

**SEMMELWEIS EGYETEM**  
**DOKTORI ISKOLA**

**Ph.D. értekezések**

**2602.**

**ZSÁK ÉVA**

**Mentális egészségtudományok**  
című program

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# **ANALYSIS OF THE CURRENTLY APPLIED PRACTICES REGARDING PERINATAL AND INTRAUTERINE DEATH EVENTS AND OF THEIR EFFECTS ON HEALTHCARE PROFESSIONALS**

**PhD thesis**

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Budapest  
2021

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### List of Abbreviations

ABJ	Alapvető jogok biztosa
EAPC	European Association for Palliative Care
EMMI	Emberi Erőforrások Minisztériuma
EOL	End of Life
(G)W	(gestational) week
HCP	healthcare professional
ICPCN	International Children's Palliative Care Network
ISTAT	Istituto Nazionale di Statistica
IUD	intrauterine death
KSH	Központi Statisztikai Hivatal
NICU	Neonatal Intensive Care Unit
NILMDTS	Now I Lay Me Down To Sleep
OBDK	Országos Betegjogi, Ellátottjogi, Gyermekjogi és Dokumentációs Központ
PBC	perinatal bereavement care
PLIDA	Pregnancy Loss and Infant Death Alliance
PMR	perinatal mortality rate
SANDS	Stillbirth and neonatal death charity
TOP	Termination of Pregnancy
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

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## 1 INTRODUCTION

### 1.1 General introduction

#### 1.1.1 How it all started

*For sale: baby shoes, never worn*

E. Hemingway

Legend has it that once Hemingway won a bet with this short story of his, in which he was asked to prove whether he was able to tell a whole story by using solely six words. The short text may make the tragedy it tells more accentuated. Expecting a child, their arrivals are considered significant events in the life of a family that involve the promise of the future, of dreams coming true and joy. Most people do not even dare to think about the chances of something bad happening which may then utterly alter the joyful plans and hopes. When it still happens, void, pain, grief and shattered dreams are all that are left for the parents. What is more, their loss may cause, causes pain and feelings of grief to those healthcare professionals with whom they meet in this tragic life situation. Their attitude and their attention towards the parents greatly depend on how they think about the losses, how they experience these truly sad events. Nevertheless, talking about bereavement care in perinatal context until some time ago was unthinkable, a non-existent option, since it was not considered to be a proper loss or grief. Yet, we have come to understand that it is a real need of those families who must face the loss of the baby as early as the beginning of life. It may help them elaborate their pain and experience the best possible quality of life. Therefore, healthcare professionals active in this field must be prepared to provide this type of care, as well.

It is easier said than done, though. Professional background and human presence are both required, where the emotional involvement and difficulties of the care-providers may appear as a significant factor. Approximately 10 years ago I was doing my summer nursing practice in one of the largest hospitals in Hungary, at the department of obstetrics and gynaecology. During this time I witnessed how an experienced midwife refused to touch the lifeless body of a foetus, aborted during the second trimester of the pregnancy. She said that she would not want to put the body into the carrier dish, someone else should have done it for her and then carry it to the pathology department.

A couple of days later I overheard a conversation between two doctors, when one of them asked the other to inform his patient about the fact that there was something wrong with the pregnancy, probably the foetus died intrauterine, because he did not want to do that. It was when I started thinking about the likelihood of the occurrence, how and why it was so difficult for these excellent professionals to tackle sad situations and pay due respect towards their patients.

Some years later while attending an international conference, I listened to a lecture of a middle-aged Israeli doctor who was talking about the interruption of pregnancies, how they do it in his country, where it is possible to terminate a pregnancy for solid reasons even until right before the due date. While he was talking about the method of administering a K-injection into the foetus's heart, there was a crack in his voice and he tried to choke back tears. Adding it to my previous, related experience, I realised that facing loss in perinatal context was a demanding and serious phenomenon, with potentially influencing the care-providers professionally as well as personally, all of which was to be researched and investigated. Originally the research was planned to focus on Hungarian realities only, however, when during a postgraduate specialisation course in clinical perinatal psychology at the Università degli Studi di Brescia I could present the idea, I was also offered the opportunity to conduct some interviews in Italian institutions with Italian colleagues. This allowed me to keep the focus of the research on the Hungarian professionals, while placing it into a broader context, to confront and understand differences, possibilities provided by the cultural and institutional diversities.

#### 1.1.2 Definitions and usage of specific, characteristic expressions

It is fundamental to clearly define some specific terms related to pregnancy and childbirth used along the pages since their understanding will serve as a basis for discussion.

The clinical, medical definitions of *prenatal* and *perinatal periods* divide pregnancy into two halves. '*Prenatal*' denotes the weeks and months up to the defined threshold of prematurity, while '*perinatal*' indicates the period around birth, i.e. after the prematurity threshold up until the first week of extrauterine life, after birth. Due to the national differences in the definition of threshold, as it will later be indicated, the same period

can be regarded as prenatal or perinatal, depending on the actual countries in question, and will also result in differences of potential care.

On the other hand, it must be underlined that in perinatal psychology there is no such distinction between pre- and perinatal periods, it considers the period between conception and the end of the first year of the child as a whole, denoting it as '*perinatal*' from the very beginning. For the sake of simplicity, unless otherwise emphasised in focused topics, the expression '*perinatal*' is used in general in the thesis, following the clinical psychological concept, thus referring to the period as a whole and not distinguishing the involved care-providing personnel either, since their activities also overlap to a great extent.

The complexity of the period is also reflected in the terminology regarding the expected child. (Zsák, 2021) Subtle distinctions are recognisable in the notions. While intrauterine, at any gestational age, the baby is referred to as '*foetus*' in the relevant legislative and guideline measures. In case of a live birth (at any gestational age, when the vital signs are detected) the baby can be a '*child*' or a '*newborn*', as well. If stillbirth occurs, or early newborn death is registered, '*deceased newborn*' will be the used expression. All this may mean, for example, that a premature baby, born at w34 is called a '*child*', however, until unborn, intrauterine, a '*foetus*'. The actual birth event and the predefined threshold of preterm birth are decisive regarding the designation, which also precondition the status of the child. In case of early pregnancy losses, before premature birth events, official texts also use the expressions '*aborted foetal material*' and '*healthcare waste*', both of which carry sad connotations.

### 1.1.3 The outline of the thesis

In order that the significance of the bereavement care elements can be understood, the emotional weight of adverse outcome perinatal events and the importance of the attitude of the healthcare providers can be highlighted all the different aspects of perinatal loss are to be examined from the point of view of the care-giving personnel.

The definitions of pre- and perinatal loss, and statistical data are followed by the description of grief, of its progression so that they can be compared to the special characteristics of complicated grief of child loss. Here the factors accompanying pre- or perinatal loss are also considered. Ethical dilemmas connected to pregnancy and prematurity and the moral distress they may lead to follow the presentation of scientific

background. The subsequent section deals with the relevant legislative background, with those related healthcare regulations and guidelines that are currently valid in Hungary and in Italy. Partly, these indications are nationwide rules, nonetheless, the individual institutions may and do have their own specific measures, as it will be demonstrated. An overview of the international guideline recommendations regarding support of staff in case of demanding loss situations demonstrates how policy making attempts to present available solutions and to promote staff well-being.

The sections of the Results chapter present the difficulties and challenges of the healthcare professionals via the deductive and inductive coding structures, based on the thematic analysis of the interview contents. The illustrative quotes from the narrative interview materials serve to highlight the most noteworthy segments of the identified themes, and are indicated between inverted commas, also with different font size and paragraph if longer than two lines. At the end of each quote the profession of the interviewee is indicated in brackets. The final part of the Results describes a planned continuing education programme (Perinatal Bereavement Care in Every Practice), followed by a proposal for further research activity on the basis of the findings in international studies and findings of the conducted PhD research activity. Lastly, recommendations for Perinatal Bereavement Care Guidelines, with focus on staff support are proposed.

## **1.2 Perinatal loss definitions and figures**

### **1.2.1 The relevant indicators**

The adverse outcome events of the wider interpretation of the perinatal period - starting from conception to the end of the first childhood month – may be outlined in more terms. Loss at the beginning of pregnancy is early pregnancy loss, while in the second trimester and later we talk about late pregnancy loss or even stillbirth. Stillbirth rate is a characteristic number of a country's healthcare system and well-being. Perinatal death, together with stillbirth, also incorporates neonatal death, when death occurs within days of birth. Perinatal mortality rate (PMR) is the mortality registered as late intrauterine death and death until d6 after birth, i.e. early neonatal death. Prematurity is a fragile state of the newborn child, thus babies born prematurely may potentially be prone to worse health conditions than children born after w37, thus it is also a significant

indicator of perinatal loss events, defining PMR to a great extent. Neonatal mortality may happen within the first week of extrauterine life or until the end of the first month. All these figures, while also interdependent, together may portray a detailed picture of child loss spectrum before or shortly after birth, therefore, all of them are to be presented on the subsequent pages. It must be noted, however, that there are some notable differences in registering the adverse outcome events due to differences in guideline definitions and measures. Although all attempts have been made to present synchronised data, in some cases it could not be fulfilled. The variations will be indicated where necessary.

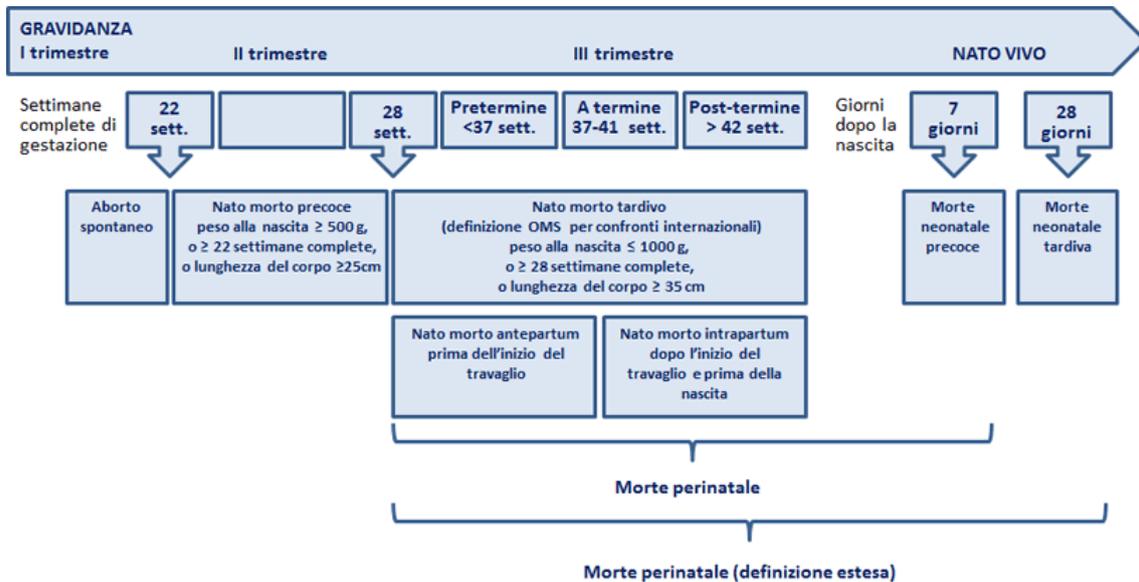
### 1.2.2 Guideline definition of pregnancy and childbirth related loss in Hungary

According to the presently valid Hungarian medical guidelines regarding pregnancy and childbirth related loss (Hivatalos Értésítő, 2010), prenatal (intrauterine foetal) death is when the death of the foetus occurs before the 24<sup>th</sup> week of pregnancy, when the child stills lacks the necessary skills for survival outside the womb, during the first or the second trimester. Perinatal death, on the other hand, means either the intrauterine death of the child after the 24<sup>th</sup> week, with a minimum of 500g weight and 30cm length, or the death of a live born baby, within the first 168 hours of life.

It is important to emphasize, furthermore, that w24 is the Hungarian arbitrary distinction between the pre- and perinatal period, since, for example, while this cut-off falls on w20 in the USA, thus defining the preterm birth itself, in Italy, on the other hand, it is w28. This medical status, depending also on the possibilities of medical technology, significantly influences our concept of the child/foetus as a human being, since before these time limits (while talking about the same physiological, developmental status) intrauterine death is considered to be a late pregnancy loss, birth, any chance to live can be after these points in time, and, as it is clearly visible, it may differ to a great deal from one country to another.

These dates also indicate the starting points when a (very early) preterm baby will be given any medical treatment to live. Moreover, these definitions and all the notions originating from them will considerably delineate the care-providers' attitudes regarding the losses occurring during the period in question.

## 1.2.3 Guideline definition of pregnancy and childbirth related loss in Italy



**Figure 1.1 Perinatal death definitions in Italy**

Source: <https://www.epicentro.iss.it/itoss/EpidMortPerinatale>

The above infogram (Figure 1.1) from the *Istituto Superiore della Sanità*, the Italian national institute for epidemiology, well summarises the main chronological steps how the development of the pregnancy shows the main milestones when presenting perinatal death events. The timeframes indicate the following distinction:

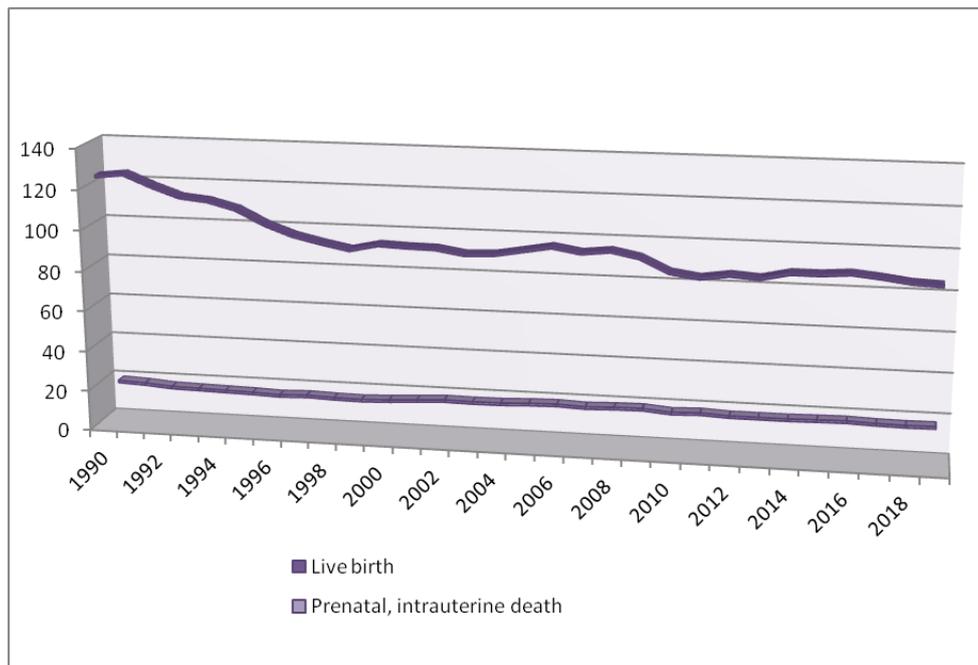
- ◆ 22 sett/ w22 before that Italian guidelines talk about spontaneous abortion,
- ◆ between w22 and w28 (22 sett-28 sett) early gestation stillbirth, with  $\geq 500$  g birth weight and/or  $\geq 25$  cm length, and/or w22 completed,
- ◆ between w28 (28 sett) and w37 (<37 sett) premature birth, w37 and w41 (37-41 sett) birth regular birth, while after w42 (>42 sett) postterm birth,
- ◆ during the period of w28-42 if death occurs, late gestation stillbirth is defined in the following ways: birth weight  $\leq 1000$ g,  $\geq 35$  cm length, and
- ◆ antenatal death happens before labour starts, while intrapartum death takes place after the start of labour and before birth,
- ◆ postnatal death is categorised as early newborn death (within 7 days after birth - 7 giorni) or late newborn death (within 28 days after birth – 28 giorni).

Comparing the Hungarian and Italian definitions, one may recognise a noteworthy difference in the definitions. The date of premature birth in Hungary is w24, while in Italy it is w28. This difference may have an impact also on the indicators regarding loss, and recurring in other markers, too, yet, the nationally set cut-offs are the background data to our understanding of the phenomenon.

#### 1.2.4 Early and late pregnancy loss numbers in Hungary and in Italy

In Hungary early and late pregnancy losses, including stillbirth, have been registered between 15,200 in 2000 and 16,500 in 2019, with a peak of 17,500 in 2009, with a fluctuation in between. (Table 1.1) The number is more significant when compared to the constantly decreasing number of live birth events, in 2018 this rate was 18.1%, while in 2019 it increased to 18.5%. (KSH, Népmozgalom 2019) In other words, it means that 1 in each planned and/or wanted 7 pregnancies ended with losing the baby.

**Table 1.1 Live birth and prenatal intrauterine death events in Hungary between 1990 and 2019**



The vast majority of the losses were registered as early pregnancy losses, whereas in 2018 383 and in 2019 391 loss events were recorded as late foetal death events, occurring after w24. (KSH Népmozgalom, 2019) In Italy for the same years approximately 82.000 early and mid-gestation period losses were registered yearly,

whereas the number of late intrauterine deaths were 1070 in 2018 and 1068 in 2019. (ISS and ISTAT data)

### 1.2.5 Stillbirth definition and rates

For international comparison the WHO recommended definition of stillbirth is a baby born with no signs of life at or after 28 weeks' gestation. (Definition available from: [https://www.who.int/maternal\\_child\\_adolescent/epidemiology/stillbirth/en/](https://www.who.int/maternal_child_adolescent/epidemiology/stillbirth/en/)) Depending on the national guideline definitions it is possible to define early (before w28) and late (after w28) gestation stillbirth.

**Table 1.2 Stillbirth definitions**

Source: [https://www.who.int/maternal\\_child\\_adolescent/epidemiology/stillbirth/en/](https://www.who.int/maternal_child_adolescent/epidemiology/stillbirth/en/)

Country	Stillbirth (GW) acc. to guidelines
<b>Hungary</b>	<b>24</b>
<b>Italy</b>	<b>25+5</b>
<b>United States of America</b>	<b>20</b>
<b>Australia/New Zealand</b>	<b>20</b>
<b>United Kingdom of Great Britain and Northern Ireland</b>	<b>24</b>
<b>Ireland</b>	<b>24</b>
<b>France</b>	<b>22</b>
<b>Israel</b>	<b>24</b>
<b>WHO</b>	<b>28</b>

As the WHO data show in Table 1.2, the Italian definition of stillbirth is w25+5, which is also indicated on the Istituto Superiore di Sanità website (<https://www.epicentro.iss.it/itoss/EpidMortPerinatale>), leaving thus some incongruence in interpretation, since the condition of prematurity is defined as birth after w28. At the same time, unlike Italy, Hungary applied for the indication of stillbirth definition the prematurity limit w24, too. The Euro-Peristat Report also reveals the differences in provided data regarding the cut-offs, showing that Hungarian data was registered only after w24, while Italy uses an official registration threshold of 180 days, but records stillbirths below this threshold. (European Perinatal Health Report, 2015) According to

latest The Lancet Stillbirth Series from 2016, the Stillbirth Rate in Hungary was 3.7 ‰ and in Italy 3.3 ‰ in 2015 in the late gestation (after w28) stillbirth range. (The Lancet, 2016)

#### 1.2.6 Prematurity

It has already been mentioned that the limit for premature/preterm birth is defined according to national standards and shows differences from one country to another. In Hungary it is established at w24 of the gestational period. It must be underlined though that the Hungarian prematurity definition has been w24 since 1996. Before 1996 it used to be set at w28, a whole month later. (KSH-Statistikai Tükör Születés körüli halálozások Magyarországon, 2011) The rate of premature birth was 8.9% in 2010 and 8.7% in 2015, while in 2018 8.9% (KSH Népmozgalom, 2019) In Italy, the cut-off is set to w28. The Italian rate for prematurity was 7.4% (2010), 7.6% (2015) and in 2018 6.9%. (ISS/ISTAT - <https://www.epicentro.iss.it/itoss/EpidMortPerinatale>)

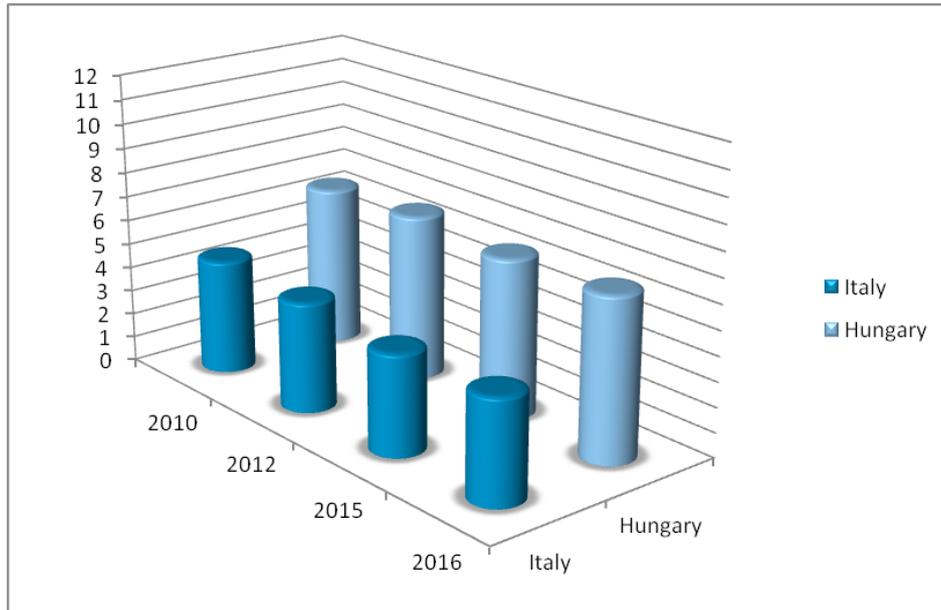
#### 1.2.7 Neonatal mortality

When classifying neonatal mortality rates, it is possible to make a distinction here, too, and define early neonatal mortality (between days 0-6) and late neonatal mortality (days 7-28) for the first month of the postnatal period. In case of Hungary, early neonatal mortality in 2015 was 1.7‰, while the rate of late neonatal mortality was 1.0‰ out of 91.680 live births. For Italy the rates are fairly similar, 1.7‰ for the early neonatal period and 0.5‰ for the late period, when the total count of live births was 484.777. Early neonatal death rate is used to provide Perinatal Mortality Rate, applied as a significant indicator of a country's maternal and perinatal health. (European Perinatal Health Report, 2015)

#### 1.2.8 Perinatal mortality rate

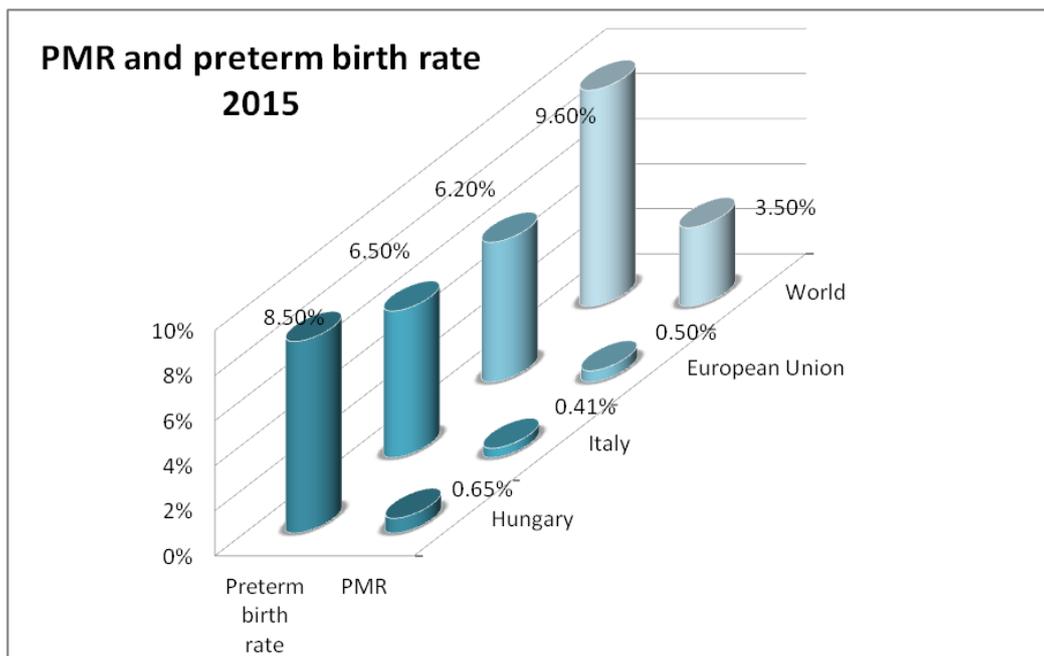
The Perinatal Mortality Rate (PMR) is the sum of the number of perinatal deaths (stillbirths and early neonatal deaths) divided by the number of pregnancies of seven or more months' duration (all live births plus stillbirths). Regarding data from the last decade (Table 1.3), it can be claimed that the Hungarian figure has fluctuated around 6.6‰ while its Italian counterpart has been approximately 4.3‰, as the table below demonstrates.

**Table 1.3 PMR in Hungary and Italy between 2010 and 2016 (%)**



Finally, in order that a bigger, worldwide perspective may also be obtained, the graph below presents prematurity rate and PMR in the two relevant countries in comparison with the European and global rates from 2015, shown in Table 1.4. (European Perinatal Health Report, 2015)

**Table 1.4 Preterm birth rates and PMR**



### 1.2.9 A closer look at the numbers

On the basis of the available data it is well worth looking at the single numbers of the different loss events connected to the perinatal period in the two countries, as indicated in the infograms below (Figure 1.2 for Hungary and Figure 1.3 for Italy), to see how many families and through them, in connection with them, wavelike, a multitude of other people in their surroundings must face loss and grief.



Figure 1.2 UNICEF, KSH data for Hungary



Figure 1.3 UNICEF, Euro-Peristat and ISTAT data for Italy

### **1.3 Theoretical background - Personal loss and grief experiences of healthcare personnel in pre- and perinatal care**

#### 1.3.1 The *normal* course of grief and loss

Experiencing grief, loss in a *normal* way

To experience the loss of a beloved one is a demanding task for everybody. The reaction to the loss, the *normal* course of grief, its natural proceedings may happen in manifold ways, depending on the individual and on the loss, as well. (Campione, 2012) Even though giving a proper definition and describing the characteristics of grief as a phenomenon, yet, it is possible to portray the distinguishable phases of *normal* grief. (Benczúr, 2016) In Hungary the best known description of the grief process comes from János Pilling (2003), describing anticipatory grief, shock, controlled phase, recognition, re-structuring, and adaptation as the significant stages. Yet, the grieving process can be characterised by great individual differences as far as their time limits are concerned, moreover, it must also be added that the stages may occur in a different order, they may re-appear from time to time with all the characteristic feelings, intensity even during later phases. (Benczúr, 2016) The process in which the griever learns to live his or her new normal life, without the beloved person now, is highly individual, with a lot of recurrent loops along the way. (DeSpelder and Strickland, 2005)

#### 1.3.2 What kind of grief follows pre- or perinatal loss?

Childbearing, giving birth to a child are significant milestones in the life of a family. The relationship between the child and the parents differs from other family relations. Therefore, the pain, grief following the loss of a child bears specific features, too.

