

# **Finding the positive in loss: stillbirth and parental empowerment**

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## **Abstract**

This paper reports on PhD research that investigated parental experience of stillbirth. Drawing on in-depth interviews with ten couples and twelve mothers, it argues that while the experience of stillbirth is, to some extent, a stigmatising one – parents recount feeling like failures and report social difficulties after the loss (author's PhD thesis, 2009) – there are positives that may be taken from the experience. These, however, are more likely to emerge in the medium and longer term. Far from being 'passive victims of prejudice' (Shih, 2004), some parents may be empowered to take action to improve local and, in some cases, national maternity services, as well as raising people's awareness of stillbirth and breaking the silence that surrounds it.

**Key words: stillbirth, qualitative research, stigma, empowerment, status**

## **Introduction**

Despite being a relatively rare event in the UK, 4100 babies were stillborn in 2010 (Sands, 2012). Losing a son or daughter – at any age – is a tragedy for parents but bereavement by stillbirth – the loss of a baby between 24 weeks’ gestation and birth – can be particularly difficult for people to deal with: parents have not had the chance to see their child alive, much less introduce the new arrival to their family and friends. Guilt, especially on behalf of mothers can characterise the experience, too, as mothers seek to understand what went wrong and wonder if they themselves were to blame (Murphy, 2011). The unusual nature of this type of death marks parents out as ‘different’: it is, in Erving Goffman’s (1963) terms ‘stigmatising’. The concept of stigma is one that has been used extensively in academic research and there is a tendency for social scientists to see its affects as wholly negative (Shih, 2004). However, Goffman (1963) suggested that some positives could be found in stigmatised identities. This article suggests that, while to be bereaved by stillbirth is, on the whole, a negative experience, for some parents there may be positives to be found in their loss.

## **Losing a baby**

Over the past 40 years, understandings of stillbirth and its affect on parents have changed markedly. Up until the 1970s, medical management of stillbirth meant that parents would not see the baby and they would then normally be advised to go home and try again (Kohner, 2001). Stillbirth was not considered by medical staff to be a ‘proper bereavement’ (Lovell, 1983) and this belief was often reinforced by the friends, families and colleagues of the parents. This was, despite the fact that parents were obviously grieving for their dead baby (Peppers and Knapp, 1980).

Practices in hospital have now changed markedly: the Stillbirth and neonatal death society (Sands), formed in 1978 by bereaved parents angry at the lack of recognition of their loss (Allsopp *et al.*, 2004) has made important progress in this area with their work with hospitals and health professionals and publication of guidelines for health professionals, the most recent being in 2007. It recommends that parents should be offered the chance to see, hold and spend time with their baby (Schott *et al.*, 2007) and many hospitals now have a bereavement midwife who will oversee the

management of care following loss and train staff to support parents. This recognition of the seriousness of the loss by the medical profession has not necessarily been mirrored by the general population, though, with many parents feeling that their social circle does not recognise their loss (Rajan and Oakley, 1997, author, unpublished PhD thesis, 2009) and, for first-time mothers and fathers, they feel that they are not categorised as parents by their friends and family (author, forthcoming; McCreight, 2008). Layne (1997), too, has also talked about the silences that surround pregnancy loss and Hazen (2006) has noted how women would silence themselves following a loss. The sociologist Deborah Davidson (2011) recounts, in an examination of her own experience of perinatal loss in the 1970s, of not mentioning her losses for fear of upsetting her social circle.

While parents may experience silence – either their own or other people’s – around pregnancy loss, the grief that is experienced by parents following stillbirth is now well-documented in academic literature. Often the focus is on the differences in grieving styles between men and women. In 1980 Peppers and Knapp noted that men had a tendency to suppress their grief after a pregnancy loss or infant death with women being more expressive in their mourning. This, they argued, led to couple conflict as mothers tended to think that a lack of expression of grief meant that their partners were not as attached to the unborn child as they should have been. A lack of the display of grief, rather than the emotion of grief, was the problem. This was reported too by McCreight (2008). Fathers in her study stated that their experience had been marginalised by medical professionals, as well as family and friends who directed their support to their partners; indeed, it was expected of them that they should put aside their own feelings in order to support their partner too.

