrast, Walker and Davidson (2001) found that early pregnancy loss could lead to anxiety, loss of sleep, feelings of fear, and helplessness. Frost and Condon (1996), following a comprehensive review of the literature, identified that miscarriage leads to high levels of guilt, loss of part of the self, and has a negative impact upon personal identity. Similarly, Engelhard et al. (2001), in their prospective longitudinal study of 1,370 women who experienced early pregnancy loss, found that pregnancy loss, regardless of the gestation period, may not only be a loss event, producing depression, but, also a threatening one, putting women at risk of developing post-traumatic stress disorder.

Although feminist research has tended to neglect the area of pregnancy loss, a few such studies have been carried out (Layne, 1997, 2003, 2006; Letherby, 1993; Lovell, 1983; Oakley, 1984). Layne suggests that ongoing taboos surrounding death, failure, and women's biology, work together to limit social acknowledgement and support for pregnancy loss. Layne carried out ethnographic research with three pregnancy loss support groups in the United States and noted how such groups break the silence which surrounds loss by creating a space for women to share their experiences. In examining attitudes and procedures which deconstruct the identities of mother and baby when a pregnancy loss occurs, Lovell asserts that 'it is suggested that all too often there seems to be no physical or psychological space for a maternity case without a baby. Is she a mother or is she a patient?' Lovell suggests that both roles may be lost simultaneously. Oakley, notes how the process of mourning after miscarriage can be the same as that following any bereavement, but it may be more difficult because the person who is mourned was never known as a person. Letherby suggests that miscarriage in contemporary society is now a medical event and that birth, death, and illness have been medicalized in Western industrial societies; consequently this may have made miscarriage harder for some women to cope with.

Cecil (1994) carried out an anthropological study of women who had experienced a miscarriage in Northern Ireland. The findings from the study indicate that while support came mostly from the woman's partner or mother, family support may be inadequate, and was for many women frequently unavailable, inappropriate, or of limited duration. It has been shown, however, that availability of social support has significant implications for the mourning process, owing to its therapeutic effect on the emotional well-being of women, legitimizing their needs and enhancing their capability to exercise autonomy (Rajan, 1994). Furthermore,

studies have shown that the consequences of pregnancy loss can be long lasting; a major risk factor in relation to enduring grief is the absence of professional support (Brier, 1999).

Studies have shown that many women who have suffered pregnancy loss report dissatisfaction with the care they received from hospital personnel (Layne, 2006; Simmons et al., 2006; Smith, Frost, Levitas, & Garcia, 2006). A survey carried out in a hospital in Northern Ireland (Moohan, Ashe, & Cecil, 1994) found that while women generally reported positively on the management of their miscarriage experiences, some areas of the management of care were inadequate, in particular, provision of information and advice to women at the time of discharge, and the attitude of medical staff. Similarly, St John et al. (2006), in their Australian study of women who have experienced a pregnancy loss, found that lack of care and support available, or offered, to women encouraged them to seek help outside the realm of health-care professionals. Communication is revealed as problematic in respect of perinatal care provided for many women.

RESEARCH METHOD

Contact with the women in the study was initiated through pregnancy loss support groups throughout Northern Ireland. The groups included Stillbirth and Neonatal Death Society (four groups), Remember Our Child (one group), and Miscarriage Support Group (one group). Members and facilitators of the self-help groups granted permission for the researcher to attend the meetings throughout Northern Ireland intermittently over a period of three years. During group meetings women were told that if they wished to volunteer to take part in individual interviews they could do so at a venue suited to them. All the women who volunteered to take part in the research chose to be interviewed in their own home. Interviews were tape-recorded and later transcribed. Data gathered in the form of field notes from observations of group meetings provided a framework for highlighting important issues during individual interviews. During observations of group meetings it became apparent that women constructed their experiences of birth, death, and bereavement through narratives. This enabled women to reflect on the personal experience of their loss and to tell their story in their own words. To begin the interview, women were asked: "Tell me your story of the events surrounding the loss of your baby." The opening question was designed to simply elicit a description of their experience; in practice the response to this question initiated lengthy narratives. Since there were strong similarities in the terms employed by participants, and among the feelings they articulated and contexts they described, it was possible through repeated comparisons to map recurring areas of concern, characteristic effects and kinds of sense-making that emerged for women. Validation of data was obtained through triangulation (Denzin & Lincoln, 2000), and involved comparison of interview data with observation notes taken at group meetings. Contact was also initiated with 10 hospitals throughout