A strong relationship may be created between the expectant mother, the father and the child as early as during pregnancy, thanks to the available medical equipment, and because of the psychological changes. The death of the foetus, of the newborn baby for any reason primarily involves the loss and the breaking of this relationship. Perinatal death touches upon the construction of a parental identity, damaging the parents' common image of the future, as well. (Cena and Imbasciati, 2018) The expectant couple may experience feelings of shame, guilt and isolation since they have not been able to reach, construct their parental role. (Kovácsné, 1995) The child is the realisation of a relationship in which parental qualities are also formed, the woman and the man become a mother and a father (Cena and Imbasciati, 2015), the fantasies about the baby the

woman carries will transform into an individual being. All this means that death during the pregnancy or right after birth will have an effect on these representations, will obstacle or distort them. Grief will not be connected to the already shared experiences, but to the future lost this way. (Cena and Imbasciati, 2018) Moreover, in most cases there are no concrete physical experiences, no memories about the child to support the grieving process. (Kovácsné and Szeverényi, 1998) Experiencing continuity, thus defying death this way, since parents continue to live in their children, enrich the parental self, too. (Kovácsné and Szeverényi, 1998) In case of pre- and perinatal loss there exists no continuity between the life before the loss of the child and the ‘new normal’ life after if, the parents struggle to find handholds, new points of reference. (Ravaldi, 2011–2013) A major part of our society – including the caregivers themselves – still treat these losses, deaths as taboo, thus impeding supportive and helping communication concerning these events. By actually creating a wall around the parents and their families in their loss, the social alienation strives to lessen, or to not even acknowledge their pain. (Cena and Imbasciati, 2018) Thus their grief cannot be experienced in a larger social context, with the support of a social network, therefore they become isolated. The death of a child during pregnancy or childbirth is related to so many aspects of the parents’ life that the pain and grief of the loss cannot be classified as *normal*. While the grieving process always shows individual patterns, yet, certain features may be seen in prolonged, complicated grief. (Campione, 2012) The sudden and unexpected occurrence of loss is one of the predisposing elements of complicated grief. It can be easily recognized that the losses during pregnancy and around childbirth bear this quality in most cases. (Kersting, 2012) The relevant literary sources list the loss of a child at any age as a significant factor. (Pilling, 2003) In case of pre- and perinatal cases this is the primary reason, all the other aspects of loss are added to this like onion skin. Another characteristic feature is a rather strong connection with the deceased. (Pilling, 2003). The fantasies, dreams and desires about the child, created prior and during pregnancy, shape the tie between the child and the parents well before the corporeal changes, thus forming a powerful bind with the child to be born. (Cena and Imbasciati, 2015)

Social relationships of poor quality may intensify the isolation of the grievers, the harsh experience of a break in the course of one’s life, with no option of turning back. The

taboo around perinatal loss conveys an increased external pressure in the people's lives who go through this tragedy. In a lot of cases funerals, commemorative services are not possible, which otherwise would facilitate grief work (Kersting, 2012). The lack of future orientation and the factor of being unable to accept the reality of the death event are also listed among the diagnostic criteria of complicated grief in literature (Benczúr, 2016). A sudden, traumatic death during a pregnancy experienced with the hope of a joyful future and new beginnings meets both conditions. The currently valid relevant Hungarian healthcare guidelines cite further particulars that may intensify the grief over the loss (Hivatalos Értesítő, 2010). Recovery from grief may, to a great extent, be helped or impeded by how the healthcare operators communicate the news to the parents, its quality may determine the parents' grief. Another central condition of grief is the quality of the period of time between the communication of the news and the induction of birth, if necessary, i.e. where and how parents spend this period, what kind of support they may receive.

### 1.3.3 Professional trauma and personal feelings of loss and grief

Pre- and perinatal loss and grief tend to be referred to as complicated grief denoting the experience of ongoing trauma. It is considered a burden for the affected parents, their families and the helping professionals alike. (Nuzum, 2014; Musodza et al., 2021) Yet this phenomenon remains an underrepresented field in analytical studies. The above-mentioned complex issue deserves greater attention, as the personal and professional challenges experienced by healthcare personnel when facing perinatal loss have only been acknowledged recently. (Brunelli, 2005; Gold, 2008; Nuzum, 2014) This newly arisen interest has generated relatively few scientific publications, the majority of which cover study reports of individual researches, whereas a small number of them venture to provide a systematic critical reading of theoretical and research-based studies of the last two decades approximately. (Brunelli, 2005; Epstein, 2008; Modiba, 2008; Gerow, 2010; Pastor-Montero, 2012; Nuzum, 2014) The systematic review considers publications until early 2021, focusing on the quality of individual studies and theoretical discussions, highlighting the ever-increasing global need to support staff in perinatal departments. The analysis of HCPs' loss and grief experiences - including the study of coping strategies and competencies to process these significant work-related events - is a relatively new field of research at international and domestic (Hungarian)

levels (Epstein, 2008; Kovácsné 1995), through the recent recognition that traumatic events influence their professional and personal attitudes as well. (Modiba, 2008; Ravaldi, 2014; McNamara, 2019) As grief and trauma caused by perinatal loss - if not assisted and confronted properly - may easily develop into a phenomenon of complicated grief (Kersting, 2012), thus, it represents an increased burden for the affected families, their immediate environment and also for the professional staff helping them. (Fernández-Alcántara et al., 2020; Marguiles, 2020) Moreover, even ethical and sepulchral problems may arise at the loss of infants who die in the womb or are stillborn. The objective, therefore, is to systematically review the international literature regarding professional attitudes and solutions related to the impacts of pre- and perinatal infant death. (Zsák, Németh and Hegedűs, 2019)

#### 1.3.4 Propositions for practice and protocols in international research

The importance of support and the educative formation in the field of perinatal care is underlined, showing that the provision of more profound information and skills development training may significantly help healthcare professionals to face perinatal loss and act according to the standards of their professional expectations. On a more systematic level, the formation of national protocols and national guidelines is accentuated.

#### 1.3.5 Applied methodology for the literature analysis

##### 1.3.5.1 Selection criteria regarding the articles consulted in the analysis

The overview includes studies which deal with the difficulties and/or attitudes related to grief and loss as experienced by those working in pre- and perinatal healthcare. Literary synopses and research studies are also in focus, offering tangible solutions to tackle the identified problems. Dissertations and doctoral theses, however, are excluded from the resources. The majority of subjects in the studies are nurses (women only, underscoring an occupation that is vastly female-dominated) and medical doctors. Fewer studies deal with the doctors' attitudes and their experiences of loss. (Gold, 2008)

##### 1.3.5.2 Research methods and databases

The databases that I consulted include PubMed, Ovid MEDLINE, Ovid PsycINFO, Proquest, Scopus, CINHALL and the Hungarian Medical Bibliography (Magyar Orvosi

Bibliográfia). Initially, the terms ‘perinatal loss and grief’ were the keywords that we applied to perform a search, then I narrowed it down by adding the words ‘nurse’ and ‘doctor’. When searching the Hungarian database, I also applied the keyword ‘perinatal loss’ (*perinatális veszteség*). As the aim was to collect the most recent publications, the publication period was set between 2005 and 2021, allowing formerly published significant articles focusing on the topic of our interest to be included as well.

I also searched for information using specific websites of pre- and perinatal loss: <http://www.perinatalhospice.org/>; <http://missfoundation.org/>; <http://www.ciaolapo.it/>; <https://www.nowilaymedowntosleep.org/>.

### 1.3.5.3 Data collection and analysis

The database search results are shown in Table 1.5 below:

<b>Database:</b>	<b>No. of hits:</b>
<b>Ovid MEDLINE</b>	741
<b>Ovid PsycINFO</b>	108
<b>Proquest</b>	1511
<b>Scopus</b>	213
<b>CINHAL</b>	87
<b>PubMed</b>	103
<b>MOB</b>	3

When examining the findings, I narrowed down the results focusing on healthcare professionals’ experiences of grief and loss, as follows in Table 1.6:

**Table 1.6** Number of hits of publications focusing on the grief and loss experiences of healthcare personnel

<b>Database:</b>	<b>No. of hits:</b>
<b>Ovid MEDLINE</b>	32
<b>Ovid PsycINFO</b>	6
<b>Proquest</b>	27
<b>Scopus</b>	-
<b>CINHAL</b>	-
<b>PubMed</b>	13
<b>MOB</b>	2

Since there are significant overlaps among different databases, the search results are not 100% accurate. Eventually, 37 scientific publications were identified that met the pre-set search criteria. The collected articles were firstly divided into categories on the basis of the targeted HCPs. Both doctors and nurses (midwives) were in the focus of 17 studies. 13 published researches focused on nurses, whereas doctors represented the exclusive subjects of only 4 analyses. Other professionals also present in pre- and perinatal care (i.e. psychologists, perinatal specialists, general practitioners) were not included in any international studies. The qualitative analysis of the publications was performed according to the following criteria and order: author, place and time of publication, country, type of study, applied method(s), number of participants, field of activity, main research topics and results.

The secondary diagnostic criterion was the publication date. I strived to focus on and select for the overview the scientific writings of the last decade or so. In terms of the limits of the literary overview, several publications concerning the topic of interest are healthcare recommendations or protocol measures, which are not available directly in the searched databases but only via specific homepages dedicated to pre- and perinatal loss, for example, <http://www.perinatalhospice.org/>; <http://missfoundation.org/>; <http://www.ciaolapo.it/>; or <https://www.nowilaymedowntosleep.org/>.

All in all, 37 studies could be collected on the basis of the pre-set research criteria. Pre-2005 publication dates were also considered if the works published then shared the focus of the present review. The categorisation of the articles - based on their nature - is, as follows: original publications: 29, out of these research reports: 25, theoretical

analyses: 4; while literary overviews: 8. According to the place of publication and the nationality of the authors, 13 publications come from the United States, 5 are British, 3 are Hungarian and Irish, 2 works per country belong to Italy, Australia and Israel, while Australia, Brazil, Singapore, Slovenia and South-Africa have 1 material each.

### 1.3.6 Analysis and findings of the literary resources

A noteworthy tendency can be recognised in the publications, namely that growing attention is paid to HCPs' personal and occupational problems arising from chronic distress, emotive involvement, personal grief and the non-appropriate elaboration of their feelings of grief and loss, underlining the significance of research and prevention policies. (Gandino, 2019) A correlation can be identified between the help provided to bereaved families and the effects of personal involvement, the existence or lack of supervision and of expected training facilities. Should the latter ones become available on a regular basis, the elaboration of grief and loss may be much easier. (Epstein, 2008; Kovácsné, 1995; Gold, 2008)

While emphasising the moral distress and the different roles of the staff, Epstein also puts special emphasis on the importance of 'creating the best possible experience for the parents' (Epstein, 2008). The lack of competencies in communication, in crisis management and in care guidelines for bereavement support (Fernández-Alcántara et al., 2020) may significantly add to the feeling of professional and personal failure, incompetence in caregivers (Kovácsné, 1995), who consider perinatal loss as an emotional burden. (Gold, 2008) According to the survey Gold carried out, 10% of the interviewed 804 American obstetricians 10% have already thought of changing profession because of this. Their main coping strategies are conversations with colleagues (87%), family or friends (56%). Thanatology courses could be of help to provide adequate support and to elaborate their own feelings. (Gold, 2008) Margulies has also demonstrated that the negative repercussion of adverse outcomes includes career change and even substance use. (Margulies, 2020) Regarding earlier relevant analyses, the novelty of this study lies in the recognition that the acute and chronic experiences of loss impact not only the physical health of staff but their psychosocial wellbeing as well. (Brunelli, 2005; Nuzum, 2014; Musodza et al., 2021) Brunelli's study focuses on the grieving process experienced by the HCPs. The main objective is to develop nursing care through research and education, while improving self-protecting

skills, too. (Brunelli, 2005). The Irish analysis furthermore points out how great the personal impact of perinatal loss and stillbirth is on personnel (effecting the provided care for patients) and underlines the weight of professional responsibility (professional burden and medico-legal concerns). They also claim specific need for specialist training in bereavement care. (Nuzum, 2014) Medical and nursing staff must be able to acknowledge that all experiences of loss – including their own personal non-elaborated ones - affect their physical and mental health. (Gold, 2008; Musodza et al., 2021) ‘Cushioning’ the psyche is mentioned as a quasi instinctive coping strategy against the experiences of loss by Gerow et al. (Gerow, 2010) They emphasise the necessity of appropriate elaboration of grief and loss for an adequate level of continuous professional performance. Their findings show the possibility to work only with a ‘protective curtain’ as a survival skill, pointing out that understanding the grieving process and improving coping strategies may enhance competencies and the provided support. Gold et al. (Gold, 2008) argue that such objectives can only be achieved via death education and competency development, by examining the problem on one of the largest scales: out of 1,500 doctors, more than 800 filled in and returned the questionnaire.

The researches show that the source of distress caused by loss and grief is differently experienced by nurses and doctors. While both professions consider help provided to patients as their highest priority, in the case of doctors proper decision-making regarding therapeutic solutions is equally essential (Nuzum, 2014), while for nurses caregiving and establishing a good relationship with individuals are of key importance, too. (Epstein, 2008) As Willis’s study shows, nurses struggle with emotions, they want to be present for the patients, acting professionally, and take care of themselves at the same time. They carry the experience of loss, the patients’ story with them further on, too. (Willis, 2020) Most of the interviewed doctors claimed that perinatal death and loss represented significant emotional burden for them, some of them even considered changing their profession because of the experienced difficulties. (Nuzum, 2014; Ravalidi, 2014; Modiba, 2008; Puia, 2013) The observed non adequate attitudes are due to inadequate levels of skills and competences among the staff members. All these generate sensations of powerlessness, tension and frustration in them. As McNamara underlines, serious adverse events, while being rare, can have a largely negative effect

both personally and professionally on the involved personnel. (McNamara, 2019) Well planned, supporting formative programmes could provide a solution to the arising problems and improve the elaboration of the experienced trauma. (Ravaldi, 2014; Modiba, 2014) Skills, competencies and actual care possibilities for bereavement care (e.g. cold cot) (Smith, 2020) could give staff a sense of well provided support for the patients. This tendency can be recognised among nurses as well, although their personal attitudes are fairly dissimilar, as demonstrated previously. (Puia, 2013; Rogers, 2008) The professional problems related to perinatal and child-loss are manifested as the feeling of 'surviving the shift', feelings of grief and loss, frustration, providing adequate support, the need for elaboration of grief and living memorable experiences. (Puia, 2013) The analysed samples, except for the study of Roger et al from 2008 (n=890), are all rather small (n≤100), they mostly present results of researches conducted in a given institute (Epstein, 2008; Gerow, 2010; Modiba, 2008; Rogers, 2008; Pastor-Montero, 2012), focusing on the attitudes and issues of their own staff. In Brazil, there appears a necessity of publishing appropriate guidelines, too, in order to better support the professionals in perinatal care. (Pastor-Montero, 2011)

Two publications regarding Hungarian approaches to the problem should also receive critical attention. In the two decades between the two relevant researches no similar article was issued. (Kovácsné, 1995; Zsák, 2015) The subjects in Török and Szeverényi's studies are obstetricians (Kovácsné, 1995), while the research of Zsák et al also focuses on neonatologists, paediatricians, obstetricians, nurses, childcare specialists and psychologists (Zsák, 2015). According to their results, no significant change can be observed between the two Hungarian healthcare subject groups regarding the topic of our interest. The subject groups are characterised by very similar communicative, psychological and interpersonal difficulties as well as by similar attitudes concerning pre- and perinatal losses. It appears that facing these traumatic events is a specially demanding task, their lack of concrete communicative skills and competences to help patients, lack of coping strategies to elaborate loss form high walls that are almost impossible to overcome. Competency development and improvement, focused training programmes should be implemented. Interestingly, the majority of the relevant publications consist of reports of individual, qualitative studies (Epstein, 2008; Gold, 2008; Modiba, 2008; Pastor-Montero, 2012; Zsák, 2015; Hamama-Raz, 2016; Ben-

Ezra, 2014; McCreight, 2005; McNamara, 2017; McNamara, 2018; Wallbank, 2013; Mander, 2009 and Fernández-Alcántara et al., 2020), potentially highlighting the recent attention to the importance of the topic, examined in local institutional practices. The burden and challenges of loss seem to be experienced in the same way regardless of HCPs' geographical locations. Personal attitudes are investigated by qualitative research methods including IPA (e.g. Nuzum, 2014; McNamara, 2018; Fernández-Alcántara et al., 2020 and Smith, 2020), conducted via semi-structured interviews. A theoretical approach to grief and loss experiences is supplied in the articles by Mander (Mander, 2009) and Hogan (Hogan, 2017), while linguistic analysis is also implemented to enter the core of the problem (Gandino, 2017).

In general, it can be claimed globally that while education is a way to help staff grief, it still remains a very sensitive situation in need of further attention (Mander, 2009) and the emotional needs have to be fully acknowledged through recognition of the importance of managed emotion in the construction of professional knowledge. (McCreight, 2005) As McNamara's research reveals, intrapartum death profoundly and negatively affects doctors. Those directly involved are the second victim of these tragedies. (McNamara, 2018) Review of the recently published academic material is also accomplished in different sources (Shorey, 2017, Zsák, 2017 and Browning, 2005) from culturally diverse environments, Singaporean, Hungarian and American, respectively.

### 1.3.7 Proposals to solve the identified problems

Healthcare workers must be made aware of the potential health risks of untreated acute and chronic loss experiences. Likewise, they should be provided with information on the significance of supervision, psychosocial support and bereavement therapies. (Epstein, 2008; Kovácsné, 1995; Gold, 2008; Gerow, 2010; Ravaldi, 2014; Rogers, 2008, Pastor-Montero, 2012; Browning, 2005; Limbo, 2010) Gold et al. also suggest (Gold, 2008) group therapies – professional as well as personal -, highlighting the efficacy of this sort of bereavement support. Good personal relations with the patients and their families (Epstein, 2008; Gold, 2008; Gerow, 2010; Limbo, 2010) may be one of the ways of elaborating grief and a source of self-care, while external help – via psychotherapy, mental hygiene or spiritual methods – can be considered a beneficial alternative. (Epstein, 2008) Rogers et al (Rogers, 2008) claim that providing continuous

support (through external professionals) to NICU personnel after the death of each child is vital. Competencies and knowledge acquired from death education or thanatology appear to be other sources of adequate care, aiding the elaboration of subjective feelings. As per the findings of Gold et al. and Gerow et al. (Gold, 2008; Gerow, 2010), developing adequate coping strategies may contribute to the successful cultivation of relevant competencies.

For doctors the opportunity to talk, either in a personal or professional ambience (the latter one stands for 87% of the cases), is the mode to elaborate and ventilate their emotions. (Gold, 2008) On the other hand, they need individual coping strategies or competencies that - if applied repetitively - may help them move forward after each experience of loss. (Limbo, 2010) The Brazilian publication emphasises the need for a protocol, and at the same time it underlines the importance of individual care and support. (Pastor-Montero, 2012) The implementation of concrete supportive programmes is evaluated by Gallagher et al (Gallagher, 2012), Gardiner et al (Gardiner, 2016), Cartwright and Read (Cartwright, 2005), and McGrath (McGrath, 2011), with the objective of competency and skills development, focusing on the specific needs of the relevant professionals. (Cartwright, 2005, McGrath, 2011) Ratislavová has also shown how a perinatal loss care educational programme can be effective, providing essential knowledge of appropriate, sensitive care. (Ratislavová, 2019)

#### 1.3.8 The difficulties healthcare professionals experience

The manifold, and not at all consistent proceedings may refer to the fact that there exists no homogeneous judgement within the healthcare society as to the beginning of human life, or as to the appropriate procedures regarding the tragic ending of a life just begun. This might be one of the explanations to the professional and personal difficulties HCPs must face, originating from the nature of the loss, in which losing a newly commenced life may involve an almost unbearable tension for the healthcare operators so much eager to give joy. Another significant dilemma is the fact of loss itself. In general opinion, the profession of healthcare providers entails the protection of human life, restoring good health conditions. Losing a patient, or a tragic end to a much desired pregnancy may be seen as not meeting the requirements of this career, as a failure both personally and professionally.

The articles highlight the increasing attention to the personal and professional problems of the healthcare personnel which derive from their emotional involvement and from the non-adequate elaboration of loss. The support for the involved families correlates with the personal, emotional involvement, the attitude towards loss and death, and the lack or existence of supervision and required professional education. If PBC opportunities are provided, the elaboration of loss is facilitated to a great extent. (Gold, 2008) Unfortunately, however, as much as the relevant data underline it, the Hungarian possibilities to offer this support are limited. (Zsák, 2015)

Although it has already been acknowledged that acute and chronic loss experiences may cause symptoms like depression, PTSD, anxiety in the healthcare personnel, by now it has also been explained how the adverse experiences may determine their psychosocial, and general mental, psychological well-being, which, consequently, affect their professional and personal lives as well. (Brunelli, 2005; Margulies et al., 2020) Besides, the perinatal staff should, too, understand that all these experiences affect their mental-physical health. (Gold, 2008) In case of non-existing acquired skills and problem-solving competencies the ‘cushioning of the soul’ appears as an almost instinctive survival strategy against the loss experiences, as researchers report it (Gerow et al, 2010), underlining the fact that only adequately elaborating a loss experience may allow for further appropriate professional performance. This can be facilitated by thanatology and competency development, as Gold (2008) describes it, nonetheless, present educational conditions do not aid it as much as it would be required. In fact, HCPs must completely rely on their own intrinsic, not learnt resources regarding the necessary emotional and intellectual tasks to be resolved, both professionally and personally. Nevertheless, the tasks identified as the sources of thus manifested moral distress are different for the doctors and for the nurses. While the representatives of both professions consider the optimum care for their patients as their primary task, in the case of the physicians it mainly means the decision-making for appropriate therapies, for the nurses it represents care-giving and good relationship, thus these diverse aspects will be part of their experiences of loss and failure in case of children’s death. (Epstein, 2010) These negative occurrences will be resolved differently in the two specialisations, they will look for the solution in dissimilar modes.

HCPs in pre- and perinatal care may face difficulties in multiple fields. As the most significant factors, depletion of the emotional resources due to empathic care-giving, emotional involvement, non-elaboration of own experiences and communication difficulties are to be examined. Emotional attachment, involvement of the personnel working in these fields of healthcare may be higher compared to the average, because of their approach towards the fragile, vulnerable little patients, in psychologically extremely charged situations. At the same time, however, the care-providers' empathy is oriented to the members of the children's families, equally. In the long run this form of professional workload leads to the exhaustion of their emotional capacities. This phenomenon is one of the major factors of burnout, of professional emotional fatigue, as the relevant sources describe it. (Fülöp, 2013) The exhaustion of emotional capacities is strongly connected to phenomenon of depersonalisation, the tendency of distancing, which imply the lack of compassion, the treatment of patients as non-animate beings, and avoiding them. (Fülöp, 2013) The tragedies, personal life-stories occurring in pre- and perinatal care may cause secondary trauma in the healthcare professionals supporting the families (Newell, MacNeil, 2010), during which the caregivers experience negative feelings to a great extent, thus suffering from emotional and behavioural disturbances. (Fülöp, 2013) As a consequence of this, the care-providing personnel experience, may experience the same feelings and emotions their patients have. Recognising, acknowledging and accepting the reactions and emotions ('I am a human being, too') can facilitate the identification of an adequate coping strategy to alleviate the emotional burden for them. Experiencing loss as a HCP is a highly demanding task, too, no matter how much the care-provider is aware of the difficult and limiting conditions, the death of a small baby is a professional failure, in any way. It is a significantly harsh duty to face death in case of a recently shaped new human life. The attitude towards death among healthcare operators is rather particular anyhow, both losing a patient and the understanding of the finite nature of their own lives are much more negatively judged than among the non-healthcare involved population. (Hegedús, Pilling, Kolosai, Bognár, 2002) For this very reason it is of high significance that professional formative education and training opportunities offer specific programmes, courses with a focus on death, dying and grief.

Another difficulty is that professional formative education does not cover the skills development for HCPs to recognise their own, or patient-related emotions. On the other hand, as the relevant researches demonstrate it, stress control, distraction, self-punishment and acquiescence appear among the coping strategies concerning their emotional difficulties. No or just very few strategies put emphasis on the elaboration of one's own feelings. (Fülöp, 2013) A further characteristic feature is that in connection with the secondarily - through the patients - experienced traumas staff cannot express their feelings, which is a significant stress factor, endangering both their physical and mental health. (Fülöp, 2013) It is imperative that even after the formative education opportunities should be provided for courses in personal skills improvement, in stress management strategies, and for supervision of individual cases. Certain cases, experiencing the emotions of the couple involved in the tragedy, may indicate a greater psychological association for the HCPs providing support to the family. (Zsák, Kovácsné, Hegedűs, 2015) Each of the interviewed professionals was able to recall cases from their career which were highly distressing, or represented deeper involvement for them. One of the underlying reasons for it is the controversy between the professional and social expectations concerning this special field of healthcare (babies are born in the obstetrics wards, the arrival of a new life brings happiness and bliss) and the tragedies, death events occurring here, too. Another problem may be one's own birth experience, all its attributes present on a conscious or a subconscious level in one's life. A third factor is the personal and professional attitude towards death. According to general opinion, a HCP's duty is to always protect and save lives. A death, especially when it shatters an otherwise blissful event, period in the patient's life, can convey a strong sensation of professional failure for the caregiver performing their job according to their own expectations towards themselves. An additional challenge, due to educational dynamics, is the lack of proper communication strategies. Although, the present curriculum in more institutions includes the development of these skills, yet, it could not be available for the major part of the practising professionals. It means that they do not have adequate competencies to resolve communicational challenges, they do not know how to communicate the bad news in a given situation, or simply to appropriately put their sympathy into words. (Zsák, Kovácsné, Hegedűs, 2015). During the interviews HCPs often asked questions like 'What should I say?' ... 'How should I

put that?’ ... ‘What should I ask?’, revealing the communication challenges, the existence or need for adequate communicative skills. If own, intrinsic resources are required to supply for needed competencies, in the long run it can easily develop into self-distancing from the situation as an instinctive protective measure, subsequently into burnout, complete compassion fatigue and apathy. Even though the guidelines also provide suggestions for communication tasks and for helping-supportive behaviour under given circumstances, a major part of the involved professionals are not familiar with these guidelines, thus have no opportunity to use them. (Lipcsei, 2013)

Besides creating awareness of the physical and mental health effects of the acute and chronic loss, it is of high priority to offer grief therapy and social support, even in supervision, for the healthcare professionals. (Epstein, 2008; Limbo, 2010) International literature makes useful and well applicable propositions to facilitate the elaboration of loss. Gold et al recommend in-group – professional as well as personal – sessions, underlining the opportunity for the elaboration of loss, grief in professional life and its positive effects. (Gold, 2008) A good relationship with the patients and their families is one of the modes of individual grief work (Gerow, 2010), while asking for external help – through psychotherapy, mental hygiene or spiritual ways – is another alternative. NICU personnel need continuous support, following the death of every child, via the help of external specialists, as Rogers et al claim. (Rogers, 2008) Thanatology can offer help in adequate support and the elaboration of emotions, while developing coping strategies may contribute to advances in acquiring competences, as Gold (Gold, 2008) and Gerow (Gerow, 2010) both affirm. All of them aid proper specialized and personal performance as much as the individual elaboration of loss. The recommendations highlight the significance of institutional as much as individual support, competence-development. Informational, self-knowledge and supervision training techniques one by one and together can contribute to a great extent to the competency development of pre- and perinatal professional which enable them to act in their professions according to their own self-expectations, equipped proficiently and psychologically, too. (Zsák and Hegedűs, 2019) The supporting, care-providing staff are significantly challenged emotionally as well as professionally in order to offer the best possible help for the patients. It is a seriously demanding task personally and professionally, too, with little actual knowledge regarding loss and grief, with non-adequate communication skills

towards the grieving families, or even to elaborate their own feelings. They thus suffered secondary trauma and experiencing the patients' negative emotions considerably deplete their emotional capacities. (Zsák and Hegedűs, 2017) All these factors represent an increased risk to develop burnout syndrome and compassion fatigue. As potential solutions, overcoming communication difficulties, developing coping strategies in grief and loss elaboration, recognising and accepting own feelings, in-group and individual support, focused trainings, supervision are recommended among the facilities to reduce the psychological burden of healthcare professionals.

#### 1.3.9 An overview of the accentuated findings

The findings of the literary overview clearly demonstrate the significance and complexity of the main subject matter, namely, that more attention must be paid to the aftermath of the professionally experienced traumas. This could include the provision of dynamic, accessible and up-to-date supervisory programmes available on each formative level of professional education. Although the publications consulted so far focus on the attitude of already skilled and active personnel, they also support the fact that early integrative educational programmes can be exceptionally beneficial. One of the greatest advantages of such opportunities is that they simultaneously centre on loss, grief and mourning as well as on the development of individual coping strategies, communication skills and emotional competencies in psychological, social and spiritual ways alike. On a more systematic level, the formation of national protocols and national guidelines is accentuated in the findings. Similarly to the previous solutions, these arrangements may greatly ease the difficulties and challenges that healthcare operators face when encountering cases of perinatal loss in their practices.

### **1.4 Ethical dilemmas in perinatal care**

#### 1.4.1 Introduction

The high standards of peri- and neonatal medical care may provide curing options for the needs of children born or to be born with complex malformations, thus improving the quality and the prospects of their lives. At the same time, the number of bioethical dilemmas has increased which are linked to the pre-, peri- and postnatal periods, or may lead even further with their consequences. The aim here is to give an overview of these problems, since these ethical dilemmas are present in every day medical practice and

have a great influence on the healthcare professionals' work. During pregnancy and then after the birth of the child the bioethical problems have different focus, although some of them are valid throughout the whole perinatal period. While the presented dilemmas may highlight some possibilities under given circumstances, one of the most significant features of perinatal - palliative - care is finding individual solutions, by carefully evaluating individual conditions, special circumstances.

