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The impact of perinatal grief on siblings in the family

PhD Thesis Booklet

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1. Personal background

Initially, as a family care public health nurse, I came into contact with families who had lost their child during pregnancy or childbirth. Many questions arise in this under-researched area. As a practicing professional, I could only find answers to my questions through extensive study of grief, especially perinatal grief. Since 2006, my interviews, 18 years of grief counseling work, and experiences in public health nursing among families have made me realize the profound and complex nature of this problem. It became apparent that the processing of perinatal loss plays a key role in the families' relationship with their already born or soon-to-be born children, and the support they received or will receive in this matter.

Since 2018, I have been teaching the theoretical and practical steps of processing loss and perinatal grief in the midwifery and public health nursing education at the University of Pécs, Faculty of Health Sciences. My current research has reinforced the importance of expanding the knowledge of future graduate healthcare professionals who will deal with pregnant women and young families about this unspoken topic.

2. Introduction

“Perinatal loss is a prevalent health concern with one in four pregnancies ending in loss (Armstrong, 2004; Christiansen, 2017). Around 2.6 million stillbirths are reported globally each year” (Herbert et al., 2022, p. 118)

Perinatal loss can cause trauma in expectant mothers regardless of gestational weeks. This mental burden often leads to psychiatric disorders. Significant correlations have been found between depression, anxiety, and Post-Traumatic

Stress Disorder (PTSD) in women who have experienced perinatal loss (Herbert et al., 2022).

The phenomenon's concealment and suppression are common in family life. However, the unprocessed grief of parents and siblings can lead to physical and mental health impairments (Funk et al., 2018). The impact of perinatal loss affects the entire family system. Surviving children struggle to find their place in this changed environment (Hooper, 2011). Furthermore, parents are no longer the same for surviving siblings after the loss. Parentification – when a child tries to care for their parents and siblings – almost always occurs, influencing the personality development of surviving siblings. If children are forced to take over the role of parents, it can become part of their identity, overburdening them, and preventing balanced personality development and a normal childhood life. Thus, surviving siblings not only lose their deceased sibling but also their right to their own life and identity.

These children often experience a crisis epitomized by the thought, “I didn't know where I belonged.” In some cases, parents attempt to replace the deceased infant with another child's birth. However, this mission is unattainable, as the unprocessed loss makes the lost child irreplaceable and idealized in the parents' eyes. Children growing up in such scenarios are not just reminders of their lost sibling; they themselves become the memories, thereby unable to live their own lives (Bakó & Zana, 2021; Balogh et al. 2021).

In the family, roles and functions need to be reinterpreted. Everyone in the family and the family as a community experiences loss and grief. This grief extends beyond individual family members' loss, manifesting in systemic effects (Murray et al., 2005).

3. Basic concepts

The concept of grief

“Grief is the feeling of having lost a part of oneself with the deceased; this is accompanied by the painful sensation of experiencing death as a personal loss.” (Kovácsné Török et al., 1995:243)

“The essence of grief is loss and sorrow.” (Pilling, 2003:27)

In the literature, various models describe grief differently. Lindemann, in his 1944 article, was among the first to deal with the symptoms of acute grief (Lindemann, 1998).

This study also addresses anticipatory grief reactions, stress-induced physical symptoms, immersion in memories of the lost one, guilt, irritability, changes in daily behavior, and symptoms bordering on pathological grief reactions, like exhibiting traits reminiscent of the deceased. Later authors in the 1960s delineated three phases in the loss process: emotional shock, realization of loss, and recovery. Subsequent models in later years are similar in the first and third stages but present more differentiated characteristics of the process. These models vividly capture the diversity and dynamics of the grieving process, delineating the boundaries of each stage. One well-known but critiqued model by Elisabeth Kübler-Ross, initially based on her observations of the dying phases, which was later applied to grief processing, includes denial, anger, bargaining, depression, and acceptance (Kübler-Ross, 1988; Pilling, 2003). Pilling (2003) mentions the following stages:

- Anticipatory grief, which can ease the burden of loss but also create overly strong attachments hindering normal grieving.
- Shock stage characterized by emotional numbness, weakness, or uncontrollable emotional outbursts.

- Controlled stage where the reality of death is acknowledged.
- Realization stage marked by participation in the funeral and expression of emotions.
- Processing stage where memories of the deceased become more controllable.
- Adaptation stage, the conclusion of grief processing, where the deceased is carried as a memory, allowing for a return to normal life and future planning (Pilling, 2003).

