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Women's lived experience of embodied disenfranchised grief: Loss, betrayal and the double jeopardy.

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Title

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Abstract

The experience of disenfranchised grief has many twists and turns. This is particularly the case in situations that have external cause for celebration, but, in fact, contain internal loss, embodied betrayal and double jeopardy. Focussing on a significant embodied experience, that of pregnancy after a previous pregnancy loss, we suggest that the lived experience can be vastly different from the normative experiences of joy, celebration and 'moving on'. Drawing on existing literature, we find the lived experience of a subsequent pregnancy, instead reignites anxiety, guilt, grief and loss; a profound sense of betrayal by one's body; and the liminality of the double jeopardy. Women maintain an inexpressible continuing bond to the lost baby amidst struggling with the paradox of a new pregnancy. The past seems to contradict the present, and even cloud the future. To understand such complexity, we then theorise these experiences from the Heideggerian perspectives of Being-toward-death; Angst and unheimlichkeit; and the authenticity of lived experience. We propose that phenomenological ways of seeing the world, can enrich our understanding of disenfranchised grief.

Key Words

Pregnancy loss, disenfranchised grief, phenomenology, lived experience

Introduction

The experience of disenfranchised grief has many twists and turns. In this article, we explore the lived experiences of pregnancy after a previous pregnancy loss, to discover the ways women outwardly hold the paradox of a seemingly celebratory life event, amidst still grieving the previous loss. We suggest that there are many psychosocial factors that contribute to the lived experience of disenfranchised grief, and that collectively as a society we run the risk of perpetuating the silences surrounding these events, thus unwittingly becoming co-conspirators together.

To explore these issues further, we offer a brief explanation of why phenomenology is an appropriate methodology to explore these phenomena. We then provide an overview of the existing literature, focusing on pregnancy after a previous pregnancy loss. Drawing on predominately qualitative evidence, we highlight the women's experiences as they navigate life after their loss. We discuss how family, friends, colleagues and health professionals all play a part in the experience of disenfranchised grief, unknowingly contributing to the anxiety, guilt, grief and loss that is reignited by the new pregnancy. Finally, we examine this significant life experience from the Heideggerian perspectives of Being-toward-death; Angst and unheimlichkeit; and the authenticity of lived experience, positing that phenomenology can help us to understand the complexity of the issues raised, and enrich our understanding of disenfranchised grief.

Phenomenology and pregnancy after a previous pregnancy loss

As a method for examining subjective human experience as it is lived, phenomenology was the obvious choice for us to use to explore these phenomena. Being able to describe and interpret women's first-hand accounts of what it was like to have lost a baby, and then experience the paradox of emotion and experiences that a new pregnancy brings brought into sharp focus the challenges, often unnoticed, that these women face daily. Within phenomenology there are different views and emphasis placed on how phenomena are portrayed. For Husserl (1952/1989) this was a description of the phenomena as it was experienced and perceived. For Heidegger (1962/2001), the emphasis was on the meaning that was made of the phenomena being studied. Thus, phenomenology enabled us to describe women's perceptions and experiences, as well as the meaning they made of them. Heideggerian phenomenology (also known as hermeneutic phenomenology) was chosen because the approach not only incorporates the perspective of the individual (their lived experience of the phenomena), but also the significance of the socio-cultural context on how those experiences are interpreted. Furthermore, this approach acknowledges that the researcher's pre-understandings of the phenomena cannot be successfully separated out from the research process. As such, our own values, past experiences, role, culture, vested interest will shape the way we experience and understand the world. We both acknowledge that our interest and passion for this subject has been borne out of our own experiences of disenfranchised grief and differing types of loss. Meaningful reflexivity on these pre-understandings allowed us to use them positively throughout the research process instead of denying or minimising their existence (Smythe, 2011).

