PTSE 17 (2), 69-77

The Journey of Parents Bereaved by Prenatal and Perinatal Loss to Professional Helpers

Dora MONOSTORI[1], Andras ZELENA[2]

[1]University of Pécs, Doctoral School of Health Sciences, Faculty of Health Science, Pécs, Hungary
[2]Budapest Business School University of Applied Sciences, Faculty of International Management and Business, Institute of Social Sciences and Pedagogy Department of Communication Studies, Budapest, Hungary
dr.zelenaa@gmail.com

Received: 10.06.2022; Accepted: 31.08.2022; Published: 15.09.2022

Abstract: *The study of prenatal and perinatal loss is a topic frequently discussed in international scientific research. Several forms of the absence and bereavement experience, characterized by complex pain, occur in the period following the loss of an infant. We use the concept of complicated grief, which replaced the earlier stigmatizing expression of pathological or distorted grief. In our practice, many parents reported having symptoms such as sleep deprivation, isolation, reality perception disorder, depression, and suicidal ideation. We present best practices in psychological support for parents who have experienced prenatal and perinatal loss through Hungarian examples. Our practical and field research fits well into the international scientific public discourse, and we place the presentation of applied methods in a theoretical framework. In our review of the Hungarian practice, we aimed to present the full range of support services in Hungary, but the complexity of the topic allowed us to focus only on best practices in psychological support services available to parents bereaved by prenatal or perinatal loss.*

Keywords: prenatal and perinatal bereavement, bereavement care possibilities, best practices in Hungary

Introduction

In our paper, we present best practices of psychological support for parents who have experienced prenatal and perinatal loss through examples from Hungary. Hungary is a Central European country located in the middle of the Carpathian Basin with a population of 9.798 million (2017). It is bordered by Slovakia in the north, Ukraine in the northeast, Romania in the east and southeast, Serbia and Croatia in the south, Slovenia in the southwest and Austria in the west.

In international scientific research, the study of PTSD (Horowitz, 1990) and the publication of the research results have attracted lively interest from the early 1990s. It is often cited that professionals working with parents who have experienced prenatal and perinatal loss and trauma encounter a wide variety of absence and bereavement experiences characteristic of the complicated grief (de Mézerac & Caeymaex, 2017; Malacrida, 1999). Dealing with the heavy burden imposed by grief is an important professional and social challenge and a complex task. This study summarizes the opportunities available to families coping with tragedy. We are therefore consistently using the concept of complicated grief (Wolfelt, 1991), which has replaced the earlier stigmatizing term of pathological or distorted grief. Numerous national and international scholars have proposed a more subtle use of this terminology. In his work Symptomatology and Management of Acute Grief (Lindemann, 1944) the author summarized the stages of the grieving process and used the term grief work (Lindemann, 1944:141). The importance of a family-centred approach was discussed in the study of Kenner and his colleagues (2015). Numerous parents from our practice reported that they had been suffering from symptoms such as sleep disorder, isolation, reality perception disorder, depression, and suicidal fantasies (Zelena, 2017). In her Ph.D. dissertation entitled Depression and grief-reaction Symptomatologic comparison especially of suicidal symptoms (Kiss, 2003), the author provides a problem-centred description of how to distinguish between major (or even seasonal) depression and symptoms of complicated grief, and how to navigate diagnostic criteria. In she distinguishes between major depression during the grief period and normal grief according to the DSM-IV codes. Symptoms associated with prenatal and perinatal loss perfectly match those described from a diagnostic perspective.

According to Hungarian practice, bereaved parents who have experienced prenatal and perinatal loss are being encountered by members of the care team (obstetrician-gynaecologists, neonatologists, midwives, nurses, and assistants) in the clinical phase following the death notification. These encounters usually precede the arrival of the mental health professionals, psychologists, and bereavement counsellors of the hospital to the bedside. Unfortunately, during the clinical phase, the resources of the care team are very limited in terms of bereavement support, as the main services of the institutions are healing and patient care. However, prenatal and perinatal loss experienced by the parents is a specific traumatic experience. Individuals are overwhelmed by the pain caused by loss, and the tormenting feelings keep returning during both active and resting time. These disorders manifest themselves not only in behaviour but also in the mental and physical life and in the maintenance of vegetative functions.