One of the strongest critiques of Kübler-Ross's theory is that healthy grief is characterized by the ongoing maintenance of a transformed bond (continuing bond), rather than detachment and acceptance. This critique, articulated by Klass and his colleagues (1996), suggests a different understanding of the grief process. Additionally, reviewing the stages of grief is useful for a deeper understanding of the topic and highlights the significance of memory in grief processing, as noted by Pilling (2003). This approach allows for the possibility of interconnectivity among different models of grief.

Currently, alongside stage models, we encounter various other theories in grief research. Five main perspectives have shaped theories and research on loss to date. Freud's grief work concept (2003) denotes the process that individuals who have experienced grief must undergo to cope with loss. Bowlby's attachment theory (1969; 1973; 1980) considers the grieving process from the perspective of the bond between the mourner and the lost loved one (Stroebe et al., 2010). Neimeyer's meaning reconstruction theory (2001) emphasizes the cognitive process of finding meaning in the experienced events. The cognitive stress theory approach examines negative and positive emotions in processing loss. The dual-process model focuses on the dynamic nature of processing.

In the initial stages of processing grief, there is a predominant focus on “loss orientation,” while the conclusion of processing is marked by “restoration orientation”. The model describes grief as a dynamically evolving process where changes in emotional state determine the intensity of each stage. During loss, elements of recovery and deep pain-focused aspects alternate. The model posits that the grief mechanism is defined by a dynamic coping strategy, involving the alternation between confronting and managing emotional states. The individual grapples with pain and emptiness, while simultaneously planning and rebuilding a future without the loved one. Emotions fluctuate in intensity and are unpredictable, leading to waves of pain and emptiness, sometimes subsiding entirely, creating “time out” periods that facilitate recovery (Stroebe & Stroebe, 1991).

Complicated grief refers to a mourning process that significantly deviates from the norms of the individual's cultural environment and is accompanied by physical and psychological symptoms that necessitate therapeutic intervention (Pilling, 2012).

When can a grieving process be considered complicated, prolonged, chronic (accompanied by prolonged anxiety, limited social relationships, idealization of the dead), hypertrophic (excessive intensity), delayed (symptoms of acute grief are absent, denial comes to the fore), magnified, or masked (unprocessed loss behind the bereaved person's symptoms and behavior) (Worden J. W. 2009; Pilling, 2012; Petruzzi, 2019)?

The DSM-5 considers a grieving process prolonged and problematic, warranting treatment, if it persists for over a year following the death and continues to dominate the mourner's emotions and thoughts. Associated

symptoms, such as feelings of meaninglessness in life, loneliness, pain, and emotional numbness, differ from cultural norms and are not explained by other mental illnesses.

Besides depression and anxiety disorders, Post-Traumatic Stress Disorder (PTSD) can also be a potential outcome of the complicated grief mechanism. While many recover in the months following the trauma, in a significant group of patients, symptoms can persist for years (Ehlers & Clark, 2000). According to the DSM-5 classification, PTSD occurs when a person experiences or witnesses severe injury, death, near-death situations, or sexual violence. This disorder is characterized by the reliving of these events through memories or dreams, physical or emotional pain, and avoidance of people, objects, or places that are reminders of the trauma. (Nussbaum, 2013; Réthelyi, 2020).

Overall, unresolved grief significantly predisposes individuals to various somatic, psychosomatic illnesses, and addictive behaviors. Unprocessed or delayed grief maintains a constant level of loss experience, leading to inexplicable depression due to suppression. Depending on the stage at which the grieving process is stuck, different symptoms may be encountered. Suppression can have an effect across generations. Anxious and worried parents and grandparents raise anxious and worried children, thus transmitting unprocessed loss from one generation to the next (Kovácsné Török et al., 1995; Polcz, 2000; Kast, 2002; Pilling, 2003).

Disenfranchised grief (Doka, 1999), a problem supporting suppression, occurs when the environment deprives the mourner of the right to express emotions and experiences during grief and to receive support. This leads to siblings becoming forgotten mourners, and the trauma of sibling loss becomes a silenced loss.