#### 1.4.2 Looking back

The status of children born or to be born with malformations has always created complex ethical dilemmas. The possibilities provided by contemporary Western medical care have allowed for the prospect of an anticipated diagnosis, thus parents may make decisions about their child's life earlier, assessing their options. In previous decades serious congenital conditions – as the word itself indicates – could only be identified at childbirth, causing moral, ethical problems for doctors and parents likewise. The question, when considering the child's life-prospects, could only be about the quality and duration of the applied cure, knowing well that in certain cases full recovery could not be obtained, only the dying process prolonged. (Kovács, 2006) Here, for example, the children born with anencephaly, or the babies born without a properly functioning gastro-intestinal tract must be mentioned. The conditions of the children born with spina bifida created a complicated legal and medical status, for they were simply let die without cure until the middle of the 20<sup>th</sup> century because of the complications of removing the excessive cerebrospinal fluid. (Kovács, 2006). Due to a technical solution medical cure became possible, nonetheless, afterwards its remaining collateral effects resulted in serious difficulties. This led to administering elective treatments by the '70s, i.e. in the most complicated, serious cases the non-treatment of the children was chosen, in accordance with the parents.

Although the right of the decision making belonged to the parents in theory, nevertheless, they generally accepted the doctor's opinion, advice. Active euthanasia of the children was also brought to light, since many people argued over it being more human to kill the non-treated neonates to their prolonged, painful dying process. (Kovács, 2006) The results of the discussion revealed that non-treatment had already been applied as practice, in which even extremely powerful painkillers could be used (i.e. passive euthanasia actually), thus advancing death. Nonetheless, it was only in the

1980s when the Congress of the United States issued a statement regarding the possible retrieval of children's life sustaining treatments, in connection with the Baby Doe case. Permanent, irreversible coma, curative treatment with no improvement, or medically futile cure were defined as the criteria on the basis of which life sustaining treatment could be withdrawn. Yet, the controversy between the applied medical practice and the legal standing point was maintained. (Kovács, 2006) Due to the lack of appropriate, observant legal directives in these conditions the single possible moral and ethical conclusion could only be that each newborn had to be treated according to the medical possibilities and options. (Kovács, 2006)

#### 1.4.3. Ethical problems during the prenatal period

##### 1.4.3.1 Genetic screening

In the prenatal period the tests to identify incidental, diverse malformations and the steps to be taken after a confirmed diagnosis represent ethical cases. Nowadays the ever more developed diagnostic means of modern medicine provide complex, reliable, non-invasive screening exams, in forms of genetic and genomic tests as early as the very first periods of pregnancy. With these techniques it is possible to identify, beyond the sex of the child to be born, chromosome disorders (e.g. trisomies – Down Syndrome, Patau Syndrome), nervous system malformations and illnesses with early, childhood onset, or even with later, adult age onset manifestations (e.g. autosomal dominant polycystic kidney disease – ADPKD). (Bowman-Smart et al., 2019) (De Rechter et al., 2017) The objective of the screening is to obtain information regarding accidental malformations, on whose basis parents may make responsible decisions. To their conscientious decision-making, however, the HCPs must responsibly support them, having obtained their valid informed consent, communicating relevant information adequately, bearing in mind the best interest of the child to be born and the available resources as well. (Horn and Parker, 2018) Privacy regulations and information overload involve further ethical complications. (Stapleton, 2017) (Stapleton et al., 2019)

##### 1.4.3.2 Malformations

The diagnosed malformations (e.g. heart malformations, trisomy of the chromosome 13, causing Patau Syndrome, or anencephaly, a severe malformation disorder of the nervous system) may indicate life-threatening or life-limiting conditions. Nevertheless, at the

moment of the diagnosis it is hard to estimate the life prospects of the child, just as much as to clearly understand the severity of the malformation in the specific case. (Wilkinson, De Crespigny, Xafis, 2014) Conditions formerly regarded as lethal are not to be seen as such anymore, while the most severe forms of the malformations will result in intrauterine foetal death, lighter manifestations may allow for postnatal survival, even for years. (Pawelec et al., 2015) (Biasco, Gemelli, Trombetti, 2013) At present medical sciences, however, are still to define lethal malformations properly (Wilkinson, De Crespigny, Xafis, 2014), just as much as to define the conditions belonging to the category. Moreover, HCPs cannot provide accurate information to parents about what it may mean to live together with the given disorder, due to the lack of experience and lack of proper knowledge regarding future life-prospects. (Crowe et al., 2018)

#### 1.4.3.3 Termination of pregnancy (TOP)

In case of an identified malformation parents may choose to terminate under specific conditions, or to continue with the pregnancy, undertaking the altered conditions and accepting the fact that their child may survive only for a couple of hours after birth, or even that his/her prospect of life, quality of life would be limited compared to other, healthy children. Making a decision of this weight is an enormous emotional burden for the parents. (Blakeley et al., 2019) The doctor participates in the decision-making process applying the doctrines of benevolence and autonomy. (Abi Tayeh et al., 2018) TOP because of severe malformations is allowed on the basis of diverse criteria in different countries. In countries like the United Kingdom, Belgium or Israel, termination is allowed until the very end of the pregnancy, upon medical recommendation. (Crowe et al., 2018), (Abi Tayeh et al., 2018), (Rimon-Zarfaty, Raz., Hashiloni-Dolev, 2011) In other countries, like in India, Poland or even in Hungary, after one specific moment in time, defined by local legal measures – in case the diagnosis is made fairly late – parents are not allowed to opt for the termination of pregnancy, regardless of the expected outcome of the diagnosed condition. (Pawelec et al., 2015), (Nimbalkar and Patel, 2019) In Hungary pregnancies may be terminated until week 20, or exceptionally, in case of a prolonged diagnostic process, until week 24, if the risk of the genetic malformation of the expected child reaches 50%, in case of life-limiting, severe chromosomal malformations. In case of a malformation causing life-

threatening postnatal conditions TOP is allowed regardless of its maturity. (EMMI – Down Syndrome Guidelines, 2016) These conditions, however, as we have already seen above, cannot always be defined unequivocally. When opting for or against termination, the life and the life prospects of the child as essential, valuable *per se* are considered. The decision over the pregnancy is significantly encumbered by the uncertainty of the diagnosis, in most cases accurate results can only be obtained postnatally, with further examinations. (Bucher et al., 2018) When it comes to non-life-threatening malformations, TOP can be ethically acceptable for HCPs on the basis of how they consider the life prospects with the recognised condition, moreover, of what disadvantages, pain it may cause to the child to be born to live together with the disorder. (Crowe et al., 2018) When providing support for the parents in their decision-making, directly or indirectly likewise, the – professional and personal – opinion of the healthcare staff plays a significant role, similarly to the way they express it. (Janvier et al., 2012) The parents’ decision is considerably determined by their understanding of the diagnosis and of the expected altered conditioned they should face. (Cerovac et al., 2019)

#### 1.4.4. Ethical questions in the perinatal period

##### 1.4.4.1 The *grey zone* of prematurity

The ethical dilemmas of the perinatal period –with the narrower medical interpretation of the expression – can be connected to the life expectancy of the child to be born/recently born. Neonatal care development has dominantly improved the prognosis of severely ill and/or extremely premature babies, their chances of survival, moreover, thanks to it, the threshold of viability, the ability to survive autonomously outside the womb has become a reality at lower and lower gestational ages. These latter particulars are mainly established on the basis of the foetus’ biological maturity and on epidemiological conditions described by the survival rates. (Orzalesi and Cuttini, 2011) The time-thresholds of the premature status defined by national guidelines differ from one country to another, depending both on the competencies and on the possibilities of the HCPs, how they can meet the challenges when four fundamental ethical values define the provided care: the protection of biological life, the best interest of the child, human dignity and parental authority. (Orzalesi and Cuttini, 2011) Most probably the greatest complexity lies in the care provided for the premature babies in the so called

*grey zone*, since they have been born at the threshold of viability, their periviable condition is extremely fragile. The *grey zone* and the care to be provided, however, have not been very clearly defined in the guidelines yet, thus the circumstances and the actual institutional practice become more accentuated in the care of the extremely premature neonates. (Aujoulat et al., 2018) When examining the lower confine of prematurity, we may recognise significant differences. While children born at week 20 are regarded as premature neonates in Australia and the United States of America, in Belgium and the Netherlands this happens only at week 24, furthermore, in Italy the limit is GW 28. (Aujoulat et al., 2018) Consequently, the time limits of the *grey zone* will be considered in a different way in the given countries, thus it resulting also in differences in medical care when in different country from home, depending on the defined gestational age as a limit for NICU admission. (Kovács, 2006) The later the gestational age for the premature birth, the more mature the baby can be and the better chances he/she may have for a healthy life, it is fundamental. Nonetheless, having a look at the problem from another point of view, the question we may ask is when the earliest possible time for any chance to survive can be during which the child is provided medical treatment, and chances to live, as well? (Zsák, 2020)

#### 1.4.4.2 Active, curative treatment vs palliative care

Active care, then the initiation of intensive curative treatment in this period is mainly decided by the care-providing team. (Geurtzen et al., 2016) (Aujoulat et al., 2018) Of course, the same is valid for the babies with severe malformations in whose cases the parents, having learnt about the diagnosis, even before the expected date of birth make the decision to have active treatment or palliative care. (Dombrecht et al., 2018) In these cases the decision concerning the provided care may be made in advance, upon the shared consensus of the doctors and the parents, while in case of an unexpected preterm birth there is less time to plan, thus the medical decision-making prevails. (Aujoulat et al., 2018) Selecting between active treatment and palliative care at birth thus depends on the baby's maturity and prospects for life. Continuing an already initiated active treatment as intensive care, or withdrawing it and changing for palliative care already belong to the postnatal period. (Biasco, Gemelli, Trombetti, 2013) The main reasons for this can be the intensified, unbearable pain and the conditions caused by the severe, life-limiting malformation. (Aujoulat et al., 2018) Analgesia for neonates has still not yet

been applied on a larger scale, according to the results of a Greek study in the field (Voultos and Chatzinikolaou, 2014), despite the fact that the majority of the specialist consider the administration of analgesic and sedative drugs necessary, even along with the risk of non-intended consequences in certain cases, although it is difficult to evaluate the pain the child feels. (Bucher et al., 2018) The problem, at the same time, leads us towards the ethical dilemma of euthanasia, too, which in case of newborn babies is even more complex than in paediatric or adult medical care. Concerning newborn babies the life-shortening intention of the physician can be (1) no intention but taking into account a potentially life-shortening effect, (2) the potentially life-shortening effect is not the main goal but partly intended (co-intention) or (3) an explicit life-shortening intention. (Dombrecht et al., 2018) The Groningen Protocol, from the Netherlands, allows the active euthanasia of newborn infants, in case of children born extremely prematurely and/or with severe malformations. The countries prohibiting euthanasia, e.g. Greece, do not even allow its passive form, i.e. withholding or withdrawal of active curative treatment, arguing the ambiguity of ‘unbearable pain’, too, in this respect. (Voultos and Chatzinikolaou, 2014)

#### 1.4.4.3 Options for a *good death*

The great tragedy of perinatal death is that a human life which has just begun comes to an end, leaving a void and taking away all its promises and beauty. The family has got only little time together with the child, yet, or for this very reason, this short period is truly significant. To prepare for the death of the so much expected, newborn child is an immense emotional demand for everyone involved. The question of *good death* is one of the main focal points of palliative care (Hegedűs, 2017), being imperative in perinatal palliative care, as well. (Zsák and Hegedűs, 2020) But how can a little child who has, in reality, not even lived have a *good death*?

One of the few, available resources for this may be preparation. Both the parents and the HCPs should be aware of the potential difficulties, and they all need information and emotional support equally. With advance care planning the care-providing team should think it over a priori how they can accompany the family in this period, prepared to anticipate the planned trajectories according to the current conditions. (Moore, Carter, Beaven, 2019) The provided care is centred around the whole family, together with the newborn patient, this is how the weight they carry may be alleviated and allow for them

to parent the child, and to have all their needs met in an adequate way. (Biasco, Gemelli, Trombetti, 2013) Furthermore, the continuous, conscious and active caring presence, care-giving accompaniment may establish the circumstances in which the net of connections will emerge as a supportive power. End of life care in perinatal circumstances does, too, exceed the professional tasks of the medical staff, it involves human presence, empathy and attention to a great extent. (Moore, Carter, Beaven, 2019)

#### 1.4.4.4 Organ donation

In the context of perinatal palliative care organ donation should also be discussed. The representatives of organ donation associations should be especially well prepared, according to the relevant regulations, since donating organs and tissues in the perinatal period can only be realised following complex conditions. After withdrawing life-sustaining treatments only limited time is available to make the necessary measures and steps, which can further be limited if this happens as early as at birth. The donation of organs or tissues from the body of a minor can only be done with the written consent of the parents, therefore, it is imperative that HCPs talk with the parents about all the details in appropriate time, on carefully set occasion(s) and with proper consideration. (Limbo, Wool, Carter, 2020)

#### 1.4.5. Ethical dilemmas, generally valid for the whole perinatal period

##### 1.4.5.1 The special moral status of the foetus, newborn baby

As it regards the developing child, one of the greatest dilemmas of bioethics, also in connection with abortion-debates, is the beginning of human life, how and when biological life develops into human life, into a person. This question is extremely imperative in the prenatally made decisions of the cases when the parents should decide about giving birth to the child or terminating the pregnancy because of a diagnosed malformation. (Rimon-Zarfaty, Raz, Hashiloni-Dolev, 2011) The perception of the developing child's moral status is a truly significant element in this process. While the Christian religion considers this moral status as total from the moment of conception, the Jewish religion sees biological life changing gradually into a person, thus growing in the moral status. This latter viewpoint is generally characteristic of the Anglo-Saxon medicalisation, too, with two major steps in the process: the threshold of the ability of an autonomous life outside the womb, and the moment of birth. (Denney-Koelsch and

Cote-Arsenault, 2020) Neither a foetus, nor a newborn baby is capable of verbally expressing their needs, problems, nonetheless, it does not entail that they are not capable of expressing the suffered pain or difficulties; it is the task of their care-provider, curing staff to be able to evaluate their signals and to find the adequate answers to them, bearing in mind the child's best interest. (Limbo, Wool, Carter, 2020)

#### 1.4.5.2 The dilemmas of parental authority and decision-making

The patient-quality of the foetus or the newborn child has become increasingly important due to the intrauterine surgical interventions. The subject of the operations in the intrauterine period is the foetus developing in the womb, however, the option to perform these interventions involves the mother's patient-quality and necessitates her consent, for the planned operation involves both of them. Thus a complex state is created, which has no counterparts in other medical fields. (Moore, Carter, Beaven, 2019) The above mentioned 'patient in the patient' situation, which describes the pregnancy, bears dual authority. The expecting mother makes decisions regarding her own health and body, over which she exercises full authority, whereas over her child she bears a more limited, parental authority as a mother, considering the baby's moral status, as well, thus her decision-making is limited concerning obligatory or unnecessary interventions as proposed by given guidelines. (Wax, D'Angio, Chiafery, 2020) In the case of the newborn child, the parental autonomy is similar, the child is not part of the mother's bodily integrity, anymore, he/she is an individual, yet not a fully autonomous being. This limited parental decision-making may be a source of conflict with the HCPS, if the two parties have contradictory opinions regarding the child's best interest. If supposedly parental responsibility does not serve the child's best interest in the optimum way, a guardian may be nominated who shall exclusively care for it. It is, furthermore, the professional obligation of the healthcare personnel to maximally represent the child's interests. (Denney-Koelsch and Cote-Arsenault, 2020)

The decision about the withdrawal of active, curative treatment can be a shared, common task of the parents and physicians, with mutual responsibilities (Bucher et al., 2018), even though some authors claim that physicians consider it right to spare the parents from the painful strain of this decision. (Aujoulat et al., 2018) A somewhat contradictory approach is to be recognised in Gillam and Sullivan's article from 2011, in which they underline the potentially beneficial effects for the parents to be able to act

for the child as parents, with their maternal and paternal responsibilities. The solution for every single case should be individual, where the HCPs understand the parents' attitudes, possibilities, moreover, even to what extent they wish to be part of the decision-making process. (Gillam and Sullivan, 2011)

A professionally and emotionally difficult situation occurs when the views of the HCPs and of the parents do not concord regarding the most favourable treatment for the child. An ethical consensus is required for these disagreements, as presently this problem is under discussion, too. (Bucher et al., 2018) Some years ago enhanced international attention was dedicated to the case of Charlie Guard, the small English boy. (Zsák, 2017) The care-providing physicians of the child born with a rare genetic disorder wanted to change for palliative care, while the parents did not accept this decision and turned to court to pursue their rights. Having nominated a guardian who represented the child's interest solely, the judge decided for palliative care, taking into consideration the parents' hardship and the high level of professional care equally.

#### 1.4.5.3 Moral distress

The above described, professional and ethical responsibility in everyday practice, the conflicts of manifold sources, contradiction in values bring about personal ethical dilemmas for the healthcare professionals, which is best defined as moral distress. This condition differs from burnout, grief inasmuch as it indicates a psychological, mental state which is a direct consequence of the ethical challenges and the responses given to them, causing moral dissonance and damage in their individual integrity. (Wax, D'Angio, Chiafery, 2020) Not elaborated dissonance in the long run may lead to leaving the profession, while its short term effects include anger, guilt and insomnia also.

As potential causes of moral distress researchers have identified the following conditions: non-adequate interprofessional communication, measures prolonging only the patient's dying process, inadequate interventions, not in the patient's interest, futile medical interventions, prolonging life-sustaining treatments when they do not serve the patient's best interest anymore, thus burdensome, not sufficient pain management/control because of fearing the non-desired side-effects, difficulties in communicating bad news, disagreement with the parents over the administered therapeutic solution, and lack of resources. (Mills and Cortezzo, 2020) Whereas measuring moral distress is fairly subjective, there exist some intervention options to

diminish the pressure suffered by the healthcare professionals. Among these structured ethical decision-making meetings, ethical case-discussions, moreover, a supportive and caring environment must be mentioned. In case of challenging ethical problems applying a shared decision-making model can be emphasised, which takes into consideration ethical problems as much as the different stakeholder interests, viewpoints, the potential solutions and it aims to propose a consensus-based action plan. (Wax, D'Angio, Chiafery, 2020)

#### 1.4.6 Conclusive remarks

The high standards of contemporary peri- and neonatal care allow for the appropriate cure of children to be born or born with complex congenital malformations, according to their needs, as early as possible, thus improving their quality of life and their life prospects significantly. At the same time the number of relevant ethical dilemmas has increased considerably, too, which regard the periods between conception and postnatality, or go well beyond them in consequences. The aim has been to outline the ethical dilemmas, since they regularly appear in everyday medical practice and decisively influence the actions of the care-giving operators, however, due to the novelty of the care, they have not been widely known so far. During pregnancy, then after childbirth the medical-bioethical problems have diverse foci, they can be well defined, although some of them are valid for the whole perinatal period, and even onwards.

The most emphasised feature of perinatal palliative care is finding individually tailored solutions by understanding individual conditions, specific circumstances. All this can be the result of a high level, synchronised and outstanding professional and personal medical activity, which, thus, may provide the holistic care of the child and the parents, as early as during the diagnosis of a prenatally recognised malformation, through the perinatal period way into postnatal times in forms of bereavement support, along the above illustrated ethical settings.

## **1.5 Valid, relevant legislative measures, institutional regulations regarding bereavement procedures in case of stillbirth, perinatal and prenatal, intrauterine death**

### 1.5.1 Definition of pre- and perinatal death in Hungarian legislation

In accordance with the medical guidelines, the currently valid Hungarian legal regulations define perinatal death as the intrauterine death of a foetus after the 24<sup>th</sup> pregnancy week, or if the length of the foetus reaches 30 cm, the bodyweight 500 g, or as the death of a newborn baby within 168 hours after birth. (Act CLIV of 1997 on Health, §216 da); db) and e) sections regarding perinatal and prenatal death definitions.) In cases of perinatal death, stillbirth the physician must fill in a death certificate, afterwards send the corpse to the pathology department. An autopsy is always required in case of perinatal death according to the Hungarian legislation. (Act CLIV of 1997 on Health, §217, Sections 4 and 5) Once the post-mortem examination is completed, the corpse of the baby can be buried and the fact and reason of the death is registered by the national statistical authorities, too, since the relevant documentation is to be sent there. The 351/2013 (X. 4.) Decree claims (§35, Section 2) that the burial falls under the responsibilities of the institution except if, upon their own request, somebody else wants to do it. The burial place of the child must be designated – in accordance with the Gov. Decree 351/2013 (X. 4.) §49 – with the indication of the burial day and the number of the burial place. In case of a non-institutional burial, the first name can also be indicated.

If the intrauterine death occurs before the 24th pregnancy week, or the length and/or weight of the foetus is below 30cm and/or 500 g respectively, the physician is not obliged to fill in a death certificate, according to the currently effective regulative measures. (Act CLIV of 1997 on Health, §217, Section 5)

### 1.5.2 Burial procedure options and documentation for prenatal, intrauterine and perinatal death

In cases of prenatal, intrauterine loss the corpse of the baby is transported to the pathology department, where the histological examination of some tissue samples is performed, whereas the rest of the dead body is put into a so-called ‘gratis-box’ together with other human remains and it is buried in a designated part of the cemetery or it is cremated. The human remains buried this way are indicated with a separate burial

headstone by the cemetery owner/funeral service provider. (Gov. Decree 145/1999 (X. 1.) §12, Section 6 and AJB 4291/2010 Report, 2010) However, the Act CXXVII of 2013, §157 (3) allows for the parents the burial or cremation of the child's body in cases of intrauterine death, upon their written request. In these circumstances the parents are responsible for laying the corpse to rest. When stillbirth, perinatal or prenatal, intrauterine death occur, it is possible to bury the child, with a cross, headstone or any other memorial object on the tomb, also indicating the first name of the child. [Gov. Decree 351/2013 (X. 4.) §49] In the case of prenatal, intrauterine death, however, no death certificate is to be issued (Act CLIV of 1997 on Health, §217, Section 5), nor is the baby registered as a person. While the relevant legislation defines rather clearly the procedures, data and options to follow, the families may rely on the communication from the healthcare personnel or on the documentation provided to them by the OBDK, which, however, only claims the necessity of a pathology examination in case of perinatal death and not much more. (OBDK Kegyeleti kiadvány, 2015, 4.2) All the above described details and possibilities are omitted from the informative brochure, unfortunately.

The legal distinction between perinatal and prenatal, intrauterine death is also conveyed in the necessary administrative procedures. The documentation of the adverse event in a prenatal context entails no death certificate, while the death certificate is an obligation in perinatal death, with the name, place and date of birth and other particulars of the child. [Annex 2 of Gov. Decree 351/2013 (X. 4.)] The certificate is the proof of the child's legal existence, giving them identity, the right of being registered as a person. As the legal measures show, this may be done at and after w24 of the gestational period, when considering the timeframe. However, §34 of Gov. Decree 351/2013 (X. 4.) also claims that a child born at any gestational age, showing any vital signs outside the mother's body is to be considered born alive.

### 1.5.3 When does a foetus become a person?

The distinction between intrauterine and perinatal death, as it can be seen above, significantly determines the procedures to follow in pathology, administration and statistical data management, too. Evidently, the earlier the child is born the less chance they have for survival without medical intervention, even with proper care. Nevertheless, how the care providing personnel treat the extremely premature babies,

born before w24, whether they record the vital signs at an earlier gestational age define the baby's identity as a person in legal terms and also the bereavement procedures. A sad example of what may happen in the ambiguity is documented by the report of the Commissioner for Fundamental Rights from 20105. (AJB-5213/2014 Report, 2015).

In this particular case the Commissioner of Fundamental Rights examined the circumstances of a child born alive – with detectable vital signs – at w21. Unfortunately, the attempts to keep her alive were futile and she passed away after a short time, yet, the procedure that followed demonstrated that despite the circumstances of her birth, the care providing staff failed to follow the relevant measures and they proceeded as if it had been a late intrauterine death, despite the fact that the child was considered to be born alive and thus a person on her own right. The malpractice had further impact on the relevant documentation at hospital, the pathology examination, the burial procedure as much as the registration and the death certificate of the child as a person. As the commissioner claims it, the grieving process of the parents was effected to a large extent, similarly, since for them to be able to ask for a death certificate it was necessary to file for a juridical decision and at the time of the report it was still an ongoing procedure, more than 8 months after the child's death, which caused further emotional burden in their loss. (AJB-5213/2014 Report, 2015) The failure to apply the relevant measures violated the parents' human dignity and burial rights, as well. It is a well-documented example of the fragility of the situation, how much a well prepared, skilled and attentive personnel may influence the family's circumstances of childloss.

#### 1.5.4 Current practice in some Hungarian institutions

The overall Hungarian situation is characterised by the option for the individual institutes to design their own regulations and proceedings, nonetheless, the contents are largely defined by cohesive legislative measures and professional guidelines.

As an example the policy applied at Semmelweis University could be studied. The Decree No. 6/2002 (I. 31.) ET. of the Council of Semmelweis University determines the treatment of the corpse of stillborn or aborted children via further regulations. Section 54 of the decree states that the corpse of a stillborn and not registered newborn baby must also be placed into the gratis-box, in case the family are not willing to proceed with the funeral. If the baby was registered, but the family are not willing to bury the

corpse of the child, an institutional university burial must take place according to the procedures of the Institute of Pathology. A similar procedural regulation can be identified in the policy of the University of Pécs (Regulative measures regarding the treatment of corpses - Halottkezelési szabályzat, effective since 13<sup>th</sup> Dec 2016) In accordance with the effective legal regulation [351/2013. (X. 4.), §35, Section 2], IV. 4 declares that it is the responsibility of the institution to bury the child unless somebody else formulates a written request. While it may leave some space for the family to plan a funeral, a prerequisite of this to happen is that they need the relevant information to be able to do it. On the other hand, as it can be seen in the Regulations of the Erzsébet Hospital in Jászberény (in effect since 24<sup>th</sup> March, 2017), the burial of the child happens following the family's request (section 13). A copy of the institution's perinatal post-mortem examination certificate can be found in the Appendix (Appendix 1).

Although in case of stillbirth and abortion, too, even if they do not occur in hospital; the nationwide legal regulations allow for the possibility for the close family to bury the child themselves, however, the potentially offered memorial choices or burial opportunities are not everywhere equally available. Thus, unfortunately, informing the patients rarely happens in an adequate way, as the examined institutional practices have also revealed. While information is disclosed, options and time to make the necessary decisions are fairly limited. The remains of an intrauterine death before w24 are habitually placed into the box which contains other human remains (organs removed via operation, amputated body parts) as well; the corpses of these foetuses are treated as some sort of *human waste*. (AJB 4291/2010 Report, 2010) In cases like these it often happens that the family is not allowed to ask for funeral services, they are not even aware of the fact that by law they are given the opportunity. Since the judgement of the personal status of foetuses may strongly depend on institutional and/or individual views, consequently, the treatment of their corpses is not evident. For this reason the funeral procedures of these small babies can differ to a great extent, from one institute to another basically. There are some institutes where it is possible to stay together with the child in a dedicated commemorative room, while other places deny even the possibility for the parents to hold, or even to see the child. (AJB 4291/2010 Report, 2010) The differences between the institutional procedures may very well exist due to the fact that

facing death and loss for healthcare professionals is a much more demanding task than for the rest of society in general. (Hegedűs, 2002)

#### 1.5.5 Italian legislation for perinatal death events

The presently valid Italian legal measures regarding perinatal death events have been in effect since 1990. (D.P.R. 10 settembre 1990, n. 285) Section 7 of the Presidential Decree foresees it as the responsibility of local authorities to provide permissions of transport and burial for foetuses between the gestational age of w20 and w28, in case they were not registered as stillborn. [Sect. 7, (2)] Upon the request of the parents the same procedure is to be followed for the foetuses below the gestational age w20. (3) Within 24 hours of the event the burial request must be presented to the local authorities together with the medical certificate stating the (presumed) age and weight of the child. [Sect. 7 (4)] For stillborn babies the valid legal regulation is that of §74 of 1238/1939 Royal Decree. (Art. 74 del R.D. n. 1238/1939), namely that when at birth the child is stillborn or dies after birth, the declarer of the death must state this fact together with the cause of death. In both cases a medical certificate is to be provided. At the registry procedure the stillborn child will have a birth certificate with a note of the stillborn event, while for the children born alive and died postnatal a death certificate is also to be issued.