International literature defines the continuous outburst of suppressed content as acting out (Johnson & Szurek, 1952), a process by which the bereaved parent becomes increasingly aware of the loss of their child despite their denial. Expanding Freud's acting out theory, it can be argued that for bereaved parents, the loss of a beloved and expected child can also mean the loss of self. In this way, the energies sustained for parenting tasks are not being redirected to the infant but are released and return to the individual (Gyáni, 2006). According to Freud's theory of trauma the feeling of guilt and shame resulting from this loss is also a step in the process, which, unfortunately, we also encounter when working with grieving parents.

Bereavement, however, rarely disappears spontaneously, in most cases it accompanies the individuals throughout their lives, and according to some theories, it is transmitted to the next generations by a (transgenerational) mechanism of transmission.

Methods - Helping bereaved parents with best practices

Psychologist, mental health professionals, pastoral counsellors

Similarly, to A. Tammer Aker and his colleagues (2007) who presented the clinical practice and research of psychological trauma through a Turkish example, we would like to present the bereavement support options available at the departments of neonatology and obstetrics of Hungarian clinics and hospitals. "*To identify U.S. obstetricians' experiences and attitudes about perinatal death, their coping strategies, and their beliefs about the adequacy of their training on this topic. A total of 1,500 randomly selected U.S. obstetricians were mailed a self-administered survey about their experiences and attitudes in dealing with perinatal death. Physicians received up to three copies of the survey, a reminder card, and a $2 cash incentive. Eight hundred four physicians (54%) completed the entire survey. Seventy-five percent of respondents reported that caring for a patient with a stillbirth took a large emotional toll on them personally, and nearly one in 10 obstetricians reported they had considered giving up obstetric practice because of the emotional difficulty in caring for a patient with a stillbirth. Talking informally with colleagues (87%) or friends and family (56%) were the most common strategies used by physicians to personally cope with these situations*" (Gold et al., 2008:29-34). In the Hungarian hospital and clinical setting, where psychologists or mental health workers are employed, parents are often present during the bereavement period following the loss of their child. We consider the presence and legitimacy of pastoral counsellors in service units a best practice. Regardless of religious affiliation, pastoral counsellors often have the possibility to welcome parents for counselling in rooms and time slots allocated by the institutions. And the number of those interested in this service type is increasing. Legitimizing the presence of non-professional helpers in the institutions is also a best practice, which gets increasing attention both in the Hungarian and international discourse. The presence of non-professional helpers is extremely supportive. While the rejection of professionals and the offensive behaviour triggered by their outsider

position is always present in the attitudes of the bereaved, the similar traumatic experiences shared by the non-professional helpers and their partner status make it easier to open conversations and can function as a catalyst for later involvement of professionals.

Bereavement support groups

Our practice experience of supportive conversations with bereaved parents has led us to the conclusion that after a traumatic event there is a phase dominated by the lack of comprehension and trauma processing begins only after a certain incubation period. That is, the irreversibility of the loss is not felt for a while, the burden of the pain is incubated. Bereaved parents described this phenomenon with a dream metaphor during our data collection. They felt as if they were part of a bad dream and they hoped their dream would end and they could wake up.