Northern Ireland to investigate hospital practice and procedures for dealing with the remains of the baby.

The organization of the sampling arrangements was designed to ensure that no harm was caused to an already vulnerable group of individuals. All participants had already volunteered to take part in the self-help groups and later freely consented to take part in the research. A limitation of the study was that many interviews were based on data collected from women several years after their pregnancy loss, which may have influenced their memories. Caution should also be exercised in extrapolating the findings to other women who had experienced pregnancy loss and did not attend a self-help group. Pseudonyms were used to preserve anonymity. Ethical approval for the study was obtained from the Research Ethics Committee, University of Ulster, Northern Ireland.

Sample Characteristics

Twenty-three women were interviewed for the study. At the initial interviews, the period since the pregnancy loss ranged from two months to 34 years. The ages of the women ranged from 19 to 60; two had no living children. Three members were group facilitators who had experienced loss more than five years previously. Of the remaining 20, 18 had experienced pregnancy loss no more than three years previously, and attended the groups for emotional support. Two women had experienced loss more than three years previously, and attended for reasons arising from a variety of particular circumstances. For example, one woman who had lost a baby five years previously, was now pregnant again, and had returned to the group to obtain reassurance in anticipation of a hoped for live birth. Lily, an older woman who had experienced loss five times, more than 34 years previously, had joined the group to share her own losses with others for the first time, and to help other younger women in a situation for which she had received no support in her own life. Eight women had experienced stillbirth; eight both stillbirth and miscarriage; six experienced miscarriage; one woman experienced twin stillbirths.

Data Analysis

There has been considerable debate within the academic literature on justifications for narrative research approaches (e.g., McCance, McKenna, & Boore, 2001; Mishler, 1995; Polkinghorne, 1995; Reissman, 1993), and the lack of a single unifying method (Riley & Hawe, 2005). Polkinghorne's (1995) account of how paradigmatic analysis can be inductively constructed from respondent narratives, transforming individual stories into data for subsequent analysis, remains the most convincing and helpful framework, and was used in this study.

Individual narratives of loss, though unique, were taken as exhibiting related common features, derived from the particular kind of loss experienced by each narrator; in this case, the loss of a child that had never been born. Though each loss was unique, the configuring elements of loss would have a general, or

paradigmatic character, a unifying set across the otherwise unbridgeable griefs of the bereaved parents. On this principle, data analysis involved detailed scrutiny, or content analysis, of the transcripts of individual narratives. These subjective accounts of women's individual lived experiences of pregnancy loss were permeated with individual expressions of emotion. Yet, common themes could be identified and later re-examined from notes taken during observations of self-help group meetings. In this way, a single coding frame was established (Green & Thorogood, 2004).

The coding procedure was carried out using the QSR NUD*IST Vivo software package. Themes identified included 'emotional responses to loss,' such as grief, anger, depression, and self-blame. Emergent themes of the 'medicalization of pregnancy loss,' and reactions to burial arrangements, were also elicited from readings of the interview data. An iterative process of interrogating the data was adopted, as precaution against the construction of partiality and bias in interpretations, and to avoid introducing unrepresentative language into respondents' accounts and so obstruct or obscure intended or realized meanings.

