



**University of
Sunderland**

Brierley-Jones, Lyn, Crawley, Rosalind, Lomax, S. and Ayers, S (2014) Stillbirth and stigma: The spoiling and repair of multiple social identities. *OMEGA: The Journal of Death and Dying*, 70 (2). pp. 143-168. ISSN 0030-2228

Downloaded from: <http://sure.sunderland.ac.uk/id/eprint/4942/>

Usage guidelines

Please refer to the usage guidelines at <http://sure.sunderland.ac.uk/policies.html> or alternatively contact sure@sunderland.ac.uk.

Stillbirth and stigma: The spoiling and repair of multiple social identities

Lyn Karen Brierley-Jones¹, Rosalind Crawley², Samantha Lomax², and Susan Ayers³

¹ Department of Pharmacy, Health and Well-being, University of Sunderland, Sunderland, UK

² Department of Psychology, University of Sunderland, Sunderland, UK

³ School of Health Sciences, City University London, London, UK

Address for correspondence: Dr. Lyn Brierley-Jones, Department of Pharmacy, Health and Well-being, Faculty of Applied Sciences, University of Sunderland, City Campus, Chester Road, Sunderland, SR1 3SD, UK. Tel: +44 (191) 5153492, e-mail: lyn.brierley-jones@sunderland.ac.uk

This is the Author's Accepted Manuscript of the article: Brierley-Jones, L., Crawley, R., Lomax, S., and Ayers, S. (2014-15). Stillbirth and stigma: The spoiling and repair of multiple social identities. Omega: Journal of Death and Dying. 70 (2), 143-168.

Abstract

This study investigated mothers' experiences surrounding stillbirth in the UK, their memory making and sharing opportunities, and the effect these opportunities had on them. Qualitative data were generated from free text responses to open-ended questions. Thematic content analysis revealed that "stigma" was experienced by most women and Goffman's (1963) work on stigma was subsequently used as an analytical framework. Results suggest that stillbirth can spoil the identities of "patient", "mother" and "full citizen". Stigma was reported as arising from interactions with professionals, family, friends, work colleagues, and even casual acquaintances. Stillbirth produces common learning experiences often requiring "identity work" (Murphy, 2012). Memory making and sharing may be important in this work and further research is needed. Stigma can reduce the memory sharing opportunities for women after stillbirth and this may explain some of the differential mental health effects of memory making after stillbirth that is documented in the literature.

Keywords: stillbirth, stigma, spoiled identity, identity repair, memory making, memory sharing, moral career, mental well-being

In the UK the rate of stillbirth is estimated to be 1 in 200 pregnancies, a rate that has changed little over recent decades (Flenady et al., 2011). Stillbirth is a tragic event that prospective parents in high-income countries like the UK and the US are not prepared for (Kelley & Trinidad, 2012; Layne, 2003). It has been described as one of life's most traumatic events; an emotional, spiritual and physiological experience (Cacciatore, 2007), untimely and tragic (Gudmundsdottir & Chelsa, 2006), the greatest of all losses (Rosof, 1994). Not surprisingly stillbirth is associated with anxiety and depression in many family members associated with the loss, particularly the mother (Badenhorst, Riches, Turton, & Hughes, 2006; Boyle, Vance, Najman, & Thearle, 1996; Cacciatore, Schnebly, & Frøen, 2009; DeFrain, Martens, Stork, & Stork, 1990; Rådestad, Steineck, Nordin, & Sjögren, 1996; Vance et al., 1995). Even where professional psychological support services are available, as in many high-income countries, the incidence of anxiety and depression in mothers of stillborn babies is about 20% (Frøen et al., 2011).

Research suggests that in the event of stillbirth, mothers value opportunities for physical contact with the baby and memory making (DeFrain et al., 1990; Downe, Schmidt, Kingdon, & Heazell, 2013; Erlandsson, Warland, Cacciatore, & Rådestad, 2013; Godel, 2007; Kelley & Trinidad, 2012; Rand, Kellner, Revak-Lutz, & Massey, 1998; Riches & Dawson, 1998) and that such activities may benefit maternal mental health. Rådestad et al. (1996) reported that mothers who did not have tokens of remembrance and had not seen their babies for as long as they wished experienced more anxiety and depression symptoms following stillbirth compared with those who had engaged in such practices. Similarly, Surkan, Rådestad, Cnattingius, Steineck, and Dickman (2008) found increased depression symptoms in mothers who did not spend as long as they wanted with their stillborn babies. In a study of 2,292 women, Cacciatore, Rådestad, and Frøen (2008) found lower anxiety and

depression symptoms in mothers who had seen and held their stillborn babies compared with those who had not.

The beneficial effect of creating memories has been explained in terms of a mother's need to "hold on" (Riches & Dawson, 1998) rather than "let go" of her stillborn baby. Holding on is thought to assist in creating a biography for the lost child that includes "imagined, or wished-for, rather than lived, experience" by means of images, artefacts and narratives (Godel, 2007, p. 259). Such memorialisation serves to incorporate the dead baby into the family biography as well as the wider society. When engaged in voluntarily, memorialisation enables bereaved parents to take their relationship with their deceased child into the future and so preserves family continuity (Grout & Romanoff, 2000; Janzen, Cadell, & Westhues, 2004). The increasing (if politically controversial) issuing of birth certificates for stillborn babies (Sanger, 2012), as well as the establishment of monuments by parents can be seen as part of this process, integrating the stillborn child into the worlds of the living and the dead and giving the baby a social identity (Godel, 2007; Peelen, 2009). Such practices also create material testimony to an otherwise invisible, ambiguous loss (Boss, 1999; Cacciatore, DeFrain, & Jones, 2008; Lang et al., 2011) and provide a means of publicly displaying previously disenfranchised grief that is "not openly acknowledged, publicly mourned or socially supported" (Doka, 1989, p. 4).

Nevertheless, the practice of encouraging parents to create memories of their babies following stillbirth has been questioned (Hughes & Riches, 2003). Some evidence suggests that contact with the babies and the making of memories following stillbirth does not always improve maternal mental health and may influence mothers' relationships with subsequent children (Hughes, Turton, Hopper, & Evans, 2002; Hughes, Turton, Hopper, McGauley, & Fonagy, 2001; Turton, Badenhorst, Pawlby, White, & Hughes, 2009; Turton, Hughes, Evans, & Fainman, 2001; Turton, Evans, & Hughes, 2009). Hughes et al. (2002) found that during

and one year after a subsequent pregnancy mothers who had not seen or held their stillborn infants from previous pregnancies had better mental health outcomes. They also found that if mothers had held their stillborn babies their next-born infants were more likely to show disorganised attachment behaviour, supporting the results of an earlier study (Hughes et al., 2001). Turton et al. (2001) reported evidence suggesting a relationship between mothers who had seen and held their stillborn infants and Post-Traumatic Stress Disorder (PTSD) in the pregnancy following the stillbirth, although their findings were not statistically significant. In a further study following up the same mothers seven years after stillbirth, Turton et al. (2009) showed that mothers who had held their stillborn babies had more partnership breakdown and higher scores on the re-experiencing and arousal clusters of PTSD symptoms. Even the previously cited study of Cacciatore, Rådestad et al. (2008) showed that the beneficial effect of contact with their babies was not without qualification. Mothers benefited from having seen and held their stillborn babies *unless* they were subsequently pregnant, in which case their depression symptoms were lower but their anxiety symptoms were higher.