A significant element of the relevant legal measures is the definition w28 for the upper time limit of foetuses. It reflects the cut-off of premature birth established also in the professional guidelines. On the other hand, as it has been shown above, the possibility for bereavement procedures even in early pregnancy losses was created much earlier in Italy than in Hungary. Consequently, it may have given way to a deeper knowledge and acknowledgement of bereavement needs in the perinatal period.

#### 1.5.6 Commemorative options in the institutions

Due to the regional independence regarding healthcare services, Italian institutions show a wide range of available option for bereavement care in perinatal death, provided they have available support. It can firmly be claimed, however, that even within a region big differences may exist among the institutions, due to financial and managerial diversities, attitudes. A reference for bereavement care and bereavement options is a non-profit organisation in Tuscany, CiaoLapo, which, due to their efforts and ever

growing recognition nation-wide, provides memory boxes, on-site trainings, information materials and supplies for the hospitals willing to have bereavement options. ([www.ciaolapo.it](http://www.ciaolapo.it)) At the same time the individual support from the professionals' side to those suffering from loss is a more characteristic Hungarian tendency. In the footsteps of Anglo-Saxon examples, photos, footprints can be taken, which the parents can take home or leave in the hospital, as they prefer. (Although here exist some, not yet clarified and defined, ethical and legal, privacy aspects, too.) Other examples are providing privacy and time together with the baby if wanted, or lighting candles in the silence of the delivery room. These commemorative initiatives originate from physicians, midwives, nurses, and are individual cases in different healthcare institutions, with no links between them. (Zsák, 2021)

Moreover, the more characteristic and generally applied practice is that the burial of death foetuses and even stillborn babies is carried out by the institution, on the basis of its own measures, in accordance with the effective legislation, and, sadly, without the parents knowing the resting place of the child. The couple, still experiencing the shock of the loss, is drifted with the events, hardly understanding what is happening to them and when they realise in retrospect that they could have done things differently, it is too late, irreversible.

## **1.6 Supporting healthcare professionals in pre- and perinatal loss events - international guideline recommendations**

### **1.6.1 From research interest towards policy making**

The literary review of the relevant articles regarding the emotional involvement of the personnel in case of adverse outcome pre- and perinatal events has shown that the attention towards the problem is rather recent, significantly increasing since the beginning of the 21<sup>st</sup> century. This interest has also been transformed into pragmatic and applicable policies, where setting up bereavement care standards involved care for the healthcare providing staff likewise. Clearly, good quality bereavement care in pre- and perinatal context goes hand in hand with wide-ranging support and adequate care for the professionals. In the last decade a tendency has been detectable from policy makers' side for the need to formulate nationwide recommendations to protect the care providers. Even if this goal has not been reached in a lot of countries yet, also because of intraterritorial differences, some good examples can already be found. Here a

chronological review follows from different international organisations to demonstrate the spectrum of attention dedicated to healthcare operators.

#### 1.6.2 Hungarian guidelines for prenatal and perinatal loss, 2010

The still valid Hungarian national guidelines from 2010 regarding pre- and perinatal loss underline the involvement of the care providing personnel, highlighting the specific characteristics of the designated population regarding death. The national protocol also accentuates the significance of healthcare professionals' death attitude in adverse outcome perinatal context and the need for bereavement care recommendations for optimal support. Furthermore, they emphasize the significance of self-awareness and being able to recognise and control own feelings and involvement, since, as they claim, these factors may be an impediment in adequate care. (A Nemzeti Erőforrás Minisztérium szakmai irányelve a pszichológiai feladatokról szüléshez társuló veszteségek során, Hivatalos Értesítő 2010. évi 104. szám) It is well worth noting that these are presently valid guidelines, no updates have been issued during the last decade so far.

#### 1.6.3 Italian guidelines

In Italy there are no national guidelines regarding bereavement care or the support for healthcare professionals involved in adverse outcome perinatal events, due to the fact that the management of healthcare institutions is the competency and responsibility of regional governments. However, the previously mentioned non-profit organisations, CiaoLapo and La Quercia Millenaria, have formulated the standards of proper bereavement care in perinatal context and have also accentuated the importance of adequate attention for care providers' needs. The recommendations are available upon the institutions' individual request and open to adaptive modifications, for local needs. Moreover, the organisations provide training programmes and support for the personnel to obtain the proper know-how and competencies with which they can formulate their own protocol.

#### 1.6.4 Guidelines of the Royal College of Obstetricians and Gynaecologists, UK 2010

Still in 2010 the guidelines formulated by the Royal College of Obstetricians and Gynaecologists propose a best practice model for care of staff who are involved in

adverse outcome perinatal events. The model is composed of clinical and psychological support focusing on occupational health concerns. The importance of coping strategies, informal support and proper bereavement training are highlighted, while competency development in communicating bad news, in postmortem examination, in background clinical knowledge and care, moreover, early training involvement for trainees are all listed among the aspects of training. (Late Intrauterine Fetal Death and Stillbirth, Guideline No. 55, Oct 2010)

#### 1.6.5 National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death Ireland, 2016

In 2016, following a nationwide needs analysis of bereavement care in perinatal institutions, the national standards were issued in Ireland. It is the first document of this kind dedicating a whole chapter for staff training and support needs, formulating criteria and detailed recommendations. (National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death Ireland, Aug 2016) The document clearly describes the functions of a bereavement team, with dedicated tasks and responsibilities in end of life care and compassionate bereavement and highlights the significance of professional ethical code of conduct. The possibility to access continuous education and training according to one's role and responsibilities is a core element of providing appropriate bereavement care. Staff should also be knowledgeable about practice and current legislation measures, as the guidelines claim. As for support for HCPs, the protocol foresees peer support and professional support systems, in which supervision, individual debriefing, time-out, peer group support, professional counselling services are all mentioned, underlining the importance of staff well-being and self-care. Moreover, the guidelines define it as the responsibility of management to provide debriefing opportunities for staff in case of trauma or sudden death and to observe for signs of stress and difficulty. Informal support among staff is also encouraged as much as participation in assistance programmes, if needed. In case of ethical decision making challenges further resources are also to be sought for. Last, but not least, the guidelines make recommendations for the availability of private space for personnel to discuss any related issues when facing perinatal death and providing bereavement care. A full spectrum of the requirements of compassionate bereavement care is described and definite emphasis is put on staff needs and support, as a prerequisite of proper care.

#### 1.6.6 Perinatal Society of Australia and New Zealand (PSANZ) Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death, 2018

The guidelines from the Perinatal Society of Australia and New Zealand declare how the actions of healthcare professionals and their timing are critical to high quality care. Therefore, they must be prepared for a wide range of responses when providing perinatal bereavement care. (Perinatal Society of Australia and New Zealand (PSANZ) Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death, Third Edition, June 2018) From their side it requires skills and competences to support parents and the knowledge of where and how to look for their own support and ability to develop resilience to avoid distancing from parents, feeling overwhelmed and burning out. Another significant element to consider when caring for bereaved families is the grief and loss from their own lives, since the personal experiences may affect the quality of care as well as increase the vulnerability of the care-providers. Thus support for the HCPs' own loss is of the essence. Education, training, resources and support are defined as the key elements for best practice care in perinatal bereavement by the guidelines. When addressing the emotional and practical aspects of care, trainings should also focus on the emotional impact of the adverse outcome and on strategies to promote self-care and coping competencies. Burnout, compassion fatigue or secondary traumatic stress should be managed and prevented on organisational level, in the forms of debriefing, support, supervision and mentoring. Rotation to avoid repeated exposure and early inclusion into training and mentoring opportunities are as important as employing a specific bereavement staff. Moreover, formulating local policies may provide space for institution based practices, for the use of a symbol to indicate baby loss or a life limiting condition. These also allow for potential storage of images and mementoes for parents and adequate informational resources.

A significant feature of the PSANZ guidelines is the IMPROVE (IMproving Perinatal Mortality Review and Outcomes Via Education) Workshops educational programme, which is a concise formative training with relevant clinical evidence, appropriate standards and skills development focus. It provides a systematic, one-day formation opportunity to deepen knowledge and develop skills regarding communication, post-mortem examination, bereavement and clinical data, as well.

### 1.6.7 The National Bereavement Care Pathway for Pregnancy and Babyloss, 2020, UK

The interests and provisions of all types of stakeholders and perinatal care providers were formulated in the National Bereavement Care Pathway for Pregnancy and Babyloss documents from the United Kingdom, covering the whole perinatal period from very early pregnancy losses to sudden infant death events. (The National Bereavement Care Pathway after Pregnancy and Babyloss, Jan 2020, UK) All the available documents dedicate special attention to staff care, training, support and self-care needs. The guidelines also shed light on the special and rewarding feature of high quality bereavement care, a unique satisfaction of those who work with bereaved families. As for training and education, the significance of multilevel - under-, postgraduate and in-service - training opportunities for perinatal professionals is defined by the guidelines. Practical and emotional staff support should be available so that their comfort, confidence and competency can be developed for high quality care and to reduce staff stress. Sensitive and empathetic communication skills, awareness of the needs of the bereaved families are also stated as important elements.

In order that staff members could provide appropriate, individualised care, they need to manage their own emotions of their own loss experiences, their feeling of professional failure following a baby death and the anxiety of ‘wanting to do something’, according to the protocol. To this end, good support means open and caring work environment, debriefing and reviewing opportunities on organisational levels, depending also on the specific situations. Professional counselling should be available as a confidential service, to avoid stigma and concerns about not being able to cope. The responsibility of the management is to look for signs of distress, to encourage and to provide and ask for support at the same time, when necessary. Another significant element of proper professional support is the individual’s responsibility for self-care. In this spectrum enough sleep, a healthy diet, exercising, time off, friends, outdoor activities are mentioned among others as means of attending to own needs.

### 1.6.8 Highlights and common elements in the guidelines

The collected national or organisational guidelines all underline the potentially adverse emotional effect of perinatal loss events on healthcare professionals as a risk factor in their high standard vocation. The importance of education regarding perinatal loss and

bereavement care, with special focus on communication, empathy and support throughout continuous trainings starting with early involvement is essential to provide high quality and adequate individual care.

In general, the available guidelines from Anglo-Saxon countries reveal the importance of a key, skilled and specifically formed team for perinatal child loss, the bereavement care team. With its multidisciplinary knowledge and multiprofessional competency background it focuses on the individual families' needs and accompanies them with adequate administrative, social, spiritual and psychological help when experiencing perinatal loss. The team generally consists of a perinatal bereavement specialist/coordinator, of a doctor, a nurse, a social worker, a psychologist, a spiritual/religious advisor and other temporary members, depending on the local needs and possibilities. With each team member having a well-defined role and area of responsibility, they may significantly ease the caregiver medical personnel's emotional burden and involvement as much as they help the family in their grief. (Black et al., 2016) Having institutional, well known among the staff and suited to the institute's needs local bereavement protocol standards may provide an appropriate frame and background to attend a loss event when necessary. All these elements may contribute to the satisfaction of the care-providers, seeing the immediate effect of their efforts and attention for the families.

For staff care and support the level may come from different sides. Debriefing occasions for the care-providing team, with special focus on signs of fatigue and extreme reactions are as significant as peer consultation for team members, formal and informal support opportunities, too. Last, but not least, self-care skills and competencies must be accentuated and taught in order that each member can find their own extra coping resources in times of need.

These guidelines may offer the opportunity to adopt their recommendations to specific institutional or even national needs where no such protocol measures exist yet. The objective is the same everywhere, namely, to care in the best possible way for those who need to carry the burden of perinatal loss on their shoulders. Therefore, while weighing individual options, too, policy makers may profit to a great extent from the already functioning, well formulated and detailed perinatal bereavement protocol measures.

## 1.7 Anticipating research – report of the Students’ Scientific Association Study

### 1.7.1 Introduction

The antecedent of the PhD research was a study realised in 2014 and 2015 and presented at the Annual Conference of the Students’ Scientific Association of the University Semmelweis, Faculty of Medicine, Section Psychiatry, in February, 2015. The topic was defined as **A perinatális veszteségek és intrauterin magzati halálások aktuális szakmai gyakorlatának, valamint a szakemberekre gyakorolt hatásainak vizsgálata**, similarly to the topic of the PhD research. The gestor-institute of the research was the Institute of Behavioural Sciences, with Katalin Hegedűs supervising the activity. For the research method and design a semi-structured interview was created to be completed personally, at a pre-defined time and place.

The motivation to study the phenomenon came from a summer internship experience spent at an obstetrics and gynaecology department of a tertiary level medical institution. One of the young residents explained why she was attracted to this field, claiming that there everybody was happy, since children are born there and people leave the hospital full of joy. On the other hand, a couple of days later I witnessed how one of the experienced and popular midwives refused to touch the small body of a second trimester aborted baby, asking a colleague to do it instead. These contradictory appearances regarding child-bearing pointed to complex emotional involvement of the healthcare professionals, well worth of further examination. As a consequence of this ambiguity, I presumed, avoiding the patients who suffered perinatal loss and not giving them any support, nor the opportunity to see their child was common practice, since facing their grief and sorrow was uncomfortable, a phenomenon to be dismissed simply.

### 1.7.2 Objectives

To be able to obtain a detailed perspective of the effects of perinatal loss on the healthcare operators, I aimed to get insight into the existing practices of the preselected Hungarian institutions and into the professional and personal challenges, difficulties of the care-providing personnel active in the related field.

On the one hand, it became of high interest to understand if there were any differences, with special attention to bereavement practices, between the institutions. On the other hand, to see perinatal loss from the healthcare professional side, regarding difficulties in communication and providing support, specific strategies and instruments to help with

bereavement, moreover, concerning coping strategies to elaborate their own feelings of loss and grief. My hypotheses were that (1) an existing correlation could be found between the level of provided bereavement support and the professional and personal attitude regarding perinatal loss, and (2) the attitude of healthcare personnel had a decisive effect on bereavement possibilities.

### 1.7.3 Methods

For the sample the potential interviewees were selected among the care providers active in gynaecology and obstetrics, perinatal intensive care, and district nurses of general medical practice. This way more levels of the care could be seen together, starting from a smaller scale family care to tertiary level regional units. Prior to the interviews consent was asked, with the opportunity to withdraw the answers at any time and not to answer questions. Altogether 5 interviews were carried out, with two doctors (obstetrician-gynaecologist, neonatologist), a psychologist, a nurse and a district nurse. For the experience the obstetrician-gynaecologist had a more than 25-year practice in the field, followed by the psychologist, neonatologist and district nurse, with 10-20 years of experience, whereas the nurse had just started her healthcare practice after college.

The analysis of the interviews happened with closely examining the verbatim text of the conversations, identifying the elements of applied practices and the sources of personal and professional difficulties, challenges in perinatal loss. The first level of interpretation followed the primary structure of the interview, while the second level established themes and topics derived from the content of the answers. The findings were presented orally with slides at the conference and later published in the Hungarian Medical Weekly journal. (Zsák et al., 2015)

### 1.7.4 Results and discussion

While legal regulations and guidelines allow for bereavement support and burial options in perinatal loss, access to these opportunities is based on whether it is communicated to the parents in a relevant timeframe. The study of institutional practices revealed that in most cases the knowledge of relevant guidelines and legal measures is not sufficient so that it could be seen as part of the everyday institutional protocol. Therefore, parents could not have the chance to see or hold their children after a stillbirth, for example, or

have burial services for them, due to lack of proper background knowledge. In case of prenatal loss, it was even rarer to find cases where all these options became available for the families. Moreover, mental health or psychological support could not be offered all the time, with psychologists being involved at more departments and chaplains being there only for request during the patients' stay at hospital. Once leaving the hospital, patients' follow-up only means physical controls, even child care specialist nurses lose all contact with the previously pregnant women. The lack of competencies, available protocol measures were a source of frustration, incompetence for the care-providers. 'What can I ask? Shall I ask "how are you" when I can see she is not well?' claimed the district nurse and explained that when perinatal loss happens, expressing her dissatisfaction (with herself) and lack of communication strategies. The conversations with the nurse and the district nurse confirmed that a noteworthy effort was required from their side to find solutions to communication difficulties, to which they had no skills coming from their professional education. No guidance was offered to them during the formative studies or the continuous trainings as to how to deliver bad news, or deal with delicate and challenging situations. As they put it, 'we learnt about smoking or protection against lice, but even at college we only generally spoke about loss and grief'. For the district nurse another difficulty was that they simply lost the patient from their care after the perinatal loss event, since there was no communication between her and the hospital where the pregnant women were treated.

Other interviewees revealed further challenges when facing perinatal loss as a professional. The obstetrician-gynaecologist from a tertiary level institution highlighted the significance of the research by claiming that 'the topic is important, [...] it is absolutely indispensable, since our opportunities are limited and the walls are high'. The wall symbol here refers to the refusal of some medical staff recognising the weight of such a loss for any reason, personal or professional. The interviewed specialist, having felt the need to provide more adequate support, attempted to find ways to care for families over the medical duties, too, by taking pictures, for example, of the babies. To what extent personal and professional cannot be separated in healthcare is well illustrated by the example of the psychologist of the obstetrics-gynaecology department at a tertiary level regional hospital. Having known about her pregnancy, she called in for a longer sick leave because she felt it would have caused her professional and personal

conflicts following women after perinatal loss events. For her there was contradiction in the situation where she was supposed 'to sit there with a big belly and console a woman grieving her child'. Moreover, the conversation with her also revealed another significant aspect of the institutional practice there, namely, that she had to investigate herself if she wanted to find the patients who had gone through babyloss, because nobody else of the staff (doctors, midwives or nurses) informed her about these events. The interviews with the healthcare professionals gave evidence that facing perinatal loss was a demanding burden for them. They became emotionally involved, moreover, in most cases they had no opportunities to ventilate their ambivalent feelings, nor to elaborate them, among the team they worked with, or with the help of a mental health specialist.

#### 1.7.5 Conclusion

In conclusion it was possible to claim that incongruence was to be recognised between the existing guidelines and the applied practice, this, furthermore, had influence on the bereavement practices and facilities offered to the families. Moreover, it became evident and confirmed that dealing with cases of perinatal loss was a specially demanding task for the healthcare personnel, because of the lack of specific skills and competencies to face these situations and because of the lack of relevant coping strategies to elaborate their own emotional involvement and grief. The original hypotheses gained affirmation and thus provided motivation to continue the research as a doctoral thesis study.

## 2 OBJECTIVES

### 2.1 Objectives of the doctoral thesis

A fundamental purpose of the PhD research has been a more profound understanding of the emotional involvement, impact and encumber of healthcare professionals in perinatal events with adverse outcome. The aim has been to explore the underlying practice-related factors and personal psychological modes and present the results so that they could serve as a starting point for improvement in care and support.

To this end the main objectives of the research are

- (1) to present an overview of the international research activity and achievements in the topic which later can serve as a starting point and reference for future research interest,
- (2) to outline the presently valid and applicable legal measures and institutional regulations applicable in cases of pre- and perinatal death events with a focus on bereavement options,
- (3) to collect relevant recommendations of national and organisational guidelines, where available, with the focus of support and attention to healthcare professionals' needs in adverse outcome pre- and perinatal events,
- (4) to study the presently applied institutional practice in the relevant Hungarian and Italian healthcare institutions, in order that the applicable and valid guideline recommendations can be compared to the effective support provided to the patients;
- (5) to analyse how the adverse outcome events and losses affect the care-providing personnel, what professional and personal challenges, difficulties they encounter when facing these situations,  
and on the basis of all the findings;
- (6) to propose interventional strategies and educational programmes aimed at providing adequate individual and team development opportunities and support for the involved care providing personnel.

### 2.2 Fundamental foci of the research

The authenticity of the research is supported by the fact that the grief caused by perinatal loss may turn into a phenomenon of complicated grief. Experiencing and facing it carries a burden for the families, their closer and wider environment and for the care-providing personnel similarly, yet, it is a relatively understudied problem,

especially regarding the professionals' psychological and emotional involvement. Death, the end of life and its related sorrow may multiply in case of a newly started, small life and frequently even burial procedures are obstructed due to the particular nature of childloss in perinatal context.

In order that improvement could be obtained in the care-providing practices it is essential to understand the characteristics of the presently provided emotional and bereavement support, with a focus on legal, policy and institutional background at the same time. Furthermore, it is decisive to gain a perspective of the professional and personal attitude, the experienced difficulties of the related care-providing healthcare staff and to recognize how their attitude influences the efficacy of bereavement support and creates differences between institutions. Potentially available support measures and self-care solutions, coping strategies may facilitate adequate care, thus their existence and utility are of great importance in elaborations of work related loss feelings. Finally, private life loss experiences may precondition HCPs' attitude, provided help and the weight of the experienced trauma.

Having obtained the results of the research, it may be possible to formulate a methodology concept and continuous education programme which may provide the healthcare professionals with efficient means of adequate bereavement support towards the families and elaboration resources for their own grief, easing the negative professional and personal impact of the adverse events.

The general focus of the research is explorative and qualitative, aiming at a closer comprehension of the psychological, emotional and moral burden perinatal loss conveys for the health professionals at any stage and level of the provided care. While the relevant, valid Hungarian guidelines emphasise the self-protecting measures of the care providers, seemingly, it still remains an understudied, and consequently, a scarcely supported part of their activity. Therefore, the objective of the thesis is to serve as a starting point for future research related to the topic, providing a background of relevant literary and reference materials, too, and thus supporting further academic activity.

It also aims at proposing potential educational options, so that the burden of perinatal loss could be eased on the side of the personnel and thus the offered bereavement support could be improved accordingly.

The research material is a reflection of the personal narratives of the interviewees regarding experienced perinatal loss events. While the semi-structured interviews provided a certain thread to their narration, it also allowed for them to express themselves freely. It was the task of the researcher to reflectively discover the complexity, the potential associations, the characteristic features in them, while striving to be an outsider observant of the phenomenon.

At the same time, the research cannot undertake the task of measuring the effects of perinatal loss on the healthcare personnel on a nation-wide scale, since its limits, objectives and methodology are not suitable for this end. Neither can it serve to form any moral or subjective prejudices concerning the examined field or the personal attitudes. The researcher wholeheartedly acknowledges the personal trust and openness of all those who answered the questions according to their best intentions.

### **2.3 Hypotheses**

1. I presume that the healthcare professionals whose attitude regarding grief and loss is negative tend to escape from loss situations, as well as to avoid the involved families, and may provide less support for them.
2. I presume that the healthcare professionals' knowledge of perinatal death related legal measures is inadequate.
3. I presume that the inadequacy of healthcare professionals' knowledge of perinatal death related legal measures will affect the applied/suggested burial and bereavement care opportunities.
4. I presume that the lack of national and/or institutional guidelines regarding perinatal bereavement care creates challenging situations in case of perinatal death events.
5. I presume that the management of the perinatal death cases depends on the attitude of the healthcare professionals, resulting in differences of available support for involved families.
6. I presume that healthcare professionals do not receive satisfactory communication and psychological formation during their education and continuous trainings to adequately help the related patients, or to elaborate their own feelings of loss and grief.

7. I presume that the lack of communication and psychological skills influences the previously mentioned factors and strengthen the healthcare professionals' avoidance behaviour patterns.
8. I presume that the emotional effect of a perinatal loss event can be identified in the healthcare professionals' private life, as well, with consequences regarding their physical and mental wellbeing.

#### **2.4 Ethical approval**

The research plan and the research were granted approval by the Regional, Institutional Scientific and Research Ethics Committee of the Semmelweis University on 4<sup>th</sup> Feb. 2015 (Ref. no. 8/2015 SE TUKÉB).

### 3 METHODS

#### 3.1 Applied methodology for the analysis

3.1.1 Interpretative phenomenological analysis, NVivo 12 Pro – theoretical background

##### **Interpretative phenomenological analysis - IPA**

Interpretative phenomenological analysis (IPA) is an approach to qualitative, experiential inquiry, used in psychology, human, social and health sciences. Its objective is to explore the participants' sense-making of their personal and social world (Smith, 2015), through the lenses of phenomenology, hermeneutics and idiography. (Smith, 2009) **Phenomenology** is the philosophical approach to the study of experience. The analysis of human experience requires a reflexive move, an inward perception of the world outside. Thus 'we grasp the corresponding subjective experiences' in which we become 'conscious' of them, in which (in the broadest sense) they 'appear'. Via the phenomenological method, as Husserl sees it, the essence of the experience, the core can be found and captured through a series of reductions. (Husserl, 1927) M. Heidegger (1889-1976) claims that knowledge (and thus, knowledge of an experience) is only possible within an interpretative stance, which implies one's reflexive awareness as well as the existence of others. For him the person is a worldly 'person-in-context', with a rather explicit intersubjective feature. At the same time the experience of the world will always have a particular, individual part, because one's knowledge can only be gained from one's own particular point of view, as M. Merleau-Ponty (1908-1961) points out. (Phenomenology of Perception, 1962) Since one's perception of the others' experiences develops from one's own embodied experience, we can never fully share or capture the others' experience. JP. Sartre (1905-1980), too, underlines the intersubjective nature of the human experience, as one's perception of the world is largely shaped by the presence of others. The phenomenon becomes an experience for the participant by the meaning it represents for him, in the philosophical sense. Pure experience nonetheless is never accessible, but the meaning people impress upon it. Access to the personal experience depends on the researcher's own conceptions (Smith, 2015), thus the notion phenomenology denotes can be interpreted through hermeneutics.

**Hermeneutics**, accordingly, offers means of interpretation. Grammatical and psychological interpretations of an experience convey an objective meaning and an

individual layer at the same time, as F. Schleiermacher (1768-1834) sees it, since the use of the language will necessarily bear the characteristics of the individual. The analysis may allow meaningful insights into the first-hand account of the experience, offering thus another perspective. Moreover, the interpretation cannot be done without the interpreter's fore-conception, assumptions regarding the experience. A third influential voice here is that of HG. Gadamer's (1900-2002), who highlights how fore-conception plays a role in interpreting a phenomenon. During the interpretative process, there is a continuous dialogue between the interpreter's former mindset and the examined subject. The dynamic relationship can be portrayed between the part and the whole in the analysis of a phenomenon, the perspectives of interpretation keep changing while proceeding with the examination. In IPA, furthermore, there is a special emphasis on 'double hermeneutics', namely that the researcher interprets the participant's account of his interpretation of a phenomenon, with a commitment to the person as a cognitive, linguistic affective and physical being. (Smith, 2015) Thus, the researcher makes sense of it, through his own, experientially-informed lens, allowing for different levels of interpretation. The importance of the particular is visible in the **idiographic** sensibility of the IPA. A systematic and thorough analysis will be able to focus on the details, whereas it also offers the opportunity to see a particular experience, from the perspective of particular people, in a particular context. From the examined cases theoretical explanations will be derived via analytical induction. An initial hypothesis will be scrutinised, reflected upon and modified in the analytical process and its final revised form will be the outcome. (Robson, 1993)

### 3.1.2 Data collection and analysis when using IPA

The design of a research using IPA puts special emphasis on collecting events which elicit stories, feelings and thoughts from the participants. To this aim, semi-structured, one-to-one personal interviews are the preferred ways to collect the sample data. During the personal encounters there is time and space for a rapport to be developed, participants may have the proper conditions to reflect on their own experiences, speak about them and be listened to. The interview is a purposely directed, one-sided conversation, and thus, in this sense, also an artificial one, where the researcher asks and the participant describes the experience in their own words, mainly. (Larkin, 2006) The interview questions are open and expansive, allowing for responses at length. The effect

the interview may have on them is to be monitored constantly, it is the researcher's ethical responsibility to fully respect the participant and to decide how to proceed should the participant encounter any difficulties during the interview.