FINDINGS

Emotional Responses to Pregnancy Loss

By participating in the narrative approach used in this study, women were able to reflect upon their personal experiences and articulate their grief in terms of emotional responses to loss. The women's narratives highlighted themes relating to emotions such as grief, denial, anger, and self-blame. Leder (1984) points out that grief is an example of emotional pain inseparable from the 'gut churning, nauseating experience' itself, while physical pain bears within it a 'component of displeasure, and often of anxiety, sadness, anger that are fully emotional.' In other words, pain, can be described as not only physical agony but also emotional turmoil and spiritual suffering. The way in which women placed emotion at the center of their meanings provides a powerful indicator that the support they require from professionals should take account of how they have constructed their experiences. Emotion was designated for many women as an unhelpful, if unavoidable concomitant of loss, to be managed through processes of rationalization. The focus for the women was on the need to recover their capability to express emotion and reconstruct it as a valid form of grief.

The following narratives highlight significant themes of denial, self-blame, and the women's bodily and emotional expression in grief:

When they showed me there was no heartbeat I was gutted. It was like some-one had ripped out my heart, my heart broke and it's never gone back right. I couldn't go out of the house. I just couldn't cope with it all and I didn't eat for weeks, I just wanted to die, badly" (Katherine, 1 stillbirth, 2 miscarriages).

I remember waking up on his first anniversary and looking at the door and I actually believed that somebody was going to walk in and say 'you've proved yourself this year that you can be a mother, and give him back to me. But when that didn't happen that was when I started to really grieve" (Deirdre, 1 stillbirth, 1 miscarriage).

I couldn't believe you could hurt so badly, and then the anger, but the anger was directed at myself thinking I had done something wrong, there must have been something that I had done for this to happen" (Rachael, miscarriage).

There has been a tendency for human emotion to be perceived as a problem needing to be resolved. It is of crucial importance that the notion of 'feeling' or 'emotion' is not conceived of in terms of pathology. A powerful reason for the engagement of women in self-help groups was the need to have access to a forum where emotional communications could be exchanged in a non-judgmental setting. Even more important was the need to have recognition for emotional expression within a clear understanding that these communications were social, that is intended for a social arena and intimately connected to the need to relate to the experiences of others. The status of such expression was not only cathartic, but communicative and informative.

From the analysis of interviews it was apparent that women were searching for meaning in their experience of pregnancy loss. For most, this entailed a search for causality (Simmons, Singh, Maconochie, Doyle, & Green, 2006). Most women who experienced a stillbirth had agreed to a post-mortem in the hope of finding an explanation for their loss. In only two of these cases was a medical explanation revealed. This very often led to feelings of guilt and self-blame, because, in the absence of a medical explanation, they were even more ready to blame their own negligence for the loss of their baby. Hale (2007), suggests that women who blame themselves for their pregnancy loss are raising moral claims, and it is important for medical practitioners, psychologists, social workers, and philosophers alike to bear this in mind when dealing with women. Several studies have shown that women who have undergone a pregnancy loss experience high levels of guilt (Barr, 2004; Hutchon, 1998), as well as self-blame (St John et al., 2006; Stirtzinger et al., 1999). Malacrida (1999) points out that a great part of the remorse and guilt parents feel stems from uncertainty as to the reasons for the death. Medicine does very little to assuage these doubts and the guilt they engender. This view is demonstrated by Rachael, who lost her baby through miscarriage and was told by the consultant at the hospital that she may have miscarried because she was overweight. Rachael felt that her feelings of self-blame and depression had been exacerbated by this remark. Letherby (1993) asserts that miscarriage is now primarily a medical event, and no longer a merely personal misfortune for which women were cared for in the community. She notes that the fact that birth, death, and illness have been medicalized in Western industrial societies may also have made miscarriage harder for some to cope with.

Letherby also points out that since the medical profession has been unable to reduce the incidence of miscarriage, the problem has been reconfigured by responsabilizing women themselves, defining them as personally inadequate.