It was Cathy Caruth (1995) who introduced the term "awakening" to describe the trauma recurring in the mind. In her theory, understanding can exist in the form of re-presentation and re-thinking alike. She regards symptoms such as flashbacks and nightmares as the literal representation of the original traumatic event. We must note that Freudian theory does not speak of literal, unprocessed experiences. This contradiction was also noticed by Ruth Leys (2000). At this stage, joining a bereavement support group might help. Organizers of such groups can be non-professional helpers, mental health professionals, theologists, social workers, psychologists, psychiatrists, university students, teachers and nurses. During the forming phase, they welcome bereaved people who feel they are having difficulties with the process of detachment, with saying goodbye or who are afraid of remaining alone with their pain. There are usually 10-12 sessions in a process involving 6-10 participants. Groups led by professional helpers are run on a regular basis while non-professional helpers recruit ad hoc groups in a similar framework. Non-professional helpers organize heterogeneous groups (gender, type of loss experience, etc.), but in case of prenatal and perinatal loss, distinct thematic groups are also common in the Hungarian practice. During the first two occasions, the group is open for new members to join, while for the next 10 occasions the group becomes closed. This allows for the building of trust which can relieve the pain caused by loss. The practice in Hungary is similar to phenomena encountered in other parts of the world. Bereaved people with religious beliefs are now able to find qualified pastoral counsellors, as many Churches offer their theologists grief counselling and mentoring training in association with university research centres (Tomcsányi et al., 2008).

Every informant in our practice reported that they had rejected assistance in the first few days following the loss or, if they had encountered it in that period, they would have rejected it. That is, we, as support professionals, must be mindful of the incubation phase and the rejective attitude during the initial period (Malacrida, 1999) and people must be repeatedly reminded of the bereavement care possibilities.

Online and social media-based support groups

During our data collection, we asked the bereaved parents we met in sessions about the tools and channels they used to obtain information and find support possibilities. Analysing only the age-related information of all the data available on the socio-economic status of the informants, we found that the members of Generation Y make up 59%, members of Generation X make up 40% of all informants (N=241), with only 1% representing members of previous generations.

In Hungary, the answers to our question show a close correlation. The extreme over-representation of the Internet among the answers of the informants is not surprising, especially if we consider the technical skills of the two generations and their Internet usage habits.

Parents of Angels Facebook Page

To describe and interpret the culture of an online perinatal loss group. This qualitative study used ethnography, the study of culture. Methods included participant-observation, review of 447 e-mails, and participants' feedback about the findings. The setting was online in a perinatal loss listserv consisting of mothers and one grandmother who had experienced a perinatal loss through miscarriage, stillbirth, or neonatal death. In this changing group, there were between 82 to 87 participants from North America, Europe, Asia, and Australia (Capitulo, 2004). According to joint research by the Hungarian Association of Content Providers (MTE) and the NRC (with a survey conducted in 2015, N=500), Facebook is the most popular social networking site in Hungary. It is used by approximately five million Hungarians and the average time spent on the site by a person was 86 minutes a day. There are about 2 billion Facebook users around the world (Hutchinson, 2019).

Analysing the search results, we found that the Parents of Angels Facebook page is one of the most visited ones on the topic. The page, which displays an average of eight posts a day, has slightly more than a thousand members (on 11/16/2017=1,093 people) and operates as a closed group. A closed group means that the internal communication, shared content and the profiles of the group members can be seen only by approved group members.

The comments of the parents who are current or former members of the group clearly show that the closed group creates a sense of isolation for the first time, but over time, as a member of the group, this perception changes and members appreciate that their communication is not disturbed by external users, also termed tourists.

www.everrip.com

The webpage, which was called into being based on a creative idea and was launched as a start-up, is also an important platform for coping with grief. It was inspired by the creator's own loss experience and makes it possible for the users to overcome geographical barriers by offering international online funeral services that can complement the framework of bereavement support group sessions.

Unfortunately, a deeper structural analysis of the site reveals that few users are using the site, while the number of visitors and users of the website gyertyalang.hu (meaning candle flame) is much higher. In the introductory section of Everrip, the creator states that the main motivation behind creating the page was his strong feeling ”I don't want to forget”. He also wanted to share photos and memories with those who also wanted to remember as a more expressive alternative to the limited information contained by the laconic tombstones. It may be helpful to recommend this site to people who cannot visit the graves of their relatives because of geographical distance.