Data analysis also reflects upon the researchers' own preconceptions about the data, and attempts to suspend these in order to focus on grasping the experiential world of the research participant. IPA's hermeneutic stance is one of inquiry and meaning-making (Larkin, 2006), using double hermeneutics in interpretation. The analysis in IPA tends to be 'bottom-up', the researcher generates codes from the data, rather than using a pre-existing theory to identify codes that might be applied to the data. The patterns in the codes are emergent themes, recurring patterns of meaning (ideas, thoughts, feelings) throughout the text. (Smith, 2009) A degree of transparency (contextual detail about the sample, a clear account of process, adequate commentary on the data, key points illustrated by verbatim quotes) is crucial to estimating the plausibility and transferability of an IPA study. (Larkin, 2006)

### 3.1.3 NVivo 12 Pro

Since the focus of the PhD research is the deeper understanding of a specific phenomenon, qualitative analysis has been the selected path to obtain the details. To realize the study and the analytical steps I have chosen the *NVivo 12 Pro* software, which allows the accomplishment of several research tasks, moreover, the whole research project can be carried out by using the programme. Thus it is possible to manage the collected data and ideas, to query the data and visualise it as much as the results while one can keep a journal of the analysis by taking memos and notes. Mind maps and concept maps facilitate connection of the ideas and reflection on the results. The units of analysis in the programme are *cases*, regarded as a specific and bounded instance of a selected phenomenon (Jackson and Bazeley, 2019), in correlation with anthropological and sociological literature. A case is a core structural element in NVivo, uniting different components of qualitative and quantitative data about that entity. Attribute values (e.g. demographic and numeric data) can be connected to each case, and used to sort out the cases.

*Codes* are abstract representations of an object or phenomenon (Corbin & Strauss, 2008), through which it is possible to identify themes in the text. By coding in qualitative research we index the data for later availability as singular concepts. Coding

allows to de- and recontextualise the data, when moving from individual document analysis to theorising. Coding involves a continuous assessment and rethinking. Considering coding as not unchangeable, one may code from broader themes to more refined subthemes. From the initial grouping the text into more general topic areas one moves to taking stock of the diversity of opinions in each code while simultaneously coding the data into more discrete subcodes. This deductive approach results from the structure of the research interview where the questions themselves are grouped around specific themes, following a certain order. These allow for a *priori*, theoretically derived codes in the analysis on the one hand. On the other hand, *in vivo* codes are identified during the text analysis, directly from the data. (Jackson and Bazeley, 2019)

*Nodes* in NVivo designate a topic or a concept, containing coded passages related to these. They incorporate all the references regarding the given topic or concept. The description of the node carries the basic meaning characteristics. The nodes, then, are structured into a branching hierarchical system, with categories and sub-categories. The organisation of the nodes allows conceptual grouping and theoretically connecting of the elements, through which it becomes possible to identify patterns of association. By running *word frequency queries* or *text search queries* word frequency and words or phrases of interest are identified and then displayed in different forms (e.g. word cloud, summary list or tree map). Different groups of files, cases, codes, etc. can be made comparable with each other when grouped together into *sets*. Moreover, it is possible to render one item into diverse sets, thus when establishing hierarchy among the elements the researcher will have an easier task to analyse them. (Jackson and Bazeley, 2019)

## **3.2 Research design, sampling, data analysis**

### **3.2.1 Design**

A qualitative approach was adopted when carrying out the research. The main aim of the explorative research was to discover and understand the underlying notions regarding HCPs emotional involvement and difficulties in adverse outcome events of the pre- and perinatal period. Since no other nationwide research has focused on the investigation of phenomenon yet, a qualitative method promised to be the most efficient one, providing potential basis for quantitative options in future analysis. Furthermore, the method of the semi-structured interview allows for a profound observation of the research topic, investigating the subjects' understanding, representation, moral and

professional standards at the same time. A neutral, open and non-subjective approach from the researcher's side may lessen the influence of preconceptions and prejudices, therefore the decontextualisation of the interviews and abstraction served major purposes.

### 3.2.2 Sampling

Research data was collected from individual interviews between Sept 2016 and Nov 2019. Individual interviews allow telling the same experience from individual points of view and the opportunity to explore how these experiences are discussed by the professionals working in the same field. By collecting data via this method, behavioural patterns, motivation and personal attitudes can be investigated. Interviewees were contacted individually after a formal administrative process of permission and consent, the time and place of the interviews were agreed one by one. The aim was to reach as many professionals working in the related healthcare fields as possible, preferably more than one from the related healthcare institutions. Another objective was to reach healthcare professionals with a wide spectrum of practice, including freshly graduated and more experienced personnel, too. In order to get a wide picture of the investigated phenomenon, different professionals involved in different segments and levels of perinatal care were to be included. No distinction was set up regarding gender. Out of the total 18, the proportion of Hungarian and Italian interviews was 2:1, Hungarian being more accentuated (HU N=12, IT N=6). In the Hungarian context the gender proportion is 10:2, while in the Italian 5:1. The involved professions are: midwives (N=4), neonatologists (N=2), OB-GYNs (N=2), perinatal specialists (N=3), physicians (other) (N=1), psychologists (N=3) and child care counsellors (N=3). A more detailed sociodemographic description of the research sample is found in the next chapter.

### 3.2.3 Data collection and analysis

#### 3.2.3.1 Interview structure

A semi structured interview was developed for the individual conversations. The interview questions were grouped into 4 thematic sections, each of them addressing diverse aspects of the personal and professional challenges of perinatal death events in healthcare context. Part 1 covered the personal particulars of the interviewees, partially used for statistical data, nevertheless, it proved to be useful as a 'warm-up', as well. Part

2 in 7 questions focused on the professional background and experience, institutional practices related to perinatal bereavement care. Part 3 in 6 questions addressed the skills and competences utilised when facing perinatal death occurrences in any relevant professional context. Part 4, in the end, investigated, with 5 questions, the personal involvement, feelings, effects and required support to elaborate the weight of the adverse outcome events. The settings and schedule of the conversations were established with the comfort and well-being of the participants in mind, due to the difficulty of the discussed topics. The complete interview, both in Hungarian and in Italian, is found in the Appendix. (Appendices 2 and 3)

#### 3.2.3.2 Data collection and privacy

In general, the interviews required 40-45 minutes, however, there was time and opportunity to discuss certain aspects if required. All of them were recorded, transcribed and translated into English for the NVivo programme to be used for analysis. Translation was also used to create a one language context for the research as the interviews were made in Hungarian and in Italian. During the interview answers to any question could be refused, or withdrawn at any later date.

Participants of the study were asked to give their written consent to the interviews prior to the actual meetings. Together with the invitation and request to participate the interview questions and the relevant documentation regarding privacy and data protection were sent out, too. The signed consents and the relevant documentation is to be found together with the research resources. The recorded material is preserved and protected from non-authorised handling. The transcribed material has been made anonym and deprived of any revealing referential details. Data analysis and elaboration has been carried out with the utmost care and attention regarding privacy.

#### 3.2.3.3 Data analysis

Template analysis was employed, with deductive and inductive approaches, on the basis of the previously described Interpretative Phenomenological Analysis, IPA. The interview questions and the structure of the interview allowed developing a preliminary code framework *a priori*, establishing nodes and coordinating major themes contemporarily. Further themes and nodes emerged from the thorough reading and re-reading of the transcripts, with the hierarchy of parent and child nodes reaching more

levels. The secondary, inductive coding structure emerged from the hierarchy of the dynamically changing nodes, through abstraction, providing a concept framework to the studied phenomenon. The programme *NVivo 12 Pro* was used to analyse the verbatim transcripts and organise the nodes into conceptual maps and coding tree structures. Conceptual saturation was achieved having examined approximately two thirds of the registered materials.

### 3.3 Coding structures

#### 3.3.1 Primary, deductive coding structure

The primary, deductive coding structure (PD1) follows and is based upon the interview structure, where the arch of thematic questions leads from the professional experiences of adverse outcome perinatal events to personal feelings and private life interferences. The principal parent nodes are the following 7: **Loss events in numbers, Personal experiences, Present institutional practice, Professional experience, Skills and competencies, Support and coping for HCPs and Training and structural needs for best care** altogether with 31+80+17 child nodes on 4 hierarchical levels. The complete coding structure can be found in Appendix (Appendix 4) and it is presented in the Results chapter.

#### 3.3.2 Secondary, inductive coding structure

The secondary, inductive coding structure (SI1), emerging from the hierarchy of individual nodes, offers the conceptual framework of professionally experienced chronic loss events. Through abstraction and de-contextualisation the following 5 governing super-ordinate nodes could be defined: **Perinatal death, Cognitive elements, Emotive elements, Own, personal loss experiences and Functional behaviour patterns**. The 'bottom-up' structuring thus results in 5 principal governing nodes, altogether with further 20+31 child nodes on 3 hierarchical levels. The complete coding structure can be found in Appendix (Appendix 5) and most of its elements are presented in the Results chapter, together with a schematic conceptual framework.

## 4 RESULTS

### 4.1 General sociodemographic characteristics of the research data

Research data was collected from individual interviews between Sept 2016 and Nov 2019. The invitation for participation partly was due to former, personal contact, partly due to an intermediary contact, mainly in the case of the Italian interviews, where the Osservatorio di Psicologia Clinica Perinatale of the Università degli Studi di Brescia provided the background. Prior to the actual conversations, interviewees were contacted individually, together with a formal administrative process of permission and consent. Afterwards the time and place of the interviews were agreed one by one with each participant.

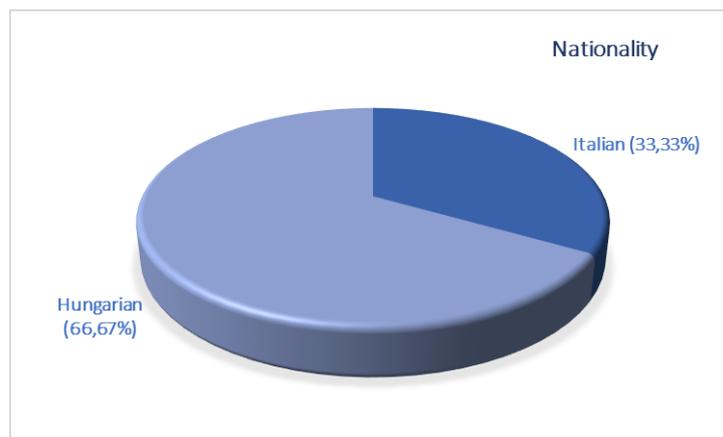
According to the original objectives of the planned research, participants were to be invited from any field of specialisation related to perinatal bereavement. With this aim in mind, neonatologists, paediatricians, obstetrician-gynaecologists, nurses, midwives, psychologists, perinatal specialists, child-care specialists, doulas, grief-counsellors in griefshare groups, funeral service providers, hospital chaplains and nonprofit organisation representatives were invited to participate, in a total of 34. Nevertheless, during the examination it became recognisable how the distinction had to be more closely on perinatal healthcare, therefore, only the portion of the interviews could be incorporated into the thesis which were strictly related to perinatal specialisations in healthcare. All in all, 18 interviews of different specialisations were included in the presented research. The primary aim was to reach as many professionals working in the related healthcare fields as possible, preferably more than one from the related healthcare institutions, while covering all institutional levels and the highest possible number of the related institutes. Another objective was to reach healthcare professionals with a wide spectrum of practice, including freshly graduated and more experienced personnel, as well.

In order to get a wide picture of the investigated phenomenon, different professionals involved in different segments and levels of perinatal care were to be included and asked for an interview. No distinction was set up regarding gender, nonetheless, the final count is 15 women and 3 men from the related specialisations. The proportion of

Hungarian and Italian interviews was 2:1, Hungarian being in the focus of the research. In the Hungarian context the gender proportion is 10:2, while in the Italian 5:1. In general, the interviews required 40-45 minutes, the transcription and the translation into English happened subsequently, together with the anonymization of the final versions, eliminating all references to identifiable particulars, while preserving distinctive features. The subsequent pages will demonstrate further demographic details of the research sample, regarding the involved professions, the working experience, the related departments and institutional levels, as well as the availability of a local, institutional protocol concerning perinatal bereavement care.

#### 4.1.1 Participation according to nationality

Figure 4.1 offers a proportional representation of the interviewed HCPs' nationality, indicating the 2:1 ratio among Hungarian (N=12) and Italian participants (N=6).



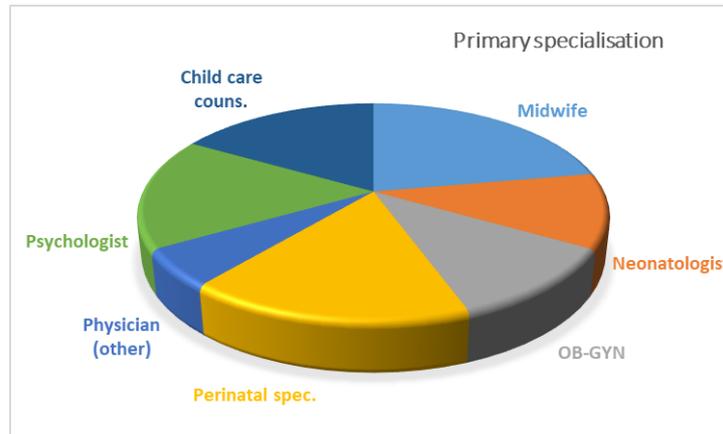
**Figure 4.1** Nationality of the research participants (N=18)

#### 4.1.2 Specialisation characteristics of the involved healthcare professionals

The invitation for participation was motivated by the primary specialisation of the perinatal healthcare professionals, nonetheless, it was possible to identify secondary specialisations in several cases, as well, not unrelated to their primary vocation. For this reason, both the primary and the secondary professions are presented below.

#### 4.1.2.1 Primary specialisations

As Figure 4.2 reveals, the professions represented in the analysis are: midwife (N=4), neonatologist (N=2), obstetrician-gynaecologist (N=2), perinatal specialist (N=3), physician (other) (N=1), psychologist (N=3) and child care counsellor (N=3).



**Figure 4.2** Primary profession of the HCPs

#### 4.1.2.2 Secondary specialisations

When asked about their specialisation, approximately one third of the interviewed HCPs (7 out of 18) indicated a second one, too, which was always in connection with their primary qualifications. The nominated secondary specialisations are the following four: doula (N=1), mental hygienic specialist (N=1), perinatal specialist (N=2), grief counsellor (N=3). It was most characteristic of the midwives to have another specialisation, followed by the psychologists and child care specialists, while the doctors did not indicate any. The existence of a secondary specialisation may correlate with an increased sensitivity regarding newly incorporated foci of perinatal care, thus the need and openness for proper bereavement in perinatal loss events.

#### 4.1.3 Working experience in perinatal specialisation

The experience of work in perinatal context was distinguished on the basis of the years of activity. Three main categories were established as follows: 0-5, 5-15 and 15+. Most

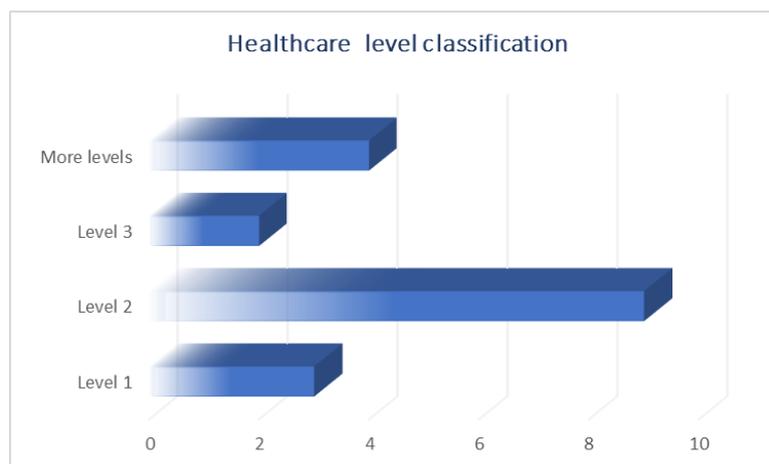
of the interviewed HCPs belong to the 15+ category (N=8), while one third of them (N=6) has 5-15 years of relevant experience, and 4 HCPs have just started their career.

#### 4.1.4 Affiliation – related departments

Regarding the departments where the participating HCPs perform their activity, obstetrics and gynaecology (N=7), NICU (N=2), family medicine (N=3) are nominated, while interdepartmental (N=2) and interinstitutional (N=4) practices are also reported.

#### 4.1.5 Healthcare level of the related institutions

The interviewees belonged to primary, secondary and tertiary level healthcare institutions, as Figure 4.3 below shows. Moreover, some of them were related to institutions of different levels, as well, due to their activities. The majority of the participants were affiliated to secondary level institutions (50%), working in specialised care of major regional hospitals, one third came from primary, basic care, belonging to family medicine or with a connection between primary and secondary level centres, while 10% from tertiary organizations, specialised national institutes or university clinics. Altogether 20 different healthcare realities were related to their activities.



**Figure 4.3 Healthcare level of the related institutions**

#### 4.1.6 Local, institutional protocol for perinatal bereavement care

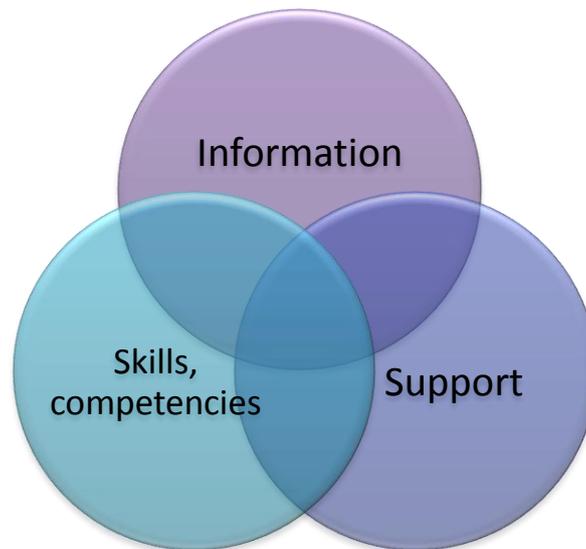
A key indicator of the research is the question of local measures for perinatal bereavement care. Among the interviewed HCPs, the majority of them – as it is indicated in Figure 4.4 – reported the lack of a local, institutional protocol in all the related healthcare organisations, while only 20% could refer to the fact that their institution created and utilised their own practice to follow pre- and perinatal loss cases.



**Figure 4.4** Local perinatal bereavement protocol

#### 4.2 The elements of optimum bereavement care represented in the research

When facing adverse outcome perinatal events, the healthcare personnel's main aim should always be providing optimum bereavement care for the families who have lost their children at any stage of the pre- or perinatal period. In order that the optimum level of care could be obtained three equally important pillars should be balanced in care-providing, as it is demonstrated below in Figure 4.5:

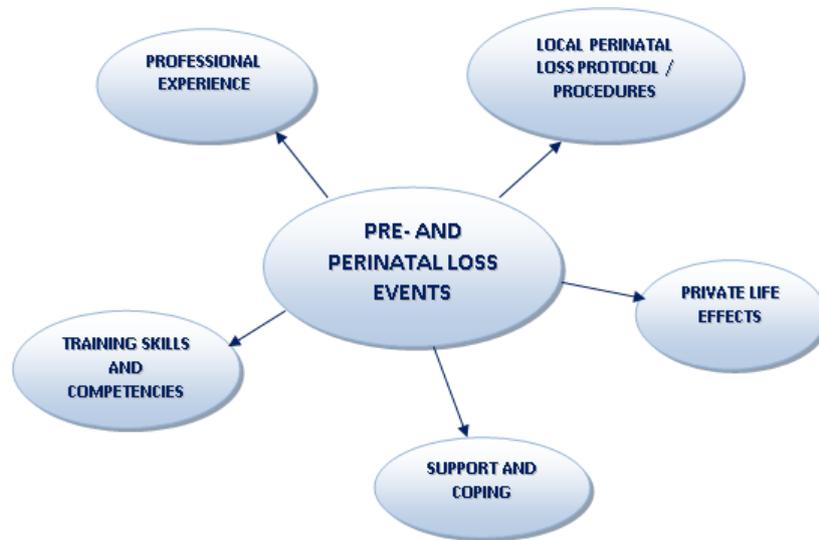


**Figure 4.5 The constituents of optimum perinatal bereavement care**

The innermost part, the intersection of the three constituents represents what can be defined as optimum perinatal bereavement care, with all the pillars present. In it information covers all forms of basic and continuing education trainings, up-to-date know-how of effective guideline recommendations, applicable legal measures, relevant ethical dilemmas and the use of institutional protocols regarding the loss of a child and grief processes. Skills and competencies stand for the application of all the previously mentioned knowledge in everyday context, for individual cases, delivered with compassionate communication and empathy. The third constituent, namely support, at the same time, denotes the help and care provided for the healthcare staff so that they can cope with the distress of chronic trauma and eventual difficulties they may face during their work.

Bereavement care in the perinatal context is rather specific in the sense that it involves and affects more medical specialisations and all the other professions around them. As it has been shown in the introductory part, the nature of perinatal loss also bears significant characteristics, with clear consequences regarding the quality of life and the future prospects of the involved families. For these reasons optimum accompaniment will have a noteworthy impact in the life of those who lose their children in the pre- or perinatal period. To understand how the above mentioned elements are balanced in everyday practice, whether they allow for appropriate bereavement care the research

activity had to bear the three-pillar element approach in mind and construct the analysis with a specific focus on them.



**Figure 4.6** Main focus areas of the interviews

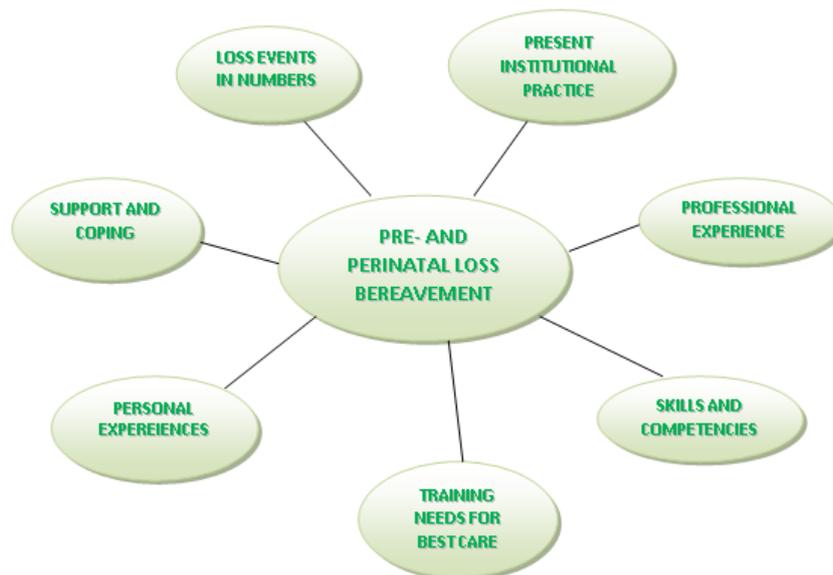
### 4.3 Primary, deductive coding

When designing the research process, a semi structured interview was developed to allow for the individual conversations and for a close insight into the central topic, as it can be seen in Figure 4.6. The interview questions were grouped into 4 main question sections, each of them addressing diverse aspects of the personal and professional challenges of perinatal death events in healthcare context, from the point of view of the care providing personnel. Part 1 covered the personal particulars of the interviewees, used for statistical data, inquiring about the age, qualification, affiliation and the level of the institution, marital status and own children of each interviewee. Part 2 in 7 questions focused on the professional background and experience, with questions also paying attention to perinatal death events in the career and how they are to be managed in the institute of affiliation.

Part 3 in 6 questions addressed the skills and competences utilised when facing perinatal death in any relevant professional context. Therefore, it was the aim of this section to discover former courses, available protocols, potential collaboration with colleagues, all of which allowed for a facilitated confrontation with the professional challenges in perinatal death. Part 4, in the end, investigated, with 5 questions, the personal involvement, feelings, effects and required support to elaborate the weight of these sad events. The emphasis here fell on investigating how a traumatic event at work can be

elaborated, even after long time, how it influences one's private and family life and what kind of support is needed to overcome the accumulating difficulties. It must be added here that several questions in the interview parts could overlap with other parts, thus recurrently validating the same topic at a later section. (Part 1 and 2/ 1, 2, 3, 4; part 2/ 5, 6, 7 and 3/4; part 3 and 4/5)

The questions and the structure of the interview allowed for developing a preliminary code framework a priori, setting codes and themes, since the different sections approached the topic from diverse points of view, even though some questions could treat relevant elements from other parts, too. The analysis of the transcripts then revealed further themes and codes. Having finalised the coding structure, the primary, deductive coding principal themes, parent nodes took forms as seen in Figure 4.7:



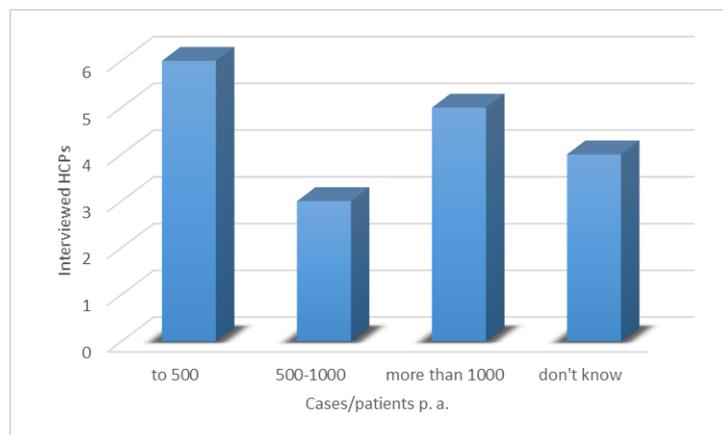
**Figure 4.7 Deductive coding structure of the analysis**

The thus identified central themes could be further subcategorised, with major and minor groups of child nodes belonging to them. From the 1<sup>st</sup> part of the interview here the questions concerning the loss events are dealt with, the numeric data is also seen together with a personal, subjective evaluation of the number of experienced losses, as it will be seen further on. As it has been indicated above, the overlapping topics allowed for recurring themes in the subsections of the interview, thus, when finalising the deductive coding structure, six further main codebooks of parent and child nodes were to be identified, apart from the numbers, all of which will be described in details on the

subsequent pages. While the listing of parent nodes and their child nodes follows an alphabetical order, the thematic analysis moves from the numerical categorisation, through the professional aspects and via the information, competency needs to the personally lived background of the loss events and ends with the support and coping solutions the healthcare professionals find so that they could bear the emotional and psychological weight of the adverse outcome experiences they face. The order of the child codes in the sections represents the proportionate ordering of the references, as well. The nodes/ child nodes in the text are indicated in bold letters.

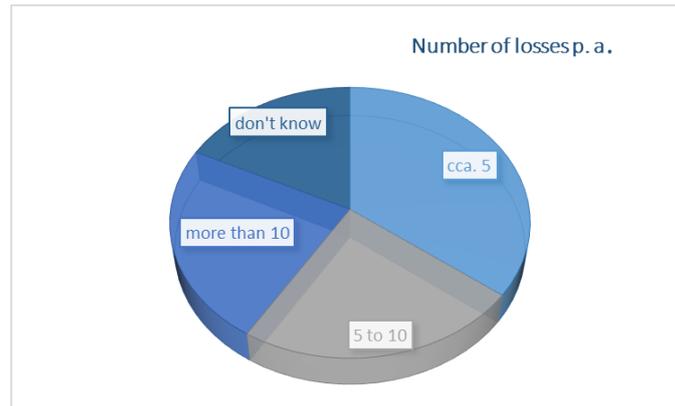
#### 4.3.1 Loss events in numbers (PD1.1)

The interview questions' focus on the numerical representation of **pre- and perinatal losses** has been manifold. A solid reference point was established by the yearly number of patients (PD1.1.3), where the categories fell between -500, 500-1000 and over 1000. Figure 4.8 shows the distribution of the interviewed HCPs according to the patients seen yearly in their practice. As the figure below demonstrates, the majority of the interviewees belonged to the above-500 categories, whereas some of them could not recall an estimation of the yearly cases they attend in general.



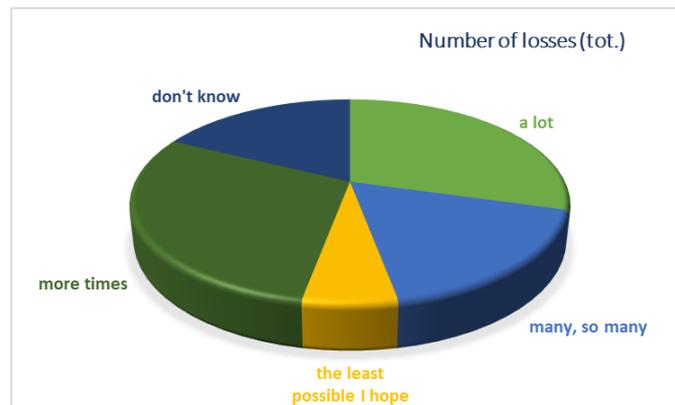
**Figure 4.8** Number of patients-cases/ year

As for the loss events, the **total number** during one's professional activity and the annual occurrences have also been investigated (PD.1.1.1 and PD1.1.2). The total range, as it has already been discussed earlier, where the interviewees could define it, moves on a spectrum of 30 and over 60, while annually they face from approximately 5 to 15 child losses, with the majority of them defining 5 as a yearly estimation (Figure 4.9).



