

## Providing Comfort Giving Support and Raising Awareness: Stillbirth Communication in Online Communities

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### Abstract

Currently there is little progress in reducing the number of stillbirths that occur worldwide and most of the causes leading to stillbirth remain undetermined. Further, outside of hospital settings, the parents of stillborn children are deprived of emotional comfort as a result of the discomfort the topic causes in their social interactions. Nonprofit organizations bear the responsibility to break the taboo around stillbirth, provide comfort to bereaved parents, and raise awareness and funds. For this purpose, these organizations can make use of social media platforms to create online communities. This paper draws on interpersonal communication theory to provide guidelines that nonprofit organizations can use to deliver comfort and raise awareness about stillbirth in online environments.

### Introduction

To date, stillbirth continues to represent a global public health issue and little progress has been made in the past decade to address it on an international scale [1]. Each year around 2.6 million babies are lost to stillbirth worldwide [2] and the number of stillbirths is dwindling by solely 1.1% per year [1]. Globally, over one thousand families lose a child to stillbirth every hour of every day [3]. While the majority of stillbirths occur in developing countries [3] as a result of inadequate healthcare services, the first world is facing a rather high rate as well. For example, the UK has the most alarming number of stillbirths in the developed world and loses 11 babies daily [4]. Conversely, Finland, Singapore, Denmark, and Norway record the lowest rates of stillbirths [1]. While the US is facing 25,500 per year [5]. To a certain degree the causes of stillbirth are known and range from childbirth complications, congenital abnormalities, and maternal disorders [1] to lack of adequate healthcare and malpractice. Yet, in 80% of the stillbirths the causes remain undetermined despite postmortems [4].

The unknown causes of stillbirth require further and immediate research, a process dependent on the availability of resources. However, the allocation of funds is triggered by the visibility and urgency of the issue. Unfortunately, outside of the healthcare system and apart from the families affected by the loss of a child, stillbirth remains taboo. For example, past research in developing countries [6] showed that one in five women who experienced stillbirth faced stigma and marginalization as a result of perceptions of failed motherhood, all of which decreased the bereaved mothers' chances to receive support in social and professional settings. On the other hand, the stigma and the lack of dialogue around stillbirth were also found to be present in past research studies conducted in developed countries. These studies shed light on the discomfort the topic engendered in social interactions with the interlocutors being left mortified and in shock at hearing about the parents' loss [7,8]. Specifically, the majority of the parents who lost a child to stillbirth can identify with the statement made by one of Worth's [8] interviewees, a father of a stillborn child who recalled the discomfort the topic caused in his social interactions whenever we told anybody people avoided us. It's like they didn't want

to deal with it. They couldn't handle it. Was like we had the plague. The situation is no different for the researchers outside of the medical field. As a result of the way stillbirth is perceived in the society, researchers in general and female researchers in particular fear that their interest in the topic equates with self-disclosure. Finally, the lack of dialogue around stillbirth was shown to lead to a poor understanding of the topic by pastoral caregivers and ministers who are expected to cater to the grieving process of their faith communities [9].

The reactions that the bereaved parents receive in their social interactions, namely those of shock and avoidance are normal since, to date, our society is not ready to view stillbirth as a tragedy that is part of our lives but rather as a topic to shun as a result of the awkwardness it produces. Unless we manage to break this taboo and treat stillbirth as a reality and a tragic event that does indeed happen, stillbirth will be assigned less importance and, therefore, fewer resources for medical research, and counselling. From this perspective, stillbirth remains a communication issue: how we define and frame it determines how it is perceived as well as how much significance it receives. Breaking the taboo around stillbirth will engender increased awareness and funds and will hasten the healing process of the bereaved parents by triggering appropriate social interactions within which comforting messages can emerge.