The Medicalization of Perinatal Grief

One participant in the study, Susan, gave birth to stillborn twins. She recalled that the doctor had examined her and stated, "Your babies will be born immediately and they will die," after which the doctor left the room. The first baby was born under covers, in bed, in a corridor leading to the delivery suite. The nurse neither pulled back the cover nor acknowledged the event. The second baby was stillborn 10 minutes later. Susan's account demonstrates how the process of birth had been marginalized by reducing it to a physical event which had already been predicted by the doctor. Susan also recalled that when photographs of the babies were taken by the hospital staff, the babies had not been cleaned or dressed. The babies' bodies were treated differently from other deceased persons. For example, a dead person is normally presented in such a way that evidence of injury or illness is minimized. But with the stillborn babies, the staff had ceased to think of them as dead persons and so had devalued, if not negated, the mother's grief. Susan felt that the nature and extent of her grief had not been recognized, and that the trauma incurred through her experience had not been acknowledged. Susan is articulating her experiences here in a context where the notion of 'bio-power,' the use of mechanisms of control for the productivity and health of human bodies and populations, increasingly viewed as resources and manageable objects (see Hakosalo, 1991) has become a dominant feature of practice. The focus on productivity exemplifies, for Hakosalo, the intrusion of political rationality into individual lives through medicine. Hakosalo draws on the work of Foucault (1991) who claims that power techniques are used to make the body docile so that it can be subjected, used, transformed, and improved. Through this perspective, the woman who has suffered a pregnancy loss is a 'blip' on the production line. Her medical and personal needs become invisible, since there is no place for her, or her lost baby, in the rationalized processes of production to which medicine is now subordinated.

Several women in the study who experienced a miscarriage recalled being upset when medical staff referred to their miscarriage as a 'spontaneous abortion.' Rachael said: "I felt the doctor was implying that I had had an abortion and that I was to blame." Oakley et al. (1984) also found that women who had experienced a miscarriage often blamed themselves, and that the term 'spontaneous abortion' implied that the woman herself had taken a decision to end the pregnancy. It is important for hospital staff to recognize that the medical terminology of 'foetus,' 'spontaneous abortion,' or 'product of conception' is understood very differently by women who may suffer deep distress at the use of such terms in their presence.

A pregnancy loss is usually unexpected. For most women, the first signs that ‘things have gone wrong’ occur during a routine ultrasound scan. Several women related how medical staff were abrupt in manner when informing them that their baby had died. One woman stated:

I went for my 28 week scan and the doctor mumbled something and walked out of the room. I didn’t know what he said so I asked the nurse, and she said ‘your baby is dead’ (Angela, stillbirth).

Other studies (Malacrida, 1999) have reported blunt disclosures from medical personnel during routine ultrasound scans, as well as lack of sympathy and compassion from professionals (Simmons et al., 2006). It is apparent that training for medical personnel in the emotional and caring aspect of ‘breaking bad news’ during routine scans needs to be re-examined. While advances in ultrasound imaging have advantages for women, providing early indications of abnormality, the ultrasound scan is, paradoxically, the most explicit example of the way in which the body is rendered an object of specialist knowledge and inspection. The image that explains the medical status of the event also manifests the total objectification of women’s personal experience.

Although health professionals cannot be expected to understand the needs of bereaved women unless they are equipped with relevant knowledge and skills, communication between medical staff and women is equally important, and medical staff need to listen to the concerns of the mother. Negative comments during medical encounters was a theme that emerged from several women’s narratives:

Before I had the anaesthetic I couldn’t stop crying and the anaesthetist said ‘could you stop crying, you’re not the first, you won’t be the last, my wife’s had four of these.’ And I asked him if they could take my baby out in one piece and he said ‘if it comes out in one piece, it comes out in one piece’ (Katherine, 1 stillbirth, 2 miscarriages).

I was pregnant again when I went to see him (psychiatrist) and having concerns that this baby might also die. He told me that his wife had just had a baby and they were being kept awake all night, and I would soon know all about once this baby was born (Natallie, 1 stillbirth, pregnant with second baby).

