

# 'Treat Them with the Reverence of Archivists': Recordkeeping and Online Grief Communities

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## Abstract

The poster reports early findings of an exploratory research project studying how bereaved parents of stillborn babies participate in online grief communities, and how these communities function as a particular type of archive. Emerging concepts, including the notions of archives of aspiration, continuing social existence, and archives of feeling are introduced, extendable ideas are identified, and next steps in the research are proposed.

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## 1 Introduction

This poster reports early findings of research studying how bereaved parents participate in online grief communities. Focusing on recordkeeping and sharing, the research considers how these communities function as archives of the experience of grief and of the lives of deceased children.

## 2 Characteristics of the community

The research focuses on a particular type of online grief community: those formed by parents of stillborn babies. Definitions of stillbirth vary, but typically denote the death of a fetus past 20 weeks gestation, in utero or during labor. In Canada, 7 in 1000 pregnancies end in stillbirth (Joseph et al., 2013), a small but significant number of losses, which, since stillbirth remains a mostly taboo subject, are often suffered privately by parents who feel isolated and misunderstood (Lang et al., 2011; McCreight, 2004; Weaver-Hightower, 2012).

### 2.1 Disenfranchised grief

Studies confirm that “compared to other types of mourning... the loss of a child is associated with a grief experience that is particularly severe, long-lasting, and complicated” (Lang et al., 2011, p.184; Arnold and Gemma, 2008). However, stillbirth has been treated as a less traumatic and prolonged type of grief. Parents report feelings of disenfranchisement resulting from the “juxtaposition of personal feelings of extreme grief with society’s dismissal of such a short-lived or even ‘unborn’ life” (Lang et al., 2011, p. 184; see also Cacciatore et al., 2008).

### 2.2 Role of record keeping and the creation of archives

One response to feelings of disenfranchisement is to make efforts to “assert the realness” of the stillborn baby. Layne (2000) explores how parents rely on their baby’s “things” – clothes, gifts bought for their babies, memorial jewelry, etc. – to “make the claim that a ‘real’ child existed and is worthy of memory” (p. 324). Similarly, Godel (2007) examines how parents use images to “integrate the stillborn [baby] into the family” (p. 258). Hospitals typically provide memory boxes containing things like the baby’s hospital ID bracelet, a lock of hair, footprints, handprints, photographs, etc. Parents also create new things as part of the grieving process, including, for example, personal journals, artwork, letters addressed to, or more recently, blogs dedicated to, their babies. This accumulation of things can be considered a type of recordkeeping and it is increasingly recognized that such recordkeeping plays an important role in the grieving process (Riches and Dawson, 1998; Mander and Marshall, 2003; DeGroot and Carmack, 2012, 2013; Blood and Cacciatore, 2014; Brubaker, and Dourish, 2013).

### 2.3 The community: online

Parents of stillborn babies meet the key criteria of people who seek comfort in online grief communities, particularly a sense of stigmatization, and limited access to other support networks (Swartwood, 2011). Godel (2007) refers to parents’ participation in memorial websites; in recent years, an increasing number of parents are using social media tools to build communities of understanding. A bereaved parent can

connect with other bereaved parents on Facebook; on Twitter; through community websites; and through the blogs of individual bereaved parents.

Sharing takes many forms in these communities. In forums such as those hosted by the MISS Foundation ([www.missfoundation.org](http://www.missfoundation.org)) parents share memories of their pregnancies, of their labor and delivery, and of the aftermath of leaving the hospital without their baby, arranging for his or her burial or cremation, and learning to cope with the grief associated with the loss of a child. As networks and friendships form over time, parents remember and acknowledge the children of other parents by writing posts *for* them, about *their* children, on important anniversaries, or, more simply, at times when they find themselves thinking of another parent and her child.