### Stillbirth communication online

The lack of dialogue around stillbirth in everyday life renders the bereaved parents voiceless, alienates, and deprives them of emotional comfort. Not-for-profit stillbirth organizations such as the Action for Stillbirth Awareness & Prevention Coalition (ASAP) in the U.S., the Stillbirth and Neonatal Death Society (SANDS) in the UK, and the International Stillbirth Alliance (ISA) have been focusing their efforts on raising awareness and funds as well as providing comfort to families affected by stillbirth. For this purpose, these organizations made use of social media platforms such as Facebook or Twitter. However, past studies on the nonprofit use of social media in general [10-12] and on stillbirth in particular [13] determined that nonprofits fail to take

extensive advantage of the potential of the Web 2.0 to raise awareness and funds. Specifically, nonprofits were shown to engage in one-way communication practices [12] and to fail to create dialogue around their causes. Creating dialogue would, in turn, help establish online communities with increased interaction and interactivity around a cause.

Online communities involve intense support, empathy, and friendship [9,14] and have the potential to engender interactivity that spreads further awareness, helps to raise funds, provide comfort, and break the taboo around the topic. In addition, online interactivity is known to facilitate word-of-mouth as organizations create a personal connection with their constituencies [10] and have the potential to lead to offline interactions. Because online communities are formed around a common interest, [14] they can provide support for interpersonal communication and, consequently, can help build and maintain relationships, which are of paramount importance in the aftermath of a stillbirth.

There has been much debate around what drives individuals to join online communities and what triggers their online contribution [16-19]. For example, research showed high self-efficacy, group norm, and social identity to be predictors of online participation [14,19,20]. In addition, online platforms provide a means to regain the sense of community long lost in offline interactions [20] and to erase marks such as gender, status, conventions or codes, therefore facilitating equality [21]. With regard to online communities for health-related purposes, Turner, Grube, and Meyers [19] found that cancer patients participated more in online communities when they perceived the support received online to be more substantial than what they were provided with in offline settings and when they felt skeptical about the accuracy of the information received offline. In addition, patients were shown to contribute more content when they shared a common identity with other users and when the online dialogue reinforced their individuality [19].

Because stillbirth is rarely discussed in offline interactions due to the discomfort it causes, the affected parents are likely to join online communities in an attempt to find new information and to receive emotional comfort and support. Moreover, bereaved parents are inclined to share a social identity and exhibit high self-efficacy provided that nonprofits engage them in dialogue that enables them to take part in stillbirth awareness.

For the past years the number of online communities has been staggering. For example, in 2010, almost half of the internet users worldwide were active members of online communities [14]. Corporations were quick to seize the potential of online communities while nonprofits were slow in embracing it as a result of their lack of staff and reliance of volunteers [10]. However, with the right communication tools, nonprofits can develop and maintain online communities with minimum resources. The following paragraphs provide details about the communication strategies that can be used for this purpose.

## Comforting Messages

Stillbirth was studied extensively in the past and appeared mostly in medical journals. For example, researchers looked into the social support parents received in the aftermath of a baby's passing, [3,7,22,23,24] the mothers' risk for post-traumatic stress disorder, [2-27] the impact of social deprivation in the aftermath of a stillbirth, [23,28] the extent to which hospital care influenced the healing process

of the bereaved parents, [22,29,30] and the impact of parents' occupational exposure on stillbirth risk [31].

Additionally, longitudinal studies were conducted to determine the psychological changes in parents of stillborn children [32,33] while others aimed to determine the best ways the medical staff should communicate with parents in the aftermath of a stillbirth so as to decrease the magnitude of their trauma. Specifically, Trulsson and Radestad [34] determined that the psychological impact of a stillbirth was diminished if the medical staff engaged the bereaved mothers in open communication, a strategy that can be translated online and used by nonprofits to provide comfort in the aftermath of a stillbirth. Further, Downe et al. [23] found that a collection of physical memories of stillborn children among which photographs, locks of hair, or footprints, exerted influence on the parents' perceptions of the quality of care received at hospitals. A similar argument was made by Basile and Thorsteinsson [22] as well as Godel [35] who discussed the importance of photographs in triggering parenthood acknowledgement. In this respect, online communities can facilitate the sharing of memories through visual communication or text, a communicative process that would take place within the safe boundaries of a shared identity.