These comments not only reveal a failure by medical staff to convey reassurance, they also overlook, and so fail to acknowledge, emotional aspects of the loss. In the interaction between doctor and patient, the patient often has difficulty making the voice of the life-world heard, because it is the doctor who dominates the interaction (Hydén, 1997). Layder (1996) points out that a doctor is able to define a patient’s state of health in terms of a body of medical knowledge based on scientific evidence. The patient, on the other hand, usually has to take the doctor’s word for it, accept advice, and comply with instructions. Greenhalgh and

Hurwitz (1999) suggest that the core clinical skills of listening, questioning, explaining, and interpreting may provide a way of mediating between the very different linguistic and imaginative worlds of patients and health professionals.

The concept of 'skill' in birthing contexts is itself problematic. The notion that there is a core of segmented, interpersonal communication skills, to be deployed as a necessary part of a medical 'repertoire,' may lead to a woman's pain and grief being considered an objective entity, one that can be processed through the application of standardized skill-sets. What is required, however, is a human engagement with a woman's experience and acceptance that her meanings and perspectives must exert a privileged claim within all decisions on the nature of an appropriate professional response. This is illustrated through the comments of one woman, Jenny, subjected to a clinical encounter that may have seemed appropriate, but was ultimately shaped by a rationality that masked the nature of the problem:

They brought me down to the labour ward and broke my waters, the doctor gave me an epidural. I didn't want an epidural but he said 'look you are not going to suffer, this baby is dead' So I cried and they had to hold me down to give me the epidural" (Jenny, 1 stillbirth, 2 miscarriages).

As the above narrative shows, the focus of the doctor was, understandably, on reassuring the woman in relation to her physical pain. But Jenny's comments reveal an intuitive momentum toward resistance against imposition of the doctor's rationalized priority of pain-reducing medical assistance. In her wish to assert the ontological primacy of emotional suffering over her physical pain, Jenny challenged the medical 'solution,' but was over-ruled. Shilling (1991) argues for recognition of the intimate relations between knowledge, language, and being, claiming that bodies may be interpreted through discourses, but are not ultimately reducible to objective knowledge, since the body, a material phenomenon, exists in a dialectical relationship with knowledge. The body, in Shilling's terms, creates and constructs knowledge and meaning and brings this knowledge into the world through a process of interpolation, for which, in these circumstances, resistance is perhaps the only available mode of expression, even if the meanings being asserted are denied or disregarded. The woman in question had a history of pregnancy tragedies, and her resistance can be understood as the emergence of a form of knowledge, an attempt to alert the medical staff to the need to recognize that medical definitions of pain are inadequate when the patient does not receive a hearing.

Burial Arrangements

Writing in 1989, Prior found that ritual burial of stillborn babies was still rarely found in Northern Ireland hospitals, and that the mechanical character of their disposal was a direct reflection of their still unrecognized position in the social

structure, a consequence of largely unchallenged, traditional belief systems. He notes that, although rare, a few stillborn babies were accorded a Christian burial and buried in individual plots. Most, however, were contracted out to undertakers who collected the remains from the hospitals and buried them in common plots without religious ritual.

A number of writers (Donnelly, 1999; Garattini, 2007; Lysaght, 2003) have explored the history of Irish wake customs in which the bereaved family and community celebrate the passing of their deceased kin, sharing food, alcohol, and tobacco in the very home and presence of the corpse. Death was seen as a natural continuation of life, a step into the spirit world (Donnelly, 1999). In Christian belief also death was traditionally understood as a passing from the community of the living into a (mystical) community of saints. Admission to this religious community was by baptism only; hence the traditional exclusion of stillborn babies from religious rites and burial in consecrated ground, a restriction vigorously upheld from mediaeval times by the Roman Catholic Church. Babies who died without baptism were buried in separated areas, at night and without ritual, alongside other categories of 'excluded' such as suicides, heretics, and women who died in childbirth (Garattini, 2007, p. 194). It appears that influential and mutually reinforcing traditions, supported by both folklore and religious belief, have led to the continuation of restrictive funeral practices that prohibit burial for stillborn babies into very recent times.