**Figure 4.9** Loss numbers/ year

On the other hand, **how they see these rather objective figures** (PD1.1.4) is well expressed by their responses (Figure 4.10) referring to the numbers as *'a lot'*; *'many, so many'* or the *'the least possible, I hope'*, with *'a lot'* being the most frequent among them. Interpreting the self-referred data this way could be a noteworthy pre-indicator of the HCPs' understanding of the emotional weight of the event.



**Figure 4.10** Verbal references to the occurrence of loss events

### 4.3.2 Present institutional practice (PD1.3)

Under this main theme the subthemes could be identified with a focus on the **particular features of institutional procedures** (4 child nodes) and among them the different aspects of **institutional case managements** (PD1.3.2) from the point of view of perinatal bereavement care (10 child nodes) are described in details.

#### 4.3.2.1 Characteristics of present institutional practices

In case of the affiliated Hungarian institutions no **institutional protocol** (PD1.3.1) was referred to, which, however, did not exclude the existence of a *'we do it this way*

usually' practice. Depending on the general attitude of the staff and their sensitivity, it may include several practices of bereavement options, though. On the other hand, some of the Italian colleagues, who belonged to a specific healthcare structure, confirmed the written local protocol regarding perinatal bereavement procedures, underlying the fact that the staff of the different departments were involved in the process of creating a unified, institutional programme.

*'...we now, for a couple of months, have had an agreement with [...] an association [...] and then some, some of their recommendations have been integrated, and mainly regarding a fatal diagnosis, already prenatal, also on the level of birth plan, etc. And integrating from those, with their suggestions, with their experience, and also a bit with our protocols for curing the terminal child, pain, from point of view of respiration, then a sole protocol was created, valid for a fatal prenatal diagnosis, an extreme premature, because it had some postnatal problems, i.e. for any kind of reason. Then, clearly, each case is one of its kind, but at least there is this thing as a base ...'* (doctor).

Where the protocol measures help it, a standardised path is followed in both **pre- and perinatal circumstances (PD1.3.3 and PD1.3.4)**, and is well known for all the staff members.

*'The situation changes a lot if it is .... a death in the womb, i.e. an intrauterine death'*  
(doctor)

*'...there is, how shall I put it, a discourse of, of common approach, well, yes ... More professionals are involved in these, in these situations'* (midwife)

*'the possibility to let them [the parents] enter, i.e. to let them stay allows to render that child more real whom they may not even have seen, since from the delivery room you arrive directly here, thus they have some pictures, some stories, nothing else, but also as some support for the parents'* (doctor).

This concerns, however, the activities inside the department, because **what happens afterwards (PD1.3.5)** and how it is managed is not known for most of the personnel:

*'I don't know if it is our competency at the obstetrics or it is the pathology's regarding the burial, so that they can bury the child, I don't know who should mention this. I can't recall that we talk about this. We don't talk about this, we only follow the path so that the child is carried down there.'* (midwife)

In the affiliated Hungarian institutions no local protocols could be identified, every interviewed HCP reported the fact that *'there are no professional protocol or guidelines in the institute to follow perinatal loss'* (midwife). In general, their activity is

characterised by an informal, custom-formed procedure, with differences in accompanying loss events, which mainly depends on the local working culture and attitudes.

#### 4.3.2.2 Particular features of institutional procedures for pre- and perinatal loss events (PD1.3.2)

When examining the **particular details** of the different institutions regarding bereavement care, positive and negative features could similarly be recognised in the discussions. As for the positive side, the existence of a local **protocol with staff involvement** (PD1.3.2.6), **individual case management** (PD1.3.2.1), different **memory-making possibilities** (PD1.3.2.2), special initiatives to create a **perinatal bereavement care programme** (PD1.3.2.8), the **definition of staff member roles** (PD1.3.2.7) in care providing and administrative tasks, **support for family** (PD1.3.2.10), follow up and some kind of **support for HCPs** (PD1.3.2.9) (though informal, individual cases only) can be mentioned.

On the other hand, **no adequate places** (PD1.3.2.4) for private and dedicated care, **no proper attention** (PD1.3.2.3) to case management are mentioned. While sometimes it is possible to give more privacy for the women or families facing the loss, in most cases, local organisational difficulties do not provide opportunities for that. Moreover, in some cases if there is some, real bereavement care, it is only because one staff member has this particular sensitivity, it denotes a **‘one-person care’** (PD1.3.2.5). While for the involved family the care is provided, the HCP’s emotional burden becomes a chronic occurrence.

*‘At the hospital [...] the colleagues know that it is one of my so called „special fields” and if there’s a stillbirth then they call for me. On the one hand, because the colleagues don’t like these births – who likes them?, – on the other hand, the presence of a colleague who only deals with the family in question helps the family too, since she doesn’t need to share other delivery room tasks.’ (midwife)*

#### 4.3.3 Professional experience (PD1.4)

The questions related to professional experience revealed aspects of collaboration as well as difficulties regarding adverse outcome events, moreover, highlighted the potentially required changes for a better quality of care providing.

The **working experience (PD1.4.1)** of the participants falls mainly in the 15+ years intervallum, while younger colleagues with 0-5 and 5-10yrs of working in the field, also contributed to the research in smaller proportions.

#### 4.3.3.1 Collaboration with colleagues (PD1.4.2)

Due to the nature of pre- and perinatal care, **collaboration** between colleagues is an essential part of their activity. How it takes place has a great impact on the outcome towards the families. This is all true in cases of bereavement and how the staff members relate to its management, similarly. Examples of **positive collaboration** (PD1.4.2.2) demonstrate a shared understanding of the responsibilities, of tasks carried out together

*'... now things are going well. Yes, the relationship is absolutely great. [...] thus we have always worked in collaboration. Always. I have never had an obstacle in obstetrics-gynaecology with ..., especially not over these problems. Never.'* (psychologist)

*'... the other, nevertheless, said that if I should have any kind of problem because of this, I should just tell him, because he completely agrees with it, it is a very human action'* (midwife),

while **negative patterns** (PD1.4.2.1), like disagreement about the importance of bereavement care or expressing emotions culminate in sensations of rejection, of failure as a professional:

*'... among the doctors there was a sort of weird attitude, one of them said that I should not, I should not be making a crematorium out of the delivery room and I should stop this'* (midwife)

*'... my colleagues could think that 'Oh, she is crazy!', 'She is just oversensitive!' or 'Who knows from where she gets these?' or 'Of course, we can accept her, this is the way she is...' 'We just let her cry together with them...'* (midwife)

*'... the others would rather meet the expectations „all right, let's not pay attention to perinatal grief, because the chief nurse and the elderly midwife should not know about it, they can't know about it, because they may have some negative reactions", and I feel the consequences of it. And I can see this fear of being rejected, excluded in my young colleagues. They strive to meet the expectations [...] the midwives who think it inappropriate [...] suggest that 'you do not belong in here', or 'it's not how we do', 'you are not a good professional', 'we don't accept you', 'we don't prefer this attitude', etc.'* (midwife).

The importance of collaboration is highlighted by the **potential solutions** (PD1.4.2.3) it

may involve, how it improves the quality of provided support, allowing for more adequate attention and meeting diverse needs:

*'It really depends on who needs what. Now, what comes to my mind is that expectant woman whose baby had a heart failure and she knew that the baby would die, for her, for example haptonomy was of help'* (perinatal specialist).

#### 4.3.3.2 Professional difficulties (PD1.4.3)

Ten distinct categories could be identified in the analysis of questions focusing on the difficulties HCPs face when dealing with pre- or perinatal loss events. In the vast majority of the discussions, the **emotionally heavy demand of the situation** (PD1.4.3.4) was nominated, revealing the effects and the feelings it conveys.

*'... this aspect of the profession, despite the years passing by and you having seen more things and being more prepared, having more experience, etc., always remains the Achilles' heel'* (midwife)

*'... more or less all of us are looking for, a bit for ... i.e. at least to leave the room every now and then and take a breath because ... eh... it is a ... demanding situation...'* (doctor).

What renders it even more difficult is **the repetitive nature of the experience** (PD1.4.3.2), how well they know that they cannot avoid a similar situation when doing their job:

*'... for the couple that is an important experience, hard, but perhaps lived few times. For us instead it is continuous. And all the times we face it, it is a bit like challenging our emotionality as well, no, our emotionality plays a big role. Thus you learn, as I say, to build a bit a certain type of a, of a small wall in front to impede that this thing could hit you too much. Because sometimes certain situations hit you harder than others.'* (midwife)

The last sentence of the above quote emphasises the fact that for certain reasons, let them be professional or personal, **there may be loss events which are more demanding** (PD1.4.3.10), with more emotional impact on the operators, consequently with more difficulty to perform their responsibilities according to their own standards and expectations. High standard care and professional performance will also be influenced by **differences in attitudes among colleagues** (PD1.4.3.3), as it has been mentioned before, leading to uneasiness and disagreement. The **lack of proper skills and competencies** (PD1.4.3.8) to support and accompany appropriately is another

significant negative element, which leaves behind a troubled mindset for the validity of one's actions:

*'...we have few, few instruments, but also of cognition, in the sense that also what to say, what is better to say, timing, we do a bit of everything... mmm... with so much good will, but with, maybe, with lack of competence. [...] I have noticed that I tend to do the medical part more because it is easier. If I have to manage an emergency, no problem, if I have to manage a family with a dying child ,... if I can I escape every now and then [...] how shall I put it?, eh... but in reality it happens to you all the time, because you are there ...'* (doctor).

The **tasks to be fulfilled** (PD1.4.3.9) in adverse outcome events may be regarded as sad, unwanted, yet necessary, some of them administrative and bureaucratic related to death certificates, funeral arrangements, all of which *'bring in a reality that in that moment shouldn't be lived'* (midwife).

**Fear** (PD1.4.3.6) appears under diverse masks for the HCPs, it manifests itself threatening with failure and causing death

*'... it has never happened to me to have done perplexing things for which then, well, 'the child had that end because I made a huge mistake', so I hope that it'll never happen to me, but even that is not so sure that it won't happen, since in the end we are fallacious ...'* (doctor),

with losing control

*'...the idea that I could lose my head is very frightening for me, because it is me who must manage the situation, and thus if I lose it, all the other people are authorised to lose their head in that moment ...'* (doctor),

or with change

*'... neither the obstetricians, nor the midwives have this practical knowledge at hand. So, for me it's ok that they are afraid. Not so much ok that they do not want to open towards these and they become absolved in their fear, or set comfortable in their fear'* (midwife).

A further demanding aspect of professionally experienced loss events is the **non-proper management of one's own feelings** (PD1.4.3.5) and emotions. The failure to find adequate means of elaboration endangers one's mental health (*'if you carry it with you all the other days to work, it's much worse'* midwife) and professional behaviour (*'if they don't elaborate it well, they may risk to transfer it onto their patients all that which is not elaborated'* perinatal specialist) likewise.

**Accepting the death of a child** (PD1.4.3.1), however, challenges professional competency and the belief in the natural order of life, bringing in the difficulty to see a child die and not to be able to help anymore to keep them alive. Child loss in perinatal context seems irreconcilable with one's expectations:

*'I'm a midwife, and my job is to deliver the children, to see them cry, to see them in their, in their beauty'* (midwife)

*'... we haven't got power of life, of death [...] even if sometimes we would like it, but it doesn't function..... we start from the supposition that basically we are resuscitators and thus we are much more capable of acting rather than accompanying, even the perspective is to deliver a child, yes, perhaps with some problems, but his story goes on, [...] It is a child... it is much more complicated to accept it than a 90-year old who has already lived his life'* (doctor).

The cold impartiality and harshness of death, nonetheless, clearly set limits to professional competencies and the recognition of this fact generates feelings of **impotence and incompetence** (PD1.4.3.7). Recognising the futility of one's actions or wanting to do something, anything to help, but not knowing what are all incorporated in the following lines, when the participants talked about the emotions they experienced:

*'... the absolute, absolute impotence to try to do any kind of thing and then anyway at a certain point you understand that anything you are doing, even the best one in that condition, has no, no effect on that child anymore. And thus the absolute impotence.'*  
(doctor)

*'So this is a very difficult, incompetence, or 'something should be done but does it make sense? doesn't it?' - so it was this distressing helplessness and sadness [...] stuck in a situation where I just stand incompetently and wait'* (midwife).

#### 4.3.3.3 Required changes (PD1.4.4)

For perinatal bereavement care, as it has been described in the introductory part of the chapter, up-to-date information, proper skills, competencies and support for staff are the essential constituents. However, firstly a **change in attitude** (PD1.4.4.1) is required that could bring about major development potentials, as one of the interviewed midwives claims it, regarding rethinking *'the activity of the department, then yes, but it requires a change, transformation in attitudes that would be based on self-awareness questions'*. This change would allow for the recognition of bereavement care needs and the **development of local protocols** (PD1.4.4.4) where necessary. How professionals act in

loss situations depends also on their understanding of the importance of certain behaviour patterns, care modes, how much they can influence the involved family's elaboration of loss and quality of life:

*'It is very important that someone as a professional would see it of high significance because the person in that situation is busy with 'what is happening to me?' and will realize it only too late, if there is no help, how much difference it would have made if she had had any kind of memory'* (perinatal specialist).

This can be ensured by **profound knowledge of bereavement care** (PD1.4.4.5), concerning information about all relevant processes, legal measures, psychological and social aspects of grief together with the medical know-how. Moreover, HCPs are very much aware of the emotional weight of their vocation the management of which is yet to be resolved:

*'... the need that I feel is to be able to more frequently re-unite the group of professionals and talk, talk exactly about the experiences, talk about what in some ways makes us feel so uneasy, and it is some unease that we take home with us, and it is not limited to our check-out from work when we have finished our turn, but it is some unease that in some ways keeps troubling us all the time, clearly. Thus, sometimes we lack to be able to find the instruments that may help us to manage our, our experiences, properly.'*

(midwife)

Therefore, a local protocol should also foresee the possibility of **formal support for the team** (PD1.4.4.2), under the frame of organised, institutional debriefing and peer activities for the involved operators, to go through the specifics of the case together. Additionally, informal possibilities, **individual support solutions in work context** (PD1.4.4.3), would mean having realised *'a psychological approach in the management of the cases'* (psychologist).

#### **4.3.4 Skills and competences (PD1.5)**

The skills and competences concerning perinatal bereavement may not be very much diverse from the basic ones any HCP needs in their profession. Yet, on the basis of the answers a full spectrum was completed, with aspects of practicalities and essential soft skills, to be considered also in programmes of continuing education. Accompanying a bereaved person cannot be done without **empathy** (PD1.5.1), the interviewees see it as a fundamental constituent of care, openness and attention to personal needs. Physically noticeable, **practical help** (PD1.5.2) means lighting candles, bathing and dressing the

baby, holding the child, taking pictures and providing memory making possibilities, footprints, name tags and labels, and even a memory box. Moreover, it also involves dedicated attention, more privacy in giving birth, or staying in a separate room and together with the partner and guidance with information. Being able to provide adequate care depends on the personnel's **sensibility** (PD1.5.4), it must be understood that in that situation

*'it's like walking on eggshells because in that moment the person is like as if they were without skin, I mean, as if they had been burnt alive'* (child care counsellor).

Being able to support families in child loss conveys feeling of **satisfaction** (PD1.5.3), the sensation of having done a good job. Being present in an emotionally demanding situation and providing proper help can leave the HCPs

*' to feel satisfied when you see that you had the means and you could use them. It may even be an automatic feeling, it doesn't need to become conscious at all. The system may run in the right way in these cases.'* (midwife)

#### 4.3.4.1 Previous formation in pre- and perinatal loss (PD1.5.5)

One main aim of the research has been to gain an understanding of the potential educational needs of HCPs. To this end, questions also focus on previous courses regarding grief and loss. During the **basic formative education** (PD1.5.5.1) none of the interviewed colleagues received relevant training in bereavement care. In the **continuing education possibilities** (PD1.5.5.3) courses dedicated to ethics, EOL care, grief in general and empathic - non-violent communication were mentioned. The sensibility towards the specific needs of perinatal loss has also led some of the interviewed HCPs to find **dedicated materials of care** (PD1.5.5.4), from non-profit organisations active in this field, (CiaoLapo, La Quercia Millenaria) or working together with professionals dedicated to EOL care. **Books, international journal articles and conferences** (PD1.5.5.2) also mean significant resources of relevant information.

#### 4.3.4.2 Social expectations (PD1.5.6)

In bereavement care HCPs are influenced by social expectations regarding their behaviour and attitude when dealing with loss events. **Professional behaviour patterns** (PD1.5.6.1) are defined by own expectations regarding one's role and tasks

*'we often feel a bit like God, that we can resuscitate, we can get better the children who are at the end of life [...] it is me who must manage the situation, and thus if I lose it, all the other people are authorised to lose their head in that moment, thus somebody who remains composed in that moment is needed. [...] I set it for myself from professional point of view'* (doctor),

*'I'm a midwife, and my job is to deliver the children, to see them cry, to see them in their, in their beauty'* (midwife),

as well as expectations of the colleagues:

*„the midwives who think it inappropriate, teach the young midwives that it is inappropriate and if the young ones feel in another way, they suggest that 'you do not belong in here', or 'it's not how we do it', 'you are not a good professional', 'we don't accept you', 'we don't prefer this attitude'"* (midwife).

All these expectations seem, however, to be preconditioned and influenced by the larger scheme of **social expectations concerning grief and loss** (PD1.5.6.2):

*'in some ways society tells you that you need to be strong, you need to move forward, the show must go on [...] you have a series of automatic mechanisms that society gives you with full hands, to switch off that pain, to keep it away'* (child care counsellor).

#### 4.3.4.3 Training needs (PD1.5.7)

The recognition that perinatal bereavement care has got its own specific needs allows for the definition of the **training needs** necessary for care development. The practical, related know-how in care-providing should focus on **skills and competencies development** (PD1.5.7.3) in communication regarding what to say, when and how, in the openness for new solutions and learning, and in emphatic case management. The elements of professional behaviour patterns needed for optimum care should be formulated in a **code of conduct** (PD1.5.7.1), while the opportunity to **elaborate experiences** (PD1.5.7.2) may ease the weight of emotional involvement.

#### 4.3.5 Training and structural needs for best care (PD1.7)

The criteria of optimum level bereavement care are defined in more components. **Specific courses** (PD1.7.1), with focus on childbearing, grief and loss, own experiences, can provide a scientific background for a change in attitude and of profound knowledge which can be applied in everyday activity. Simulation activities

could prepare HCPs to situations in which medically not much can be done, moreover, it would be necessary to re-formulate *'automatisms coming from sediment previous experiences'* (perinatal specialist).

#### 4.3.5.1 Specific needs for optimum bereavement care (PD1.7.2)

Among the specific needs for optimum perinatal bereavement care, dedicated **attention and empathy** (PD1.7.2.1) are defined as fundamental, while the **theoretical knowledge and practical skills and competencies** (PD1.7.2.3) also represent a significant factor, as it has been described previously. A specially formed **staff** (PD1.7.2.4), dedicated to bereavement care needs could follow all the involved families, whose presence may disengage colleagues from particular tasks regarding loss events. Nonetheless, in some institutions, even the presence and help of a psychologist is a need that has not been met yet, unfortunately. Organisational, institutional **facilities** (PD1.7.2.2) should provide physical solutions, separate delivery and post-delivery rooms, dedicated spaces, for the privacy of the patients as well as privacy and de-stressing options for HCPs, when necessary. A locally formulated protocol may provide the appropriate measures for that, whereas, at other institutions it has not been solved yet, causing difficulties for everyone present:

*'But something that would be much required and we don't have it is that we can't really separate these families. Yes, a separate room would be good, to give the families more privacy with the child. So, for example, in case of losing a premature baby in NICU there are about 6 incubators, and we were taking care of this child for about two hours with the mother and the dead child, that all the other mothers weren't let in to their own children, so, they also knew that it is a very bad situation, but they couldn't do the usual daily routine and couldn't enter, because we couldn't separate this mother, we couldn't take her anywhere else.'* (psychologist)

#### 4.3.6 Personal experiences (PD1.2)

The questions focusing on the HCPs' personal experiences aimed at exploring the effects of pre- and perinatal death events, regarding their emotions, attitudes and ways of own support solutions. **Fragility** (PD1.2.1), as a common governing experience, appears in several ways in adverse outcome work events. It may be seen as the vulnerability of the personnel in a demanding case ending in death, or as the fragile conditions of the premature child, as a sign of emotional involvement and its

consequences, or even as the effect of previous own loss experiences enhancing the effect of a new loss situation. Further main effects could be labelled as changes in self (4 child nodes), the effects on private life (7 child nodes), emotions and feelings (6 child nodes), problems with self (3 child nodes), and support solutions (5 child nodes).

#### 4.3.6.1 Changes in self (PD1.2.2)

The changes the loss experiences brought about affect various aspects of the interviewees' personalities. Many of them talked about the potential of a **personal development process** (PD1.2.2.2), chances of growing and development for themselves, seeing the values of life. Furthermore, the professional experience also defines and forms their own, **personal responses to loss** (PD1.2.2.3), which will have an influence on their work as well as on their family. Nevertheless, accepting the potential occurrence of loss in their profession does not lessen its negative effect. As it is an event over which one has little control, trying to establish **control** (PD1.2.2.1) in other aspects of one's life may be a way to regain the balance. Yet, a more fundamental **transformation** (PD1.2.2.4) may also occur as a result:

*'I once used to be rather religious. Since I started this work I stopped being one [...] It was a profound transformation [...] when you see these things ... you become another person'* (psychologist).

#### 4.3.6.2 Effects on private life (PD1.2.3)

The emotionally demanding negative outcomes leave an imprint on HCPs' private life, where the **adverse effects** (PD1.2.3.1) manifest themselves in sleep problems, wanting to talk about what happened, being more apprehensive for own children, as much as in losing faith. **Taking the experience home** (PD1.2.3.7) seems inevitable, as

*'it is not limited to our check-out from work when we have finished our turn, but it is some unease that in some ways keeps troubling us all the time, clearly'* (midwife).

**Emotional involvement** (PD1.2.3.2), being touched in certain situations more than in others influence the interviewed HCPs relationship with partners and their own children, too. Family is the emotional hinterland to discuss difficulties at work, to recharge, to find support. Thus **keeping the balance** (PD1.2.3.4), personal integrity may be easier, also due to the long years' experience and being able to control the feelings. How the professional attitude is reflected on the person's behaviour is the result of the **self-control** (PD1.2.3.6) measures they take. Their **increased sensitivity**

(PD1.2.3.3) to loss creates opportunities for others to find support, however, on the other hand, it also involves being more appreciative towards having healthy children and needing to face ‘normal’, everyday problems. A noteworthy notion of this part is that in more cases, the first answer to questions related to private life effects of perinatal loss events was a ‘no’, indicating that **no effect** (PD1.2.3.5) was seen, nonetheless, as the conversation went on, this ‘no’ always turned into a ‘yes’, with diverse underlying explanations.

#### 4.3.6.3 Emotions, feelings (PD1.2.4)

A work-related pre- or perinatal loss may bring to surface the professional and the personal emotional challenges HCPs experience (6 child nodes). **Feelings regarding their professional competence** (PD1.2.4.2) and performance are based on their own evaluation of the actions they made:

*‘the absolute, absolute impotence to try to do any kind of thing and then anyway at a certain point you understand that anything you are doing, even the best one in that condition, has no, no effect on that child anymore’* (doctor).

As a consequence, the constant chronic stress may culminate in perceiving one’s status in the following way:

*‘... then I felt very tired. Like, when you don’t feel like doing anything, no? [...] sometimes I feel trapped because I am alone’* (psychologist).

**Feelings of grief** (PD1.2.4.1) and sorrow are commonly experienced emotions, when talking about childloss the interviewees with different professional backgrounds share this sensation:

*‘it’s always painful. It’s some personal pain, no? which then you share with the couple’* (midwife)

*‘a sense of sadness and desolation [...] you are destroyed’* (child care counsellor).

**The difficulty of the loss event** (PD1.2.4.6) is due to its emotionally demanding circumstances for everyone, the unnaturalness of losing a child when joy should be expected, the recurrence of the adverse outcome event as well as some personal experiences influencing the professional attitude. The emotional weight of certain cases may lessen with the passing of time, yet, **recurring thoughts and feelings** (PD1.2.4.4) are rather common even after years, multiplying the effect:

*‘... all the times that you must deal with a loss, of any nature, it resends you all your losses, thus, you always have particular resentments, no, eh, your personal experiences,*

*well, everybody has their own losses in life, right, thus there's always this sad thing that, that works [...] And all the times it is always difficult. Let's say that fundamentally this aspect of the profession, despite the years passing by and you having seen more things and being more prepared, having more experience, etc., always remains the Achilles' heel, it remains the same as the first time you, you have seen a situation of this type, it doesn't change. From the point of view of, of private pain. It's always the same.'*  
(midwife)

At the same time, to make it possible to face a loss situation at work, HCPs struggle to find a reason for the 'why' of loss, see it from different perspectives, or understand its nature, if possible, thus, they make efforts to see **how to render a child's death** (PD1.2.4.3). For some of them it seems irreconcilable:

*'It is a child... it is much more complicated to accept it than a 90-year old who has already lived his life'* (doctor),  
*'how come? What sin have these people committed, that is? [...] There are no explanations, but why?'* (psychologist),

while others formulate their own reasoning for the unreasonable:

*'I had sometimes to appeal also to a religious credo that may perhaps justify, no?, these experiences, as all the negative experiences of life. Or they destroy you, or you give them a justification, you give them a name. I.e. you try to justify the reason why this thing may happen. And I have done this work for myself, [...] Because if, if it hadn't been like this, it'd be... destructive for me, in the sense that 'then why?' 'Why the mother next to her could have her baby, and she is fine and this person is not?'. Thus, I have given it a name, I have given it an explanation, which is a personal explanation, of mine, which, however, helps me, which, I believe, has also helped other people.'* (midwife)

In the course of their professional careers HCPs must face numerous loss events. On the basis of their experience they recognise of the diversity of loss events, how, for different reasons, **some cases hit them harder than others** (PD1.2.4.5), being emotionally and psychologically more demanding:

*'About some cases you ponder more, and perhaps you also tell yourself that 'but it is better this way even for him, rather than a life full of suffering only', but no one can claim that then in reality that child would have been destined to such a life. And what is perhaps suffering for me is not the same for the parents [...] So there remains the fragility a bit, which appears in those moments'* (doctor),

*'... that moment is always particularly violent, terrible to experience, etc. However, some situations are worse than others, thus, they have a much greater effect than others.'*  
(midwife)

#### 4.3.6.4 Problems with self (PD1.2.5)

An adverse outcome event may also generate feelings of dissatisfaction, disapproval in HCPs. They may see the death of the child as the result of their failure to do something, to have found the solution. This **self-conflict** (PD1.2.5.3) regarding the validity of professional actions and the recognition of the limits of one's power appears together with feelings of **doubt** (PD1.2.5.1) and **guilt** (PD1.2.5.2) of having missed something important, undermining the HCPs self-confidence and competency:

*'... always the doubt of ... and to rethink of saying "but have I done everything, could I do it before, could I do it better, could I do it faster", I mean, the doubt anyway remains. Also when we talk about it, no, but no, you couldn't do it before, no, because we are, I mean, even when you understand to have done everything in the way it had to be done, the root remains, to say 'if we had thought of it before, done differently, if the mother had arrived a bit earlier in hospital, if we had done a C-section', I don't know, anything to be done differently in order to change'* (doctor),  
*'So this is very difficult, incompetence, or "something should be done but does it make sense? doesn't it?" so it was this distressing, helplessness and sadness'* (midwife).

#### 4.3.6.5 Support solutions (PD1.2.6)

When asked how they find ways to ease the burden of loss, HCPs nominated 5 alternative solutions at their hand. For one third of the interviewees **private psychotherapy** (PD1.2.6.5) is an important source of help, either because of other motivation, coming from their private life or because of the nature of their profession. In all cases, they have been followed by therapists for several years. **Individual coping solutions** (PD1.2.6.2) also include potential supervision and creative or physical activities, like keeping a diary, writing or yoga. Equally important are the **help from the family** (PD1.2.6.1) and the **informal help from the colleagues** (PD1.2.6.3), their attention and the possibility to share the most challenging experiences allows HCPs to rebalance themselves. At the same time, what everywhere appears as a need for support is establishing a **formal, management driven institutional support** (PD1.2.6.4), the regular opportunities of a peer group and debriefing options:

*'... the need that I feel is to be able to more frequently re-unite the group of professionals and talk, talk exactly about the experiences, talk about what in some ways makes us feel so uneasy ...'* (midwife).