In addition, several studies [8,36,37] pointed to the inefficiency of messages that aim to engender comfort while diminishing the magnitude of child loss, ("you're young, you can have others," "at least you have two children") the lack of social recognition for the parents of stillborn children, [8] as well as the fact that bereaved parents find comfort in sharing stories with those who underwent a similar tragedy [8]. The preceding aspects of the healing process pointed out in these studies such as stillbirth as a taboo, the lack of support in face-to-face interactions, and the need to share and hear similar stories, would trigger parents affected by stillbirth to join an online community where they can receive the emotional support needed [13,37,38].

To create an online community around stillbirth, nonprofit organizations should adapt and use constructs of emotional support previously tested in the field of interpersonal communication [13,37,39,40]. Specifically, past research on comforting messages showed that communicating around the concepts of encouragement and respect not only fastens the healing process but also leads to close bonds among individuals [40]. These close bonds can lay the basis for the establishment of an online community. First, the implementation of encouragement implies that nonprofits would trigger dialogue around stillbirth that makes online users comfortable enough to share their stories. As previously mentioned, encouraging story telling meets the emotional needs required to speed up the healing process. Currently, the encouragement displayed in the nonprofit online communication is limited to asking users to share or like a post, and participate in offline events meant to raise stillbirth awareness [13]. This type of encouragement is undoubtedly useful as it increases the parents' self-efficacy, but remains a one-way communication style that should be coupled with the encouragement of story telling.

Second, to communicate respect online, nonprofits should focus their efforts on emphasizing the social recognition of the bereaved parents, who should not be deprived of their parenthood status as a result of child loss. In time, the implementation of the aforementioned communication tools would lead to the creation of close bonds among the online community members and will emerge in the communication practices they display, showing intimacy, closeness, and care, [13,40]. Such constructs were shown in past studies to denote ties and rapport [40]. Specifically, the more encouragement and

respect an organization is providing, the closer the ties within the online community (closeness), the more information (intimacy) and care the users display. Closeness can be assessed by determining the extent to which the bereaved parents offer support to one another, intimacy will appear as they share personal stories and share memories of their loss, while care would be present when their communication exhibits familiarity with previously shared stories as well as with each other's names [13]. Past studies indicated that many of these online interactions translate in offline settings [14] and, therefore, an online community around stillbirth can enable further offline interactions, therefore leading to increased comfort.

A past study conducted on the emotional support provided by SANDS on Facebook [14] revealed little success on the organization's behalf in triggering an online community. Specifically, SANDS predominantly asked for reposts, likes, or shares. Further, respect was present in connection with stillbirth-related events the organization was promoting, among which the Wave of Light campaign. While partaking in such events undoubtedly provides comfort, communicating around respect and encouraging users to share their experiences, offer advice to others, etc. would prove more effective in leading to increased user involvement that can trigger further disclosure and strengthen the relationship among the online users.

Finally, communicating around encouragement and respect can help the bereaved parents through the stages of grief [7] that range from denial, numbness, disorganization, and despair to reorganization. In time, these online interactions can assist them in finding ways to adjust to a new reality, as users learn from each other's experiences.

## Conclusion

Raising awareness of stillbirth and providing comfort on a global scale requires further consideration. For example, online communication strategies should include gender differences. Specifically, past research showed that bereaved fathers might be receiving less emotional support offline since they tend to rely on their social network which may comprise acquaintances and friends who lack direct or indirect experience with stillbirth [37]. In addition, mothers of stillborn children may be prone to a quicker recovery than fathers as past studies showed that women are more inclined to accept pregnancy loss than men [26]. Finally, in male-dominated cultures such as those present in Africa, Asia, and Eastern Europe, online emotional support should be provided differently to women than to men as a result of the stigma that society assigns to the mothers who have lost a child [3]. Moreover, in developing countries nonprofit organizations need to take into account the degree to which stillbirth awareness can be raised via social media platforms since access to the internet is significantly lower than in the first world.

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