The findings reported by Turton et al. (2001) and Hughes et al. (2002) led to changes in the 2007 practice guidelines for antenatal and postnatal health in the UK. The National Institute for Health and Clinical Excellence (NICE) recommended that “Mothers whose infants are stillborn or die soon after birth should not be routinely encouraged to see and hold the dead infant” (NICE, 2007). This replaced the 1985 UK guidelines from the Royal College of Obstetricians and Gynaecologists which recommended that after a stillbirth “staff should create an atmosphere which encourages parents to see and hold their baby [...] Parents may need to be informed that if they do not see their baby they may regret it as it could make mourning more difficult” (Royal College of Obstetricians and Gynaecologists, 1985). The change to the guidance issued by NICE in 2007 was controversial and was challenged for not being based on conclusive evidence and for potentially restricting parents’ choice (Lovett,

2001; Schott & Henley, 2009; Sheehan, 2001). Following pressure from stillbirth charities (Schott & Henley, 2009), NICE clarified the guideline in 2010 to emphasise that this did not mean mothers should not be offered the choice to see and hold their stillborn babies but that they should not be routinely encouraged to take up this option if they did not wish to do so (Royal College of Midwives, 2010). More research is needed because of the inconsistency in evidence associating mothers' mental health with contact with their stillborn babies and the importance of this evidence for health care practice.

The findings reported here were generated as part of a larger study we conducted to examine the possibility that it is not the opportunity to make memories *per se* that affects mental health but whether mothers have the opportunity to share and process these memories afterwards (Crawley, Lomax, & Ayers, 2013). Following the birth of live babies mothers share their birth stories as a way of integrating this major life event into their life narrative (Callister, 2004). This is likely to be equally important for mothers of stillborn babies yet they often find sharing difficult, either because those with whom they might share their memories undervalue the impact of the loss (Scott, 2011) or because the discomfort others feel means that they respond with silence or platitudes that trivialise the loss (Kelley & Trinidad, 2012; St John, Cooke, & Goopy, 2006). The aim of our larger study was to further examine the influence of creating memories and to examine the opportunities mothers had to share memories of their babies and whether this was associated with their mental health. We used online questionnaires to capture the experiences of women in the UK who had experienced a stillbirth in the previous ten years. Women completed one questionnaire to report symptoms of depression and anxiety, another to report symptoms of PTSD and a third to report how they had made and shared memories of their babies and how they felt about their memory making and sharing opportunities and the professional and social support they had received. Results showed that good mental health was most strongly associated with time

since the stillbirth, perceived professional support and the number of opportunities mothers had to share their memories. Poorer mental health was associated with a wish to talk more about their babies (Crawley et al., 2013). It has been acknowledged that there is little research to date on women's experiences of stillbirth (Lee, 2012) so a further aim of our study was to examine women's own reports of their experiences. Mothers were invited to provide free text responses to open-ended questions about their experiences of memory making and sharing and professional and social support. Their responses were many and detailed. This paper is based on a qualitative analysis of their responses.

Method

Participants

The participants were 162 women aged 18 years or over who had experienced a stillbirth where the infant was of 20 weeks gestation or more in the UK in the previous ten years. The UK was chosen for the study as it is a country where memory making has been widely practiced and the ten year inclusion criterion was to ensure the experience was fairly recent. Although the UK's Stillbirth Definition Act (1992) defines stillbirth as 24 weeks gestation and over we included six mothers of babies born between 20 and 23 weeks because there is no consistent international definition of stillbirth by gestational age (Mullan & Horton, 2011; Spong, Reddy, & Willinger, 2011) and because the mothers themselves identified their births as stillbirths. Participants were self-selecting and thus a convenience sample. Recruitment was via websites that support parents who have lost a baby, mostly from the Stillbirth and Neonatal Death (Sands) charity website ($n = 141$). The questionnaires were available online for six months from February to July 2010. Women were excluded if they were pregnant or if their stillborn baby was born at the same time as a live-born twin.

Of the 162 women who completed the questionnaires, 93% were married or living with a partner, 95% were Caucasian, and 72% were educated beyond school age. Their age

ranged from 18 to 47 years ($M = 32.9$, $SD = 5.9$). The stillborn baby was their first child for 61% of mothers, and 42% had given birth to another baby since the stillbirth. More babies died before labour began ($n = 134$) than during labour ($n = 28$). The stillborn babies ranged in gestational age from 20 to 43 weeks ($M = 35.4$, $SD = 6.1$), and time since the stillbirth ranged from 0.25 to 120 months ($M = 27.9$, $SD = 29.4$). Of the 162 mothers who completed the questionnaires, 141 responded to at least one of the open-ended, free text questions.

Data Collection

Participants gave informed consent before completing the Making and Sharing Memories Questionnaire (Crawley et al., 2013) and two further questionnaires measuring mental health symptoms. Symptoms of depression and anxiety in the previous month were measured with the Depression, Anxiety and Stress Scale, DASS-21 (Henry & Crawford, 2005; Lovibond & Lovibond, 1995). PTSD symptoms experienced in the last month were measured using the Posttraumatic Stress Symptom Scale (Foa, Riggs, Dancu, & Rothbaum, 1993) adapted to ask women only to report symptoms in relation to the stillbirth. Demographic and obstetric details were also collected by self-report.

In the Making and Sharing Memories Questionnaire mothers responded to a checklist of items describing what their memories might include (e.g., holding or bathing the baby) and how they had shared their memories (e.g., talking to others or sharing photographs) and rated how they felt about their memory making and sharing opportunities and the support they had received from health professionals and from family and friends. Data from the closed questions and the mental health measures have been reported elsewhere (Crawley et al., 2013). The five open-ended questions of the questionnaire asked mothers about their experience of stillbirth, memory making and sharing, and the aftercare and support they received (see Table 1).

Table 1 about here

Analysis

Data were subjected to initial thematic content analysis according to the pre-determined core categories embedded in the questionnaires regarding memory making, memory sharing, professional and social support and other experiences surrounding stillbirth (Marks & Yardley, 2004). Participant responses were collated according to the question they related to and then analysed for similarities in content across responses. This first sweep revealed many positive memory making experiences and frequent professional and social support. However, this stage of analysis also revealed many negative experiences with resultant distress which was extreme and longstanding in some instances. Closer analysis showed that the majority of these negative experiences shared a common theme of “stigma”. In the spirit of grounded theory (Charmaz, 2006; Glaser & Strauss, 1967) we considered this theme naturally emergent and subsequently analysed the entire data set in terms of Goffman’s Stigma theory (Goffman, 1963). This methodology permitted the inclusion of minority and “extreme” responses to establish the parameters of stigma in the context of stillbirth. The quotations included below were selected because they reflect core themes. Most represent expressions made by a number of respondents but some key points made by single individuals are also included. All quotations are followed by a unique signifier for each respondent using the format [participant number: months since stillbirth] e.g. [no.86: 15 months]. Where it is appropriate, spelling and grammar have been corrected to improve clarity.

Results

Whilst our data revealed instances where mothers, their partners and their stillborn babies were treated with dignity, respect and compassion by medical staff, family and friends, work colleagues and the wider community there were many occasions when this was absent. Often mothers had mixed experiences so that some aspects of their care were good whilst other aspects were not. Sometimes care was good from one sector of the medical profession

and poor from another. In some cases immediate family members remained at a distance whilst more distant family members offered support. A spectrum of responses to mothers of stillborn babies was also found among friends, neighbours and work colleagues.

Participants reported that stillbirth remains a taboo subject. Our data showed that mothers commonly experienced isolation, exclusion and abandonment and were prone to feelings of guilt and shame. These varied phenomena can be seen as indicative of stigmatising processes and analysis showed that stigma could affect three social identities of women after stillbirth; those of “patient”, “mother” and “full citizen”. These three identities are considered separately below although in practice the spoiling of one identity may impact on other identities.

Spoiling of Identity as Patient

Isolation, exclusion and abandonment. Mothers were often told before the birth that their baby had died and this frequently led to mothers losing the identity of a regular patient in the eyes of medical staff. The themes of exclusion and isolation repeatedly emerged in the mothers’ comments. In hospital some mothers described being left alone in a side room or ward (often with their partners) “*to get on with it*” [no.1: 0.25 months] where they were not talked to, reassured or cared for by medical staff who seemed to have “*washed their hands*” [no.119: 36 months] of them. Some mothers failed to receive even basic medical care such as pain relief during delivery or attendance during and immediately after the birth:

I gave birth in a bereavement room without access to pain relief such as gas and air.

