Grieving mothers: design of thematic blogs about loss of a child

Mães enlutadas: criação de blogs temáticos sobre a perda de um filho

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Abstract

Objective: To understand motivations of grieving mothers to create and maintain a blog about the loss of their child.

Methods: This was a qualitative study on virtual ethnography from narrative analysis of data obtained from i40 blogs about the loss of a child, according to theory proposed in dual process model of grief.

Results: Defined categories were as follows: to share the experience of loss and challenges in moving forward; to create a relationship network to support, comfort, and support other grieving persons; to guarantee a space of refuge to express feelings and emotions in order to overcome loss; to honor and perpetuate the image of the child lost; and to engage in social activism.

Conclusion: The expression and validation of grief in blogs help mothers to develop strategies to cope with stressful factors related to the loss.

Resumo

Objetivo: Compreender as motivações de mães enlutadas para a criação e existência de um *blog* sobre a perda de um filho.

Métodos: Pesquisa qualitativa por meio da Etnografia Virtual a partir da análise narrativa dos dados registrados na ficha de identificação de 40 *blogs* sobre a perda de um filho, segundo o referencial teórico *Modelo do Processo Dual de Compreensão do Luto*.

Resultados: As categorias definidas foram: compartilhar a experiência da perda e do desafio de seguir em frente; criar rede de relacionamentos para apoio/conforto/suporte a outros enlutados; garantir espaço de refúgio para expressão de sentimentos, emoções e superação da perda; homenagear e perpetuar a memória e imagem do filho(a) perdida; ativismo social.

Conclusão: A expressão e validação do luto nos *blogs* contribuem para o desenvolvimento de estratégias de enfrentamento para lidar com estressores relacionados à perda.

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Introduction

Contemporary Western culture offers few options for supporting the process of loss and grief elaboration. Finding a social space that enables those grieving to speak, experience feelings, and change their experience related to their loss is essential to facing grief and restoring life after a loss. During the experience of grief, the pain and suffering are intense, expressed by feelings such as anxiety, sadness, fear, and guilt. These feelings can be expressed in several forms and at different times for each person, in a dynamic, individualized, and multidimensional process. However, social spaces are not always receptive to this process, and this reality can have a direct impact on the relationship of the grieving person with him- or herself and the surrounding world. To deal well with grief means to face feelings activated by loss and the new reality that is imposed, as well as the need for times to avoid pain and the need to focus on life.[1]

At the same time that grieving persons experience pain and loss, they must also reorganize their life because of the absence of their loved one; this takes place amidst a constant and cyclical experience of stressful events that can destabilize their life. To enable this reorganization of life, it is important that grieving persons find support to assist them in seeking strategies to cope with and adapt to loss. Such support will allow grieving persons to transition between grief stressors and reorganization and reestablishment of their own life, in a continuous process called the dual process model.[2] This model is considered a valuable instrument to understand the process for coping with grief and constructing meaning and elaboration of the loss using, when necessary, defensive resources to focus on daily life tasks.[2]

One of the social spaces available for expressing grief in contemporary Western society is the virtual or cybernetic space, which gathers individuals with a common interest online and off-line. Cyberspace can contribute to the constructing of emotional bonds that, when consolidated, can offer social support. The Internet can create a feeling of intimacy because people are anonymous to each other, which

leads people to share their life experience; in addition, the virtual gathering can interfere in pathways of a study about a specific disease, as well as in created public policies.[3] Based on this precepts, grief expression has been constantly shared and manifested in different virtual environments, especially in social media and blogs. Blog spaces are understood as virtual communities that gather individuals, subjects, and common interest in a network.[4] Thematic blogs about grieving, because they are publicly accessible, are particularly considered a space for demystification of themes considered social taboos, such as death and dying. Specialized literature on the subject has identified cyberspace as an opportunity to express condolences, elaborate on obituaries, and profile the deceased persons; it has become an important and needed space for expression, elaboration, and repercussions of grief.[5,6]

Virtual space can bring reflections related to support for both the care teams that are in constant contact with loss and grieving person who seek to the understand the restructuring of life after loss of someone with whom a significant bond was established.

A recent literature search by the authors of this study indicates that most blogs available on the subject are authored by grieving mothers who describe the grief experienced after the loss of their child. This is an experience that will be never overcome, but the feelings change as years pass and the mother begin to find means to deal with the death of her child. The loss of a child cannot ascribe more meaning to life, and can lead to feelings such as willingness to die. These feelings do not always suggest pathological grief. This experience needs to be understood and accepted by people surrounding the grieving person because it is a reality. Maternal grief must be respected, including the mother's needs and limitations in facing the loss, regardless of social requirements.[7]

This study sought to understand the motivation of grieving mothers in creating and maintaining a blog on the loss of a child and to explore and comprehend how this experience is related to the grief process. A deep understanding of this theme can support the implementation of care strategies to

cope with death and dying, contribute to the qualification of nursing professionals and other health professionals to support grieving persons, and help demystify the subject.