Stroebe and Schut (1999) have argued for a dual-process model of grief where the bereaved individual oscillates between a ‘loss-orientation’ and a ‘restoration-orientation’. Briefly, loss-orientation refers to the grief-work undertaken by individuals where they focus on the deceased person and resist moving on with their lives. Restoration-orientation is where the bereaved begin to do new things and take on new identities. Initially developed to explain reactions to the death of a partner, they argue that this model has application to other types of bereavement. Considering the gendered differences in grief after a stillbirth noted above, it might be concluded

that the suppression of grief by men is 'restoration-orientation' as they seek to distract themselves from their bereavement while women, in the early aftermath of the loss, may be seen to be 'loss-oriented'. As a sociologist I would argue that, when experiencing a stillbirth, the differing orientations that men and women exhibit after loss is related to societal expectations of men and women. It is expected that women will be the primary caregiver to a child and many will have decided to take a leave of absence from work in order to do so. The lost role of mother impacts to a greater extent on mothers than it does on fathers who are expected to return to work shortly after the baby is born (ref to author's PhD thesis,2009). Fathers, then, are in the position where they are necessarily distracted from the loss as economic considerations force them to return to work and, therefore, a 'restoration-orientation'.

Words and phrases used to describe pregnancy loss in the literature, especially those published by Sands, are often negative. 'Taboo', 'dismissal', 'embarrassment', 'out of place' and 'failings' suggest that to experience a stillbirth is to take on a stigmatised identity. This concept, elaborated by Goffman (1963) sees the individual who has the stigma as discredited in some way. This will manifest itself in two ways: 'felt' and 'enacted' stigma. Felt stigma is where the individual considers themselves to be discredited – they have taken on societal values over what constitutes normality and applied those values to themselves. Enacted stigma is where people with the stigma are discriminated against by others. While many researchers who have worked with this concept have focused on the negative aspects of stigma, Goffman did note that stigmatised individuals would sometimes see their trials as a 'blessing in disguise'. Shih (2004), too, has noted that, in the literature around stigma, there are individuals who are able to overcome, or at least mitigate, its harmful effects. Citing Oyserrmman and Swim's (2001) work, she notes that one way in which individuals can do this is through empowerment and, rather than being "...passive victims of prejudice....[the stigmatised are] active participants in society who seek to understand their social worlds and create positive outcomes" (p. 180). This paper explores the idea of empowerment as a way of overcoming the stigma of stillbirth to some extent.

## **Methods**

In seeking to understand the social worlds that individuals bereaved by stillbirth inhabit, the research method chosen here was a qualitative one. Parents bereaved by stillbirth after 1992 (this year was chosen as it was the year that the legal definition of stillbirth changed from deaths after 28 weeks' gestation to deaths after 24 weeks' gestation) and not less than six months before the interview took place were recruited through support group networks, pregnancy loss websites and personal contacts. In-depth interviews with ten couples and twelve mothers were carried out with five of the couples having joint interviews as well as follow-up interviews and the data was analysed using grounded theory (Strauss and Corbin, 1996). Nearly all of the participants were white apart from two south Asian mothers and most were from social classes 1 to 3 with the exception of two fathers and two mothers. This is more than likely a result of my recruitment methods: members of support groups tend to be white and middle-class (Allsop et al., 2004). However, both south Asian mothers were recruited via support groups as did one of the mothers who was in social class 5.

Ethical permission for the research was given by a local NHS research ethics committee and by the University of Surrey. Participants were assured of anonymity and confidentiality and assured that they were under no obligation to answer all questions and could stop the interview at any time. In the event, no participants chose to withdraw from the research or refuse to answer any questions. While the accounts gathered for this research project reflect the participants' subjective experiences, the findings presented here are not able to be generalised to the population of bereaved parents as a whole.