Results and discussion

In order to ensure the complete reliability of our conclusions and those of the non-directive and structured interviews, we have chosen the multistage sampling method (Babbie, 2008) for the presentation of our research focusing on the advantages and limitations of individual bereavement counselling and support group services. Our study is not representative despite this social science methodology, as many of the potential informants would have been retraumatized (Rüsen, 2004) or hindered in their grief work if they had been asked to complete a questionnaire or sit through an interview. The number of our informants is N=52 people, of whom 47 women (90.38%) and 5 men (9.61%). This percentage shows that women are overrepresented in the Hungarian bereavement support groups because, unfortunately, men are often stigmatized if they seek help and join a group.

The analysis of in-depth interviews (N=24) with professionals working in Hungarian hospitals shows that in many cases, mental health professionals, psychologist and pastoral counsellors provide individual counselling (71% individual counselling, 29% ad hoc groups). In the case of non-professional helpers (N=19 persons), we find proportional distribution of support-group sessions and individual supportive discussions. Recent experience, however, predicts a change in this field. The common experience shared by both bereaved parents and non-professional helpers is that allowing non-professional helpers to the bedside is becoming more widespread. And the result of this process is a radical shift towards non-profit grief support services and growing public awareness of the support possibilities. In the event of a more complex traumatic grief, it would be important for the bereaved to be treated by clinical psychologists and grief therapists or psychiatrists. Compliance with competence boundaries should be emphasized, as it is extremely difficult and demanding for leaders of

bereavement support groups to manage group dynamics when the members have diverse loss experiences, and their grieving process is individual as well.

There is a significant difference between the services offered by profit-oriented and non-profit organizations. While non-profit organizations (public sector employees, non-professional volunteers, NGOs, etc.) do not urge people to join a group and start the process, leaving time to incubate the pain and choose the right moment, profit-oriented service providers emphasize the need for urgent help, and in some cases their underlying goal is to keep the bereaved in their practice for as long as possible, thereby maximizing their income. The background of this phenomenon is the shortage of psychologists in healthcare institutions and the long patient waiting lists. Thus, besides the consultations and counselling advertised by psychologists and mental health professionals, there are life coaches, psychodrama graduates and other service providers, many of whom non-professionals, who are advertising their paid services. Non-professionals advertising support services should be familiar with The Protocol for Psychotherapeutic Methods, which was written by professional associations and adopted by the Hungarian College of Psychiatry on the recommendation of the Council of Psychotherapy, and which stipulates: "*Duration of sessions: the normal session is 1 hour long (of which 45-50 minutes with the patient), double or triple sessions are usual for group or family therapy, but half-sessions might also take place*" (Zsák & Hegedűs, 2019).

Music therapy, bibliotherapy and the memory box

Bibliotherapy and music therapy are rarely applied in Hungarian clinical practice although they can be successfully used in rehabilitation, according to the explanation provided on the website of the Hungarian Bibliotherapy Association. Although the professional protocol of the Hungarian Music Therapy Association does not specify the applicability of the method in bereavement support, the general field of psychiatry is listed among its fields of application.

Feedback

We stress the importance of the development of a framework for remembering as a therapeutic option. By implementing the use of the memory box in Hungary, the spectrum of supportive gestures is widening, as the parents can keep the baby's armband, a lock of hair or first blanket in the box. In some foreign PIC Centres, items such as the baby's first outfit may be placed in this box accompanied by a photograph and handed over to the bereaved parents. Creating a memory box has many benefits because it is accessible at any time, its content helps to evoke the memory of the infant, but it does not retraumatize family members, as it is easy-to-hide thus ensuring an intimate framework for remembering.

During the research period, parents who made or received a memory box said the following in the group session:

- "At first I was afraid to take it out, now it is a part of the recollection and I am glad to have it."
- "This is my way of remembering, as these objects are the only memories I have."
- "By touching the photos, I can touch the baby a little bit again."
- "I felt resignation, joy, pain and sadness alternately, but today the positive experience is dominating."

When developing the framework for remembering we must take into consideration the phenomena described in international literature as mummification (Kaplan, 2010), as a children's room preserved with great care, like a mausoleum, is an inappropriate framework for the grief work and might hinder the grief work of siblings and other relatives.