Methods

This qualitative research used virtual ethnography as the investigative method.[8,9] Data were collected from the insertion and immersion of researchers in a virtual environment, and the initial focus was in grief expression in thematic blogs.

Virtual ethnographic techniques enable instrumentalization of research in observing and promoting intersubjective contact with the object of study from insertion in the community to be investigated;[10] in this case, the community is the virtual environment, more specifically blogs.

Participants were selected by a Google search using the keywords "blog" and "grief." We also used the snowball technique, which means identifying blogs that were mentioned other as a follower or being followed.

Initially we identified 48 blogs; 40 were authored by mothers who described the grief process experienced after the loss of a child, therefore justifying the reason for the research. Inclusion criteria were thematic blogs on the loss of a child, written by a mother in Portuguese. Data were collected in a virtual environment by using information available in the blog, including the creation process and the registration date of the blog. This information is a requisite for blog registration on virtual hosting platforms and includes the interests and motivations of authors to create the blog. In this study, we did not use data related to the virtual interaction between the author and the blog's audience.

The study was approved by the Ethical and Research Committee in Nursing of the Nursing School at Universidade de São Paulo - USP / SP based on resolution 466/2012. Protocol no. 1088/2011.

According to the guidelines on ethical decision-making research based on recommendations from the Association of Internet Researchers Ethics Working Committee, blogs are virtual spaces clas-sified as open to the public, which means they are available to everyone without need for privacy control of data.[11] It is important to highlight that although the data are publicly available in the blogs as open information, care was taken to preserve ethical procedures related to the guarantee of privacy and confidentiality protection so that the personal data of authors of blogs and participants of the study were not identified. Data were analyzed according to narrative analysis, understood as "a spoken or written text of an event/action or series of events/actions chronologically linked".[12] Data were analyzed by using the theoretical reference dual process model[2-15] and narratives were systematized in thematic categories.[11]

Results

The analyzed narratives express the authors' reflections on themselves, the death child, and their audience. Narratives are based on a tentative seeking or constructing meaning to the loss, and sometimes they are supported by beliefs and religious values. Blogs and authors' data are identified by the letter B (corresponding to the word "blog"), followed by an identification number. The thematic categories are the following.

To share the experience of loss and discuss future challenge

This category expresses the interest of mother to tell the history of the loss, share difficult times, and challenges in moving forward.

"This blog is about my angel, my loss, and how I could move forward, living day by day. This is what I intend to share with you in this blog, you all are very welcome". B2

"The blog was created to share the most difficult time of my life after losing my loved and awaited daughter. Her name is L - a beautiful angel that God had sent". B4

There is an interest in seeking alternatives that could ameliorate pain and suffering because of the loss, especially in relation to the need to share experiences and express emotions and feelings.

"Using this blog I intend to reveal the history of my pregnancies. I had a dream that was interrupted twice, and I could affirm that only those who go through this experience could understand this feeling."

To create a relationship network to give support and comfort to other grieving persons

This category expresses an invitation of the mother to create a relationship network and seek new friendships to share the experience of losing a child, as well as to legitimate the blog as a place for support and encouragement of other grieving persons.

"…This blog will bring love to the heart of those suffering. It is designated for all persons who have suffered the loss of a loved one. This blog will transform your pain into love." B2

Creating a blog shows a desire for space to express pain and suffering. It also is a way to gather together people who have experienced similar situations.

"A blog dedicated to all moms and dads who suffer the biggest pain a human being can experience: the loss of a child. This is the reason why I created the blog: to tell my history and also read what mothers who have experienced the same situation have to say…. This is a way of not feeling we are alone…"B6

"It is important to share our histories. Perhaps we can support a little more those experiencing this anguish". B9

To guarantee a space of refuge to express feelings, emotions and overcoming loss

This category shows the mother's interest in validating the blog as a space to express emotions, feelings and beliefs. In this space, beliefs and values are expressed in relation to death.

"This corner is my refuge in moments of despair". B4

"To lose a child is very difficult; to lose two children is even worse, and this is my case: I lost two babies. Today I had huge pain in my heart, and in this blog I put my love and grief for my children. Welcome…"B3

The mothers use blogs as way to validate their pain and suffering from loss and the grieving process.

"…Talk about them, look their pictures, listen to their favorite songs we know how painful it is, but all these keep them close to us…. But, above all to pray for them. Always. I put them in the hands of the lord, we know that God is a good father and does not leave men and women alone". B31

Honor and perpetuate the memory of the deceased child

Mothers frequently reported creating a blog to honor and perpetuate the memory of the deceased child. Such blog commonly feature a dialogue with the deceased child; sometimes the child is called "enlightened angel," "angel," "princess," and "star."