[no.86: 15 months]

I was ... left alone for the whole labour, even the final stage, where we had to try and call someone in. I was also left with a retained placenta unattended and had to

attempt to pull it out myself which was also distressing. [no.73: 10 months]

...I felt like [the midwives] just washed their hands of me... My husband and I were put in a room out of the way and ignored until they got rid of us without even checking if we wanted to see our baby again. [no.119: 36 months]

Several mothers reported that aftercare was inadequate or absent. Support services such as counselling, highly valued by the majority of mothers in our study, were notably lacking and often sought out by the mothers themselves. Many women reported feeling terribly alone following discharge from hospital when they attempted to return to “normal” daily life. Some mothers failed to receive a postnatal medical check. Communication was reported as poor between different health service sectors so that surgery staff and their own GPs sometimes remained ignorant that a stillbirth had occurred and mothers had to inform them themselves. Those women who sought counselling or the results of post mortem examinations frequently had to access these through a postnatal clinic and found themselves sitting among women who had given birth to live babies, adding to their hurt. Some doctors and consultants were found to be distant and unsympathetic, delivering devastating news in an aloof and uncaring manner whilst other medical personnel were described as inadequately prepared:

Communication between hospital and doctors was very poor - when I went in to ask for sleeping tablets four days later I was asked why I was upset - and when I suggested they look at my notes there was no record of my stillbirth... [The] hospital [was] terrible at the post mortem meeting, [showing a] complete lack of care or empathy. [no.153: 84 months]

... our experience with the consultant was not the most positive. the language she used when giving us feedback on the post mortem was not accessible and she didn't seem very receptive to questions. [no.62: 6.75 months]

I felt that the care I received at the hospital was good, but I felt that the NHS abandoned me to some extent after I came home. I had to ring to book my 6 week check, and the receptionist asked if I wanted my baby checked too... the health visitors made no contact at all [no.128: 42 months]

Taboos, guilt and shame. Mothers reported feeling “*guilt*” [no.90: 21 months] and “*ashamed*” [no.1: 0.25 months] that they had given birth to a stillborn claiming the subject of stillbirth remains “*taboo*” [no.86: 15 months and no.113: 29 months] even within the medical community. Some medical personnel were reported as lacking compassion, not knowing “*what to say*” [no.42: 2.75 months] or how to behave, even some bereavement midwives. Mothers described themselves as feeling like a “*leper*” [no.113: 29 months] or a “*dead baby dunce*” [no.73: 10 months]. Many felt like failures. Some medical personnel attempted to hide babies or to conceal babies’ appearance from mothers often for no clear clinical reason and after mothers had already seen their babies. In some extreme cases babies were treated as something non-human, almost monstrous, as objects:

The hospital made me feel ashamed of what had happened... [no.1: 0.25 months]

I held my baby - didn't want to let her go but the nursing staff advised me to let them take her. An hour or so later I went looking for my daughter to be shown to a store cupboard where they had put my daughter. I still find this memory really hard to cope with. [no.158: 96 months]

Although the midwife who supported me during labour was wonderful, the midwife who replaced her at the birth was awful, cold and distant. She did not encourage me to bond with my baby. She brought my baby to our room with a blanket over his head.

[no.142: 60 months]

Many treated me like a leper... Stillbirth is too taboo..... [no.113: 29 months]

Mothers often expressed how they had been reluctant to touch and hold their stillborn babies as they were not sure what effect handling their babies would have. Several mothers adopted normative and moral language in describing their experiences relating to their stillborn babies. Babies were described as being the “*wrong*” colour [no.33: 1.75 months], or “*it didn’t seem right to take photographs*” [no.99: 25 months], and wondering about the “*respectable*” [no.24: 0.75 months] way to handle a dead infant. Expressions of fear regarding their babies’ appearance in advance of and sometimes after the birth were common. Such fears led to mothers making decisions such as not to mother or make memories of their babies which they later viewed as an opportunity forever lost:

When I was told my baby had died it would have been nice if the doctors had told me about the deterioration the baby will go through the longer I leave the delivery. My baby ended up being born with skin peeling and the wrong colour. [no.33: 1.75 months]

I was terrified how the baby would look and couldn't imagine wanting to take, keep photographs. I was so wrong. My baby was beautiful and precious and we do not have any decent pictures and I am devastated. [no.96: 24 months]

Spoiling of Identity as Mother

Denial of the identity and personhood of the stillborn. Some mothers reported that the status and identity of their stillborn babies as children was denied by some medical staff as well as by certain family members, friends and work colleagues. This impacted on their identity as mother: If the stillborn was not a child how could they be a mother? The stillbirth was portrayed by some as a failed pregnancy with reassurances that “... *it will be fine next time*” [no.91: 21 months quoting her midwife], as if one child can replace another. On these occasions stillborn babies were objectified and their deaths were not perceived as worthy of “normal” bereavement. In this way the reactions of others served to spoil the identity of mother:

They [hospital midwives] talk about the next baby. You can't even think in this way.

[no.108: 27 months]

The hospital staff were all excellent and I was 'adopted' by two amazing midwives. My original midwives were awful and caused a lot of hurt with their insensitive comments about getting pregnant again and saying things like, “at least you know you can lactate successfully”. Most of our friends have been amazing but one or two have caused hurt with their inability to recognise a stillbirth as the death of a child and not an unfortunate failed attempt to have a baby that could be simply fixed by having another one. [no.109: 27 months]

Restricted ability to mother and grieve the stillborn. Many mothers reported that they were unsure what they were “*allowed*” to do in relation to their stillborn babies [no.15: 0.25 months and no.65: 7 months] and that they were not in control of events. Some mothers chose not to mother their babies partly because of this uncertainty. The majority of mothers who did *not* engage in mothering activities reported that they later regretted it (only one

mother in our sample reported no regret). Some mothers decided in advance that they did not want to hold or in some way mother their babies. Some chose not to handle their babies as they felt responsible for having hurt or even “killed” [no.44: 3 months] their babies and had on-going fears about causing more hurt to them. Those who were persuaded otherwise and did engage in mothering activities were glad they had changed their minds. Their identity as “mother” seemed inherently bound up with having had the opportunity to see their babies in their entirety, knowing them physically, their whole body:

[I wish I had] been encouraged to hold our baby. I was too scared to hold him in case I hurt him even more. [no.4: 14 months]

I was handed my baby immediately, even though I had said I didn't want to. Oh thank you so much for that! If I hadn't been encouraged to hold my baby I would have regretted it forever. [no.17: 0.25 months]

I wish I had the chance to dress him. I only ever saw him fully dressed and I feel like I missed out seeing things like his toes and belly button. I feel like a mother should know every part of her baby. [no.143: 60 months]

Mothers revealed that others expected them to return to normal life more quickly than following other kinds of bereavement. Medical staff, family members and friends sometimes expected mothers to move on and “be over it” [no.13: 14.5 months] long before they were able:

After 3 weeks everyone thought we should move on. [no.130: 45.75 months]

Now that four months have passed, no one wants to talk about him anymore, I've been told frequently to draw a line under it. [no.51: 4 months]

Spoiling of Identity as Full Citizen

Imposed silence and a restricted world. “Full citizen” refers to “personhood”, membership of a society, belongingness, where an individual has a personal history and identity and experiences full social participation. A full citizen could be considered the opposite of Orwell’s “unperson” where an individual is stripped of rights, identity and humanity (Orwell, 1949). Identity as a full citizen appeared to be most powerfully affected by the portrayal of the stillbirth as a “non-event” by those within the mothers’ families and wider social networks. This was because such a portrayal served to constrain normal interactions, processes and relationships. Again, such a reaction was frequently experienced first in hospital, then later among family, friends and work colleagues who often avoided the topic of the lost child in conversation:

It was a surprise, however, how a small number of people you spoke to daily avoided even mentioning what had happened and haven't to date. [no.126: 42 months]

Work colleagues have been the hardest though as some have literally tried to avoid any conversation with me and have totally ignored what has happened. [no.109: 27 months]

People didn't know what to say. Many treated me like a leper and still do. [no.113: 29 months]

Normal activities such as taking subsequent children to play and toddler groups became impossible for some mothers, even years after the event. Important social support networks were often lost through mothers being avoided by pregnant friends:

I have found that people do not really want to know anything about it, or it upsets them if they are themselves pregnant or new mums. [no.48: 3.25 months]

Not being able to talk about my baby has affected my ability to go to baby groups with my subsequent children. [no.138: 55 months]

Even the most fleeting engagement with a stranger quickly posed multiple dilemmas for mothers of stillborn babies. If they were asked in a subsequent pregnancy whether this was their first baby, mothers often said that it was despite being uncomfortable doing so:

... [I] sometimes explain that we had another baby but sadly we lost her; other times, to avoid upsetting the person, I will just say 'yes, this is our first'. Sometimes, it just makes life simpler to not mention it. [no.85: 15 months]

I have had another baby since losing my first son. I am often asked if he is my first when meeting new people. I sometimes find myself saying "yes"... [no.131: 47 months]

Mothering, Memory Making and Memory Sharing as Identity Work

More frequent and broader memory sharing of their babies was closely bound up with having had opportunities to mother their stillborn babies. This, in turn, seemed to effect reciprocal identity repair of mothers and their babies. Along with holding, washing and dressing their babies, mementos including photographs, clothing, locks of hair, hand and foot prints were important. Even items their baby had touched such as a specially chosen outfit or blanket were considered mementos. Behaviours and rituals associated with live births were also important such as other children or grandparents being permitted to visit or holding a christening, other naming ritual or funeral:

Chaplaincy staff were absolutely brilliant and held a baptism for our son, which was one of the most important things that we did, officially recognising and naming him.

[no.156: 90 months]

The following mother illustrates well the association between a natural birth, memory making opportunities, later memory sharing and the repair of baby's identity as a family member:

[Baby's name] was born naturally at 2pm... We were very lucky to have a good Sands (Stillbirth and Neonatal Death Society) set up in place to provide us with photos and the memory book, and good midwives to let us hold [baby's name] once they had cleaned her up, and again later before we said goodbye. Our two children talk about [baby's name] often, especially around her anniversary [when] we go to her grave and they put flowers on before we go out for a meal. We have a rose in our garden, and many family members and special friends have some day lilies in her name - little [baby's name]. We rarely go to her grave, but do have a very small photo of her in our front room as well as a cross stitch from her birth with those for the other two children. We get cards annually from our parents and my auntie.

[no.154: 84 months]

The following mother, by contrast, shows an association between illness during labour, reduced opportunities for mothering and memory making, negative memories, subsequent difficulties with memory sharing, even with immediate family members and reliance on a bereavement website for support:

I was very ill during my labour and so this has affected my recollections of it. ... I wish... I had the chance to hold my baby immediately after her birth when she was still warm. ... when I did see her a few days later ... she was cold and heavy and it all felt wrong... My midwives that delivered my baby were wonderful [but] I found some follow up care very poor ... I wish my partner and I talked more but he doesn't want to. I wish we had told our daughter at the time because now I wonder when [we] will tell her especially as we now have another younger child which will make it harder. Family would have talked more about it but it is never the right time! My biggest form of support at the time and even now is babyloss.com. I like being able to say what I want when I want. [no.144: 65 months]

Discussion

Using some of the key tenets of Goffman's stigma theory we suggest there is evidence that mothers of stillborn infants experience stigma just like the voluntarily childless (Park, 2002) and those bereaved by suicide (Begley & Quayle, 2007; Cvinar, 2005). According to Goffman (1963) a "stigma" is "any deeply discrediting attribute", the ascribing of which leads to the "spoiling" of an individual's social identity and their disqualification from full social acceptance (Goffman, 1963, p. 9). Ascribing stigma means an individual becomes "...reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). Women in this and other studies reported this in terms of guilt and shame (Cacciatore, DeFrain et al., 2008; DeFrain et al., 1990; Downe et al., 2013; Säflund, Sjögren, & Wredling, 2004), being "*refugees in their own lives*" [no.10, 69 months], isolated and excluded (Kelley & Trinidad, 2012), feeling they were a "*dead baby dunce*" [no. 73: 10 months] or "*lepers*" [no.113:29 months]. Whereas guilt relates to isolated behaviour(s) (e.g., feeling responsible for the death of their babies), shame more powerfully leads to denigration

of the entire self (Lewis, 1995, 1998). The “central possibility” of shame in the event of stillbirth thus becomes realised via stigma, particularly in those mothers already predisposed to such a response (Barr, 2004; Goffman, 1963).

Murphy (2012) used the work of Goffman to illustrate how mothers of stillborn babies are stigmatised. Our study is consistent with Murphy’s findings that stigma comes from the women’s families as well as the women themselves. Our study also suggests that stigma can arise from medical professionals, friends, work colleagues, and strangers. The role of medical professionals is important as it has been shown that the level of support received from medical professionals both whilst in hospital and after discharge is associated with mental health outcomes after the death of a baby (e.g., Crawley et al., 2013; Murray & Callan, 1988). We found that many women experienced stigma for some time after their stillbirth, often years after the event.

Alongside social stigma, women clearly experience grief especially in the weeks and months immediately after the event. Theories of grief and bereavement can also therefore provide useful frameworks with which to examine the impact of stillbirth (for a useful overview, see Stroebe & Schut, 2010). Stigma ascription, however, is a social phenomenon and even in instances where women reported having worked through their grief in some way they still faced the negative reactions of others to their experience. Stigma theory provides a useful framework for analysing these interactive processes. Below we outline aspects of stigma theory that are particularly relevant to stillbirth and look at how our results support this framework.

Stigma Ascription and the Moral Career

Goffman (1963) proposed many different categories of stigma, some of which are particularly relevant to stillbirth. Mothers of stillborn babies may fit Goffman’s stigmatised category of “blemishes of individual character” (Goffman, 1963, p. 4) which can result in a

perception of them as less worthy than mothers of live babies. They may also fit with Goffman's category of "abominations of the body" (Goffman, 1963, p. 4) in so far as their own bodies have produced something unacceptable. In addition, mothers of stillborn babies may fall into a category of "normal deviants" (Goffman, 1963, p. 130), individuals who see themselves as possessing a stigma as a result of internalising the normative and moral code of a society which now rejects them in some way.

Stigma ascription represents a special discrepancy between "virtual" and "actual" social identity (Goffman, 1963, p.3), between the characteristics we expect an individual to possess and those that they do in fact possess. In the case of stillbirth in high-income countries this discrepancy emerges from society's expectations surrounding motherhood, pregnancy and childbirth. "Mother" as a social category is defined by the presence of a child, yet no child is present. In a society with no alternate category (for "mothers of stillborn babies") and without a sufficiently broad definition of "mother" (to incorporate incontrovertibly mothers who have experienced a stillbirth), "ambiguous loss" results (Boss, 1999; Cacciatore, DeFrain et al., 2008; Lang et al., 2011). Women become identified as both "mother" because the baby was born and is psychologically present, and "not mother" because the baby is physically absent. A mother is only a mother in relation to a dependent other (Jenkins, 1996). Further, it is not "normal" in such societies for babies to die (Kelley & Trinidad, 2012; Layne, 2003) and such an event leads to doubts regarding maternal moral probity (Murphy, 2012). Ambiguous loss results in stress for the mother (Cacciatore, DeFrain et al., 2008) whilst a tendency to "blame and shame" the mother confirms "normalcy" for the rest of us and reduces our anxiety (Goffman, 1963). The shame women may experience can arise from this tension between virtual and actual identity and can lead to the disintegration of the social fabric surrounding these women so that they realise that "*life will always be different from now on*" [no.10: 69 months].

According to Goffman (1963) stigma spoils social identity. Our results suggest that women's multiple and interdependent social identities as patient, mother and full citizen can be progressively affected following stillbirth. Once stigma has been ascribed mothers of stillborn babies must often (re-)negotiate their place in the world and embark upon a "moral career": that is, a set of common learning experiences about their plight as individuals undergoing similar changes in their conceptions of self (Goffman, 1963, p. 32). Goffman's conceptualisation of the moral career as a long term, sometimes life-long, project is borne out in this study as many mothers reported struggling with the consequences of having experienced stillbirth many years later. One mother reported accessing psychological support "*four years on*" [no.134: 50 months], another remained angry "*three years later*" [no.118: 36 months] at the way she had been shunned by some friends and colleagues. Another said, "*It's been two years now and people don't want to talk about it*" [no.99: 25 months], and another "*It's been five years and it still hurts*" [no.141: 60 months]. Time alone, then, is insufficient for recovery from stillbirth and the stigma attached to it.