"The emotional rollercoaster"

In the United Kingdom, it is reported that up to one in four known pregnancies end in miscarriage (Tommy's, 2017), and that about 15 babies die every day because of stillbirth (death after 24 weeks' gestation) or neonatal death (Manktelow, et al, 2015). The majority of these women will conceive again, with as many as 50% becoming pregnant within a year of their loss (Mills, Ricklesford, Heazell,

Whitworth, & Lavender, 2016). Although not an absolute, many women embarking on another pregnancy, following a previous pregnancy loss, experience overwhelming anxiety and mental anguish. These feelings are heightened at significant milestones in the current pregnancy, for example, in the days and weeks leading up to the gestation of the previous loss, the anniversary of the loss and during labour and the early postnatal period. Still grieving when a further pregnancy is embarked upon, women describe “the experience of another pregnancy as being like an emotional rollercoaster that they cannot get off” (Hunter, Schott, Henley, & Kohner, 2016, p.372).

A common theme in the literature is the way women try to keep their emotional hopes and fears in check in the current pregnancy, and the exhaustion that accompanies this (Andersson, Nilsson, & Adolfsson, 2012). Some may deny the existence of the current pregnancy, or delay announcing the pregnancy to family and friends until the perceived danger time has passed (Ockhuijsen, Boivin, van den Hoogen, & Macklon, 2013). For others, the unanticipated grief that resurfaces in the current pregnancy can interfere with attachment to the unborn baby, bringing with it an emotional distancing from foetus/baby and a life-long impact on the subsequent child (Meredith, Wilson, Branjerdporn, Strong, & Desha, 2017; O’Leary, Warland, & Parker, 2012; Bowlby, 1989). The loss of the previous baby signifies a loss of innocence. The naivety upon which the previous pregnancy was embarked is gone, with the parents now knowing that there is never a guarantee of a healthy baby. Furthermore, a loss of trust occurs in their body’s ability to nurture and maintain a successful pregnancy, with the resultant fear of a recurrence of further pregnancy loss (Meredith, et al, 2017; Meaney, Everard, Gallagher, & O’Donoghue, 2016).

For those who experienced a previous miscarriage, there may have been few outward physical markers to indicate that a loss had occurred, especially if it was a first trimester miscarriage (Hunter, et al, 2016; Gergett & Gillen, 2014). For these women, grief can become exacerbated by feelings of isolation, and a lack of acknowledgement of the loss. In the UK, it is fairly common practice to delay announcing the pregnancy to family and friends until after the first ultrasound scan (normally at about 12 weeks). The dilemma then, is whether to speak of the pregnancy and miscarriage, or remain silent and grieve alone. For those choosing the former, they risk encountering the “emotional suppression, the unacceptability of grief for the loss” (Peel & Cain, 2012, p.87); for those choosing the latter, they unintentionally contribute to that suppression. With a miscarriage, there is little opportunity for the outward expression of grief such as may be afforded to those who have had a stillbirth or neonatal death. There is no outward ritual of a funeral, or memories recorded through photographs or footprints, which have been shown to have a beneficial effect on the grieving process (Layne, 2012; Woodthorpe, 2012; Bremborg, 2012; Earle, Foley, Komaromy, & Lloyd, 2008). The culmination of these factors, when combined with the confirmation of a further pregnancy, can heighten feelings of anxiety and uncertainty. As one researcher noted, of her own pregnancy loss:

The trajectory of the ‘baby’s’ existence did not end with its predicted birth date. On the day the pregnancy calendars gave for its birth, I found I was pregnant with my now eight-year-old son. The anxiety attached to the miscarried foetus fastened itself firmly upon its successor (Peel & Cain, 2012, p.83).

Heidegger’s concept of being authentic/inauthentic is relevant here. In relation to death, he suggests that authentic Dasein embraces death, or being-towards-death as part of our mortality, thus opening up the possibility of accepting our finite existence to the full, whilst being inauthentic denies us this opportunity as we dismiss death as irrelevant to our present situation (Carel, 2016). For the women represented in the discussion above, this explanation would suggest that they were being inauthentic by not acknowledging the enormity of their loss. Yet this appears harsh in the reality of their loss. Birth and death rarely sit comfortably in the same space. Carel (2016) argues that authenticity and inauthenticity are necessary and equal components of our existence and are mutually dependent. The

scope of this discussion is outside the remit of this article, but we suggest seeing Dreyfus (1991), Carmen (2000) and Carel (2016) for insight into the wider debate.