The concept of perinatal death

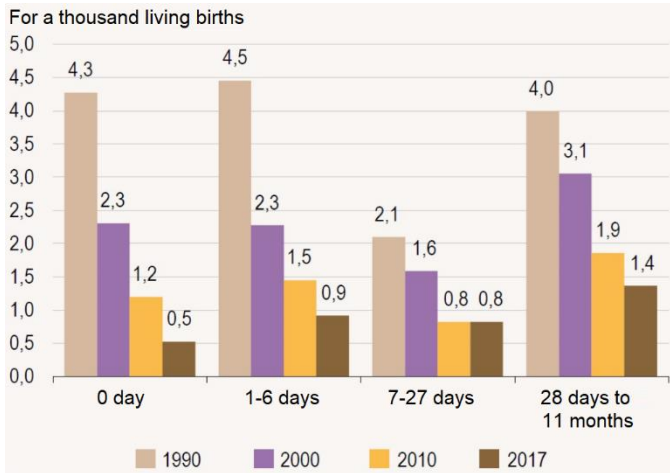
The concept of perinatal death in medical practice refers to cases where a newborn was alive at birth but died within 168 hours thereafter, or when a fetus weighing 500 grams or more and at least 30 cm in length dies in utero after the 24th week of gestation. (Szülészeti és Nőgyógyászati Szakmai Kollégium, & Országos Gyermekkegészségügyi Intézet / Professional College of Obstetrics and Gynecology, & National Institute of Child Health [SZNSZK & OGYEI], 2010).

This definition can vary internationally. In some regions like Washington state in the USA, Canada, and Western Australia, stillbirth is considered from the 20th week of gestation, and perinatal loss includes infants who die within 28 days after birth. The World Health Organization (WHO, 2006) sets the boundary at the 22nd week of gestation and defines the infant's age up to 7 days.

4. The incidence of perinatal loss

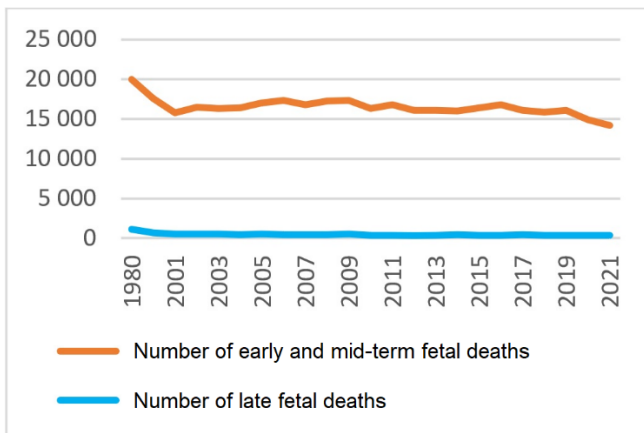
In 2022, Hungary reported a total of 14,141 cases of fetal loss, of which 420 were late fetal deaths, according to the Hungarian Central Statistical Office (KSH, 2023). Detailed data are illustrated in Figures 1 and 2.

Figure 1: Infant mortality in Hungary, by newborn age [number of cases]



Source: KSH, 2019:2

Figure 2: Fetal deaths in Hungary over the last 40 years [number of cases]



Source: own editing based on KSH (2023)

Perinatal death and sibling grief

Sibling loss is the most direct encounter with our own mortality (du Coudray, 2016). In the case of perinatal sibling death, processing is further complicated by the fact that the sibling often remains invisible, with little tangible evidence or even none for the sibling's existence (Meyer, 2015; Kovácsné Török & Szeverényi, 1999).

Furthermore, the death touches on two taboo subjects, death and sexuality. Parents become even more cautious and conceal secrets, as they often deal with small children who, at least in their view, cannot understand anything yet. Consequently, the child grows up in uncertainty, fearing something intangible and incomprehensible to them — sexuality, reproduction, and the associated risks. They may lose their parents as they knew them before the death, and also their trust in their “omnipotence” (protective power). They may even think that they are no longer as important, not cared for as much as before. Parents are frequently overwhelmed by grief to the extent that they cannot provide the same care to their children as they did before. In connection with these events, the family system undergoes transformations. The firstborn child “again” becomes an only child, or the second does not progress to the position of the middle child etc. (Fanos et al., 2009; Kiss & Sz. Makó, 2015).

Sibling grief, especially in the context of perinatal death, represents a case of disenfranchised grief, making siblings “forgotten mourners” (Kempson & Murdock, 2010, p. 740; Devita-Raeburn, 2004).