Spoiling of Identity as Patient: Spoiling the Scene

News of the death of their babies impacted on mothers' identity as patient. This is consistent with Lovell's (1983) assertion that no physical or psychological space exists for maternity cases without a baby (Lovell, 1983). Thus mothers of stillborn babies may comprise an immediate category problem (Cacciatore, DeFrain et al., 2008). This is supported by some of the reports in our study, where mothers recounted being placed in a semi-separate physical space, both to give birth and in terms of aftercare. This is consistent with women who have experienced stillbirth being identified as "not normals" which led to them not receiving "normal" medical care. Here, the spoiled identities of patient and full citizen overlapped since basic medical care is a right of all citizens in any universal health care system.

According to Goffman life itself is “dramatically enacted” (Goffman, 1959, p. 78) with roles played and action scripted. Repertoires exist around language, behaviour and events. All players, but especially those directing the scene (e.g., midwives) possess a front: that is, a set of gestures, expressions, movements and attire, appearance and manner (and knowledge). These define a situation as a situation of a particular kind, one circumscribed by a setting or “stage”. When a performance goes “off script” or becomes “non-scripted”, exclusion and disrespect can result. Stillbirth can be perceived as “spoiling the scene” in this way especially when it occurs unexpectedly during labour (Goffman, 1959). As a departure from the “norm” of childbirth, stillbirth can be seen as a non-scripted or off script event leading to role confusion and a disintegration of the social setting. Several mothers claimed that they felt pressure from medical staff to control their emotional response to the stillbirth, to “*hold it all together*” and “*not fall apart in front of them*” [no.108: 27 months]. One mother, who admitted feeling “*devastated*” and “*terrified*”, took control of the scene by trying to “*...protect [my husband] and everyone else, even the midwives!*” [no.129: 43 months]. The tendency of mothers to feel responsible for the emotional responses of others was also reported by Downe et al. (2013). In our study medical staff were reported as seeming “*nervous*” around mothers of stillborn babies: “*they all want you to pick yourself up and go on*” [no.108: 27 months]. The lack of adequate postnatal care and poor information sharing between medical services reported by mothers in this and other studies (Lang et al., 2011) support the thesis that stillbirth may be off script and a category problem for medical staff (Lee, 2012).

Spoiling of Identity as Mother: Impression Management, Defensive Cowering and Discredited Status

Just as mothers’ identity as patient can be spoiled with the news of their babies’ death so can be their identity as mother (Lovell, 1983). Such spoiling was evident in the uncertainty

mothers reported regarding how to behave and how to handle their babies. Mothers were unsure what was respectful and acceptable under the circumstances and they often looked to medical professionals for guidance in this (Downe et al., 2013; Säflund et al., 2004). One mother felt relief and reassurance when the medical staff viewed taking photographs of her stillborn baby and gathering other mementos as normal behaviour. Such normality may serve to reduce stigma. But normal behaviour has its limits in such circumstances. One mother said she would have preferred “*not having the naff toy the hospital gave us in the cot and in most of the photos! Silly thing...*” [no.81: 12 months].

Stigma theory argues that those close to the stigmatised often break contact with them. Consistent with this, some mothers reported strained family ties, even family breakdown when they returned home. One mother in our study said that her husband left her a month after her (second) stillbirth. Another said that whilst her husband continued to be “*...the most amazing support*”, most of her family did not want to talk about their baby any more but “*...I still do as he is still my son*” [no.152: 84 months]. This affirmation of her role as mother is explicit identity work.

When close pre-stigma contacts such as friends and colleagues are brought up to date vigilance is particularly necessary in “managing the situation”. A particular uneasiness surrounds pre-stigma contacts who see the stigmatised as possessing a discredited status, as “less than”. Goffman notes that such contacts “... may be unable to treat [her] with formal tact or with familiar acceptance” (Goffman, 1963, p. 49). “Normals” react negatively to the stigmatised because the latter need to confirm their own “usualness” and avoid contamination or pollution: “courtesy stigma” (Goffman, 1963, p. 44). Thus mothers reported that many of their existing acquaintances “*didn't know what to say*” and became awkward or avoidant. This led to the loss of some friendships, “*...we lost some friends who have never contacted us ...they just couldn't do it*” [no.124: 40 months].

Spoiled identities create a self-conscious need to “perform” and manage identity information and a necessity for impression management (Goffman, 1963, p. 12). Whilst evident in the private sphere, this necessity predominates particularly in the public sphere where the stigmatised and non-stigmatised come together, that is, among “mixed contacts”. Thus many mothers in our study reported on-going negotiations over sharing memories with their spouse, family and close friends. Some mothers took on “temporary” social identities as “bereaved” and as “mother” of a lost child, but the time permitted for this identity to exist varied. Its ending was usually signalled by silence, avoidance, unwillingness of others to talk about or share the babies’ photos or other memorabilia or by shifting the topic of conversation. These responses can be interpreted as a public denial of their babies’ identities and the imposition of silence on women who come to inhabit a restricted world where grieving is cut short (Cacciatore, 2009; Kelley & Trinidad, 2011; Murphy & Thomas, 2013).

The stigmatised often find themselves employing anticipatory “defensive cowering” in such uncertain terrain. They may decide to not discuss the object of their stigma, discuss it less frequently or more superficially. Defensive cowering is an attempt to (re)gain social acceptance and overcome isolation. Mothers in our study expressed uncertainty about how much to tell others and how often they should or could talk about their stillborn babies. As one said, *“I talk about her [stillborn baby] quite frequently but not in depth, I think maybe people will get fed up or think I’m morbid?”* [no.63: 7 months]. Even the question mark appended to this comment denotes uncertainty and the seeking of reassurance. Such defensive cowering can be vital to facilitating social engagement. This is important since, as Goffman warns, “Lacking the salutary feedback of daily social intercourse with others, the self-isolate can become suspicious, depressed, hostile, anxious and bewildered” (Goffman, 1963, p. 13).

Many mothers in this study reported that work colleagues were the “*hardest to deal with*” as they “... *literally tried to avoid any conversation with me and have totally ignored what has happened*” [no.109: 27 months]. Another said “*I only wanted them to say ‘I’m sorry about your baby’*” [no.118: 36 months] whilst another mother claimed work was “... *very unsupportive*” [no.86: 15 months], had no understanding of how the birth had affected her and found that stillbirth was a taboo subject in the workplace. Impression management becomes crucial under such circumstances. Mothers made attempts at “*being normal*” and “*looking quite normal*” and “*professional*” in the face of the “*ignorance*” and “*a lack of understanding*” [no.87: 17 months] of some work colleagues. Mothers used defensive covering in these social contexts by employing euphemisms to account for their maternity leave and choosing not to use their baby’s name in conversation, for fear of “...*making people feel uncomfortable*” [no.64: 7 months].

Spoiling Identity as Full Citizen: Passing, Covering and Discreditable Status

Goffman argued that when identity as full citizen becomes spoiled, a person’s sense of belongingness can be eroded making full social participation problematic. In these circumstances, a person may manage the social situation by using passing and covering. Passing occurs when an individual has the opportunity to reveal identity information but chooses not to do so. As one mother put it, after her stillbirth it became unclear to her “*how to live*” [no.64: 7 months]. Mothers who sought to maintain existing friendships sometimes found a social distance was imposed by others after the stillbirth experience, noting that friends would rather “...*back away than make themselves vulnerable to [stillbirth]*” [no.49: 2.25 months]. Many mothers therefore experienced a progressive contraction of their social world in relation to family, friends and work colleagues (Cacciatore, DeFrain et al., 2008).

