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The Multiple Impact of Stillbirth on Families: a Review of Recent Literature Exploring the Psychological Social and Economic Ramifications of Losing a Baby

Dr Samantha Murphy (corresponding author)

Head of Health and Social Care

Faculty of Health and Social Care,

Room 012 Horlock Building

The Open University

Walton Hall

Milton Keynes

MK7 6AA

Dr. Joanne Cacciatore

Associate Professor

Arizona State University

www.asu.edu

jcaccia@me.com

Abstract

This article reviews the current state of psychological, social and economic research into the impact of stillbirth on families. In doing so, we argue that while the knowledge we have of the experiential aspects of stillbirth is increasing, there is still much that remains to be uncovered particularly in respect of the impact that seeing the baby may have on mental health. Moreover, the experience of

particular social groups merits further work, in particular, same-sex couples and surrogates, mothers and fathers drawn from BME groups as well as those from lower socio-economic groups too. Particular attention needs to be paid as well to the economic impact that stillbirth has on families whether this is from a perspective that focuses on the family or the wider society within which they live.

Key words: stillbirth, bereavement, psychological, social, economic

Introduction

The death of a baby to stillbirth is a tragic event for mothers, fathers, siblings and the wider family. Researchers and clinicians studying the psychological outcomes after stillbirth illuminate the emotional and health risks to which stillbirth gives rise. Some research focuses more on the social environment and support, role identity and aspects associated with disenfranchised grief¹. Other studies, though fewer, have explored the economic cost to stillbirth, one that includes a person's potential lifetime contribution to the economy². Fox et al.³ for example, found a conservative annual burden of child death to be 1.6 billion in the U.S. alone while Malacrida⁴ noted a macro-economic cost of perinatal death to society. This was not through lost labor and productivity but because the lack of societal recognition assigned to perinatal death incites maternal vulnerability to mental, emotional, and social health risks that eventuate to global financial burden.

So where has this brought us? What do we know about the psychological, social and economic impact of stillbirth, and what remains to be discovered? The purpose of this article is to explore the existing research in order to inform the care of parents and identify the direction of future research. As such, this

paper concentrates on research published over the last 10 years but will refer to earlier work where relevant.

There is a proviso here: one of the problems with the literature on perinatal death is that many studies may be too inclusive and not precise enough: miscarriage, stillbirth, neonatal death, and even abortion are often conflated into a singular category. Wright⁵ also notes that within each nonspecific category of loss there are differences. Some of these differences may be due to variations in international definitions of stillbirth (which differ in terms of gestation) but they may also depend on the researcher's preference, bias, or the need to recruit more participants. Studies into stillbirth and Posttraumatic Stress Disorder (PTSD) at St George's Hospital, London, for example, defined stillbirth as a loss after 18 weeks⁶ rather than using the UK's classification of stillbirth as a loss after 24 weeks' gestation.

The conflation of categories within previous research, as well as the differences in international classification of stillbirth – some countries classifying by weight while others by gestational age – means that, while the focus of this review is on stillbirth, it will also include international perinatal death studies which are inclusive of neonatal deaths. In reviewing these studies, three main areas will be explored: 1) the psychological impact of stillbirth, 2) the social impact, and finally 3) the economic impact for families and society.

Psychological Impacts

Identifying the dimensions of the grief experience

Bereavement research has comprehensively outlined the range of emotions that both men and women experience, and there even exists a Perinatal Grief

Scale to measure the unique emotional experiences of a baby's death⁷. In acute grief, both mothers and fathers report similar emotions⁸ as parents struggle "with feelings of guilt and blame, regret, fear and grief"⁹ as well as shame¹⁰, stigma^{11 12}, and a sense of wanting to die¹³. More recent work suggests that if an individual is predisposed to shame and guilt then the intensity of grief following a perinatal death would be greater¹⁴. But the problem here is delineating the experience into what constructs grief and when this might tip into more long-term emotional and mental health problems. It is the latter upon which many studies have focused, particularly in mothers, although a significant minority contrast men and women's experiences. For example, based on repeated interviews with 36 U.S. couples following the birth or a subsequent live child, Armstrong et al.¹⁵, found that fathers were less at risk of depressive symptoms than mothers¹⁶. Murphy et al.¹⁶ also found that fathers had fewer intrusive thoughts, such as troubled dreams, strong emotions and unbidden thoughts than did mothers. For mothers in this sample, such intrusive thoughts tended to increase over time while depressive, anxious, and post-traumatic stress symptoms decreased over time.