“As if she/he never existed”

For many, the announcement of a pregnancy is a celebration, of womanhood, of masculinity and a rite of passage to parenthood. Murphy (2012) suggests that parenthood can be separated into two integral parts – the biological and the social. Biological parenthood refers to a genetic connection to the child. Social parenthood refers to the transition to the role of parents within society, and the growing recognition of this transition within their social and cultural context (Winson, 2017). The announcement, which often coincides with the first ultrasound scan, marks the shift from private to public arena, with friends, family, and even strangers all offering opinion, advice and judgement on the prospective parents and growing foetus. This can be anything from opinions on lifestyle choices to advice on how best to prepare for the expected arrival. These factors, along with the assignment of personhood, and the visualisation of the unborn child all contribute to the growing social connection of the child within society (Martel, 2014; Meaney, et al, 2016).

This connection is severed with a pregnancy loss. What has previously been a celebratory event now becomes a situation full of grief, awkwardness, silences and dismissal. For the parents, the loss of a child represents loss of a planned future; of their identity as parents; of control (Campbell-Jackson, Bezance, & Horsch, 2014; Ockhuijsen, et al, 2013). There is no social role for the parents to play when a baby is born dead. The personhood attached to the unborn child is conditional and is withdrawn if the baby is not born alive (Martel, 2014). Being thrown into a world over which we have no control or choice is a key theme in Heideggerian phenomenology (Heidegger, 1962/2001). For the parents experiencing pregnancy loss, this “*throwness*” is a situation that requires a response (Harman, 2007) often in the form of *angst*. The security of their everyday existence has been shattered. The anxiety that follows can be described as “*meaningless confusion..... that involves a deep crisis of meaning*” (Polt, 1999, p.77).

Following a pregnancy loss, women reported overwhelming feelings of isolation and exclusion. They spoke of a lack of social validation for the enormity of their loss, with the expectation that time allowed for grieving was finite before they were expected to “move on” with their lives. Feelings of isolation were exacerbated by a wall of silence, fuelling the experience of disenfranchised grief. Family and friends felt uncomfortable talking about the loss or seeing any of the mementoes (photo’s, hand/footprints), whilst women avoided talking about the loss in public in an attempt to protect them. Thus, what was public now reverts to the private arena. Tension can ensue, the “elephant in the room” that everyone can see but no-one acknowledges (Mills, et al, 2016; Campbell-Jackson, et al, 2014; Meredith, et al, 2017; Heazell, et al, 2016). For women whose losses may not be acknowledged by society (for example, ectopic pregnancy and non-medical elective termination of pregnancy) these silences may be especially difficult to cope with. The significance of the loss in these circumstances is often missed, with the focus on the potentially life-threatening situation the woman has just been through (and not the pregnancy that has been lost), or the perceived “choice” that the woman made to voluntarily end her pregnancy (Daugirdaite, van den Akker, & Purewal, 2015; Gergett & Gillen, 2014). Left with little choice, many women will become what Heidegger (1962/2001) calls “*resolute*”. For him, the concept of resoluteness points to grappling to come to grips with our own being-in-the-world. Often circumstance (such as pregnancy loss) can bring us to this place, where everything pales into insignificance compared with what is “*truly essential in our being-in-the-world*” (Harman, 2007, p.74). Haidt (2006) notes that people often underestimate their ability to cope with adverse life events, and that personal growth can often occur as a result of a period of great difficulty. It would be naïve, however to suggest that this is the case for everyone, with many suffering permanent effects with lifelong implications (see Carel, (2016, pp.140 - 147) for a more detailed discussion). For women who

have experienced pregnancy loss, we would suggest that it is *resoluteness* that gives them the strength to consider another pregnancy.