New “post-stigma” acquaintances create for the stigmatised a new set of concerns in managing impressions. Here the stigmatised has a “discreditable status”. That is, the stigma is

invisible or not (yet) known to the new individual or social group (Goffman, 1963). The issue here, then, is not one of managing tension among mixed social contacts (as when inhabiting a discredited status) but of managing information about a “failing” in the eyes of persons who are prejudiced against people of the kind an individual can be shown to be. To tell or not to tell, to reveal or not to reveal, to lie or not to lie and in each case to whom, where, how and when? (Lang et al., 2011). In this respect, mothers of stillborn babies can be seen as similar to members of other stigmatised groups where the stigma remains invisible, such as those who have experienced mental health problems. Each must choose whether or not to continue concealing the stigma and information about their “real” social identity.

Stigma theory argues that a decision to conceal identity information and remain in a discreditable status constitutes “passing” but passing has a price. Concealment interferes with intimate relationships and can lead to feelings of guilt. At the same time social pressure to reveal runs the risk of acquiring a discredited status and all the impression management that entails. Almost everyone who is in a position to pass will on some occasion choose to do so because of the great rewards in being considered normal. Passing was practiced by one mother who had moved to a new area and was pregnant. When asked by new acquaintances if this was her first baby she would sometimes explain that she had lost her first daughter but on other occasions she would choose not to mention it. Demonstrating clearly the dilemma of being “torn between two attachments” (Goffman, 1963, p. 109) this mother admitted; “... *I find this really difficult and always find myself apologising to our daughter in my head for denying her existence*” [no.85: 15 months]. Similarly, passing felt dishonest for another mother who claimed she sometimes would say her new baby was her first “...*when I wish that I could be honest and say no, we lost our first baby*” [no.131: 47 months]. Thus, even “small talk” between strangers threatens to touch on “secret failings”. What are unthinking

routines for “normals” become “cumbersome” negotiations for the stigmatised (Goffman, 1963, p. 111).

Those retaining a discreditable status may obviate the need for passing by trying to “cover”. Covering constitutes the avoidance of certain social situations so that the decision to reveal identity information (or not) does not have to be made. Thus one mother reported avoiding baby and toddler groups because she knew she would not be free to discuss her stillborn baby. Another said, *“I avoid certain people as they do not understand my loss”* [no.2: 1 month] and another claimed she tended to *“...withdraw from any conversations about children (at work or with friends) because I feel I can't join in ...I feel awkward... I feel excluded”* [no.117: 34 months].

Inhabiting Half Worlds: The Expert and the Wise

The discredited individual can seek out “sympathetic others” when the stigma continues to spoil social identity and obstructs full social participation, or where the pressure of cowering, passing and covering become too great. There are two categories of sympathetic others: those who share the stigma who may sponsor journals, webs, blogs and become “expert” speakers; and the “wise”, individuals whose special circumstances have enabled them to become privy to the stigmatised and their world and who, by understanding and becoming sympathetic to it, become a courtesy member of the “clan”. One mother in our study found her aunt and uncle to be sympathetic others as they were “experts” by virtue of the fact that they had shared the same experience. Her own parents, by contrast, had made her feel *“uncomfortable”* [no.107: 27 months] about her stillbirth. For others, sympathetic others were found on web sites, blogs and chat rooms supporting the findings of Gold, Boggs, Mugisha, and Palladino (2012) who reported that in the US, internet sites could be an important source of support. Our study shows that websites and blogs were particularly used

by those who also reported difficulties in making and sharing memories of their babies (see, e.g. respondent no.144: 65 months above).

The use of sympathetic others by mothers of stillborn babies is significant since it is an impression management strategy which divides the world of the stigmatised into two groups: a large group to whom nothing (or very little) is told and a smaller group to whom all is bared and whose support becomes relied upon. In such half worlds the stigmatised is able to “develop to its fullest [her] sad tale” for fellow experts within a stillbirth subculture (Goffman, 1963, p. 21). It is possible therefore that the proliferation of websites and blogs signifies the on-going stigmatisation of stillbirth and continued denial of its reality rather than its increased recognition within Western culture (Godel, 2007). Rather than signifying acceptance “chatting” may evidence spoiled identities seeking repair in a fractured world.

Attaining a State of Grace: A Role for Memory Making and Sharing in Identity Work?

Voluntary disclosure, a conscious choice to move from discreditable to discredited status, represents the mature phase of the moral career, the final well adjusted phase, “a state of grace” (Goffman, 1963, p. 125). Acceptance and respect for self negate the need for cowering, passing or covering and are often associated with a redefinition of self. As one mother in our study put it “[my friends] wanted the old me back, but she isn't coming back. *Losing my son has changed me forever*” [no.52: 4.5 months] whereas another mother wanted to go back to “*looking [and] being quite normal*” [no.64: 7 months].

Repaired (and, in some cases, new) identities for women represented a new mode of being in the world and appeared to be associated with successful making and sharing of memories. One mother who was able to spend ten hours with her baby after the birth and who claimed her GP and community midwives were “wonderful” said, “[Our stillborn] is part of our family, and we talk about her together often,... she comes up in conversation naturally for us all the time and even when we moved I talked about her to everyone...” [no.153: 84

months]. Another mother who reported having a “*great*” midwife, GP home visits, and support from family, friends and work colleagues and who was able to take photos of her stillborn baby reported that she showed these photographs on her mobile phone to people and that, “... *sometimes its people I hardly know. I have a tattoo which if anyone asks about I will tell them about my baby*” [no.41: 2.25 months]. It has been suggested that creating and sharing memories can positively affect mothers’ mental well-being by reducing their feelings of isolation (Cacciatore, DeFrain et al., 2008; Cacciatore et al., 2009). We argue that memory making and sharing may also facilitate the repair of identities for mother and baby. This is because if others are not willing to hear and validate mothers’ stories this may have consequences for memory, identity and well-being (Fivush, 2010). The relationship between memory sharing and identity repair merits further investigation: in particular, the relationship between the sharing of memories at greater social distances (e.g., with strangers) and multiple identity repair for women. Indeed, memory sharing may help to explain some contradictions in the literature. When mothers are able to share their memories then memory making may prove beneficial for maternal mental well-being but be deleterious when they are unable to share those memories. Such a hypothesis merits further investigation

Interestingly, mothers of stillborn babies reported that funeral and mortuary staff treated them as normal. Mothers often received accurate information and valued support from these sources, some of whom were described as “*amazing*” [no.13: 14.5 months]. Death is the business of these agencies, part of the normal scene that they stage every working day and in accessing these services mothers of stillborn babies possess the same social identity as other members of society: the “bereaved”. Thus, mothers possess an unspoiled social identity in this setting, enabling them to be treated, even if temporarily, as normals.

Our findings suggest that medical agencies, especially midwifery services, may need to review existing policies and procedures that are potentially stigmatising and which

reinforce the “category problem” of stillbirth. This may include introducing a mindfulness-based bereavement care model (Cacciatore & Flint, 2012) to respond with acceptance and compassion to families following stillbirth loss, ensuring effective communication between medical agencies. The provision of appropriate and ongoing postnatal services that recognise the common trajectory for many mothers following stillbirth seems desirable. Stigma can further be reduced by viewing the stillborn baby as a lost child and not a failed pregnancy or a medical event. Some of the normal behaviours and rituals associated with live births may prove beneficial for mothers experiencing stillbirth: namely, holding, bathing, naming and photographing their babies. Other studies have drawn a similar conclusion (Rådestad & Christoffersen, 2008; Rådestad, Westerberg, Ekholm, Davidsson-Bremborg, & Erlandsson, 2011). Indeed, evidence suggests that mothers feel more natural, comfortable and less frightened if staff assume they want to see and hold their stillborn babies without asking them (Erlandsson et al., 2013). In the UK NICE currently recommends that mothers be given a choice to engage in these activities, but some mothers in our study reported that they did not feel in a position to make the right choice at the time and appreciated guidance from midwives on what to do. Indeed, only one mother in our study expressed no regret over the decision not to see or hold her stillborn baby.