Stillbirth and the couple

A further focus of previous research has been the experience of couples and the potential for problematic relationships following death highlighted. Spouses can be a valuable source of support following a baby's death¹³, yet the lack of partner support can actually increase the risk of negative psychological outcomes for mothers in particular¹⁷. Avelin et al¹⁸ noted that where grieving is incongruent, marital disharmony can occur. Relationships, both physical and emotional, were affected and, though many parents reported becoming closer

rather than growing apart¹⁹, a between groups analysis conducted by Shreffler, Hill, and Cacciatore²⁰ found the risk of marital dissolution following stillbirth and older child deaths increased, while it did not increase following miscarriage.

Families and stillbirth

It is important for both mothers and fathers that siblings of the baby who died are included in farewell rituals should they so desire, and that their feelings of grief, even when expressed differently from adults, are respected²¹. Later, as the family struggles to adjust the loss, grieving siblings may have to cope with their own emotions as their parents find some equilibrium²², and parents may become anxious, fearful, overprotective²³. DeFrain²³ records the stories of Joseph and his younger sister, Mary, both adults recalling the death of his sister to stillbirth 26 years earlier. Joseph says: “I remember picking up on the emotions from people around us... we couldn’t play, laugh, or run around... I remember the feeling” (p.143). Mary, who was aged five at the time also recalls:

They told me that if I was good they would bring my little sister to the house so I could see her. I tried to be good but I only got to see her for a little while, then they took her away to the cemetery. I thought I’d get to keep my little sister. I cried at the cemetery... I was scared (p. 143).

Notwithstanding existing research on parenting a subsequent child, more recent research has focused on the wider family’s needs following a stillbirth. In Sweden, Avelin et al.²⁴ ran five focus groups with parents who already had at least one child at the time of the loss and found that they actively sought advice from healthcare professionals about how to support siblings. In the absence of such advice, Avelin et al.²¹ surveyed 411 parents (350 mothers and

61 fathers bereaved between 1961 and 2010). These parents suggested that there was a need to make the stillborn baby real to siblings, to include siblings in farewell rituals such as touching, holding and meeting their brother or sister (with careful and age-appropriate preparation) as well as allowing them to participate in the funeral.

In a further piece of research by Avelin et al²⁵, adolescents who experience the stillbirth of a half-sibling experience feelings of sadness and despair, injustice, helplessness, aggression and anxiety, much like their parents; because balancing grief for a child who died with caring for living children is often difficult, adolescents in the study noted that their parents were temporarily unavailable to them²⁵. Siblings, then, mourn both the baby and the loss of their previous relationship with their parents. No wonder then that Cacciatore¹³ found women questioned their competence over parenting their living children though those existing children can also be found as a valuable way to help parents endure in the aftermath of such loss²⁶.

To see or not to see

Up until the 1970s, mothers were not allowed to see or hold a baby who died. However, some professionals, both medical and psychological, began to assert that this practice invalidated the experience for grieving mothers and gave them a sense of unreality²⁷. Standards began to change in the 1980s with the emergence of parental grass root support groups demanding access to the child²⁸. However, in 2002, Hughes *et al.*²⁹, published a study of 65 women who experienced stillbirth which they assert demonstrated that post-mortem contact with the baby could increase the risk of PTSD. Moreover, the more enduring the contact, the team suggested, the greater the risk of mental health problems at a later stage⁶. Cacciatore, Radestad and Froen³⁰, though,

have suggested that the risk of mental health problems is more nuanced. Their research with more than 2000 mothers suggested that contact with the baby was associated with lower risks of depressive and anxious symptoms but that in a subsequent pregnancy this effect is temporarily reversed. Radestad et al.'s³¹ study of the long-term outcomes of 309 women found beneficial effects for women who had held their baby when he or she was born after 37 weeks gestation. However, in the case of earlier losses, the benefits were more ambiguous. Indeed, the same study found that where the mother had not had as long as she wanted with the baby there was a sevenfold risk of depressive symptoms³². While in some countries it is recommended that parents are given a choice to see the baby, Erlandsson et al.³³ have posited that it is better to “assumptively offer the baby, rather than asking” (p.248). In this way, the experience is normalised, and, as they point out, asking any mother if she wants to see her baby is an ‘unnatural question’.

In addition, the way the baby is offered to the mother, the degree of compassionate psychosocial care by staff, and historic variables related to the mother and her family seem to influence maternal outcomes. For example, a mother’s social situation, attachment style, and social support have also been attributed to contribute to PTSD³⁴. Cacciatore³⁵ found that attending support groups may minimise the risk of clinical levels of posttraumatic stress.

