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Introduction

In this presentation I discuss parents' accounts of personifying and memorialising their child in their everyday lives and on the web. As an extension of a real world memorial such as a gravesite, a virtual mourning space provides a space for personal narratives that otherwise are not socially or legitimately endorsed by the social networks to which bereaved parents have related. Virtual mourning sites, thus, provide a space and location for narration about a deceased child and with it a sense of community building.

To set stillbirth and neonatal death into context 17 babies die each day in the UK. In political legal context stillbirth is referred to as a death in the UK which occurs following 23 weeks and 6 days gestation while neo natal death is referred to as those deaths which occur in the first four weeks of life (Centre for Maternal and Child Enquiries, 2011). The vast majority of these deaths however, remain unexplained.

Method

Data from 28 in depth interviews and 6 focus groups with men and women was analysed using a voice centred relational method and utilising a sociological framework developed by Mauthner and Doucet (1998), based on extensive research by Brown and Gilligan (2003) at Harvard University.

This particular method to analyse parents accounts were Notion of relational ontology in that humans are embedded in a web of complex and intimate social relations. Transcripts and recordings were read at least four times, for instance in the first reading I was concerned with finding out about the plot and the sub plot to someone's narration and in another reading I was looking at they way they were telling their story intellectually and emotionally, in the third I was concerned with the way relationships mediated responses to parents loss and in the fourth, I considered the impact on the social and cultural context how, for instance how we memorialise the dead.

A real baby with real things

There were a myriad ways in which men and women sought to memorialise their child, for example by taking photographs of the baby and creating memory boxes in which to place locks of hair, hand and footprints, toys and clothes which had been accumulated in anticipation of the birth. These collections of images and artefacts are all post death activities which serve to personify and establish the existence of the baby. In gathering evidence that the child did exist parents were showing that there was a baby with real baby things. This concurs with Linda Layne's research on pregnancy loss and material culture which highlights how continuing to possess baby things acquired in anticipation of a birth and after a baby's death is "powerful proof that a baby existed" and can "help parents normalize" and "make real their experiences as parents" (Layne, 2000: 323).However, "the incipient personhood of the wished-for child is often revoked" by society, family and friends (Layne, 2000: 323).

Parents narrations testify to such denial, for instance, one parent described the response of a friend who had come knocking to see how the grieving parents fared only to react with distate, and disgust at a photograph of the baby who had died on the wall as though it was the most vulgar art to cast eyes upon. This realness problem pervades throughout much of bereaved parent narratives owing to lives that barely lived.

Stillbirth and neonatal death

A death following stillbirth and neonatal death has a number of unique elements which make it the object of focus. First, an unexpected death can create distinct problems when it comes to grieving for a much wanted child as Howarth (2001) suggests, since it "upsets the popular assumption that death now occurs in old age" (248-249). The lack of a definitive explanation for such a tragic event renders parents with the unenviable position of not knowing how to define or account for their baby's death.

Indeed, up to 60 percent of stillborn post mortems are inconclusive which leaves parents left struggling for meaning with women in particular vacillating between guilt, self blame and deep sorrow (Rando, 1993). The site of death often in hospital and the responses by family , friends, others and some professionals add to the sense of anguish which permeates the immediate hours and days afterwards. For instance, parents of children who have died following stillbirth and neonatal death report having to deal with inappropriate comments which allude to the idea that they can always replace the child by having another. Parents also struggle to respond to questions over the life course about how many children they have, leaving them repeatedly confronting the meaning of their child's death, and how such life that was barely lived.

Virtual Mourning

Hardly surprising then that it was to virtual mourning spaces to which parents turned to provide the focus and activity that they found helpful and healing. Virtual mourning spaces as they are referred to here include memorial sites which parents constructed or contributed towards.

As well as reading for men and women's account of loss I wanted to know if the "dual process model" as proferred by Stroebe and Schut (2001) which suggests that the bereaved attend to loss oriented tasks such as grief work whilst also attending to those that are about attending to life changes had a fit here. In turning to these particular avenues of expression and support as pertains to stillbirth and neonatal death, I wanted to know about the types of purpose they serve and whether they provide solace and healing.

For instance, in the following narrative we can find what the purpose of seeking out this form of support provides. The mother is able to set down restorative oriented task such as putting on a brave face to get on with life and in so doing keep her friends on side, while revealing the continuing bond with her child and sense of loss:

 "For most of the time, I feel like I'm putting on an act all the time because people don't want you to talk about it. If you're having a really bad day and the phone rings you answer all chirpy. It's only when you're in the group (off and online) you feel normal and you can say, 'I am still thinking about her and I do want to talk about her and I am missing her you know'. It's kind of nice to be able to do that because even with my closest friends even if I mention it they kind of get all awkward and they don't know what to say or what to do..."

Christina mother of baby girl Ella-Leina (born at 40 weeks, lived for 13 days)

According to parent's narrations, memorial websites constructed by parents assisted in continuing this bonds as well as providing meaning and identity reconstruction following loss. Emotional processes then and grief work that are publicly displayed on memorial sites can be understood as a form of identity construction (Finlay and Krueger, 2011). The self maybe a username or constructed as a social network page or website that may be adorned with photographs, mementoes. Texts and links to other sites, friends and groups.