## **Stillbirth as stigmatizing**

While the term stigma was rarely referred to, the participants in this study certainly used the language that would be associated with a stigmatized identity: they recounted experiences which suggested that relationships with others had been changed irrevocably and that other peoples' attitudes towards them had altered too. Crucially, when considering Goffman's ideas, their perception of themselves had changed too. As an example of 'felt stigma', Grace's narrative is an apposite one:

*Grace:* I think I was sort of ashamed to tell other people that I hadn't, um, I had failed, you see. I had, had failed again. I guess it's that failure thing, I'd failed to produce a baby and I'd failed to notice when the baby was in distress.

In the above, Grace's feelings are directly linked to societal ideals of womanhood: her perceived 'failure', and this is a phrase that other women interviewed used too, was that she could not do what every other woman could do, that is, produce a live baby. To add to Grace's distress, her baby had died several days before he was born and what Grace perceived to be another example of her own failing – not understanding what was going on in her body – was not something that would happen to a 'good mother'.

Parents were also at risk of 'enacted stigma'. Participants talked of being avoided, for example, people would cross the road from them and of being ignored. For example, Maggie, a second-generation south-Asian mother felt the stigma of losing her baby keenly:

*Maggie:* the younger women stayed away from me because, you know, I felt like I was bad luck then, you know, when I went to the temple they didn't talk to me, the younger women, just stayed away sort of. The older women did [talk to me] and um but yeah, they made you feel like, you know, I'd been cursed or something.

It is tempting, perhaps, to explain Maggie's experience of enacted stigma by recourse to her religion and/or ethnicity but white, middle-class women also experienced such treatment. Bridget was one such woman:

*Bridget:* there were a few people at work who just never spoke to me again..... I mean I definitely got the feeling ... like I was bad luck.

This treatment was not necessarily confined to work colleagues: friends, neighbours and even family members would seek to avoid the bereaved parents as the following three quotes demonstrate:

*Christina:* Everybody else just sort of, they just didn't talk to me.

*Fiona:* I had a lady, a neighbour, literally cross the road and went in the other direction, which was very hurtful.

*Tanya:* We've lost, many members of our family do not talk to us.

The avoidance of the bereaved mother reinforced ideas that they were, to some extent, discredited by the experience of stillbirth. Stillbirth, then, was experienced as stigmatizing by many of my participants to some degree. Losing a child before birth had the potential to make women feel as if they were 'failures' and both men and women had difficulties socially following their bereavement. There were, however, specific ways in which parents might attempt to counter this treatment.

### **Finding the positive in loss**

There were three main ways in which participants would specifically call on the identity of 'bereaved parent' as a way of empowerment.

#### *Challenging the medical profession*

The first way in which parents might find empowerment in their loss was by seeking to change medical practice with the ultimate aim of trying to prevent what happened to them happening to other parents. Ann, for example, went back to her hospital to ask questions over her treatment and to request that what happened to her would not happen again: she had gone to hospital at 40 weeks' gestation and had been left in a waiting room, bleeding heavily and in great pain for several hours;

*Ann:* All I actually asked them for and I actually, my GP actually put it in writing the same sort of thing, was that if anybody with any signs of pre-eclampsia and that had been in and out of for the last week like I had been monitored that closely, don't leave them sort of waiting around; get them straight up there so it doesn't happen again.

It might be expected that parents who challenged the medical profession would be those who were either in the higher socio-economic group and/or attended a support group. Ann and her husband, however, were recruited through a personal contact of mine (they had not attended any support meetings) and were from social class 5: she is a teaching assistant and he a lorry driver. They had not felt the need to go to Sands, preferring the support of their family to that of other bereaved parents. Their depth of

feeling about what had happened to them overcame any barriers of class that might have prevented them challenging the medical profession. Another example of challenging medicine came from my interview with Charlotte and Carl. Both were well-educated and ran their own businesses. They successfully sued the NHS Trust where their son was born after a series of errors and have since gone on to found their own charity. Carl told me:

*Carl:* I deal with it in a way that you know, to crusade, to campaign, to make sure things change, to try and take the positives as much as you can out of the whole situation rather than dwell on you know the terrible, you know, things that have happened because, you know, you can't change what's happened unfortunately in the past. What you can do is change things for the future so I'm always, you know, glass half full.