Our study also suggests that the ability to make positive memories of their babies and subsequent mental well-being is impacted by the health of mothers immediately after delivery and by the physical condition of their babies. These in turn are related to the time between death of the baby *in utero* and induction (Rådestad, Erlandsson, Lindgren, Malm, & Davidsson-Bremborg, 2011) and the administration of drugs during delivery. Medical personnel may want to consider practices that keep both the babies’ and mothers’ condition as healthy as possible in the important first hours after stillbirth. Places of work may like to consider return to work policies that reflect the unique needs of women returning from

maternity leave after stillbirth. Finally, stigma surrounding stillbirth suggests that stillbirth is not prominent in either public or political consciousness and that raising awareness is necessary to address the stigma surrounding stillbirth.

Limitations

Our study design generated many, often quite lengthy, free text responses to open ended questions from a large number of respondents. This may have been facilitated by the nature of the online questionnaires which possibly enabled more detachment for respondents than is possible with face to face discussions and also ensured their anonymity. Respondents may have found it easier to relate their experience of such a tragic event and express their feelings freely on an emotive topic by this means. However, free text responses have their limitations in that emergent themes cannot be pursued in depth or tested, as when using focus groups or semi- or un-structured interviews. Our respondents were self-selected and the majority were Caucasian, had received above average education and had internet access making our sample not representative of the wider population and limiting generalisation. Further research may include a wider range of socioeconomic and ethnic groups and so produce more generalisable data. Finally, the fact that our respondents were recruited via a number of stillbirth charities, principally Sands, and given the finding from our study that women who access such charities often have had the most difficult experiences around stillbirth, our sample may sit at the extreme end of the poor experience spectrum in stillbirth. These limitations mean that our findings are suggestive rather than definitive and more work is required to test our hypothesis of the nature stigma of stillbirth. In particular an issue that needs exploring and not covered here is resilience and the possibility that some women have more effective coping strategies than others in dealing with stillbirth and overcoming stigma. These may in turn relate to different personalities (Barr, 2004), biographical experiences and/or family structures.

Conclusion

In this paper, we have used stigma theory to understand and interpret women's experiences of stillbirth. It is argued that stillbirth leads to stigma which spoils the social identities of patient, mother and full citizen for women. Furthermore, successful identity repair work is fundamental to recovery from stillbirth. Such work, which may include successful memory making and sharing, can lead to both self and social acceptance, the well-adjusted phase of the moral career. It is a state of grace, however, which remains elusive for many women who have experienced stillbirth.

References

- Badenhorst, W., Riches, S., Turton, P., & Hughes, P. (2006). The psychological effects of stillbirth and neonatal death on fathers: Systematic review. *Journal of Psychosomatic and Obstetric Gynaecology*, 27, 245-256.
- Barr, P. (2004). Guilt- and shame-proneness and the grief of perinatal bereavement. *Psychology and Psychotherapy: Theory, Research and Practice*, 77, 493-510.
- Begley, M., & Quayle, E. (2007). The lived experience of adults bereaved by suicide. A phenomenological study. *The Journal of Crisis Intervention and Suicide Prevention*, 28, 26-34.
- Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief*. Cambridge, MA: Harvard University Press.
- Boyle, F.M., Vance, J.C., Najman, J.M., & Thearle, M.J. (1996). The mental health impact of stillbirth, neonatal death or SIDS: Prevalence and patterns of distress among mothers. *Social Science and Medicine*, 43, 1273-1282.
- Cacciatore, J. (2007). Effects of support groups on posttraumatic stress responses in women experiencing stillbirth. *Omega - Journal of Death and Dying*, 55, 71-90.
- Cacciatore, J. (2009). The silent birth: A feminist perspective. *Social Work*, 54, 91-95.

- Cacciatore, J., DeFrain, J., & Jones, K. L. C. (2008). When a baby dies: Ambiguity and stillbirth. *Marriage and Family Review, 44*, 439-454.
- Cacciatore, J., & Flint, M. (2012). ATTEND: Toward a mindfulness-based bereavement care model. *Death Studies, 36*, 61-82.
- Cacciatore, J., Rådestad, I., & Frøen, J. F. (2008). Effect of contact with stillborn babies on maternal anxiety and depression. *Birth: Issues in Perinatal Care, 35*, 313-320.
- Cacciatore, J., Schnebly, S., & Frøen, J. F. (2009). The effects of social support on maternal anxiety and depression after stillbirth. *Health and Social Care in the Community, 17*, 167-176.
- Callister, L. C. (2004). Making meaning: Women's birth narratives. *Journal of Obstetric, Gynecologic and Neonatal Nursing, 33*, 508-518.
- Charmaz, K. (2006). *Grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.
- Crawley, R., Lomax, S., & Ayers, S. (2013). Recovering from stillbirth: the effects of making and sharing memories on maternal mental health. *Journal of Reproductive and Infant Psychology, 31*, 195-207.
- Cvinar, J. G. (2005). Do suicide survivors suffer social stigma: A review of the literature. *Perspectives in Psychiatric Care, 41*, 14-21.
- DeFrain, J. D., Martens, L., Stork, J., & Stork, W. (1990). The psychological effects of a stillbirth on surviving family members. *Omega - Journal of Death and Dying, 22*, 81-108.
- Doka, K. (1989). *Disenfranchised grief: Recognising hidden sorrow*. Lexington, MA: Lexington Books.
- Downe, S., Schmidt, E., Kingdon, C., & Heazell, A.E.P. (2013). Bereaved parents' experience of stillbirth in UK hospitals: A qualitative study. *BMJ Open, 3*:e002237.

- Erlandsson, K., Warland, J., Cacciatore, J., & Rådestad, I. (2013). Seeing and holding a stillborn baby: Mothers' feelings in relation to how their babies were presented to them after birth - Findings from an online questionnaire. *Midwifery*, 29, 246 – 250.
- Fivush, R. (2010). Speaking silence: The social construction of silence in autobiographical and cultural narratives. *Memory*, 18, 88-98.
- Flenady, V., Koopmans, L., Middleton, P., Frøen, J. F., Smith, G. C., Gibbons, K., ... Ezzati, M. (2011). Major risk factors for stillbirth in high-income countries: a systematic review and meta-analysis. *Lancet*, 377, 1331-1340.
- Foa, E. D., Riggs, D. S., Dancu, C. V., & Rothbaum, B. O. (1993). Reliability and validity of a brief instrument for assessing post-traumatic stress disorder. *Journal of Traumatic Stress*, 6, 459-473.
- Frøen, J. F., Cacciatore, J., McClure, E. M., Kuti, O., Jokhio, A. H., Islam, M., & Shiffman, J. (2011). Stillbirths: Why they matter. *Lancet*, 377, 1353-1366.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine Publishing Company.
- Godel, M. (2007). Images of stillbirth: Memory, mourning and memorial. *Visual Studies*, 22, 253-268.
- Goffman, E. (1959). *The presentation of self in everyday life*. New York, NY: Anchor Books.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York, NY: Prentice-Hall.
- Gold, K.J., Boggs, M.E., Mugisha, E., & Palladino, C.L. (2012). Internet message boards for pregnancy loss: Who's on-line and why? *Womens Health Issues*. 22, e67–e72.
- Grout, L.A. & Romanoff, B.D. (2000). The myth of the replacement child: Parents' stories and practices after perinatal death. *Death Studies*, 24, 93-113.