Within the last 15 years attitudes toward the recognition and burial of stillborn babies have changed considerably. Unbaptized babies are no longer excluded from burial in consecrated ground and are now afforded the same funerary rituals as other deceased persons, such as taking the body home prior to burial. Hospital practices also encourage parents to grieve openly and to be involved in funeral arrangements for their stillborn baby. In the case of one recently bereaved woman, Rose, her baby was cremated by the hospital and she was later given her baby's ashes for burial, without being asked whether she preferred burial or cremation. Rose stated, "I didn't know I had a choice until I came to the support group and discovered that other women were able to take their baby home in a coffin." The narrative from Rose demonstrates that routinized application of a new understanding can remove the discursive possibilities of a practice by reducing it to a replication of the medical model of practice. What had appeared commonsense, 'the way things were done,' was now perceived by Rose as an unacceptable practice, arising from one-way communication. Discursiveness is not a strategy but inherently a contextualized and reflexive mode for expression of values, central to which is a readiness to suggest alternative possibilities. Communication should be understood as a principle of practice, and not a functional device for attaining ends.

Two women who experienced stillbirth (previously termed miscarriage) many years ago were not given an opportunity to see or bury their babies. One woman Lilly commented:

I lost my babies more than 34 years ago and in them days you weren't allowed to talk or to bury them, you were told get up, get on with it, you'll have more children. It took me so many years to find the 'Remember Our Child' group and I can talk in a way that I could never do. I can share and help other people also (Lilly, 5 miscarriages).

The social support matrix of family, friends, and community often underestimates the impact of pregnancy loss, according little grief for those who were never born (Rubin & Malkinson, 2004). This withholding of social recognition of grief effectively 'disenfranchises' the bereaved parent from the social and community comfort of recognition, conferred through customary practices of public mourning. Disenfranchised grief denotes a grieving not merely unnoticed or forgotten; but one that is socially disallowed and, therefore, unsupported (Doka, 1989, 2002). For women in the study, unable to bury or see the remains of their baby, the significance of their loss was effectively disallowed by the medical profession, family, and wider community. Women had suffered a loss but were forbidden full opportunity to mourn publicly. In this sense, their grief was disenfranchised.

Although parents are now encouraged to see their stillborn baby and to hold a funeral, in the case of miscarriage, arrangements for possession and burial are haphazard and depend on individual hospital practices, as well as on awareness and sensitivity on the part of medical and nursing staff. Nine hospitals in the study provided burial arrangements for the remains of miscarried babies. One hospital did not itself provide such burial arrangements but parents were given the opportunity to bury their baby themselves. If parents opted to let the hospital deal with the remains, they were, according to one nurse, incinerated in the hospital incinerator without ritual or burial of the ashes. In one hospital, it was established through an interview with the ward sister that the remains of miscarried babies were collected, and a religious service held. The ashes were then scattered around a tree at a Garden of Remembrance dedicated to the memory of the lost babies. The ward sister revealed that this ritual had been taking place for a number of years. When asked if the women were informed of this practice, hospital staff said that mothers might find it disturbing. The hospital staff, therefore, in acting on their own assumptions about whether it was in mothers' interests to have access to the knowledge they were entitled to share, continued to assert the primacy of professional and medical solutions. Excluding mothers in this way, the hospital appropriated and arbitrarily disposed of the baby's remains, which belonged to the mothers themselves.

CONCLUDING DISCUSSION

Hospital practices for dealing with pregnancy loss have changed considerably within the last 15 years. Parents are now encouraged to see their stillborn baby; keep mementos, such as photographs, foot and handprints, and a lock of hair, and

to hold a funeral. While women reported a positive caring attitude from nurses and midwives, limitations in the medical model of clinical practice were identified, and shown to ignore the need to deal with the feelings and emotions of women. There were indications in the study that supportive practice could most readily be developed in the nursing and midwifery professions because their professional discourse had not yet been wholly medicalized. The study therefore, points to a need to strengthen the profession of midwifery in its caring and supporting role for women in pregnancy loss. Models of care for women are needed which take account of their right and longing freely to interpret, assume ownership, and receive acknowledgment of their experiences. The research suggests that the key factor in sustaining a woman's well-being during pregnancy loss is recognition of bereavement and its attendant emotional consequences as personal experiences requiring primarily emotional and practical support from hospital staff.