Interestingly, even in cases wherein data demonstrate negative mental health outcomes for mothers who chose to hold the baby who died, the overwhelming majority of these mothers did not regret their decision to do so. Some scholars, thus, question the impetus for such ongoing research from a feminist perspective. Specifically, when mothers choose to hold their newborns after they’ve died, researchers and providers who challenge this choice, through data collection or in hospital care³⁶, are enacting a

paternalistic, non-egalitarian approach inconsistent with compassionate caregiving. Such studies are not conducted in parents whose older children die in the hospital and whose parents choose to say farewell.

Moreover, the question of what causes emotional and mental health problems is open to dispute. Rather than contact with the baby per se, Trulsson and Radestad³⁷ have suggested that the trauma identified by the London team might be due to the mismanagement of the care of parents during the time between the diagnosis of the death and the birth. Some parents report that staff lacked compassion and they did not experience the person-centered care they so needed during their traumatic losses^{2 38}. Policies around medical care may also influence outcomes. The risk to long-term psychological well-being increased the longer the baby remained in the womb before birth. Trulsson and Radestad³⁷ suggested that continuing to carry a dead baby was a trauma in itself or, at the very least that "...longer duration [between diagnosis of death and birth] increases the probability that events evoking a psychological trauma occur"³⁷ (p. 193). While research in this area goes on, it is interesting to note that a systematic review of studies in this area found that 21 out of 23 studies reported positive outcomes for parents who had seen or held their baby with the role that healthcare practitioners as being key³⁹.

Interventions and Supportive Caregiving

There is a dearth of intervention research and evidence based practice in the area of perinatal death and traumatic grief, in general. For example, a Cochrane Review by Koopmans et al. in 2013⁴⁰ found no clinical trials which assessed different types of bereavement support for families while Horey et al⁴¹ in the same year failed to find any studies around interventions for

supporting parents' decisions about autopsy. Recommendations for care re generally focused on the provision of counselling and ensuring that parental grief is acknowledged through a validation of the baby's identity. However, a systematic review by Ellis et al.⁴² has garnered parental and caregivers experiences of stillbirth in order to find ways care can be provided as well as identify future research areas. Their main findings were that parents were often dissatisfied with the ways in which the diagnosis was relayed to them, not feeling involved enough with decision-making and not having enough time to come to terms with the loss. They argue that

It was clear that staff actions and attitudes have a huge influence on parents' decision making and ability to cope with the events. There is evidence that empathy and caring staff positively influence parents memories of their child (online).

More targeted research in this area has discovered that women in India found mindfulness-based interventions such as yoga interventions might be helpful, although they did find these difficult to deliver⁴³. Similarly, Huberty et al⁴⁴ found positive coping effects of physical activity following a baby's death.

In a qualitative study, Tseng et al.⁴⁵ charted the grieving process for 21 women. The three stages of "*a pathway to peace of mind*" were 1) silent grief, 2) searching for a way out (meaning-making), and 3) achieving peace of mind. While spiritually-based coping scripts may be helpful for society, broadly speaking, these specific interventions are regionally specific and will not meet the needs of grieving mothers across cultures⁴⁶.

Parenting the next child

The subsequent pregnancy has also been of considerable interest to

researchers. Hutti et al.⁴⁷ found that mothers experienced high levels of depressive symptoms during the pregnancy that follows perinatal death. Turton et al.⁴⁸ interviewed 38 pregnant couples who previously experienced the death of a baby and found that fathers had significant levels of anxiety and PTSD antenatally that diminished postnatally, and at all points their symptom levels were lower than those of the mothers. With regard to fathers specifically, O'Leary and Thorwick⁴⁹ found that the 10 fathers in their research felt overlooked during the pregnancy subsequent to loss. They were 'exhausted emotionally' and frequently inquired if their pregnant partners were still feeling movements. Their perceived "...role of protector was intensified although they were aware that they had no control of the outcome" (p. 81), and while they had to stay strong on the outside, inside they felt stressed and vulnerable. Surkan et al³² have aimed to evaluate the impact stillbirth has on mental health and whether actions that aimed to increase bonding with the baby also had an effect. Importantly they found that not being with the baby as long as the mother wished increased the risk of depression. However the most important factor that influenced depressive symptoms in this study was not having a live-born baby in the three years following the loss. This risk increased if the baby was the third child and rose again when the stillborn baby was the fourth or fifth born in the family.