The role of early attachment in grief

We need to mention the role of attachment in grief because losses within the family direct the attention of parents and adult family members to the pain of

their own loss and the grieving process. The mother cannot be a “good enough mother” (Péley, 2004; Tóth-Varga & Dull, 2019), unable to assist the child in the process and facilitate the development of attachment. If the conception and birth of a next child happens during unresolved grief, then establishing appropriate early attachment becomes impossible. According to recent literature (Johnsen & Afgun, 2020; Barthes & Razafimandimby-Haelewyn, 2021), maintaining a continuous bond with the deceased at the family level and thoughtful meaning-making seeking answers to the loss can lead family members to genuine grief processing (Kiss & Sz. Makó, 2015).

Gender differences in grief

The stages of normal grief and their symptoms occur in the same way in both genders, with differences mainly in certain superficial manifestations rather than in the personal significance of grief.

Women tend to experience and express sadness and guilt more intensely, actively seeking external support and desiring to share their thoughts and feelings. Men's grief often involves more anger, aggression, and a sense of anxiety about losing control over events. They frequently experience hidden grief, feeling a need to remain strong and maintain a managerial role in the family. (Leon, 2001; Oikonen & Brownlee, 2002; McCreight, 2004; Kersting, 2005; O'Lary & Thorwick, 2005; Turton et al., 2006).

Women generally express their inner emotional world more openly and vividly in words, using expressions indicative of anxiety and sadness in their grief narratives. Men, in contrast, tend to use words reflecting anger, aggression, and hostility during the grieving process, often adopting an inward stance and an external observer's perspective. These characteristics can negatively impact

communication between couples during the process of grieving and adversely affect their relationship (Stelzer et al., 2019).

5. Research questions

1. How did the respondents experience perinatal loss?
2. What do they know about the events, how do they recall them, and how did they feel then and now about the loss?
3. What are the characteristics of perinatal grief in siblings?
4. How are the key explanatory principles discussed in the literature review manifested in the studied sample?
5. Are there any differences between men's and women's experiences of grief?

6. Research materials and methods

This is an exploratory study on sibling grief associated with perinatal loss. Thirty in-depth interviews were conducted with adults who had experienced the loss of a sibling during the perinatal period. The research methodology included Interpretative Phenomenological Analysis (IPA), as well as quantitative content analysis and qualitative context analysis. The data of the 30 individuals are summarized in Table 1.

Table 1: Summary data of the interviews (n=30)

#	Code	Age	Length of the interview (mins)	Lost sibling
1.	MGA	41	40	lived for 40 hours
2.	MOD	31	13	lived for one week
3.	MPB	30	12	stillborn
4.	MBM	23	20	stillborn
5.	MOMI	27	14	lived for one week
6.	MPLG	47	15	lived for five days
7.	MTLP	53	14	stillborn
8.	MVS	35	31	stillborn
9.	MHB	27	6	stillborn
10.	MKK	27	6	stillborn
11.	MRDA	33	2	stillborn
12.	MRDO	28	5	stillborn
13.	MTT	28	8	stillborn
14.	MVP	38	3	lived for only a few hours
15.	FKE	23	45	lived for 40 hours
16.	FBV	28	15	stillborn
17.	FHM	47	12	stillborn
18.	FRR	34	28	stillborn
19.	FRG	30	20	stillborn
20.	FRF	26	28	stillborn
21.	FPI	63	15	stillborn
22.	FCL	50	38	stillborn
23.	FJZs	42	45	stillborn
24.	FDN	25	25	lived for 3 days
25.	FLV	54	23	stillborn
26.	FKF	38	12	stillborn
27.	FFA	23	8	stillborn
28.	FRJ	25	6	stillborn
29.	FRV	22	7	stillborn
30.	FTD	22	9	stillborn

Source: Own editing

In the first study, we used Interpretative Phenomenological Analysis (IPA) to explore respondents' lived experiences and meaning-making strategies related to the first research question. This analysis was based on 20 interviews, involving 8 male and 12 female respondents, aged between 23 and 63 years. ($M = 37.35$; $SD = 11.73$). The average length of the interviews was around 23 minutes ($M = 23.28$; $SD = 11.32$), with men speaking less ($M = 19.85$; $SD = 10.22$), and women providing more detailed accounts ($M = 25.55$; $SD = 11.86$).

In the second study, we combined deductive and inductive approaches using a traditional word frequency analysis to identify potential gender differences. This involved using the entire text corpus and was supplemented by a further qualitative analysis.

7 Results

IPA results

The following Table 2 summarizes the research comments, themes, and master themes that emerged during the interviews.