In mourning, there are a number of online mediums from message boards to chatrooms, social networks and websites and which allow for self expression and communication through text, images, video and audio.

Online forums such as the Gonetoosoon.org provide a number of ways in which to memorialise a child. What sites such as these represent are 'Virtual Graveyard's', a place where the bereaved can 'light' a virtual candle, leave a poem or their story for others to read. That they are popular is evident with Gonetoosoon.org which to date has attracted over thousands of visitors. Further, such forums are established by bereaved men and women and demonstrate a shared understanding of grief. They provide a way to pay tribute and to receive support from on-line friends:

" Just to be able to just open up a set of questions and then obviously to hear other people's stories was important as well. I don't really know why that is, but it does seem to be incredibly useful. Just that kind of sharing that seems alien to every day life. I kind of find that family of people, that kind of knows just where you've been, you know. There's something really important about that."

Father of baby Ollie, stillborn at 39 weeks.

Identity construction and memorial websites

www.littlefootprints.org.uk was set up by one bereaved mother interviewed as it permitted a more permanent and complex online identity. Here, poetry could be shared alongside artwork depicting scenes of death whilst the more soft and oft reference to baby's hand and footprints provided evidence of the child once having existed and living on in the memory of the bereaved. While the subjectivity of audience readings is recognised, audience members who post on the site are in may respects co-authors helping to forge the identity of the site.

This bereaved parent forms part of what Greene (2010:55) has referred to as the 'dot. commemoration generation' which is changing the way society mourns. To borrow from Tony Walter and his colleagues here in the UK (Rachid Hourzi, Wendy Moncur and Stacey Pitsillides, 2013:13) pre-modern societies tended to produce a bereaved community, modern societies tend to produce bereaved individuals, and post modern mutual self help groups both online and offline produce a community of the bereaved, that is connections with others not previously known who have experienced the same form of loss – stillbirth or neonatal death.

Where face to face groups offer for some at least, validation of such loss a number of studies have found increased disclosure online and a greater sense of community with support provided to group members (Roberts, 2004). However, parents who developed such sites through free hosting services had to content with developing sites and revisiting them only to be confronted with inappropriate advertising (dating services and so on) pop up windows within seconds of navigating to it.

As such sites are vulnerable to intertextual reconstitutions via external interference. Parents were also rendered vulnerable in the belief that the site would only be visited by like minded individuals, when inappropriate and insensitive comments were left. Further, that reference to baby's full name together with the location of an offline group suggests that individuals are easily traced and located. This concurs with the findings of Finlay and Krueger's (2011: 30) study concerning parents construction of web memorialisation following SIDS, and where the desire for connection with grieving others and self expression outweighs concerns about the dangers of extensive personal disclosure.

Yet, when discussing the development of websites and engaging in chat rooms, it is evident that parents find solace in compiling detailed account of the pregnancy and birth and to the moment of death including resuscitation attempts. This conforms to research that has found in sudden or unexpected deaths, survivors "need to explain the death - not only to define it as natural or non-natural-but to explain or make sense of separation; to be able in some way, to put the dead away or locate them in an appropriate way in their own biographies." (Hallam, Hockey and Howarth, 1999: 95).

Conclusion

The development of memorialisation sites provide for a period of intensive activity in which time would otherwise be spend despondently for some parents. Such sites provided meaning and critical pieces of evidence that the baby existed because a footprint, a handprint or indeed a photo cannot deny existence they are proof of having been human even if a for a short while. Further, these sites be they chat rooms or memorialisation provide for the vacillation between grief and also trying to get on with life.

Death has been described as the event where the individual is connected to larger society (Finlay and Krueger, 2011: 33) . Indeed, funerals unlike weddings tend to be unrestricted and open to all who may have some connection to the deceased. However, few people may attend a funeral of a baby they have never even met and only do so out of respect for the parents. Virtual memorial sites are unrestricted and open to all who choose to type or search their way into a portal. Choosing to construct an online memorial website has the potential to serve solitary and social needs. Sites are constructed in isolation which is then accessed by increasing numbers who may provide comments which initiates a sense of community building. That or has been the case for some parents, a vulnerability when trolled.

What remains is that the confusion generated by stillbirth or neonatal death in the face of advanced technology which is meant to mitigate this threat of death, tends to leave parents socially and emotionally alienated and at times stigmatized. As Goffman (1963) points out, stigmatized individuals are motivated to bond with others.

The internet then is a valuable outreach tool for many bereaved parents providing for relief from isolation enabling them to find others such as their selves. Unlike physical memorials which are erected in one point in time and by and large remain unchanged, the interactice and communicative nature of the internet means online content can be amended and added to in subsequent periods of memorialisation which fits with parents biography of their child which changes over the life course as parents decide to tell which aspects of the story get told and in what way.

This does not suggest that an on line memorial is an appropriate avenue for all. On the contrary grief following perinatal death can be long lasting. It is possible that the construction and maintenance of a site is done so at the expense of support groups with an organisation such as SANDS or counselling with a professional. However, while people express themselves varyingly in their websites so too perhaps people use a mixture of support services including off and on line experiences in order to help them cope with the tragedies they have endured.