Dealing with their son's loss has changed their lives completely and has become their job. Carl's comments, to 'try and take positives...out of the whole situation' accords very much with Oyserman and Swim's (2001) suggestion that people will try and change the world around them for the better.

#### *Improving bereavement care*

Telling the story of the loss of the baby to health professionals was another way in which parents would be empowered: Una, for example, said that hospital staff needed more than just the Sands guidelines in order to deal with loss: they also *need to hear* about the lived experience of stillbirth:

*Una:* We (Sands group) gave the talk to the midwives and I made them cry when I told them what I told the girls [about their brother who died], and I actually apologised [to the midwives] and I said, "I didn't mean to upset you." "But Una" [they said] "we needed to know how important that [memory] book was, to us it's a book that we just put in the hand and footprints we didn't know it could be a bloody story book to two little girls." And I went "Oh okay." And I never thought of it like that and I thought if that's what they need to hear. 'Cos they said, "You can tell us "do this, do that," but we need to know your personal experience for us to gain so much out of it, whether it upsets us or not."

In Una's case, she was keen to change how medical professionals conceptualised the loss and for them to understand how the behaviour of midwives, doctors and other related staff might affect parents: this, she felt, was a useful adjunct to the Sands guidelines and so her experience then had become a tool for education. Una was the

other mother who came from a lower social class demonstrating again that class is not necessarily a pre-requisite for trying to facilitate change although in this case she was a member of her local Sands support group.

Moreover, many parents saw taking part in this research project as a way in which they could help to improve practice: participants were informed that the research results would be disseminated to health professionals. Sheila summarized this attitude:

*Sheila:* I know that I have to go through stuff [like this interview] because I think it's a job that we have to do in a sense to make it real to other people and to widen the understanding of stillbirth.

To apply the language of work to the identity of bereaved parent is interesting: for Sheila not only was the stillbirth a place of status and an authority from which to speak but to try to change things for other people is a *requirement* of her new identity. This place of authority had given Sheila and other mothers a certain type of 'expertise' that could be used for the benefit of others.

#### *Raising awareness of stillbirth*

It was not only health professionals that parents would seek to educate but other people in their social circles too. In the following example, Diane, a teacher, is attempting to 'educate' colleagues and neighbour:

*Diane:* Yeah. We've got a neighbour who has often said the wrong things. So she's been quite [difficult]. I did try to educate her but it, um, it didn't work. One of my colleagues came to visit me very soon afterwards and, um, that was a great help and she talked to me and listened as well and really wanted to know how I was feeling. Um, lots asked to see photos and, um, I also gave them a Sands leaflet about how to support friends and I could tell the people that read that and lots of people came to me and said. "I read the leaflet and found that really helpful."

Another mother was educating her friends, not necessarily just about how to handle bereaved parents but also about exactly what a stillbirth was: one of her friends had obviously misunderstood the nature of the loss:

*Penny:* I've had, actually it was very strange, a very, very good friend, there's five of us, that all knock about together from school and, um, we go away every year, um, for a long weekend and I'd seen them all, apart

from one, and I took [son's] little book with me on the weekend away to, to show her the photo and everything else. And she opened the photo and she said, she said, "Oh I thought he was going to be just a mass." And she said, "It's really a baby." And I was like "Well, what did you expect?" and I'm glad she said it because I never realised that people might think that. Um, and so I'm glad that she said it because it made me realise that other people might be thinking the same as that. I mean she felt dreadful but, I mean, she's a good enough friend that we could get over that and, um, I'm glad she said it actually, and she's glad she saw the photo, because it made her realise actually what we had lost.