Some researchers and clinicians have also suggested that the child born after loss might be at risk of 'vulnerable child syndrome' or 'replacement child', smothered by the over-attachment of an protective and fearful *mother*. Turton et al.⁵⁰ found that children (aged 6-8) born to a mother who experienced the loss of a baby to stillbirth had higher scores on the mother's *perception* of the child's overall difficulties and peer problems. These findings are frequently cited to argue in support of the 'vulnerable child' and 'replacement child'

constructs. However, Davis et al.⁵¹ argue that these are normal maternal reactions. Indeed, Theut *et al.*⁵² found no differentiated attitudes between bereaved parents and those who had not been bereaved, and Phipps (1985-86)⁵³ has denied the pathological existence of 'vulnerable child syndrome' among bereaved parents. There is a notable absence on the role of fathers in this literature.

The social impact

Reports on the social impact and the support (or lack of) that parents receive after loss is mixed, and cultural norms and attitudes play a role in diminishing the perceived value of a stillborn baby in society⁵⁴. Certainly, both exogenous and endogenous factors seem to influence outcomes: The presence of strong social support is a protective factor against negative long term outcomes for parents and so is individual resilience³⁴. Across the board, and perhaps unsurprisingly, poor-quality intimate relationships seem to result in higher levels of both anxiety and depression³⁴. This is possibly partially due to the fact that stillbirth is a loss that is fraught with ambiguity. Researchers have been keen to point out that parents will question how many children they have and, for the first-time parent, there is also the doubt about whether they are a mother or a father at all⁵⁵. Cacciatore et al⁵⁶ found the same ambiguity among siblings of the baby who died. The death of a baby gives rise to existential questions such as 'why did my baby die?', 'am I being punished?' or even give rise to crises of faith⁵⁶. For some women, there may be a perceived failure and this can result in an ambiguous relationship with their own bodies.

While families and relationships can (although not always) be valuable sources of support, wider social networks can be problematic particularly as often stillbirth is a loss often unacknowledged and invalidated by society¹³.

Friendship circles may change as parents feel as if they no longer fit in with other families⁵⁶. Then there is the nagging suspicion mothers may have that others may blame them for the loss of the baby. Given the myriad of advice given to mothers in pregnancy, for example, refraining from drugs, alcohol and cigarettes, bereaved mothers in Murphy's¹¹ article were keen to emphasize that they had behaved well in the pregnancy which resulted in their stillbirth. As one mother reported,

But there *has* to be a reason. There doesn't have to be; but most people think there's *got* to be a reason for things to happen. So I wonder if people look at me and think "Well, why did her baby die? What happened?" If I'd see them out, if I had a drink in one hand and a fag in the other I'd say "I didn't drink or smoke when I were pregnant you know".... I wanted them to *know*. I didn't want them to think "God, she was like this when she were pregnant" (p. 478).

This disassociation from stigmatizing behaviours aimed to stop people thinking they were somehow at fault for the stillbirth. In this way they are able to maintain the identity of a 'good mother'.

For mothers, support groups can be a valuable way of finding people who understand and will help. Cacciatore³⁵ found that women who attended support groups experienced fewer symptoms of post-traumatic stress. Indeed, qualitative data suggests that when existing relationships were fractured following bereavement, the establishment of new relationships was important for women²⁶. The advent of the internet has also been a way bereaved mothers can access support as well as fathers and grandparents too⁵⁷. The sense of being able to assist others and receive help is helpful for grieving mothers. The experience of a baby's death undoubtedly changes parents. But, as Murphy⁵⁸ has pointed out, activity such as helping newly bereaved parents is

one way of being able to make meaning from loss. The findings from her research also identified that becoming involved in grass-roots activity such as fundraising or raising awareness of stillbirth with healthcare professionals was one way in which mothers could use their bereavement to empower themselves.

Global Research

Traditionally stillbirths in low income countries have remained hidden. Mostly they have happened at home with little acknowledgement of the loss due to the stigma that is associated with them due to links with induced abortion and/or infertility⁵⁹. Having said this, over the past few years the scope of research into stillbirth has widened to include developing countries. Kuti and Ilesanmi⁶⁰ investigated Nigerian mothers' experiences in hospital and found that none of the 45 mothers in their study were offered the choice to hold, touch, take pictures or name the baby even though they wanted more contact. Sources of support were their spouse, the family, and their church. Problematic for them was that although they experienced significant grief, local practices demanded that, as the mother had not died, the baby should not be mourned. Similar taboos against mourning were found by Sisay et al.⁶¹ in Ethiopia. They ran focus groups to elicit the attitudes and values of grandmothers, mothers and unmarried girls in two areas: Amhara and Oromiya. Here they found that until the 40th day of life, neonates remain strangers to the community (not human), and mourning the death is not culturally acceptable. While Amhara women had to suppress their feelings, the Oromiya women mourned the babies in the face of social pressure not to mourn. This was a deliberately rebellious political act – to inform policy-makers of the problem and therefore help save babies lives.