When another pregnancy is embarked upon, it's as if society heaves a collective sigh of relief. Outwardly it appears that the woman is moving on and has come to terms with her previous loss. The reality is often very different. The new pregnancy is embarked upon in the shadow of the previous loss. Grief is reignited, along with fear, guilt, dread, and feelings of disloyalty to the previous baby (Hunter, et al, 2016; Mills, et al, 2014; Earle, et al, 2008). Alongside this, there is the assumption that the new pregnancy in some way replaces the lost one, with the expectation that the focus will shift to the new pregnancy, the old one being forgotten. For some women, this assumption was difficult to reconcile with their experience.

People assumed that it would make it all better because you we're pregnant again. Oh, we can forget about (first child) now, you know. That's in the past, you're having another baby, isn't that nice, let's focus on that. And I felt that was really difficult. Because it was almost like (first child) was forgotten and everyone's focus was on this new baby (Campbell-Jackson, et al, 2014, p.5).

“Not just a normal mum”

The lack of acknowledgement of the previous pregnancy was not just confined to the woman's social circle. Many women highlighted their dissatisfaction and frustration with the maternity care they received. Women felt that to be treated as any other mum denied the impact that the previous loss had on them, and argued that their care should be individualised to reflect this (Meredith, et al, 2017). Mills et al's study (2016) identified allocation of care professionals, parent education and birth preparation as lacking in providing appropriate support and content to support women's needs. Often, perceived well-meaning allocations resulted in additional unwanted anxiety for the women involved.

I hated having the same consultant and it never crossed my mind to ask for someone else. I'm sure it was felt consistency would be a good thing, but I was unhappy with the care I received from that consultant when my son died. (Mills, et al, 2016, p.7).

For others though, being allocated the same professional was seen as a blessing, with trusting and supportive relationships enabling them to take an active role in planning their care. Women were thankful when offered extra maternity appointments, although often these only brought brief respite. For some, these extra appointments offered little comfort but instead provoked further distress. Women regularly reported having to re-tell their story to multiple professionals at each consultation because their medical notes hadn't been reviewed prior to the meeting (Mills, et al, 2016).

The medicalisation of childbirth over the last century has undoubtedly brought many benefits, with the birthing process being deemed much safer than it was even 50 years ago. However, there has been debate over just how safe medicalisation has made childbirth, with some critics pointing to evidence suggesting that childbirth is safer with the least amount of intervention (Tew, 1998; McIntosh, 2012). What has become apparent, since the medicalisation of birth, is that the language of risk management now permeates the childbirth arena. Pregnant women are categorised as “high” or “low” risk, with the outcome of their pregnancies being deemed as “success” or “failure”. These medical discourses (perhaps unintentionally) all contribute to feelings of guilt, shame and self-blame for women. Shame because they “failed” to produce a healthy child, guilt and self-blame because they feel responsible. They feel that their actions (or failure to act) in some way contributed to the loss (Einion, 2017). Pregnancies (and therefore women) are “managed” by the health professionals, with the focus often being on the clinical aspects of care at the expense of neglecting the psychological/emotional aspects. This can have a devastating impact on all women, but especially those who embark on a pregnancy after a previous pregnancy loss.

In summary, a first trimester miscarriage can be just as distressing as a later pregnancy loss or stillbirth (Ockhuijsen, et al, 2013; Daugirdaite, et al, 2015). For some women who have experienced a

miscarriage, guilt can be the all-encompassing emotion. They don't feel they have the "right" to grieve, that their loss somehow doesn't entitle them to this experience. After all, it's "only a miscarriage". This dismissal of grief can be perpetuated by the attitudes of family, friends and health care professionals. Thus, a miscarriage may not be afforded the same level of social or medical recognition as a stillbirth or neonatal death.