This misunderstanding of the loss in this instance may well have impacted on the sympathy given by the friend to Penny but the education of others around stillbirth and attempts to break the silence around the subject are all ways on which parents might seek to change people's understandings even if this is only in a very small way. While in the 1970s Davidson (2011), and others like her, may have imposed a silence on themselves, some parents are now likely to try and break it.

But parents would pick and choose when to disclose their stillbirth. The question 'how many children do you have' would necessarily involve a weighing-up of the situation they were in, and of the questioner, before an answer was given. But including the child in their family was another way in which awareness of stillbirth might be raised. When Debbie's parents-in-law unwittingly revealed that they had forgotten their stillborn grandson, Debbie then made a conscious decision to remind others of his existence at Christmas:

*Debbie:* And I think, I'm going to put him on my Christmas cards this year. I know that sounds silly, but I'm making a conscious decision that I don't want people to forget him even if they never knew him.

In these ways, by continuing to include the stillborn child in their families, parents are breaking the silence of pregnancy loss that Layne (1997) referred to. A further way of doing this, one recounted by many interviewees, was by participating in awareness-raising events organised by their local branches of Sands such as balloon-raising, charity fund-raising and memorial gardens: this activity might go on for several years after the stillbirth.

However, of the parents interviewed not all would be involved in educating health professionals, attempting to change practice or even including the child in their family

and activism did not seem to necessarily relate to time since the stillbirth: many parents, Carl and Charlotte and Ann and her husband Alan were making their challenges to the medical profession within months of their loss. On the other hand, Maggie and Barbara spent years trying to forget that they had had a stillborn only for it to be dealt with ten or more years post-loss. In both cases, changes in their life had forced them to deal with the stillbirth and that had led them to activism at a later date.

A caveat to this research is that it must be remembered that the participants in this research tended to belong to support groups and so are likely to be atypical of the population of interest. However, as many parents here did find some sense of empowerment following the stillbirth, the accounts collected support Oyserman and Swim's (2001) claim that to be the bearer of a stigma is not necessarily a wholly negative experience. With regard to Stroebe and Schut's work, though, I would argue that this research raises an interesting question. Is parental empowerment following a stillbirth a manifestation of loss-orientation to grief or restoration-orientation? I would argue that at times when parents are talking to health professionals and lay people about their loss or campaigning for change, it is both. On the one hand such behaviour exhibits a loss-orientation as such actions necessarily focus around their own grief. But it is also restoration-orientation as a new identity is taken on that, in some senses, can distract them from grief in order to evoke change for the future.

### **Concluding comments**

The experiences recounted by parents in this research show that to have a stillborn baby is an event that is stigmatising. It produces socially-awkward encounters for parents and, indeed, others might seek to avoid them. This is something that is useful for those who work with those bereaved by stillbirth to be aware of. It is particularly the case that, for mothers, especially, such stigma may be felt deeply as they experience feelings of failure and perceive themselves to be an embarrassment. Running counter to this, however, some of the individuals interviewed were able to extract a sense of empowerment following their loss as they sought to change the world around them for the better. Far from being a wholly negative experience, many parents were able to take the identity of bereaved parent and re-conceptualise it

as a positive aspect of their self, if not in the short-term, then possibly in the medium- and longer-term post loss.

I am not suggesting here that, in the early aftermath of a stillbirth, those who work with bereaved parents should be actively encouraging them to think of the positives that might be found in their experience. An awareness, however, of the potential for empowerment in the bereaved parental identity might be useful for the counsellor who is working with bereaved parents in the medium and longer-term. In time, suggesting ways in which parents could seek to change medical practice, raise awareness of the loss or improve the care of the bereaved by disseminating their experience to health professionals, may be one way in which they seek to guide parents towards a 'restoration-orientation' which will, at the same time, not require them to forget their dead baby.

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