"This blog is dedicated to my dear and loved little daughter 'M,' who departed on April 21, 2011, when she was only 4 years and 10 months. My beloved daughter, you have asked for wings from God and he has turned you in an angel". B22

The content posted on blogs will remain in cyberspace, and the mothers seek to perpetuate the memory of the deceased child.

"I have created this blog to honor my child, because my biggest wish is to keep her image and memory always alive. T., my daughter, I love you, our love will never end, our separation is only for a moment. I wait anxiously for the day we will finally meet again…Now T. is a star in the sky". B24

Social activism

Situations emphasized in this category justify the interest of the mother to create a blog for social activism. In such cases, the blog has a social purpose and seeks to promote changes in Brazilian public policies, such as the increase in the number of beds at neonatal intensive care units and actions against social violence.

"My dream is all hands together to seek solutions and stop violence (…) we could not stay anonymous anymore, we need to speak up, and find our space. Families get rebellious and develop an attitude that does not contribute to peace, but generates revenge. I wish a non-violent attitude! (…) We need to be together to support others who experience the same suffering." B1

Mothers also express their indignations with violence and seek a way to unify strengths to promote improvements in health system.

"The goal of this work is try to change something in health situation of Brazil, I intend to help other babies who will need a bed in a ICU, I intend to provide any support, we know how difficult is, but we have to try, don't we? I´m also counting on you reader".B2

Discussion

The loss of a child is reported in the literature as an especially painful loss, and it tends to be a difficult elaboration process.[14] The analysis of mothers' narratives led to an understanding of the process of coping with losing a child from the expression of grief in blogs.

Dealing with loss is related to processes, strategies or management styles experienced individually by each grieving person who seeks to adapt to grief.[16] Guidance concerning grief reflects the stressful responses that emerge with loss: stress from the loss itself and the breaking of bonds with a loved one and, on the other hand, stress linked to reestablishment and the challenges of moving forward with life without a loved one. Each individual chooses to face or avoid stressful factors of loss and reestablishment, which led to interest in the concept of oscillation.[15,16]

In this context, the coping process and adaptation to grief of mothers who participated in study was at times oriented to the loss and at other times was oriented to recovery. Guidance for loss is related to dealing with the loss itself, concentrating on it and working on some of its aspects, especially related to the deceased person, need for reposition of affective bounds, and focusing on the circumstance of death.[2,16] In this case, the categories are to share experiences of loss and grief in relation to the challenge of moving forward, to honor and perpetuate the memory and image of the lost child, to guarantee a refuge space to express feelings and emotions and overcome loss, to suggest a movement from the circumstances of death, loss itself, working with issues related to the deceased person, and to seek repositioning of the affective bound.

Guidance for recovery includes suggestions for actions to reorganize one's life and develop new identities. This guidance is related to the secondary consequences of loss that constitute a source of stress that grieving persons need to deal with, as well as defining ways to deal with such stress sources.[16]

The identified categories to share experiences of loss and grief and challenge in order to move forward, to create a network of relationships in order to express feelings and emotions and overcome loss, and to engage in social activism suggest the need of grieving mother to reorganize their lives despite loss, to discuss actions they have taken, and to develop a new identity and social role after the child's death.

Oscillation is a regulatory, dynamic, and fundamental process of adaptive coping, of alternation between coping with loss and guidance on recovery and non-coping. It is also possible to cope and avoid recovery actions.[2]

The analysis of categories suggests that creation of a blog about the loss of a child helps the mother experience this oscillating movement, with the aim of adapting to grief, shown by alternation of coping with loss and guidance on recovery in a regulatory and dynamic process.

This means that sometimes the grieving person will face some aspect of the loss and other times he/she will avoid memories in an attempt to return to life. This oscillation is a process need and possibly one of the best indicators of positive coping with the grief experience.[17]

Considering the results of our study, we understand that creation and existence of blogs about the loss of a child tend to enable the mother to continue to seek internalization of the lost relationship and reconstruct their life and social relations despite the loss. Limitations of this study are the lack of data in the blogs on the mothers´ characteristics that might help us understand the history of loss and circumstances of death. Such facts motivated us to perform another study to understand the history of loss, experience in the coping process of grief by grieving mothers, and desire to find meaning in the loss.

Conclusion

This study showed a movement of mothers, who are authors, to define strategies to deal with stressful factors related to the loss of a child by creation and maintenance of a thematic blog. The results reported here can be used in the training of nursing professionals and multidisciplinary teams to help them understand death and dying, with emphasis on caring for grieving families, especially in the area of palliative care, grief, and thanatology. This study can serve as an instrument to society to support grieving persons, help demystify the theme, and develop new studies. In addition, this study can help improve understanding about the use of new communication and information technology as a strategy for coping with grief.

Collaborations

Frizzo HCF, Bousso RS, Ichikawa CRF and Sá NN contributed with conception of the project, analysis and interpretation of data, critical review relevant to the intellectual content and approval of the version to be published.

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