In our review of the Hungarian practice, we sought to present the full spectrum of support services in Hungary, but the complexity of the topic only allowed us to focus on the best practices of the psychological support services available for bereaved parents who have experienced prenatal or perinatal loss.

References

Aker, A. T., Önen, P., & Karakiliç, H. (2007). Psychological Trauma: Research and Practice in Turkey. *International Journal of Mental Health*, *36* (3), 38-57.

Babbie, E. (2008). *A társadalomtudományi kutatás gyakorlata*. Budapest: Balassi.

Capitulo, F. (2004). Perinatal Grief Online. *The American Journal of Maternal and Child Nursing*, *29* (5), 305-311.

Caruth, C. (1995). *Trauma: Explorations in Memory*. Baltimore: The Johns Hopkins University Press.

Gold, K. J., Kuznia, A. L., & Hayward, R. A. (2008). How physicians cope with stillbirth or neonatal death: A national survey of obstetricians. *Obstetrics and Gynecology*, *112* (1), 29-34.

Gyáni, G. (2006). Trauma, emlékezet, kultusz. *Élet és Irodalom, 45* (6).

Horowitz, M. (1990) Post-Traumatic Stress Disorders: Psychosocial Aspects of the Diagnosis. *International Journal of Mental Health*, *19* (1), 21-36.

Hutchinson, A. (2019). *Facebook Reaches 2.38 Billion Users*. Retrieved from https://www.socialmediatoday.com/news/facebook-reaches-238-billion-users-beats-revenue-estimates-in-latest-upda/553403/ [21.10.2019].

Johnson, A. M., & Szurek, S. A. (1952). The Genesis of Antisocial Acting Out in Children and Adults. *The Psychoanalytic Quarterly*, *21* (3), 323-343.

Kaplan, H. I. (2010). Bereavement and Death. Pocket Handbook of Clinical Psychiatry. In Kaplan, H. I. (Ed.), *Pocket Handbook of Clinical Psychiatry* (pp. 220-222). Oxford: Lippincott Williams & Wilkins.

Kenner, C., Press, J., & Ryan, D. (2015). Recommendations for palliative and bereavement care in the NICU: A family-centered integrative approach. *Journal of Perinatology*, *35* (Suppl 1), 19-23.

Kiss, K. (2003). *Depression and grief-reaction Symptomatological comparison especially of suicidal symptoms*. [PhD Thesis]. Budapest: Semmelweis University.

Leys, R. (2000). *Trauma: A Genealogy*. Chicago: The University of Chicago Press.
Lindemann, E. (1944). Symptomatology and management of acute grief. *The American Journal of Psychiatry*, *101* (2), 141-148.
Malacrida, C. (1999). *Complicating Mourning: The Social Economy of Perinatal Death*. Qualitative Health Research, *9* (4). DOI: https://doi.org/10.1177/104973299129122036
de Mézerac, I., & Caeymaex, L. (2017). Parental mourning after a perinatal loss. *Archives de Pediatrie: Organe Officiel de la Societe Francaise de Pediatrie*, *24* (9), 877-883. DOI: https://doi.org/10.1016/j.arcped.2017.06.015
Rüsen, J. (2004). Trauma és gyász a történelmi gondolkodásban. *Magyar Lettre Internationale*, *54* (14).
Tomcsányi, T., Csáky-Pallavicini, R., Harmatta, J., Pilinszki, A., & Török, G. (2008). Lelkigondozás és pszichoterápia. *Pszichoterápia, 17* (3), 170-177.
Wolfelt, A. D. (1991). Toward an understanding of complicated grief: A comprehensive overview. *American Journal of Hospice and Palliative Medicine*, *8* (2), 28-30.
Zelena, A. (2017). Veszteségkommunikáció az újmédia színterein. *Médiakutató*, *18* (1-2), 139-149.
Zsák É, & Hegedűs K (2019). Szakemberek veszteségélményei, gyásza és megküzdési stratégiái a perinatális ellátásban: Szakirodalmi áttekintés. *Kharón*, *23* (2), 1-11.