It's easy to be a bit, slightly more flippant with a very early pregnancy loss and you can be guilty of using 'oh it was just a miscarriage'. When it's stillborn, for me personally, it's a whole different level of grief (Gergett & Gillen, 2014, p. 30).

Toward a phenomenology of pregnancy loss

To understand women's lived experience of disenfranchised grief and pregnancy loss, we now turn to phenomenological ways of seeing the world, and Heideggerian theory in particular. We suggest these ways of knowing can assist us-as professionals, and family and friends- to more deeply empathise and find new ways to 'be with' grieving mothers. Furthermore, the Heideggerian concept of Being-with (Heidegger, 1962/2001) extends the concept of ethical care (Pascal & Endacott, 2010).

The previous pregnancy loss is where feelings of bodily doubt and betrayal; loss of continuity and parental identity; loss of transparency (innocence) (Carel, 2016) may be experienced for the first time. However, if there have been multiple miscarriages or still births, these feelings of bodily betrayal and accompanying loss and grief, will be deeply entangled with the subsequent pregnancy. Betrayal, loss, stigma, and disruption of motherly identity, shape the remembering of the past, and the reimagining of future, babies. The rollercoaster emotions of joy and hope, sit alongside loss and fear as temporal experience (Heidegger, 1962/2001). The previous pregnancy loss thus represents a critical juncture, with long-term and pervasive consequences.

The subsequent pregnancy, although in the present, is in light of such temporality and its accompanying meanings. There is also, now, an opportunity for a re-embodied identity as "mother", to reclaim this experience. And yet, the mother is also 'not a mother' to the lost baby, or at least this aspect of motherhood becomes further disenfranchised in light of the present pregnancy; the first baby is denied. In fact, the intercorporeality (Johnson & Pascal, 2016) and intersubjectivity (Heidegger, 1962/2001) of mother and lost baby is not articulated, sometimes not even by the mother herself (who may experience confusion and guilt at her lack of complete joy).

This baby is not that (lost) baby. That baby will never be touched, smile, crawl, cry, or be held. And yet this baby lies in the same embodied space as that baby, a cause for celebration and renewal, and yet also triggering angst and deepening feelings of disembodied *unheimlichkeit* and grief. Paradoxically, this baby is *Heimlich* (Heidegger, 1962/2001), and literally at home in the mother's body.

This ambiguity (Carel, 2016) represents felt, embodied bonds (Slatman, 2014) to both babies. The disentanglement, much wished for by family, friends and health professionals (that is, moving on) is unlikely; more likely the mother will experience extended temporal grief and ambiguity. The normative, received ideas of second chances and new beginnings are fraught.

Here we found Svanaeus (2013) concept of subjects helpful in reframing our understanding. Heidegger (1962/2001) has previously noted intersubjectivity overcomes the subject/object Cartesian dualism. Svanaeus extends these ideas in a directly applicable way to pregnancy loss; he suggests subjects (a conflation of subject and object) feel an ongoing attachment to lived bodies and identities.

Disentanglement, then, can only be partial, and we suggest the mother is carrying both the lost baby and this baby. Svanaeus re-entwines mother and baby, and de-objectifies the unspoken-about 'foetus'. Where the sanctioned social and cultural understandings of the body as 'parts' (that is, put crudely the medicalised foetus), and the heroic narrative (Frank, 1997) serve to further disenfranchise mothers' anguish, Svanaeus and Heidegger offer ways to reunite the felt bonds.

The reframing of mother and babies as 'subjects' is deeply humane and empathic and recognises the existence of the family as interconnected. Complexity and ambiguity are acknowledged as an acceptable experience, and the new pregnancy does not have to be wholly joyous save the mother be pathologized. Nonetheless, these pregnancies are not merely individual, family or socially understood, they are also experienced within a systemic context. Within Western culture, pregnancy, and almost certainly pregnancy loss, will be experienced within a medical model of health care delivery. The role of health care professionals is that of caring and attending to the mother during her experience of pregnancy and pregnancy loss. However, as discussed above, this care is not always expressed, or experienced, as deep empathy, or within an ethic of care. Mothers are often left feeling further hurt, neglected and isolated, at least emotionally.