A more detailed analysis of the identified support and coping solutions follows in the subsequent part, with special focus on already existing, required support and adapted coping strategies.

#### **4.3.7 Support and coping (PD1.6)**

The parent node '**Support and coping**' has been divided into three child nodes, namely '**Coping and defensive means**' (PD1.6.1), '**Existing organisational support**' (PD1.6.2) and '**Required help and support**' (PD1.6.3). Furthermore, as a parent node 'Coping and defensive means' has got two child nodes as '**Adaptive coping strategies**' (PD1.6.1.1) and '**Maladaptive or avoidant strategies**' (PD1.6.1.2), with 14 and 3 child nodes respectively. In the case of 'Existing organisational support' and 'Required help and support' as parent nodes, 6-6-child nodes have been identified.

##### 4.3.7.1 Coping and defensive means (PD1.6.1)

During the interviews it became clear that all the interviewed colleagues strove to find self-created solutions to carry the emotional weight of loss experiences and ease the tension they felt in some ways. How they defended themselves depended on the circumstances, family and work background as well as their own personalities. The solutions could be categorised in two distinct child nodes, **Adaptive coping strategies** (PD1.6.1.1) and **Maladaptive or avoidant strategies** (PD1.6.1.2). Here below these classes are to be presented with the respective child nodes.

##### 4.3.7.1.1 Adaptive coping strategies (PD1.6.1.1)

As it has already been mentioned, participating in **individual therapy** (PD1.6.1.1.5) is a fairly preferred coping solution, while it may originate from different needs, it may provide the emotional back-up which is helpful to face work-related loss events, too. It is always an individual, outside the institution therapy, with a therapist who is not part of the work environment. The **elaboration of feelings related to loss** (PD1.6.1.1.2) is of high importance, too, as a coping strategy. The HCPs understand how non-properly elaborated emotions may impede them when wanting to perform their vocation according to the highest standards. **Sharing the experience** (PD1.6.1.1.12) with the

team members, with colleagues in informal circumstances or with the closest family is a form of ventilation, comfort. **Keeping a diary** (PD1.6.1.1.7), either professional or private, to record the events, thoughts and feelings also seems a potentially effective way of easing the stress of chronic loss, as well as **taking preventive measures** (PD1.6.1.1.13), by having learnt from previous experiences and thus trying to avoid the repeated negative impact:

*'If they want, they can take photos, no?, if they don't want to see the child I go there all the same anyway and try to understand why didn't they want it. And I say that we have the pictures and when they want them we shall give these to them. Why is this so? It's because in some cases, no?, when they said 'I don't want to see the child', ah, ok, no? Then after six months, in all cases six, seven months, after the event, physiological period of first grief, well, right, they asked to go to pathology to see the photos of the autopsy. And there I have seen horrible things. I have done it also to protect myself, my own self, because I have not been able to see those sorts of things, no? And there I had to stay with them, together with the pathologist who explained, but it was a really brutal thing, sometimes ugly.'* (psychologist)

**Using time, experience** (PD1.6.1.1.14) to embrace oneself against adversities appears as another means, in which all previously learnt help overcome the difficulties. Giving a self-formed interpretation to the events, **finding an explanation** (PD1.6.1.1.4) this way, or deepening one's theoretical information, by **acquiring new knowledge** (PD1.6.1.1.1) in the field and by **involvement in a professional society's work** (PD1.6.1.1.6) may similarly be effective. **Reinterpreting one's professional role and self** (PD1.6.1.1.9) and thus expanding the limits of professional roles and expectations can be a significant step in professional and personal development. **Physical activity** (PD1.6.1.1.8), as the formerly mentioned yoga, **self-awareness** (PD1.6.1.1.10) and **self-control, balance** (PD1.6.1.1.11) in loss situations may all favour adaptive coping. Balance can be reached through **finding a positive way to contrast** (PD1.6.1.1.3) the adversity of the events, by doing pleasant activities, going out for dinner, maybe.

#### 4.3.7.1.2 Maladaptive or avoidant strategies (PD1.6.1.2)

While adaptive coping strategies have mainly been mentioned as solutions when looking for relief, some maladaptive or avoidant patterns could also be identified in the conversations. **Excluding emotions** (PD1.6.1.2.1) and not letting them permeate the protecting wall may be beneficial at the moment of crisis:

*'I raise such a wall through which emotions do not pass, thus I go on managing everything as if I were managing an emergency in the delivery room, i.e. I am absolutely cold in that moment, also because the idea that I could lose my head is very frightening for me, because it is me who must manage the situation...'* (doctor).

Avoiding the negative or sad feelings can also be obtained **by keeping oneself busy** (PD1.6.1.2.2), thus harmful effects may be kept at bay, while they arrive later, just as much as powerful emotions. Applying **self-soothing habits** (PD1.6.1.2.3), like smoking or eating, are *a posteriori* coping solutions, to ease the tension and find some comfort.

#### 4.3.7.2 Existing organisational support (PD1.6.2)

Since existing support solutions have already been mentioned in **Support solutions** (PD1.2.6), in connection with **Personal experiences** (PD1.2), here only the ones with relevance to organisational frames are presented. The most common, informal support solution in working context is the **informal support between the colleagues** (PD1.6.2.4), when, on the basis of mutual trust and shared experiences, a smaller group of colleagues discuss the events. Where there is an in-house psychologist, available for consultation and support for the patients, **occasional professional help from the psychologist** (PD1.6.2.6), ad hoc, in informal consultations or in form of informal emergency interventions in case of traumatic death events is available. **No other formal institutionally organised support** (PD1.6.2.5) was mentioned, yet, this, as a peer group or debriefing, was seen as a real potential to improve HCPs support in bereavement care:

*'it could be good to have someone whom they trust and even a case debriefing could be done. I mean, there is a team, everyone knows everyone, and there enters a specialist who moderates the case debriefing that the participants could profit from it. I would consider this important. The question of trust is basic. It should be someone, not someone just sent there because they will not pay attention to him/her at all, an inner specialist is needed, in my opinion, whom the given team can trust.'* (midwife)

#### 4.3.7.3 Required organisational help and support (PD1.6.3)

One major pillar of properly implemented bereavement care is the formal, organisational support provided for HCPs (Figure 5.1). Its elements may vary according to professional and institutional facilities and options, nevertheless, its advantages will be beneficial for all participants. **Individual support** (PD1.6.3.5) is required to be

available in the form of supervision, psychotherapy, emotional support or other ventilation opportunities. A constructed, formal **group support** (PD1.6.3.3), for debriefing and consultation, for the involved care-provider team is seen to be an optimum solution to revise problems, demanding cases. **Grief elaboration possibilities** (PD1.6.3.2) should be offered locally, in work context, individually or for the team. A **reference team or person** (PD1.6.3.6), who offers references and support in adverse outcome events, could be of valuable resource for colleagues as much as patients. Where no institutional protocol establishes the frames of perinatal bereavement care, the formulation of **guiding protocol** (PD1.6.3.4) measures would facilitate the HCPs' care-providing. Lastly, **continuing education options** (PD1.6.3.1) can bring in theoretical and practical knowledge development opportunities and open new perspectives.

#### 4.4 Secondary, inductive coding

The secondary, inductive code tree (SI1) emerged through a 'bottom-up' structuring from the hierarchy of the dynamically changing nodes, through abstraction, providing the concept framework to chronic professional loss experiences. The complete, detailed structure of nodes is presented in the Appendix (Appendix 4), whereas the most accentuated elements are described together with a schematic conceptual frame on the subsequent pages. The inductive analytical approach through the identified main concepts allows for a more profound understanding of the professional and personal challenges and difficulties HCPs face in perinatal death events.

##### 4.4.1 Perinatal death (SI1.1)

The **perinatal death** event (SI1.1) itself appears as the central, core concept of the framework, in which **death as an existential dilemma** (SI1.1.1), **grief definition** (SI1.1.2), **bereavement** (SI1.1.3) and **perinatal death events in words** (SI1.1.4) are the organising nodes. How HCPs relate to and understand perinatal loss is well reflected in the use of their words. The word cloud in Figure 4.11 demonstrates the frequency analysis result of the interview words concerning child loss in perinatal context:





**Figure 4.12** Word frequency in the node ‘verbal frames regarding loss situations’ (SI1.2.3.3)

The results of the word frequency analysis in another, tree structure can be found in Appendix 6. Perhaps the most characteristic in the verbalised descriptions is the frequent use of the following adjectives: *difficult*, *horrible*, *painful*, *complicated*, *bad*, *demanding*, *brutal*, *devastating*, *morbidity*, which appear in the subjective reports regarding perinatal loss. Through **reasoning** (SI1.2.3.2) one may arrive at certain justifications:

*‘perhaps you also tell yourself that ‘but it is better this way even for him, rather than a life full of suffering only’, but no one can claim that then in reality that child would have been destined to such a life’* (doctor),

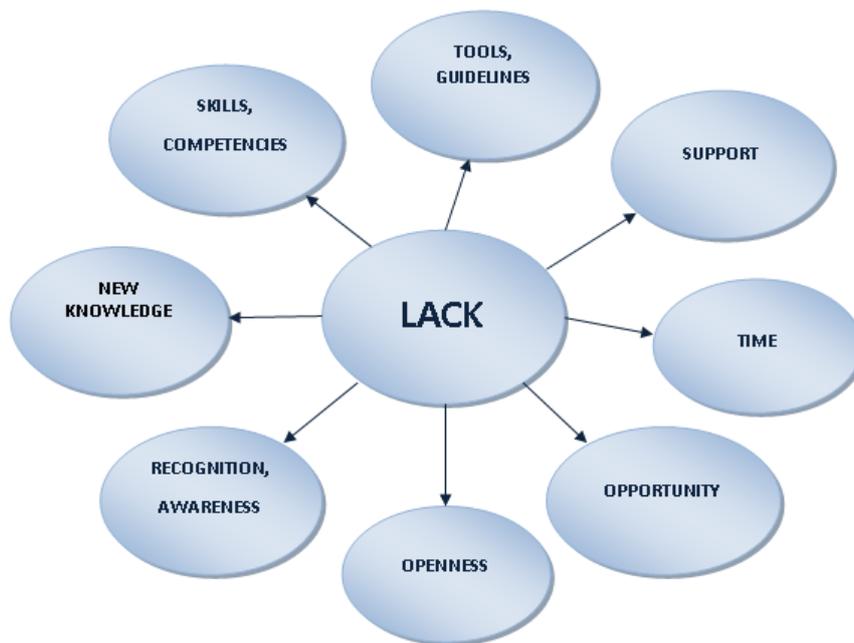
*‘I have given it a name, I have given it an explanation, which is a personal explanation, of mine, which, however, helps me’* (midwife),

which, although subjective and fragile, may help keep the balance. Rationalising attempts may easily remain futile, too, when seeking for meaning, an answer to ‘**why**’ (SI1.2.3.4) in vain or seeing it as punishment for sins.

*‘I say, excuse me, but why, that is. ... how come? What sin have these people committed, that is? So, was it ... There are no explanations, but why? So ... you see ... Another, another example is where their child died in an accident, then it takes some great work of grief in this family, etc., etc., no? And then, afterwards, this child is like this, eh, eh, she*

*stays pregnant, and has a throttling in the umbilical cord, the child dies at the end of the pregnancy. So ... you say ... but then ... so ... you see...'* (psychologist).

The weight of a loss event on HCPs may also be seen through the **lack** (Figure 4.13 - SI1.2.4) they experience in their activity. Eight child nodes construct this governing parent node, as it is revealed by Figure 4.13 below:



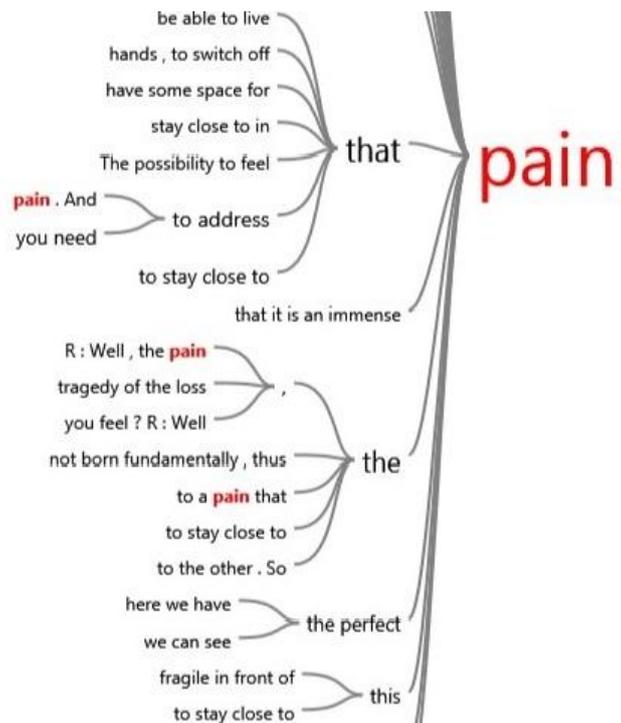
**Figure 4.13 The concept of LACK (SI1.2.4)**

The **lack of skills, competences** (SI1.2.4.5), **lack of new knowledge** (SI1.2.4.1), the **lack of recognition, awareness** (SI1.2.4.4), **lack of tools, guidelines** (SI1.2.4.8) and the **lack of openness** (SI1.2.4.2) concern professional performance in perinatal bereavement care, while the **lack of time** (SI1.2.4.7), the **lack of support, supervision** (SI1.2.4.6) and the **lack of opportunity** (SI1.2.4.3) highlight psychological case management expectations for self-care.

#### 4.4.3 Emotive elements (SI1.3)

The super-ordinate node of **emotive elements** (SI1.3) consists of eight nodes: **open door and window** (SI1.3.1), **physical problems** (SI1.3.2), **tiredness** (SI1.3.3), **escape** (SI1.3.4), **fear** (SI1.3.5), **loss** (SI1.3.6), **pain** (SI1.3.7), and **wall** (SI1.3.8). Among them **escape** (SI1.3.4) is built up of 2 subordinate nodes, as much as **wall** (SI1.3.8), while both **loss** (SI1.3.6) and **pain** (SI1.3.7) are constructed by 4 nodes. The emotional components of adverse outcome events are most noteworthy through the associations

with the concept of **pain** (SI1.3.7) in which it is possible to distinguish **pain** (SI1.3.7.1) in general, **suffering** (SI1.3.7.4), the **pain of a dead child** (SI1.3.7.2), and the **perfect pain** (SI1.3.7.3). A part of the contextual word tree in Figure 4.14 shows the arrangements where the word 'pain' is part of adjective-noun phrases: *personal pain*, *incredible pain*, *profound pain*, *private pain*, *immense pain*, *perfect pain*, demonstrating how the interviewed HCPs conceptualise the loss of a child in the perinatal period and how it affects them.



**Figure 4.14** A part of the word-tree structure of PAIN (SI1.3.7) (context and combinations)

It is the governing noun of phrases, eg.: *the pain of a dead child*, *the pain of the loss*, *to be in their own pain*. The verb-noun combinations on the one hand refer to the empathy and emotional involvement of the operators: *to feel that pain*, *to stay close to that pain*, *to be able to live that pain*, *to address that pain*, *to have some space for pain*, *the pain may resonate in patients*, while on the other hand, they may strive *to control the pain*, *to switch off that pain*, *to keep the pain away even to refuse others' pain* as means of self-protection. The complete contextual word tree can be found in the Appendix (Appendix 7).

The metaphor of **wall** (SI1.3.8) indicates another means of self-protection from the effects of emotional involvements:



The circumstances, facilities, medical and support conditions, related emotions, challenges are all together to provide bereavement care with the child and the mother in the centre.

#### 4.4.4.1 What I do in case of perinatal death (SI1.5.1.3)

One of the most important nodes regarding the concept of behaviour patterns is **what I do in case of perinatal death** (SI1.5.1.3) collecting the personal, subjective reports of HCPs concerning their own actions. It reflects the empathic attitude they represent, the attention they demonstrate and the professional patterns and self-expectations they perform every day.

*'... we leave the child, to, to the family, if they want it, explaining to them as much as possible linguistically and on the level of comprehension, because then in that moment everything is always, also complicated for them to understand, a bit what has happened, what has been done, the fact that they can stay with their child, trying to take away their sense of guilt of what they could have done, if they could have arrived earlier, all the things that perinatal death brings about a bit. Eh, eh... thus you try to facilitate the family's contact with the child as much as possible'* (doctor)

*'I take care of the most difficult part, which is to manage the administrative-bureaucratic part. And I'm saying that it is the most difficult part, because [...] you must enter transversally to ask them in that moment about something that they do not want to hear, [...] which is "do you want to bury your child?", "where do you want to bury him?", and "what would you like to do of, of, of this moment?", "do you need psychological support?", "do you want us to activate home support?". So, from one part it is emotionally less involving for the couple, but it also brings in a reality that in that moment shouldn't be lived'* (midwife)

*'... when I am in a situation like this, then I am there completely. In the present. You could say, in 'here and now'. I feel empathy that I always express, in my opinion it is the most important.'* (midwife)

*'...quickly and instinctively, or I don't know, with a sudden move, I threw into my bag some candles, like this, I didn't even think about why, I threw them in. And when I arrived there [...] the father, when they took the baby out, in the newborn care unit there was a silent place, asked for the baby. And he could be left there with the baby, and I lit a candle. What's more, even the mother asked me to put the baby on her chest, when she was taken out of the operation room. So I put the baby there.'* (midwife)

*‘What my most important task is, or what I consider important is that [...] I should meet her at least once. See, when abortion induction happens and she is in a longer process, which may last for 3-4 days, then I [...] go and see her every day. And then, always considering her openness, we try to talk a bit about how she would like it when the birth takes place or if we look a bit ahead then what she would like to happen, with the baby, and in an indirect way I speak about that ‘of course, these are difficult minutes here now, but in the long run it is surely much better if she has a look at the baby, if she sees the child, if we related to this baby as to the other important deceased members of the family.’ (psychologist)*

*‘I started to collect information, I started to see how the situation was, how she experienced it. [...] so this helped me to develop my understanding of how the attitude could be helpful, it was important to be helpful’ (child care specialist).*

#### 4.4.4.2 What others do in case of perinatal death (SI1.5.1.4)

When it comes to reflecting on team members’, colleagues’ work, the entries of the node **what others do in case of perinatal death** (SI1.5.1.4) present a background of understanding. They talk about emphatic attitudes, shared tasks and responsibilities

*‘when they know that something like this is happening, they are ready very quickly to meet the person who needs their help’ (perinatal specialist)*

*“among young doctors I often experience that they are in it emotionally, too, so this neonatologist who accompanied the stopping of the heart of the premature baby, or he was the one who pronounced that ‘she is dead’, he so carefully, in a nice way, removed all the little tubes, the fixing stripes, he paid attention to this premature baby with full respect, he handed her over to the mother, and he was there, too, and I don’t say he cried, but he shed tears as a young man in this situation” (psychologist),*

nevertheless, they also report some resistance and refusal regarding bereavement care options within the care-providing team:

*‘among the doctors there was a sort of weird attitude, one of them said that I should not, I should not be making a crematorium out of the delivery room and I should stop this’ (midwife).*

Moreover, this part of the interviews also reveals how the lack of proper knowledge of relevant measures, communication tasks and of local protocols for perinatal loss events overburdens and disconcerts HCPs, with clear consequences towards the involved families.

*'In case of intrauterine death there are some documents to be completed. The child must be weighed, so all these, we also weigh the placenta, the doctor fills in the document, and we call the patient-carrier and he takes them to the pathology department. And I don't know if it is our competency at the obstetrics or it is the pathology's regarding the burial, so that they can bury the child, I don't know who should mention this. I can't recall that we talk about this. We don't talk about this, we only follow the path so that the child is carried down there. We don't have that part where we would inform the parents in a detailed way, that they could ask for this possibility without problem. [...] The funeral is a kind of farewell, too. It is part of the grieving process. This is a challenging condition. Who should tell it, then? If this request doesn't start from the parents, that they would like to do it, then who is that professional who informs them that there is a possibility to do that? [...] it can also be part of it that as a recipe it is written down what to do, what are the actions to take in a case like this.'* (midwife)

#### 4.4.5 Own, personal loss experience (SI1.4)

Professional performance and private life mutually interfere with each other. Own, personal losses of any nature may have an effect on adverse outcome events experienced as professionals. Such private and personal question was never directly asked during the interviews, however, the experience could surface during the conversations and when it did, it could refer to **own loss experiences** (SI1.4.1)

*'all the times that you must deal with a loss, of any nature, it resends you all your losses, thus, you always have some particular pain, no, eh, your personal experiences, well, everybody has their own losses in life, right, thus there's always this sad thing that, that works'* (midwife)

*'It is part of my story that my mother, when she was a foetus, so in my grandmother's uterus, then in w20 of pregnancy, she was born in '49, around w20 her twin died. And she was there for 20 other weeks with her dead twin, she lived there [...]so, basically, I inherited all these loss experiences of my mother's, regarding death, her fear of death.'*

(midwife),

or appear as **references to effect of previous loss experiences of colleagues** (SI1.4.2)

*'we have a colleague who has suffered some child loss herself, and we try to protect her from these events and let her not attend these cases when they happen'* (midwife).

This phenomenon itself refers to a profound understanding of the emotional impact of loss situations from every care providing team member, considering also the controversial fact that the related institution does not have any bereavement practice towards the families.

#### 4.4.6 The conceptual framework

The presentation of the secondary, inductive hierarchic structure was planned in an order which reflects how a perinatal death event triggers in HCPs cognitive, emotional, and accordingly functional, behavioural patterns, as well. As the schematic concept map has taken form, the conceptual framework places the own, personal loss experiences on the same level with the perinatal death event in hierarchy, since, as it appears from the interviews, its influence and effect cannot be separated and disregarded concerning the level of emotional involvement and potential professional responses. While the effect of the personal life element was not taken into consideration as a possible influence when planning the research activity, it must be recognised how essential it is to offer responses to this emerging need in order to facilitate optimum professional performances. The conceptual framework will be discussed in details in the following Discussion chapter to present the connection between the identified components.

#### **4.5 Proposals for future education, research and policy making solutions**

The above presented results have indicated the directions concerning what intervention strategies could be implemented to achieve optimum performance in perinatal bereavement care and adequate support for healthcare personnel. In the following sections of the chapter, on the basis of the findings, I would like to propose possibilities for a continuing education programme with a focus on skills, competencies development as well as support for HCPs, for future research activities to further investigate the effect of perinatal death events on the care-providing staff and last but not least, considerations for policy measures of national perinatal bereavement care guidelines.

#### 4.5.1 Proposal for a continuing education programme

Death education, thanatology in healthcare formative education has been introduced into the curriculum only recently. It has been a significant step to provide future HCPs with means of knowledge and help when the end of life is inevitable. It has been demonstrated how the education programmes about death lessen their death anxiety and improve coping. (Hegedűs, 2017) Courses about end of life and bereavement in perinatal context to be inserted into the basic curriculum is a future objective, with some more work to complete. Here below I would like to propose a continuing education programme for perinatal bereavement care (Table 4.1) which foresees skills and competencies development, support and coping for the emotional load of the personnel, as well. The programme has been planned on the basis of the IMPROVE (IMproving Perinatal Mortality Review and Outcomes Via Education) programme of the Perinatal Society of Australia and New Zealand (PSANZ) (1.6.6) and the TEARDROP workshop programme based on the Irish National Bereavement Standards. (1.6.5)

The overall objective of the **Perinatal Bereavement Care In Everyday Practice** continuing education programme (the detailed education plan is found in Appendix 8.) is to outline the most important elements of optimum bereavement care in a small group (max. 15 participants) setting within the arch of a one-day training programme. The target audience involves any HCPs related to perinatal working contexts, from national and private healthcare services simultaneously. In the course programme relevant information regarding prevalence and causes, psycho-social aspects of perinatal bereavement, national and institutional guideline recommendations and their adoption to local realities, bereavement care possibilities are as accentuated as the emotional effect and burden perinatal loss events may convey for the care-provider personnel. For skills development communication references and bereavement support solutions are demonstrated. In order to support coping and elaboration of own, work-related and personal loss experiences, an art therapy session is included in the programme. To address all the constituents individual sessions, with predefined timeframes, are dedicated to them, with defined objectives and competencies to develop.

#### 4.5.2 Proposal for future research

The present research activity was always planned as a qualitative one, focusing on the phenomenon how HCPs in perinatal context experience adverse outcome events professionally and personally. The applied method, IPA works with the subjective reports of the participants, providing a detailed picture of the phenomenon, nevertheless, it cannot offer general, large scale tendencies and prevalences. Therefore, it is not possible to formulate general statements regarding identified characteristic difficulties of the single professions, neither is it possible to differentiate on the basis of the work experience, for the same reason. Further research, using the findings of the present one, should be implemented, with quantitative and qualitative methods, to investigate these potentially noteworthy aspects. The obtained results may provide the background to future research activities, both qualitative and quantitative, to acquire a nation-wide and international-intercultural analytical study of the phenomenon.

The qualitative part of the research should focus on

- professional difficulties linked to specialisation, work experience,
- responses to loss and adverse outcome events,
- the institutional facilities and needs for perinatal bereavement care options,
- the required educational and psychological support for institutional staff,
- the locally availability of resources and guidelines regarding perinatal bereavement care,

involving institutions of all healthcare levels and from different parts of the country.

The quantitative method for the professional and emotional challenges and difficulties may apply and validate a questionnaire based on Perinatal Grief Scale, Professional Quality of Life Scale (ProQOL5), Beck Depression Inventory, etc. questions. The quantitative research sample should include a representative sample of all the related professions in perinatal care, this way a better understanding of specialisation-related difficulties could be gained.

### **4.5.3 Proposal for guideline recommendations**

Nationally available guidelines in perinatal bereavement care may guarantee a minimum standard of provided support for families facing perinatal loss all over the country's healthcare institutions, regardless of their level or their geographical position. The currently available guidelines from 2010 (1.6.2) are to be revised and renewed accordingly, with relevant present-day legal, ethical, medical and psychological background knowledge, with possibilities for local, institutional adaptations.

National perinatal bereavement care minimum standard recommendations should propose measures regarding

- care characteristics and tasks according to healthcare level, communication possibilities between levels
- local, institutional facilities for care (privacy, separate ward, common understanding of unified signals regarding adverse outcome events)
- perinatal bereavement care team or reference specialist among staff members, with definition of tasks and responsibilities
- bereavement care options (memory making possibilities, spiritual care, follow up)
- administrative and social support (financial aid and burial processes)
- staff support (organisational formal and informal options, both educational and psychological skills and competencies development options).

The above elements may provide a framework of care, establishing the major cornerstones and allowing for individual institutional choices at the same time. The efforts of all the HCPs who dedicate additional energy and attention to families in perinatal loss could be recognised and facilitated by unified and regularly revised national standard guidelines.

## 5 DISCUSSION

### 5.1 Death and healthcare professionals

The intense emotional demand related to adverse outcome events and the need for support of HCPs have been known for some time now, together with the high level of death anxiety among care providers. (Hegedűs, 2017; EAPC Palliative Care Guidelines) How compassion fatigue, especially in high demand conditions of oncology and palliative care, may interfere with professional performance is also well known (Kegye et al, 2015). The effects of chronic emotional, work-related trauma in healthcare are visible all around the globe in this challenging period of pandemia, and nobody dares to question the need for support anymore, having seen the larger than life performance of the completely exhausted health personnel.

