"The people inside my mobile were the only ones listening to me". Mobile technologies as resources for coping with bereavement

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Abstract

The death of a child might be the most devastating loss an individual can experience in life, leaving the mourning parents with a life-long process of adaptation to the loss. In societies where death is a near-taboo, such as in the Nordic countries, implicit norms require mourning to be limited both in expression and duration. This reduces possibilities for coping with the situation, and bereaved parents experience a lack of support and understanding both in their everyday life and from health care. However, the affordances of mobile technologies and social media offer bereaved parents new possibilities on their journey of adapting to the loss of a child and learning to cope with their grief. Based on surveys, interviews and observation of interactional data in a closed community on Facebook, this study shows that constant and instant access to a peer grief support community online is of vital importance to grieving parents.

Author Keywords

Bereaved parents; mobile phones; social media; online grief support communities.

ACM Classification Keywords

H.5.m.

Introduction

The aim of this workshop paper is to illustrate the importance of mobile technologies and social media as vital resources for bereaved parents in their process of adapting to the loss of a child, and learning to cope with their grief. We base this on a study of bereaved parents use of a closed peer grief support community on Facebook.

The death of a child has been recognized as the most devastating of all losses individuals may experience in life [13, 11], leading to intense and often life-long grief (cf. [9, 10, 9, 7, 5). In contemporary Western societies, the death of a child is not as common as it has been historically, mainly due to improvements in living standards and health care. However, at least in the Nordic countries, a child's death is treated as a neartaboo subject, so uncomfortable that it is often avoided in everyday encounters [2]. Implicit norms require bereaved parents not to grieve their dead child too openly, not too intensely and not for too long. Bereavement research has shown that this type of grief may be neither shared nor understood by those who are unbereaved [2,11]. Thus, the grief of bereaved parents is both stigmatized and - in combination with the lack of support and understanding in everyday encounters and from health care - their possibilities for coping with their grief limited [2]. However, mobile technologies and social media offer new opportunities for grieving parents.

Digital and mobile technologies are increasingly intervening in and transforming many aspects of contemporary life. This also applies to communication

patterns and relations, and to how knowledge and experience are developed and negotiated. Schrock [12] proposes an affordances approach as a framework for researching "how technologies such as mobile media are integrated into routines, affecting subsequent patterns of communication" (p.1229). Four communicative affordances of mobile media are highlighted: portability, availability, locationality, and multimediality. The portability of mobile phones is perhaps the most transformative affordance as it allows for connection irrespective of time or place. Brabham [1] identifies some general significant features of social media: immediacy, reach, distribution, access, temporal flexibility, interactivity, and possibility for sharing of experiences among members in online communities. These features are of vital importance to the members in the community that we are studying, as is Licoppe's notion of connected presence [6].

Methods and Material

Data was collected between September–October 2012 and May–June 2013. Methods used were an anonymous online survey and semi-structured face-to-face interviews with members of a Swedish peer grief support community on Facebook. By posting an invitation in the grief support group the research subjects were recruited to take the anonymous online survey, resulting in a convenience sample (N=56). Those who completed the survey were invited to contact the researchers for follow-up interviews. Semi-structured interviews with four members in the grief support community (3 women and 1 man) were conducted between May–June 2013. Each interview lasted between 1–2 hours. All interviews were audio recorded with the research subjects' consent.

Results

Based on the interviews and the survey it is clear that the grief support community on Facebook is of immense value to the members in their continuous process of adapting and adjusting to their loss (cf. [4]). One member expressed that

"It [the community] has become safety for me. Sometimes even a kind of "home", when I feel like I've lost my footing" (Survey)

A number of features or affordances of social media and digital and mobile technologies are repeatedly emphasized. One of the features is the closed nature of the group and this, coupled with the knowledge that all members are peers, is experienced as a prerequisite for the community to function.

> "[It's] a breathing hole. I can say what I want and not risk being judged. It is also a relief to know that there are others sharing a similar experience." (Survey)

Having access to the abundance of shared experiences distributed among the many members within the community offers a wealth of perspectives on things that individuals may struggle with. Access to the experience of so many people at the same time is impossible to recreate offline.

"It is not like in a physical meeting in a support group where eight to ten people meet. In the Facebook group, you have access to so many people at once, this cannot be attained in any other way." (Interview 4)

The possibility of constant and instant access to the community, regardless of time and space – and for as long as an individual has need for it - is frequently stressed as an important and vital resource for coping with the death of a child. Several of the members especially emphasize the affordances of mobile phones to connect to the group. One of our interviewees, while patting the pocket where she kept her mobile, expressed that

"...the people [other members in the community] inside my mobile were the only ones listening to me [...] it was my only way of keeping in touch with the outer world" (Interview 1)

The possibility of night-and-day instant accessibility to the support of the community is repeatedly mentioned as very important, particularly if the loss is close in time.

"I can write at any time. I use the mobile phone. I have 3,000 photos. I was writing and posting several times a day in the beginning." (Interview 2)

"There is always someone available. Even if you don't get an immediate answer to your posting you've at least had the chance to get it off your chest. You feel a bit better then." (Interview 1)

Through contact with other bereaved parents who share their experience, the members can learn to cope with and adapt to their personal loss.

"Reading about how others grieve, we are all in this together, even if the causes and how far we have come in our grieving process are different." (Survey)

The closed nature of the community and contact with peers who share similar experience together with the possibility of constant and instant accessibility to the group are frequently stressed as important to the grieving parents.

Discussion

This study, however briefly introduced in the present paper, provides insight into how peer grief support communities online offer bereaved parents

opportunities for learning to cope in unprecedented ways. Most importantly, it shows that the affordances of mobile technologies and social media offer new possibilities for bereaved parents in their process of adapting to the loss of a child, and learning to cope with their grief. The potential of online peer grief support has so far not been recognized enough for its possibilities to influence health care and attitudes towards the loss of a child [3]. Interacting with peers in the community seems to complement and compensate for lack of social support and understanding and to enhance the wellbeing of the members. Aspects of Shrock's affordances approach to mobile media are resounding in what the members of the community in the present study express (portability, availability, locationality, and multimediality), as are the important features of social media, identified by Brabham [1], among others, (immediacy, reach, distribution, access, temporal flexibility, interactivity). The possibility of instant access to peers who support and understand them in their hour of need, the wealth of experience in coping with the grief of a child, distributed in the community. The possibilities of immediate connection with people in the community irrespective of time or place, through digital and mobile technologies are recurrently emphasized in our data. These aspects cannot be met by an offline peer grief support, but recognition of these affordances might be used to complement existing health care. As one of our interviewees indicated, constant and instant access to "the people inside [her] mobile" might sometimes be what keeps a person in a desperate situation standing.

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