The mother, carrying two babies as it were, embodies both life and death. For the health professional, she may represent risk, distress and even ingratitude at the second-chance at motherhood. In Western contexts, maternity care is still largely a gendered experience, with most nurses and midwives being women. We suggest there may be some gendered inter-embodiment and transference, as well as empathy, embedded in these relationships. We further suggest that, despite the feminised experience and professional role, nonetheless, these interchanges occur within the context of a predominantly medicalised and patriarchal culture. Thus the system, within which such care is delivered, can be dehumanising for both the professional and the mother-as-patient.

Despite these considerable constraints, the medical model, even if reified, offers opportunities for humanistic care. Here phenomenology can offer insight, for health professionals to consider their own Being-toward-Death and also ways that epistemic injustice (Carel, 2016; Fricker, 2007) perpetuate suffering. We now expand on these concepts.

Being-toward-Death and Epistemic Injustice

We return to the Heideggerian concept of Being-toward-Death, which calls for a full and conscious acknowledgement of death as part of life, in fact, the essence of who we are as human beings. Rather than fleeing from death into cultural amnesia, and emotional distance, Heidegger (1962/2001) calls for a staring at the sun (Yalom, 2008). Rather than struggle with, distract from or fear death, put simply, we set about gaining mortality awareness and salience (Little, Jordens, Paul & Sayer, 2001). However, we suggest many health professionals may have their own ambiguities about death (after all, preventing death, saving lives and birthing babies is fundamental) and fears of uncertainty of treatment and prognosis.

Wishing to comfort the grieving mother, the health care professional may (unwittingly) sanction the minimising of grief and loss thereby perpetuating suffering. By counselling the grieving mother to focus on the happiness of the new pregnancy, celebrate the second chance at motherhood, the double jeopardy is replayed. The underlying (or even overt) *Angst* is pushed aside. This lack of Being-toward-Death may soothe (or not) the health professionals' worries, but, also denies the lost baby a place and heightens fears about the present pregnancy.

Additionally, a lack of Being-toward-Death can form a type of epistemic injustice, privileging the medical discourses of 'cope and hope' (Pascal & Endacott, 2010) and narratives of restitution and heroism (Frank, 1997) over the mothers embodied and lived experience of loss. Mothers' complex and chaotic narratives (Frank, 1997) of suffering may be dismissed by busy and over-worked health care professionals as "irrelevant, confused, too emotional, unhelpful, or time consuming to deal with" (Carel, 2016, p 181). Despite the NHS Patient Charter and UK's Patient Association, "patients' existential concerns, need for empathy or emotional content" (Carel, 2016, p181) may remain overlooked. Combine epistemic injustice and lack of death awareness and the distress for grieving mothers may be pushed away, leading to a profoundly inauthentic (Heidegger, 1962/2001) experience of care. These inauthentic relationships of care (and not just with health professionals) entrench *Angst* and despair.

Bodily mistrust is exacerbated, and disenfranchised grief is deepened. As Being-toward-death is not privileged as an everyday or professional discourse, a form of epistemic injustice is perpetuated.

By way of conclusion, the literature points to the profound nature of pregnancy loss, and its after effects on future pregnancy, parental and family well-being and mothers' identity. The loss is temporal, social, existential and embodied. It is also disenfranchised. As many aspects of Being-in-the-World are disrupted, or even fractured we suggest this to be an extreme experience. By embracing our own Being-toward-death, and critically rethinking epistemic injustice, we can facilitate a more humane and authentic discourse about women's lived experience of pregnancy loss. Individually, socially and professionally, we would do well to extend our understanding, and rethink our ways of "being-with", a grieving mother. Heideggerian theory, as well as phenomenology more broadly (for e.g. Carel, 2016; Svanaeus, 2013) can assist us forge a new ethic of care.

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