Table 2: Emerging themes and master themes

Emerging themes (with brief comments in brackets)	Master themes
Eternal life in the other world (life of a guardian angel/"as if" saint; redemption; a soul just watching, not interfering)	Spirituality
Relations to this world (signs through dreams, drawings, and natural phenomena; imagination; auguries, e.g., giving name to the deceased sibling or predicting the loss; supernatural experiences as revelations)	
One's personal mission in life (make up for the loss; the lost sibling's fate)	
Relation to God	
Wish to see the lost baby (S/he is a person, a family member, has a name, and is to be remembered /re-membered)	Establishing the bond/ Continuing bonds
Need for rituals (funeral and other leave-taking rituals)	
Own sacrifice (e.g., giving own favorite toy to the lost sibling)	
The lost sibling's life continues (e.g., visualizing them as kindergarten children or adults.)	
Secrets and suppression (related to parents' own emotions, own divinations)	Parental grief and mourning
Parents' sadness (dark period in the life of the family, suicidal mother, impairments of the bond)	

Distancing, objectivity (“this is how it was and that’s all”)

External communication (at the hospital, at school etc.—the infant is a non-person in the eyes of others; dies alone, without ever having a chance to experience the love of the family). External reactions

Secrets (when communicating with friends and acquaintances; on part of the medical staff concerning the cause of death)

Parentification (early burden related to parents’ grief and sometimes to other traumas) Transforming power of trauma

Birth order (“where is my place?”)

Changes in identity aspirations

A series of other traumas in the family (secrets; traumas activated by or related to the loss of sibling)

Specific temporal relations reflected in the sentence structure and grammar

Post-traumatic growth

Fears from a similar experience in one’s own life

Mixed feelings and attitudes (awe, sadness, anger, guilt, appreciation of life) Emotions

Enmeshed boundaries (own emotions—parents’ emotions)

Blaming the medical staff (suspected malpractice, lack of information, mechanical handling of grief; hypothesized crime)

Who is responsible?

Fetal experiences (family conflicts)

Disturbed order (the sibling herself should not have been born so that the lost sister could live)

Source: Bornemisza et al., 2022.

I will briefly describe the master themes below, also providing a characteristic quote for each:

1. Spirituality

Each narrative contained some form of spirituality, manifested in respondents' lives as a religious faith in God, transcendent experiences, and the search for meaning in the events. The lost sibling continues to exist in another dimension: FCA: “he lives, but not here, with us on Earth ... he watches us from above and protects us as a blessed soul ... so to say, a saint. Not a canonized saint but he is in Heaven, and ... and ... and he knows that he belongs to us, and we belong to him.”

2. The deceased sibling as a person

The lost sibling is considered a member of the family, and the attachment persists even after their passing. There is a strong desire in the living siblings to identify the person responsible for the loss, which is one way of expressing the unbreakable family bonds. For FSB, his little brother was a family member, but the hospital staff did not treat him as a person – according to FSB, they did so in a mechanical and inhumane way. FSB: “and then I told my Dad... I only wanted

to put it all off ... that I wanted to see the baby. I don't care what they (i.e., medical staff) say now, I want to see him. And my Dad asked them to let us see him but they did not allow ... did not allow to, what I ... I ... and this was the other day, the story when (...) when they told us that we could not see him, and I was very, very, very angry and I just could not understand why it happened this way. (...) A child is born, and they know that he has no chance to survive, they just put him in an incubator and neither his mother, nor his father, nor his siblings can see him ... not even when ... when they explicitly ask for it ... why is it better for this child to suffer alone ... why not ... if he has to die it is not the same ... to die in the arms of loving family members. And I ... this has been very painful for me that ... if they in the hospital condemned him to die ... if ... he had injuries, or ... I cannot decide if these were the results of some malpractice during delivery (...) whether or not they made a mistake during delivery, they surely made a mistake when they let that child, my brother, die without ever feeling the loving arms.”

3. Responsibility, guilt

FPT points out the possible responsibility of the parents and the family for the loss. The speaker expresses mixed feelings through repetitions and distancing generalizations (“anyone”; “thing”; “you”; “our psyche”). While trying to avoid blaming his mother, he emphasizes the possible role of family conflicts in perinatal loss. Although this is a highly painful way to regain control over uncontrollable events, it allows him to make the most of his father's sacrifice, who quit drinking for his family when FPT was born:

PT: “I can even imagine that the, the, the ... the, the first ... uh, fetus was aborted because of this psychological pressure although I cannot tell you why ...

and that uh, uh, uh, Gergő who knows why ... I don't believe in things happening by chance. There is no such a thing as chance ... I think, uh, I do not want to claim that ... you cannot decide on a nuchal cord but, but I think our psyche does very strange things sometimes. And ... and I want to be properly understood. I do not want to blame my mother as ... as I do not think anyone would want to blame the mother for a birth fatality, but who knows, perhaps the child himself, that is, Gergő might have received some impressions and, as a result, he did not want to be here.”