- Gudmundsdottir, M., & Chelsa, C. (2006). Building a new world: Habits and practices of healing following the death of a child. *Journal of Family Nursing, 12*, 143-164.
- Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology, 44*, 227-239.
- Hughes, P., Turton, P., Hopper, E., & Evans, C. D. H. (2002). Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: A cohort study. *Lancet, 360*, 114-118.
- Hughes, P., Turton, P., Hopper, E., McGauley, G.A. & Fonagy, P. (2001). Disorganised attachment behaviour among infants born subsequent to stillbirth. *Journal of Child Psychology and Psychiatry, 42*, 791-801.
- Hughes, P., & Riches, S. (2003). Psychological aspects of perinatal loss. *Current Opinion in Obstetrics and Gynecology, 15*, 107-111.
- Janzen, L., Cadell, S., & Westhues, A. (2004). From death notification through the funeral: Bereaved parents' experiences and their advice to professionals. *Omega - Journal of Death and Dying, 48*, 149-164.
- Jenkins, R. (1996). *Social identity*, London: Routledge.
- Kelley, M.C., & Trinidad, S.B. (2012). Silent loss and the clinical encounter: Parents' and physicians' experiences of stillbirth - a qualitative analysis. *BMC Pregnancy and Childbirth, 12*: 137.
- Lang, A., Fleischer, A.R., Duhamel, F., Sword, W., Gilbert, K.R., & Corsini-Munt, S. (2011). Perinatal loss and parental grief: The challenge of ambiguity and disenfranchised grief. *Omega- Journal of Death and Dying, 63*, 183-196.
- Layne, L. L. (2003). Unhappy endings: a feminist reappraisal of the women's health

- movement from the vantage of pregnancy loss. *Social Science and Medicine*, 56, 1881-1891.
- Lee, C. (2012). "She was a person, she was here": The experience of late pregnancy loss in Australia. *Journal of Reproductive and Infant Psychology*, 30, 62-76.
- Lewis, M. (1995). *Shame: The exposed self*. New York, NY: Free Press.
- Lewis, M. (1998). Shame and stigma. In P. Gilbert, P. & B. Andrews (Eds.), *Shame: Interpersonal behaviour, psychopathology and culture*. New York, NY: Oxford University Press.
- Lovell, A. (1983). Some questions of identity: late miscarriage, stillbirth, and perinatal loss. *Social Science and Medicine*, 17, 755-761.
- Lovett, K.F. (2001). PTSD and stillbirth. *British Journal of Psychiatry*, 179, 367.
- Lovibond, S. H., & Lovibond, P. F. (1995). *Manual for the Depression Stress Anxiety Scales (2nd ed.)*. Sydney: Psychology Foundation.
- Marks, D., & Yardley, L. (2004). *Research methods for clinical and health psychology*. London: Sage.
- Mullan, Z., & Horton, R. (2011). Bringing stillbirths out of the shadows. *Lancet*, 377, 1291-1292.
- Murphy, S. (2012). Reclaiming a moral identity: Stillbirth, stigma and 'moral mothers'. *Midwifery*, 28, 476-480.
- Murphy, S., & Thomas, H. (2013). Stillbirth and loss: Family practices and display. *Sociological Research Online*, 18 (1) 16, 1-11.
- Murray, J., & Callan, V. J. (1988). Predicting adjustments to perinatal death. *British Journal of Medical Psychology*, 61, 237-244.
- National Institute of Health and Clinical Excellence. (2007). *Antenatal and postnatal mental health clinical guideline 45*. London: NICE.

- Orwell, G. (1949). *Nineteen eighty four*. A novel. London: Secker & Warburg.
- Park, K. (2002). Stigma management among the voluntarily childless. *Sociological Perspectives*, 45, 21-45.
- Peelen, J. (2009). Reversing the past: Monuments for stillborn children. *Mortality: Promoting the interdisciplinary study of death and dying*, 14, 173-186.
- Rådestad, I., & Christoffersen, L. (2008). Helping a woman meet her stillborn baby while it is soft and warm. *British Journal of Midwifery*, 16, 588-591.
- Rådestad, I., Steineck, G., Nordin, C., & Sjögren, B. (1996). Psychological complications after stillbirth - influence of memories and immediate management: Population based study. *British Medical Journal*, 312, 1505-1508.
- Rådestad, I., Erlandsson, K., Lindgren, H., Malm, M., Davidsson-Bremborg, A. (2011). Mothers' experiences of the time after the diagnosis of an intrauterine death until the induction of the delivery: A qualitative internet-based study. *Journal of Obstetrics and Gynaecology Research*, 37, 1677-1684.
- Rådestad, I., Westerberg, A., Ekholm, A., Davidsson-Bremborg, A., & Erlandsson, K. (2011). Evaluation of care after stillbirth in Sweden based on mothers' gratitude. *British Journal of Midwifery*, 19, 646-652.
- Rand, C. S. W., Kellner, K. R., Revak-Lutz, R., & Massey, J. K. (1998). Parental behavior after perinatal death: twelve years of observations. *Journal of Psychosomatic Obstetrics and Gynaecology*, 19, 44-48.
- Riches, G., & Dawson, P. (1998). Lost children, living memories: The role of photographs in processes of grief and adjustment among bereaved parents. *Death Studies*, 22, 121-140.
- Rosof, B. D. (1994). *The worst loss*. New York, NY: Henry Holt & Co.

- Royal College of Midwives. (2010). NICE clarifies its stillbirth guidelines, *Midwifery*, 25th June, <http://www.rcm.org.uk/midwives/news/nice-clarifies-its-stillbirth-guidelines>.
- Royal College of Obstetricians and Gynaecologists. (1985). Report of the RCOG working party on the management of perinatal deaths. London: Chameleon Press.
- Säflund, K., Sjögren, B., & Wredling, R. (2004). The role of caregivers after a stillbirth: Views and experiences of parents. *Birth*, 31, 132-137.
- Sanger, C. (2012). "The birth of death": Stillborn birth certificates and the problem for law. *California Law Review*, 100, 269-311.
- Schott, J., & Henley, A. (2009). After a stillbirth - offering choices, creating memories. *British Journal of Midwifery*, 17, 798-801.
- Scott, J. (2011). Stillbirth: breaking the silence of a hidden grief. *Lancet*, 377, 1386-1388.
- Sheehan, J.D. (2001). PTSD and stillbirth. *British Journal of Psychiatry*, 179, 368.
- Spong, C. Y., Reddy, U. M., & Willinger, M. (2011). Addressing the complexity of disparities in stillbirths. *Lancet*, 377, 1635-1636.
- Stroebe, M., & Schut, H. (2010). The dual process model of coping with bereavement: A decade on. *Omega - Journal of Death and Dying*, 61, 273-289.
- St John, A., Cooke, M., & Goopy, S. (2006). Shrouds of silence: Three women's stories of prenatal loss. *Australian Journal of Advanced Nursing*, 23, 8-12.
- Surkan, P. J., Rådestad, I., Cnattingius, S., Steineck, G., & Dickman, P. W. (2008). Events after stillbirth in relation to maternal depressive symptoms: A brief report. *Birth: Issues in Perinatal Care*, 35, 153-157.
- Turton, P., Badenhorst, W., Pawlby, S., White, S., & Hughes, P. (2009). Psychological vulnerability in children next-born after stillbirth: A case-control follow up study. *Journal of Child Psychology and Psychiatry*, 50, 1451-1458.

- Turton, P., Evans, C., & Hughes, P. (2009). Long-term psychosocial sequelae of stillbirth: Phase II of a nested case-control cohort study. *Archives of Women's Mental Health, 12*, 35-41.
- Turton, P., Hughes, P., Evans, C. D. H., & Fainman, D. (2001). Incidence, correlates and predictors of posttraumatic stress disorder in the pregnancy after stillbirth. *British Journal of Psychiatry, 178*, 556-560.
- Vance, J. C., Najman, J. M., Thearle, M. J., Embleton, G., Foster, W. J., & Boyle, F. M. (1995). Psychological changes in parents eight months after the loss of an infant from stillbirth, neonatal death, or sudden infant death syndrome - A longitudinal study. *Pediatrics, 96*, 933-938.

Table 1

Open-ended questions on memory making and sharing and professional and social support for mothers experiencing stillbirth

-
1. If you wish to provide any further information about your baby's birth, please do so here.
 2. What could have been done better to help you create positive memories?
 3. If you wish to provide any further information on the events immediately following your baby's birth and death, please do so here.
 4. If you wish to provide any further information on the aftercare and support following your baby's birth and death (e.g., at the hospital, or visits by anyone to you at home afterwards etc.), please do so here.
 5. If you wish to provide any further information about how you have shared your memories of your baby with others, please do so here.
-