### 3 Emerging Themes

While Godel (2007) argues that “there is no collective memory” of the stillborn child’s life, I suggest that within these online grief communities collective memory *does* develop; similarly, where she asserts that “there will be no narrative of growing up” (p. 236), I suggest that these communities provide parents with an opportunity not only to remember the past, but also to create for the deceased a present and a future. Shared online, a life that is diminished or ignored in the larger communities to which a parent belongs, and that has left few physical traces, assumes a more prominent shape as parents build collections of memories and things and insert these into networked community spaces.

#### 3.1 Aspirational archives

This type of memory work is therefore not only commemorative in nature, but also aspirational. Appadurai (2003) describes the act of archiving as a “continuous and conscious work of the imagination” (p. 23). Instead of merely preserving the past, the archive is a site of deliberate negotiation and construction of memories by “intentional communities” (p. 17). In this view, “the archive is itself an aspiration rather than a recollection” (p. 16).

As parents remember details about their children’s short lives and speculate about what those lives could have been in the company of other bereaved parents, the deceased children take on identifiable characteristics. In this way, online grief communities may allow parents a space in which they create a kind of present and future for their deceased babies, a present and future where they are made real to other parents and remembered by them, where they acquire characteristics, and where new memories continue to form.

#### 3.2 Continued social existence

Mitchell et al. (2012) note that in many cultural contexts, the idea that the dead have continuing social existence is well established. They note, however, that until recently in Western contexts, the dominant approach to bereavement has been to view death as an end point and to work toward the severing of attachment. Openly maintaining a relationship with the dead has been discouraged and is sometimes pathologized as failed or unresolved grief. In their recent article on virtual memorialization, Mitchell et al show how this “remnant taboo” (p. 413) is being broken on the Internet: while death ends a life, it does not end a relationship, they explain.

#### 3.3 ‘Archives of feeling’

Cvetkovich (2003) explains how documenting trauma can be a means of transforming loss into collective memory. She focuses on the affective dimensions of archiving, and links affect and archives to social movements to argue that an archive of feeling – which does not always conform in nature to the traditional definition of an archive – can play a significant role in facilitating change. Although it is too early to refer to online grief communities as a social movement, as parents document their experiences of trauma and loss, and their continuing relationships with their deceased children, and as they continue to develop networks of relationships, potential exists for these archives of feeling to eventually facilitate change by fostering understanding of parental grief and acknowledgement of the ‘realness’ of this type of loss.

### 4 Continuing Research

From these emerging themes, ideas extendable to other types of archives can be identified. For example, the idea of the archive as aspirational bears further examination: What does it mean to think of archives as works of the imagination? What are the acts of imagination that form an archive? Who performs these acts? Is there a place in archival theory for accounting for them and if not, how can we make one? The

archive as a continuation of its creator's social existence likewise merits attention. How is this post-mortem social life characterized and what are the ethical implications of this idea? Hobbs (2012) asks what it means to "do right by" (181) a person's archive; this question takes on new dimensions when we consider that people not only use the archive to remember the past, but also to carry relationships into the future. Finally, there is value in undertaking a deeper analysis of the affective dimensions of archiving, generally, and of bereavement archives specifically. A better understanding of bereavement archives and of the role of recordkeeping in grieving may have beneficial outcomes within the field of archival studies – by adding nuance to our sense of what archives are *for* and what they can *do* – and in wider society, if record keeping is shown to have therapeutic benefits to the bereaved.

#### 4.1 Ethics of research in online communities

To date, this research has involved qualitative, textual analysis of online grief communities to identify their characteristics and the types of records created, accumulated and circulated, as well as a consideration of the results of this analysis in relation to traditional archival theory. The next steps must involve direct interaction with particular communities. Significant ethical questions related to access and privacy must be considered first. Although many online spaces where communities form are completely open to public view, there is a general presumption on the part of participants that they are writing for and interacting with *other bereaved parents*. For the online communities to continue to function as supportive environments, it is important that the online spaces they occupy are experienced as 'safe spaces'. A crucial next step is to develop a clear understanding of the ethical context associated with these types of communities and to determine how to sensitively adapt research methodologies to them.

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