4. Importance of the bond

The idea that the deceased sibling exists in another world and sometimes connects with this world without disturbing those living here can be a source of comfort.

PT: “(...) it is possible that ... that, that in a way he sometimes appears but does not interfere with this world ... just as if he would have a look at us, “yeah, this is it here, you are here, and it is all right.” ... No ... I cannot feel that he would be filled with anger, that is, if I think of Gergő, I cannot feel that there would be any pain.”

5. Transformation of family roles

The deep grief of the parents has a profound impact on the surviving children. They may feel uncertain or threatened due to their parents' emotions. If the parents' state of deep grief persists, they become emotionally unavailable to the surviving children.

KE: “... when we buried... and then I used to live with my grandparents for about a year, with one or the other. The ones who did not care about me cared

about my mother. She, she did not want to get out of bed at all except when she went to the cemetery, and she used to spend all her day either in the cemetery or lying in her bed at home. While she was at home, someone was always around watching as she had grave suicidal thoughts. She thought that I had my father to stay with me and she could go with my sister so that she would not be alone. Practically, she would have left me if she had been able to. (...) (speaking about a photo she is showing) I have the same empty glance as my mother has ... truly, my pain is not mine; but what my parents have experienced. Their pain is mine, in reality.”

The following Figure 3 visually presents the most important results of the interviewees' meaning-making processes.

Figure 3: Conceptual Network



Source: Bornemisza et al., 2022

Mixed method content analysis (quantitative-qualitative)

- The first step involved creating a word frequency list, which includes all the words from the 30 interviews.
- • Next, words with an occurrence rate exceeding 0.1% were categorized to characterize the main contents of the narratives in the search bibliography.
- The list was supplemented with search terms that proved to be relevant in the previous IPA study, such as words related to birth, naming, and death. Out of a total of 35,646 words, 17,146 (48%) were categorized in some way.

To conduct the statistical analysis, we used the IBM SPSS Statistics 26.0 program. Our results were obtained by comparing the data of the two groups. For this purpose, we chose one-way analysis of variance (ANOVA) and analyzed effect size (partial eta-squared: $\eta^2 = SS_{\text{effect}}/SS_{\text{total}}$). We interpreted the effect size according to Cohen's (1988) guidelines: a small effect size up to 0.01, a medium effect size up to 0.06, and a large effect size up to 0.14.

To analyze potential gender differences, we needed to balance the gender ratios. Therefore, we used a Boxplot diagram to determine if there were outliers across age, which led to the exclusion of two female participants. We used the data of N = 14 females (M = 31.07; SD = 9.58) and N = 14 males (M = 33.43; SD = 8.58) for the most accurate quantitative analysis results. The search bibliography is provided in Table 3.

Table 3: Search bibliography

Category	Search term
Who	who whom about who with who
What	what about what with what
Mother	mother mum*
Father	father dad*
Only	only just
3rd singular	they them (to them, with them etc.)
First	first
1st sing. emph.	I
year (old)	year (old)
Conditional	perhaps maybe possibly might be if
Child	child children
Indeterm. Pron.	any*
Temp:moment	then when since after
Temp:phase	yet, always
Yes	yes
Good	good well
Came	came
Connective and	and
Two	two
Little	little, tiny
Demo-close	this these
Will be	will be will become
Explanatory	as because that is
me	(in with on etc.) me
Death	died dead lived not alive
Qualifiers	such so as this much that much very
Said	said
Past	was were happened became
Big	big great
Negative	no not never non neither nowhere
name	name
There	there

3rd plural	they them
Self-refl. Present	know remember can think am according to me
Self-refl. Past	said was knew thought
Many	many much a lot
Must	must had to needed should have to
Delivery	delivery birth hospital born baby
Demo distant	that about that those
Sibling	sibling*
Fillers	really of course somehow certainly let's say otherwise well surely
Connective but	but or rather
Exists	there is