There is a growing body of literature emerging from Taiwan and Tseng et al.'s⁴² 'pathway to a peaceful mind' has already been referred to in this article. Sun et al.⁶², too, were interested in practices around seeing the baby and, in particular, why parents made their decision. Interviews with 12 couples found that those parents who decided to see the baby did so because it helped them come to terms with the death as well as validate the baby. Those who did not see their child felt they wanted to sever their relationship with the child, they did not want to remember a (possibly) abnormal baby, and they wanted to follow their cultural traditions.

Economic Impact

In contrast to psychological and social research around stillbirth, there is a dearth of research on the economic impacts. What has been produced has often focused on child death rather than on merely stillbirth or perinatal bereavement. Such work, however, does give an indication of the impact that it will have on parents beyond the unexpected funeral expenses that will be incurred. Fox, Cacciatore, & Lacasse³ found a conservative annual burden of child death to be \$1.6 billion in the U.S. alone, while Malacrida⁴ (1999) noted that the lack of recognition given to perinatal death leads to mental, emotional, and social health risks that eventuate to societal burden. Bereaved parents often return to work out of financial need rather than legitimate readiness to re-join the workforce³. As such there is the economic cost of "presenteeism" (that is, time at work which is unproductive) which is even more significant to the economy than "absenteeism". While these data focused on the 6 months following loss, other researchers have indicated that there maybe longer term costs to parents in terms of lower wages over the life course⁶³. There is also the cost of health services when a baby dies. The

healthcare costs associated with caring for a stillborn child are reported to be greater than that of a live birth by 10-70%. In other words, significant costs associated with a baby's death endure into future pregnancies and beyond⁶⁴.

Where next?

At the beginning of this review article, we asked the question what is left to be uncovered. Certainly there is further scope for work on the economic impact of stillbirth, particularly what drives the possible long-term economic effect on parental employment status. For example, is reduced income after stillbirth reflective of a change in priorities for parents or is it a cost borne out of an extended break in employment³? Literature is beginning to emerge around same sex-couples suggesting that grief for lesbians who experience the death of a baby is exacerbated by the additional investment of resources required into conceiving as well as experience of systemic heterosexism^{65 66}. Cacciatore & Raffo⁶⁶ call this a 'double-disenfranchised' loss for lesbian couples. There is certainly scope for more investigation here as well as a better understanding of the impact stillbirth would have for male same-sex couples and the surrogate who carries the child.

Much of the research considered above concentrates on the experience of white, middle-class families. It would be helpful to know more about how it is experienced by women and men drawn from minority-ethnic groups as well as those from drawn from lower socio-economic groups.

As noted earlier, the debate continues over the impact of contact with the stillborn baby, and a more nuanced understanding of what causes anxious, depressive or traumatic stress symptoms rather than a straightforward reductionist explanation²⁹ would be useful. More research is necessary on

siblings in the family, those who were born before, and after, the baby's death. Studies that focus on parents' relationships and what support might aid them in continuing to parent their other children, including the responsibility of their communities, would be sociologically useful. Finally, rather than focusing on interventions to abate the symptoms related with grief, researchers might consider exploring interventions that improve affect tolerance and coping skills after the death of a baby. When considering the social support that parents receive (or lack thereof) following stillbirth, it would be also be helpful to have more insight into the attitudes that feed into people's beliefs and behaviours around interacting with bereaved parents. As Layne⁶⁷ and Cecil⁶⁸ have noted, there is an absence of 'cultural scripts' around the loss of a baby – if the population, including health care professionals, were better informed about the best ways to support bereaved parents, then the wellbeing of parents can only be improved.

Practice points

- Practitioners should be aware that parents should be offered the chance to see their baby but that this needs to be handled with care
- Parents need to have their loss validated so healthcare practitioners need to understand the enormity of the loss
- Practitioners should also pay attention to the entire family system
- Parents need additional support in subsequent pregnancy which is more costly to provide

Research directions

- A more nuanced understanding of the impact of seeing and holding the baby
- The economic impact of stillbirth for families

- The experience of same-sex couples and, where relevant, the surrogates
- Sibling experiences
- The experience of parents drawn from black and minority ethnic groups

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