The women's narratives revealed that they were reaching out to create new definitions of their needs. In this process they reviewed or reflected on their experiences and constructed alternative narratives, contesting the implications of an imposed, rationalized life-world and resisting the construction of meanings that constrained their capacity for grieving. Women began to understand their suffering as a condition and natural outcome from experiences that had been either neglected, or named in ways that disempowered them. Their relief in finding discursive arenas in the self-help groups was evident, and pointed to their need for engagement with permeable discourses to which they could contribute their own understandings¹. In this new arena they felt they could begin the task of articulating their experiences in the presence of people with shared understandings. Pesek (2002) suggests that support groups offer disenfranchised grievers a degree of recognition in a world that ignores or repudiates their grief, thus enfranchising them once again. Through their involvement with self-help groups, women began to assert an alternative view of their emotions as a resource for personal action rather than a consequence of dysfunctional behavior.

The women's action in attending the self-help groups over extended periods of time suggests that they became a center of resistance, striving to realize an extended rationality and provide new signposts for women who may suffer loss in the future. In communicating with one another, exchanging and sharing experiences, they formed a mutual association or 'bridging bond' that proved to be enduring, and which supported them in a context where they had been silenced. In this way they not only provided a forum for reconstructing their identities, but challenged the categorization of their experiences within a framework of objectifying rationality that could limit, impugn, or even deny their real interests.

¹ For further exploration of pregnancy loss self-help groups see: McCreight, B. S. (2007) Narratives of Pregnancy Loss: The role of self-help groups in supporting parents. *Medical Sociology Online*, Issue 2, pp. 3-16, <http://www.medicalsociologyonline.org/current/pdf/narrative.pdf>

Pregnancy loss is more than a medical experience, and the way in which the event of a baby's death, whether by miscarriage or stillbirth, is socially constructed and acknowledged, is crucial in helping women come to terms with their grief. Important factors in facilitating women in their handling of grief included the opportunity to hold their stillborn baby, being involved in burial arrangements, or in the case of miscarriage, having knowledge of the remains of the baby. Customary practice regarding burial arrangements for stillborn babies in Northern Ireland, where it is normal practice to bring the stillborn baby home for burial, may be different from those familiar to women in other countries.² The personal and emotional significance of these practices, therefore, needs to be examined and understood within each specific context of women's social, cultural, and legal environment.

Caring for women after pregnancy loss calls for a range of social and personal skills that may go beyond the currently recognized portfolio of competences acquired in medical education. Medical personnel need to engage with the ways in which women experience loss. This requires them to reconsider the status of the lost baby, and to accept that many women conceptualize their baby as an extension of their own being, a potential for lived life. Accordingly, the training of medical personnel should be reconstructed on foundations which accord primacy to tacit, personal knowledge (Polanyi, 1969), over exclusively medically authenticated knowledge. This is a precondition for practices that must always be mediated, problematized, and critical responses to particular socially constructed situations. When the baby dies, the medical opportunity to ensure its survival is removed; for the mother, the challenge to regain self-worth and emotional well-being is only beginning.

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² At an international conference in Washington DC, the author was approached by several women who stated that they would have been comforted by the availability of such a practice, but had been prevented by legal restrictions.

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Direct reprint requests to:

Bernadette Susan McCreight, Ph.D., BSc
University of Ulster
School of Sociology and Applied Social Studies
Shore Road
Room 12L15
Newtownabbey
CO. ANTRIM
BT37 0QB
Northern Ireland
e-mail: bs.mccreight@ulster.ac.uk