Source: Bornemisza et al., 2023

Results of the quantitative analysis

Significant gender differences were found in three codes. The first one is “name” ($F(1,26) = 6.637$; $p = .02$; $p < .05$), with a partial eta-squared = .20 (large effect): females use the “name” of their lost sibling more often than males ($M_{\text{female}} = 2.28$ and $M_{\text{male}} = .71$). The use of “third person plural/they” code is significantly more frequent in the female group ($F(1,26) = 5.404$; $p = .03$; $p < .05$; $M_{\text{female}} = 5.36$; $M_{\text{male}} = 1.78$), with an effect size of $\eta^2 = .17$ (large effect). There was a difference along the “delivery” code ($F(1,26) = 5.013$; $p = .03$; $p < .05$), with an effect size of $\eta^2 = .16$ (large effect): females used this code more often as well ($M_{\text{female}} = 14.43$; $M_{\text{male}} = 7.00$).

The qualitative component: a contextual analysis for the codes “name” and “delivery”

Naming the deceased sibling is an event that validates the sibling's existence as an individual. This is significant for surviving siblings as it protects them from the irrational threat of a child simply disappearing from the family's life. This theme is more common among women, who, however, tend to speak less specifically about it, while men explicitly mention names. Of the 30 interviews, 12 female respondents raised this theme that resulted in 36 quotations, and only five occurrences of first names could be identified. Only five males spoke about names in the altogether 15 quotations but mentioned 13 specific names in the retrieved quotations.

8. Summary

The analyzed stories revolve around losses that occurred decades ago. Perinatal loss in the family is a transformative experience for the surviving siblings, which is reflected in the content of the stories and in the fragmentation of the narratives. The main themes identified in our analysis closely resemble major themes found in other sources (Fanos et al., 2009; Kempson & Murdock, 2010; Meyer, 2015; Funk et al., 2018), such as a strong spiritual orientation (guardian angel, heavenly afterlife, sensing presence) and efforts to create a continuing bond (Meyer, 2015). In this bond, the sibling continues to live on. The stories often featured changes in family relationships as well as shifts in previously envisioned roles and identities. In our sample, the quest for meaning-making is a central element of the narratives, and this endeavor is often successful in existential-spiritual or even personal terms but less so in practical terms. The cause of death, including potential genetic risks, personal

responsibilities, and legal obligations, was generally not clear to grieving siblings. This may result from ethical and legal shortcomings in the contemporary healthcare system, as well as a lack of expected supportive and authentic communication in medical settings.

Even if grieving siblings acknowledge the lost sibling as an individual and a family member, they may not have the time to establish a meaningful connection in real life – neither in their imagination. This can further exacerbate existing disturbances (Meyer, 2015). Meyer distinguishes between continuous and symbolically constructed bonds, which often remain unique and private. However, grieving siblings make active efforts to turn them into a shared family reality. To create such a shared family reality, the deceased infant needs to be given a name, seen, buried, and the experiences need to be shared repeatedly. Contrary to earlier notions, the continuing bond can play a positive role in the grieving process (Neimeyer et al., 2014). The bond appears to be essential for surviving siblings. For them, the bond serves as evidence that the child doesn't simply disappear from the family as if they had never existed. For parents who have various concerns about their own grief, parental identity, and generativity, the constructed bond may not be reassuring. The professional literature presents conflicting data about this issue. Some authors believe that establishing the bond is important, while others argue that it may be a possible source of enduring depression and anxiety (Kersting & Wagner, 2012).

According to Neimeyer and his colleagues (2014), grief is not primarily an intrapsychic but an interpersonal process, a socially constructed response to environmental events. Numerous studies refer to grieving siblings as “forgotten mourners” (Kempson & Murdock, 2010, p. 740). Death and grief are natural experiences in life, and pathologizing these natural human experiences can do

more harm than good. “Validation is in short supply when a sibling dies. (...) the less validation, the more ambiguous the loss, the more frozen the grief” (Devita-Raeburn, 2004, p. 31). In this research, these phenomena were evident in the siblings' narratives, often identifying a dissonance between the rational, culturally endorsed interpretations of the reminiscents and the underlying emotions, such as pain, confusion, self-blame, and resentment.

Most of our results of the mixed methods analysis confirmed the main findings of the IPA study (Bornemisza et al., 2022), as there was no significant gender differences in this sample. Our findings closely resemble what Stelzer and colleagues (2019) found when examining narratives of grief: there are more similarities than differences between male and female grieving individuals.

