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The psychological, social, and economic impact of stillbirth on families

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A B S T R A C T

This article reviews the current state of psychological, social, and economic research into the impact of stillbirth on families. We argue that whereas the knowledge we have of the experiential aspects of stillbirth is increasing, there is still much that remains to be uncovered especially in respect of the impact that seeing the baby may have on mental health. Moreover, the experience of particular social groups merits further work, most notably regarding same-sex couples and surrogates, mothers and fathers drawn from Black and Minority Ethnic groups as well as those from lower socio-economic groups. Particular attention needs to be paid to the economic impact of stillbirth on families, whether this is from a perspective that focuses on the family or the wider society in which they live.

1. 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 grief [1]. Other studies, though fewer, have explored the economic cost to stillbirth, one that includes a person's potential lifetime contribution to the economy [2]. Fox et al. [3], for example, found a conservative annual burden of child death to be US$1.6 billion in the USA alone, whereas Malacrida [4] 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 refers 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. Wright [5] 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 post-traumatic stress disorder (PTSD) at St George's Hospital, London, for example, defined stillbirth as a loss after 18 weeks of gestation [6] rather than using the UK's classification of stillbirth as a loss after 24 weeks.

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

2. Psychological impacts

2.1. 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

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exists a Perinatal Grief Scale to measure the unique emotional experiences of a baby's death [7]. In acute grief, mothers and fathers both report similar emotions [8] as parents struggle "with feelings of guilt and blame, regret, fear and grief" [9] as well as shame [10], stigma [11,12], and a sense of wanting to die [13]. 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 greater [14]. 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 US couples following the birth or a subsequent live child, Armstrong et al. [15], found that fathers were less at risk of depressive symptoms than mothers [16]. 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 whereas depressive, anxious, and post-traumatic stress symptoms decreased over time.

2.2. Stillbirth and the couple

A further focus of previous research has been the experience of couples and the potential for problematic relationships following the baby's death. Spouses can be a valuable source of support following a baby's death [13], yet the lack of partner support can actually increase the risk of negative psychological outcomes for mothers [17]. Avelin et al. [18] 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 apart [19], a between-groups analysis conducted by Shreffler et al. [20] found the risk of marital dissolution following stillbirth and older child deaths increased, whereas it did not increase following miscarriage.

2.3. 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 respected [21]. Later, as the family struggles to adjust to the loss, grieving siblings may have to cope with their own emotions as their parents find some equilibrium [22], and parents may become anxious, fearful, overprotective [23]. DeFrain [23] 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 years 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 al. [25], 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 them [25]. Siblings, then, mourn both the baby and the loss of their previous relationship with their parents. No wonder then that Cacciatore [13] found that 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 loss [26].

2.4. To see or not to see

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 unreality [27]. Standards began to change in the 1980s with the emergence of parental grassroot support groups demanding access to the child [28]. 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 stage [6]. Cacciatore et al. [30], however, 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.'s [31] 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 of 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 symptoms [32]. Whereas 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 normalized, 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 thought to contribute to PTSD [34]. Cacciatore [35] found that attending support groups may minimize the risk of clinical levels of post-traumatic 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 have died, researchers and providers who challenge this choice, through data collection or in hospital care [36], are enacting a paternalistic, non-

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