It appears that the organization of texts related to trauma shares common features: the shared journey of grief is reflected in the similar occurrence of function words. This finding can be explained by the phenomenology of crisis experience: in the chaotic moments of identity transformation, an individual's state or situation often dominates over stable social roles and personality traits (B. Erdős & Jávör, 2021). Gender differences are likely to occur in contexts where gender roles are particularly salient (Stelzer et al., 2019).

We can identify distinct and noticeable differences between the occurrences of two content words and their contexts. Naming the deceased sibling is an act that validates the sibling's existence as an individual. This is significant for surviving siblings, as it reinforces the reality and significance of the child's existence. The theme is more common among women, who, however, speak less specifically about it, whereas for men, mentioning a specific name highlights a more instrumental engagement.

It is not surprising that significant differences emerged in the use of expressions related to the birth process. For men, this experience is obviously more distant; they referred to it less frequently and focused more on the possible causes and circumstances. Women's identification with the mother was much stronger, and except for a few exceptions, they tended to focus more on their emotions.

In summary, both analyses confirmed that the depth of emotional experience does not differ between women and men - but the way emotions are expressed may vary somewhat.

These studies have affirmed the long-term effects of sibling grief due to perinatal loss on the lives of surviving siblings. Early intervention, preferably involving the entire family, can protect surviving siblings from these effects, such as dysfunctional changes in family roles and dynamics, as well as potential harm to the mental health of family members.

9. Future research directions

- How and where can parents, siblings, and relatives affected by perinatal grief get help and support?
- To what extent is post-traumatic growth present among those coping with perinatal loss?
- How do siblings who have experienced perinatal loss relate to the question of having children themselves?

10. Recommendations

In 2010, professional guidelines based on progressive, contemporary principles were introduced for perinatal loss. These guidelines aim to protect

families from the potential long-term destructive effects of perinatal loss. The implementation of these efforts and the translation of guidelines into practice greatly depend on the organizational culture of the respective institution. As part of the changes, bereavement rooms were supposed to be established in every hospital, but this has not been widely realized so far. Furthermore, grieving families are still only informally informed about their right to arrange the burial of the fetus.

Witnesses to early family losses in their work are often the public health care nurses. Although, according to current laws, only a doctor can communicate the fact of death (Monostori et al., 2018), they can find themselves in situations where they must prepare the family, even if indirectly, to receive bad news. Supportive conversations with the mother and the family provide an opportunity for realizing the loss and initiating the grieving process.

In the case of perinatal loss, hospital and district public nurses, who are the first to encounter grief in the lives of families, do not receive specialized training for handling grief and supporting families. Currently, if a healthcare professional deems it necessary, they can refer the grieving family towards specialized help. In Hungary, even in larger cities, there are few mental health professionals available for free access, who can be reached through Health Development Offices or the Family and Child Welfare Service. However, those living in smaller rural communities can rely solely on the support of public health nurses within their local area (Zsák et al., 2015)

Steps and efforts have emerged to address the above-mentioned problem. Within the framework of the Health Visitor MSc program, the training program for hospital and district public nurses has already incorporated a more extensive curriculum on loss and perinatal grief, providing theoretical and practical

education. Additionally, Eötvös Loránd University (ELTE) has been offering specialized training for perinatal counselors since 2007.

Currently, within a separate course titled “Processing Loss,” available as an elective within the curriculum of the Institute of Midwifery and Health Visitors at the University of Pécs, students can acquire theoretical and practical knowledge.

For healthcare professionals working in the field, widely organized continuing education and interactive online resources would assist in shaping their mindset and deepening their competencies.

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A perinatális veszteség hatása a testvérekre. PTE ETK Doktori Iskola X. Tudományos Fórum, Pécs, 2020

Perinatal loss in the family VII. Interdiszciplináris Doktorandusz Konferencia, Pécs, 2018

Fate analysis on Szondi Lipót in the film of Szabó István “Sunshine” XXI.st Congress of the International Szondi Association Power of Fate: Past, Present, Future, Budapest, 2017

Normál és szövődményes gyász, támogatási stratégia a megküzdés során

– Országos Alapellátási Intézet kötelező szakmacsoportos továbbképzése ápolók részére. Kaposvár, Gyöngyös, Szekszárd, Debrecen, Pécs, Budapest, 2012-2016

A védőnő (egészségügyi szakdolgozó) szerepe perinatális veszteség idején

- Az Egészségügyi Szakdolgozók XXXVII. Országos Kongresszusa, Pécs, 2006
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- PTE Egészségügyi Főiskolai Kar, TDK Kari Konferencia, 2000
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