Regarding perinatal context, a recent Hungarian study focused on the wellbeing of NICU HCPs related to legal and ethical decision making impacts. (Feith, 2019) Nevertheless, how the impact of death is seen in medical fields where normally happiness is the outcome indicator has not been in the focus of research interest until recently. Unfortunately, though, the question is not *IF* but *WHEN* HCPs in perinatal context need to face a loss situation. In the last decade a growing attention has been paid to perinatal HCPs' personal and professional difficulties due to chronic distress, emotive involvement, personal grief and the non-appropriate elaboration of their feelings of grief and loss, emphasising the significance of research and prevention policies related to perinatal death events. (Gandino, 2019) As indicated, a correlation can be identified between the help provided to bereaved families and the effects of personal involvement, the existence or lack of supervision and of expected training facilities. (Epstein, 2008) The lack of competencies in communication (Testoni et al., 2019), in crisis management and in care guidelines for bereavement support (Fernández-Alcántara et al., 2020) may significantly add to the feelings of professional and personal failure, incompetence (Kovácsné, 1995). Death education, competency development, well planned, supporting formative programmes could provide a solution to the arising problems and improve the elaboration of the experienced trauma. (Gold, 2008; Ravaldi, 2014; Modiba, 2014, Testoni et al., 2019) Proper skills, competencies concerning communication, legal and ethical knowledge and actual care possibilities for

bereavement care (Smith, 2020) could give them a sense of well provided support for the patients.

The presentation of the literature in chapter 1 sheds light on the fact that the majority of the research activities in the topic are single institution related analysis (1.3.6), centred on local practices and experiences, proving the necessity to gain a better understanding of the phenomenon. While still focusing on the phenomenon of the singular experiences of perinatal loss in work context, the present study, following the concept of the research activity of 2014-2015 (1.7) was implemented on a wider scale, with more institutions on different levels involved and placed into an intercultural setting, as well. The interviews are connected to 20 different healthcare realities, on all three levels, in Hungary and in Italy. Generally speaking, the healthcare operators who accepted the invitation to the interview were aware of the significance of perinatal grief, open to the idea of PBC and talk about the personal, emotional involvement related to their professional practice. Through their personal report it was also possible to understand particulars of institutional practices, common attitudes among colleagues and potentials for development related to PBC. While the lived experience of loss was approached on the level of human observation and sensitivity, the overall analysis could be implemented in interinstitutional and intercultural aspects, considering guidelines and international settings, as well. The discussion of the results, therefore, goes on to examining the deductive (PD1) and inductive (SI1) structures, starting from the individual and opening the spectrum subsequently.

## **5.2 The deductive coding nodes and the scientific findings**

Primary coding analysis provided a four-level hierarchical structure, with 31+80+17 child nodes and seven main parent nodes, the highest parent nodes being Loss event in numbers (PD1.1), Present institutional practice (PD1.3), Professional experience (PD1.4), Skills and competencies (PD1.5), Training needs for best care (PD1.7), Personal experiences (PD1.2) and Support and coping (PD1. 6). A contrast and comparison of the research findings with the international scientific background may provide a reference for evaluation and complete the spectrum so that the results may contribute to a global, deeper knowledge in the field.

How the psycholinguistic frames used for perinatal loss events can be associated with the impact of the experience has already been demonstrated by Gandino et al. (Gandino, 2017), since they present the linguistic-mental schemes of the phenomenon in question, thus providing a background for interpretation. In the present analysis the subjective and complicated nature of loss experiences can be understood from one aspect in how the HCPs refer to the case numbers they have assisted (PD1.1.4), where '*a lot*' and '*many, so many*' are the expressions mainly used as indicators, implying the emotional weight and potential risks for care-providers. The answer '*don't know*', on the other hand, may appear as a distancing solution, allowing for the HCP to keep reality away.

References to present institutional bereavement practices reveal the need and the potential to create a local institutional protocol, preferably with staff involvement, who understand the importance of good bereavement care (PD1.3.3 and PD1.3.4). The standardised pathways HCPs may follow (Fernández-Alcántara et al., 2020) create frames and possibilities to help when staff cannot provide any other medical solutions. In the related institutions, a customised path, based on 'we always do it this way' could be found everywhere, even with no written protocol, on a wide spectrum of not paying attention to perinatal loss to dedicated attention and empathy. Allowing that it may not be the nationwide general situation, in some of the studied Italian institutions both pre- and perinatal bereavement solution frames are present, with clear steps to follow (PD1.3.2.6 and PD1.3.2.7) to facilitate bereavement care, however, without a specially dedicated bereavement team. At the same time, in the relevant Hungarian institutions only partial care elements could be identified, for example: separation and privacy, showing the dead child to the parents (though how the presentation is usually done is not entirely clear from the reports), taking photos or giving a memory box to the parents (PD1.3.2.2), although separately only, and as responsibility or care of individual HCPs, without a dedicated bereavement team or institutional protocol.

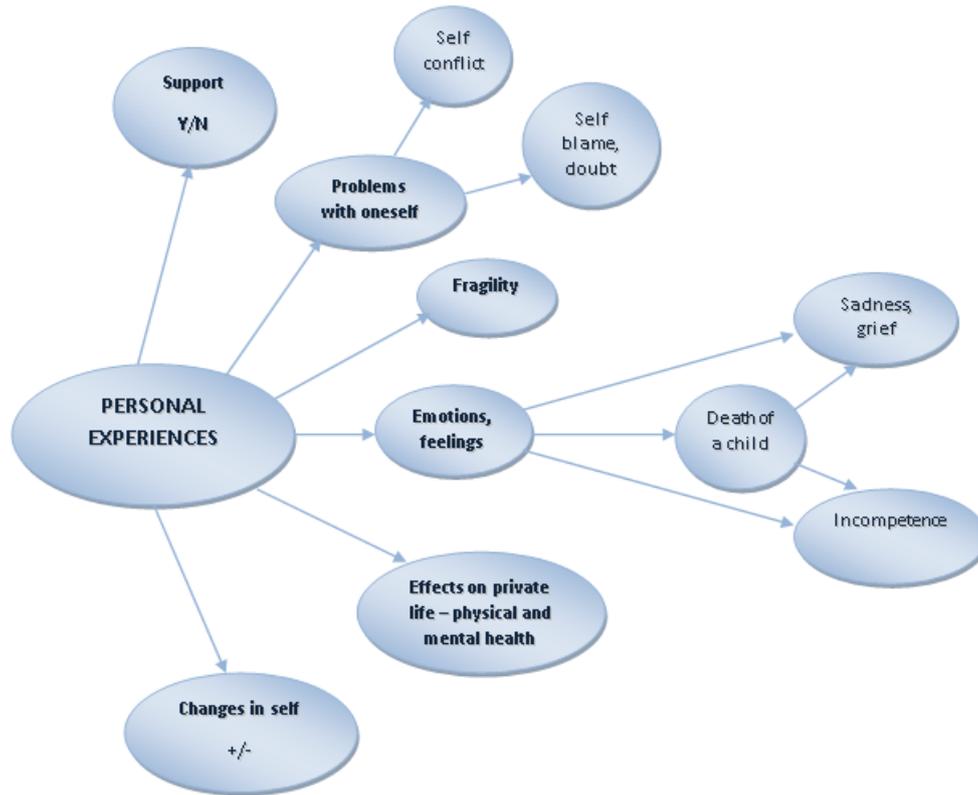
All of this indicates great potentials for future guideline measures and optimum bereavement care when seen together with the fact that among the interviewed professionals a high awareness of the significance of perinatal loss could be identified. All the required changes formulated by the interviewed HCPs (PD1.4.4), the development of protocol, proper knowledge and support, a dedicated bereavement team

denote the necessity of a professional framework regarding perinatal death events to facilitate professional performance and personal wellbeing. (Nuzum, 2014) It has been claimed that the both the chronic and acute, potentially more demanding death events impact HCPs' physical and mental health conditions likewise. (Brunelli, 2005, Nuzum, 2014 and Musodza et al., 2021) The emotionally load of the single occurrences (PD1.4.3.4) is multiplied and enhanced during the course of the professional career, and at the same time, there may be loss events which are more demanding (PD1.4.3.10). The lack of proper skills and competencies (PD1.4.3.8) to manage loss situations emphasises the feeling of professional and personal failure, incompetence (PD1.4.3.7) (Kovácsné, 1995). Differences regarding the importance of perinatal bereavement among staff (PD1.4.3.3) and collaboration challenges (PD1.4.3.3) may create conflicts in care-providing, moreover, impact the assistance provided to the involved families. Accepting the death of a child (PD1.4.3.1) challenges professional competency and beliefs in the natural order of life, bringing forward death anxiety and death concerns recognised as a considerable phenomenon among care-providers. (Hegedüs, 2017) The emotional impact and the non-proper management of one's own feelings (PD1.4.3.5) and emotions has been shown to manifest as frustration, the feeling of 'survive the shift', powerlessness and distress. (McCreight, 2005; Puia, 2013) For significant change to take place a protocol framework (PD1.4.4.4) (Pastor-Montero, 2012), proper and up-to-date knowledge and skills (PD1.4.4.5) (McGrath, 2011) and supporting schemes (PD1.4.4.2) (Limbo, 2010) are equally necessary. These results correspond to the international findings, with no differences among the examined countries.

Proper know-how and competency development at present is available only in specific courses, while it should already be part of the basic formation (PD1.5.5.1) as much as of the continuing education possibilities (PD1.5.5.7), as Gold et al. (Gold, 2008) and Gerow et al. (Gerow, 2010) both affirm.

To be able to elaborate experiences (PD1.5.7.2) and to know and utilise appropriate coping strategies is a difficulty, due to lack of competencies, which may interfere with professional performance and mental health. (Fülöp, 2013) Mapping personal experiences (Figure 5.1 - PD1.2) offers an insight into the diversity of effects adverse outcome events may trigger in HCPs private life (Brunelli, 2005; Nuzum, 2014;

Mosudza et al., 2021), clearly the emotional load of the work related events cannot be left behind at the department when leaving for home. Figure 5.1 below demonstrates a synthetic illustration of the reported elements:



**Figure 5.1** Personal experiences (PD1.2) schematic diagram

The different elements of the diagram indicate how complex personal experiences may be concerning perinatal death events. Personality changes (PD1.2.2) or problems (PD1.2.5), private life effects (PD1.2.3), difficult, negative feelings (PD1.2.4) as well as doubting professional competencies (PD1.2.4.2) are all known trends in literature in international context, too. (Brunelli, 2005; Gold, 2008; Modiba, 2008; McNamara, 2019). It has been understood that the recurring thoughts and feelings regarding the death of a child (PD1.2.4.4) deeply affect and accompany HCPs into their private life scenes (Willis, 2020), sometimes challenging them into leaving their original vocation, too. (Ravaldi, 2014) Due to the same circumstances, one of the participants decided not to follow any pregnancies in the future.

Concerning support solutions (PD1.2.6), the need for a formal, management driven institutional support (PD1.2.6.4) is clearly expressed, univocally, among the interviewed HCPS, especially group therapy or debriefing sessions (PD1.6.3.3) could be of high importance in elaboration of team experienced loss events. The efficacy of the support method has been proven to be beneficial for the whole care-providing team (Gold, 2008; Rogers, 2008), considering that the commonly shared occurrence effects all involved team members. Consequently, together with individual positive coping solutions and informal discussions with colleagues (PD1.6.2.4), adequate self-care among HCPs could be obtained to facilitate physical and mental wellbeing. (Gold, 2008; Gerow, 2010) On the whole, it can be rather firmly claimed that the identified parent and child nodes from the primary deductive structure correspond to the recognised patterns and conclusions of internationally implemented researched, regarding the effects of loss events on HCPs in perinatal context.

### **5.3 The secondary, inductive coding structure and conceptual mapping**

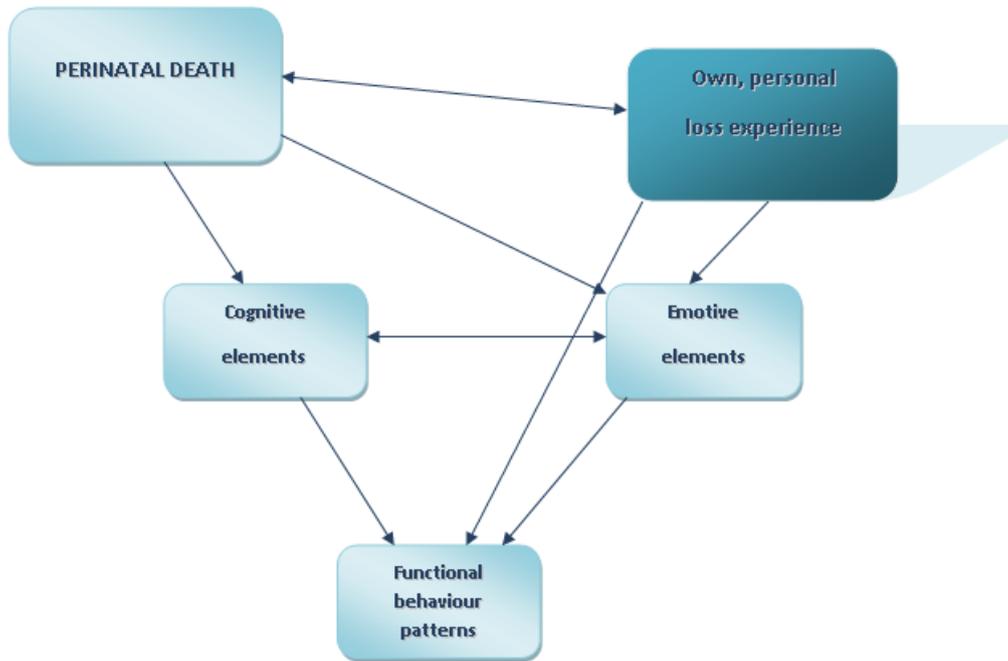
The secondary, inductive hierarchic structure reflects how perinatal death events set off HCPs' cognitive, emotional, and accordingly functional, behavioural patterns. The perinatal death event *per se* is defined by HCPs as a 'tragedy where the death of a child is accompanied with pain' (SII.1.4), on the basis of their most common words from the node regarding the event. Interestingly, the frequency of medical terms used to refer to the adverse outcome events is much lower than the use of common concepts and words, as one section of the word tree structure of the frequency analysis of the node demonstrates in Figure 5.2, no medical term appears among the first 15 most common expressions:

child	loss	dead	even	away
		pain	life	born
	death	baby	moment	died

**Figure 5.2** Section of the frequency word tree of the node ‘perinatal death events in words’ (SI1.1.4)

The cognitive and the emotive responses create those behaviour reactions which will drive the care provided for the involved families. It is of high importance, therefore, that the governing concept node among the cognitive elements is that of **LACK** (SI1.2.4) related to knowledge, competencies, facilities and support, while **LOSS** and **PAIN** (due to and originating from perinatal death) (SI1.3.6 and SI1.3.7) appear as the most significant among the emotive ones. Organisational responses to balance the negative concepts on policy making level, on institutional and departmental levels, in formal and in informal ways equally (Fernández-Alcántara et al., 2020, Denney-Koelsch, Cote-Arsenault, 2020) should ensure that ‘the best possible experience for the parents could be created’ (Epstein, 2008), while easing the emotional burden of the healthcare staff, too. (Gold, 2008) Functional behavioural reactions can also be considered by the model of Terror Management Theory (TMT) (Greenberg et al., 2015). Facing the unpredictability, yet, the inevitability of death in a medical field where the expected and preferred outcome is the hope and happiness of a new human life, offering continuity and immortality, generates a personal and professional conflict for the care-providers. Moreover, it also conditions the reaction patterns rooted in their cultural and social settings.

The conclusive schematic conceptual framework, mentioned earlier and presented here in Figure 5.3, too, highlights the decisive nature of the own, personal loss experiences (of any kind) when facing the perinatal death event as a professional.



**Figure 5.3** Conceptual framework of chronic professional loss experiences with focus on personal loss

The preconditioning effect of this personal grief experience on provided bereavement care was originally not taken into consideration, was not investigated in the interviews, however, the research results reveal that it surfaced during the conversations, either directly or indirectly, as a relevant and decisive experience for perinatal HCPs. Consequently, it must be recognised how essential it is to offer responses to this emerging support need in order to facilitate optimum professional performances. (Rogers, 2008)

While the most influential subjective personal experience can be related to the perinatal period, coming from own perinatal losses or from family loss experiences, any other personal grief will influence one's professional attitude and performance, as it is evident from the result. An event of this weight will mark someone's private and professional life equally:

*'the first one was born with malformation and died, but then we couldn't know it in advance. Then with the following baby they made the embryonic fluid examination and for me, it was that I lost the pregnancy'* (perinatal specialist).

On the one hand, it may increase one's sensitivity and openness to assist other people in a similar situation

*'everyone has their own previous experiences, you choose healthcare professions also because of some life experiences, so, for this reason it is not easy even for them'*  
(midwife),

on the other hand, however, the HCPs fragility becomes more evident and elevated due to the former loss events, due to the mutual effect. Therefore, formal, institution-offered individual support solutions should be foreseen as part of the organisational support scheme to manage own loss experiences and grief elaboration, to help professional activity. Private life loss and professionally experienced loss have mutual influence on each other and thus it may create a vicious circle, resulting in enhanced negative reactions. At the same time, debriefing occasions can facilitate the involved team's elaborating the commonly shared work related loss experience.

The effect of personal loss can be considered in relation to the concept of secondary trauma. (Fülöp, 2013) On the basis of the findings it can be claimed that secondary trauma of HCPs has a professional and a personal element, which mutually affect each other. The professional element is the functional reaction to a work related traumatising event, on the basis of know-how, specialisation skills and competencies, while the personal element consists of emotional involvement, personal attitudes and previous private life experiences. Non-elaborated personal loss experiences have a decisive influence on the personal element of secondary trauma, as it could be demonstrated. The two elements mutually enhance each other's effect, thus the experienced secondary trauma will be manifested with more extensive harmful consequences and a higher risk of compassion fatigue and/or burnout.

#### **5.4 Perinatal loss and HCPs in intercultural settings**

Studying the effect of adverse outcome perinatal events on HCPs is a relatively new research interest, as it could be seen from the literary overview of Chapter 1. (Tables 1.5 and 1.6) While more and more countries recognise the necessity to provide a framework of perinatal bereavement care in national and institutional guidelines, only a few countries have been able to meet this requirement so far, for different reasons. It can be seen in 1.6.5 and 1.6.6 that Australia-New Zealand and Ireland are in all probability the

two countries worldwide which have been able to create a detailed and all-inclusive care framework in which a dedicated section for support is foreseen for the care-providing personnel, as well. As the documents demonstrate, the support solutions are available on formal, organisational level, with team debriefing and individual therapeutic solutions, whereas informal support among colleagues and self-care coping strategies are also accentuated. (1.6.5 and 1.6.6) In other settings medical societies (UK) or international organisations (ICPCN) also make recommendations, moreover, institutional protocols are also known from US realities (<http://perinatalhospicecare.org/>). Non-profit organisation, scientific societies and associations can contribute to bereavement care to a large extent. The former ones (e.g. Return to Zero, NILMDTS, SANDS, etc.) have been established originating from private loss experiences, while scientific organisations (International Stillbirth Alliance, PLIDA, etc.) are umbrella organisations with diverse research and activity related to perinatal death events. The available resources, the theoretical and practical know-how they possess can be references for any potential need worldwide.

Italy and Hungary, the two countries in the focus of the research, have a different status in this respect. In Italy more and more institutions have a locally written protocol for perinatal bereavement care, although, it is still not to be found everywhere, unfortunately. Local protocols were created using the already mentioned CiaoLapo and La Quercia Millenaria recommendations (PD1.3.2.8). Both non-profit, civil organisations offer bottom-up initiatives, based on the personal loss experiences of the founding families. Upon institutional request, through their regional branches, they provide trainings and support for protocols and means, as well as formative courses. On the other hand, in general no organised support is foreseen for the HCPs in perinatal settings. Burial possibilities for the ‘*never born children*’ (*bambini mai nati* – as they are often, quite unfortunately referred to in common language) are also available in cemeteries. In the cities of Vicenza and Brescia, for example, a specific part of the cemetery is dedicated to the small white tombs. If HCPs have the support of a locally created protocol, the demanding tasks of supporting the families and providing them with appropriate information seem to be facilitated by following thoughtfully created measures. As it can be understood from the conversations, in these cases everyone in each related perinatal specialisation knows what to do, what the next step is for them in

supporting the family. Yet, the emotional load of the loss still takes its toll, here the HCPs struggle with their feelings and psychological difficulties. Where no protocol foresees the guidance, however, the situation may be more challenging, causing also professionally demanding case management.

In Hungary the ever growing awareness and respect for perinatal loss still awaits the renewal of the 2010 guideline recommendations for bereavement care, which can then provide the minimum standard conditions valid nationwide, allowing for local, institutional modifications. The non-commonly shared recognition of perinatal bereavement care may result in limited options and ‘one-person care’ (PD1.3.2.5) within the given institutions. No formal debriefing or individual support options for staff could be identified through the implemented interviews, coping is self-managed, with own resources. Recent Hungarian legal measures also authorize the burial in case of both early and late perinatal death events [Act CXXVII of 2013 and 351/2013 (X.4)], nonetheless, as it is understood from the conversations (PD1.3.5), the lack of knowledge among care-providers impedes the possibility to occur in most cases. Managing perinatal loss events claims professionally and personally demanding performances for Hungarian healthcare staff, where they need to find ways to support families and cope with their own feelings from their own resources. As it can be understood from the interviews, while the general attitude of perinatal HCPs regarding perinatal bereavement care is considerably altering and a lot of improvement has occurred lately, with proper means significant changes could be enhanced.

On the first pages of the thesis the distinction between the clinical medical and clinical psychological definition of ‘*perinatal*’ was illustrated, claiming that the clinical psychological interpretation includes the whole period from conception until the end of the first year, while the medical usage is more restrictive, and refers to the late pregnancy period preceding birth (depending on the threshold of viability) and the first postnatal week. (Table 1.2) Interestingly, the distinction, while not searched for, was also recognizable in the interviews, related to the definition of perinatal death events. When talking about perinatal death, the Italian HCPs –regardless of their specialisation and profession – applied the wider, psychological interpretation of it, indicating all losses connected to the pre- and perinatal periods. In contrast, the Hungarian HCPs –

again, regardless of the profession and specialisation – used the narrower, medical sense of the word *'perinatal'*, when referring to perinatal loss events, thus mainly talking about IUD after w24, stillbirth, intrapartum death and early neonatal death. The international trend of the literature is to be more inclusive, with the use of the wider interpretation and only making the distinction between *'prenatal'* and *'perinatal'* when required. (Limbo et al., 2020) A plausible explanation of the recognised element may be the underlying, already more available care and burial options in Italy, which also influence the attitude regarding child-loss in perinatal context.

The framework for PBC ensured by a local, institutional protocol may provide pathways to accompany the families in perinatal death, however, it does not lessen the emotional effect of the occurring death on HCPs. When comparing the conversation elements of operators working with or without protocol, in Italian and Hungarian context, similarly, it can be seen that the aftermath may bring professional satisfaction and facilitate the provided care if the operators know how they can offer help and support and the protocol is the background for it. (PD1.5.3) Nevertheless, the event itself, the fact that death happens, takes its toll, and leaves an imprint professionally and personally, as well, regardless nationality or local protocol framework. As one of the participants expressed it,

*'that moment is always particularly violent, terrible to experience [...] the loss of a child is even more difficult because it is unnatural, because it is out of anyone's thoughts'*

(midwife).

Consequently, policy making efforts to support HCPs should also focus on the circumstances of death, how to help grief elaboration and offer possibilities in thanatology and death education to lessen the adverse impact. (Gold, 2008, Limbo, 2010)

## 5.5 General observations

How HCPs manage professional and personal problems related to perinatal death occurrences will affect their performance in care-providing, their reaction will furthermore be decisive in parents' grief elaboration. (Epstein, 2008; Gold, 2008)

Human factor is a major part of good care, therefore, the physical and mental/psychological wellbeing of care-providers must be kept in the focus, since without this element good accompaniment and presence cannot be obtained. A clear consensus regarding the importance of PBC among the interviewed HCPs could be recognised, they identified its elements in shared knowledge, common understanding/awareness of adequate bereavement care, providing practical and psychological means of care, the need of institutional formal and informal support for staff (PD1.6.3 and PD1.7). (Modiba, 2014) In most cases the willingness to care is present but the lack of facilities, opportunities and frames, the lack of support represent demanding challenges for the personnel, often resulting in negative feelings. While the existence of a local protocol may lessen the harmful impact of the death events, nonetheless, as the subjective reports show, the experienced emotional trauma, effect is similar in all circumstances, moreover, without support it is an enormous burden (SI1.1.4 and SI1.3.7), regardless of the work experience, existence of local, institutional protocol or even of nationality. Skills and competency development is required in communication and its settings as much as in knowing what help can be offered in particularly demanding situations (PD1.4.4, PD1.5.7 and SI1.2.4.5):

*‘.. when it is twins, one of them dies, then I keep seeing the parents all the following days, perhaps for two months, then [...] you anyway meet again these parents whose child has died, the other twin is still there, in the very same room, it’s still us, they see us, even your credibility to say “everything is all right” is different. Compared to when the other one was also alive.’ (doctor)*

The role of the psychologist in perinatal circumstances presents opportunities and dilemmas, too. While their presence is still not guaranteed everywhere (or they share their time with other departments, e.g. with oncology), if they are part of the medical team, not all colleagues accept the psychological approach in care, refusing its importance. This can be a source of conflict of interests and significant difference in attitude regarding PBC. On the other hand, they can also perform a key role for informal support for colleagues, in forms of emergency meetings and private counselling, when they feel overwhelmed by the demanding experiences. From the point of view of the research, the interviews with the psychologists offered an insight into the colleagues’ attitudes and difficulties, too, whereas the conversations with the other colleagues

generally did not. Two of the participating psychologists - working in secondary and tertiary level institutions, performing interdepartmental responsibilities, being present both in obstetrics and neonatology - could be seen as key figures in creating local bereavement care pathways, in particular since they are also specialised in grief counselling and try to find ways for improvement. In one of the Italian institutions the framework of the local bereavement care protocol was the psychologist's achievement, with all the practical steps to do and the methodology behind them, as well. The knowledge and the experience of bereavement care needs of private, non-profit organisations and the phenomenon of 'one-person' care (PD1.3.2.5) could also be beneficial in the activity of potential institutional bereavement teams or of a potential reference bereavement specialist. The presence of the specifically formed and skilled people could have key roles and responsibilities in care providing and could significantly ease the caregiver medical personnel's emotional burden and involvement as much as they help the family in their grief, as the international guideline recommendations indicate. (1.6.8)

## **5.6 Hypotheses – validation**

At the beginning of the research I formulated several hypotheses which offered a frame to the interviews and to the analysis of the results. In this part of the discussion, I would like to validate them one by one, reflecting on the results and on the relevant sections of the doctoral dissertation.

1. The first hypothesis presumed that the healthcare professionals whose attitude regarding grief and loss is negative tend to escape from loss situations, as well as to avoid the involved families, and may provide less support for them.

The management of adverse outcome events has proven to be professionally and personally challenging, according to the research results, from more aspects. The death of a child is difficult to accept, against the natural order of things, all the related tasks are difficult to complete, which originally are not part of the professional expectations related to the perinatal specialisations. The controversy between reality and the desired positive outcome is harsh, death seems to have no place where children should be born and cured. Avoidance and escape from loss situations, as means of self-protection,

directly lead to less support and accompaniment for the families. Therefore, on the basis of the research findings, the first hypothesis is validated.

2. The second hypothesis was that the healthcare professionals' knowledge of perinatal death related legal measures is inadequate.

In the institutions where no local protocol has been formulated perinatal bereavement care is provided upon the initiation of some healthcare professionals, utilising means, e.g. taking small footprints or baby photos, thanks to their awareness, nonetheless, without knowing the relevant legal and protocol measures. As it has been reported, it is not entirely understood whose responsibility it should be to inform parents about the proceedings and their possibilities and what the relevant directive measures are. Thus, the second hypotheses can be confirmed this way.

3. The third hypothesis assumed that the inadequacy of healthcare professionals' knowledge of perinatal death related legal measures will affect the applied/suggested burial and bereavement care opportunities was that the healthcare professionals' knowledge of perinatal death related legal measures is inadequate.

Where perinatal bereavement protocol measures provide no frame for bereavement care, parents do not always see or spend time with the child, receive adequate grief and follow up support, moreover, they are not informed about the possibility to bury the child even in case of early pregnancy loss. Due to the short timeframe, the options for action are limited, therefore, right information at the right time is of high importance. When for any reason this cannot be realised, burial and bereavement care opportunities will be influenced to a great extent. On the other hand, the institutions which have formulated their own protocol, with the involvement of their own care-providers, have also been able to define the responsibilities and tasks of the healthcare professionals for bereavement care, therefore adequate attention and support for the families may be offered. Consequently, the assumption of the third hypothesis can be confirmed.

4. The fourth hypothesis related to perinatal bereavement care measures claimed that the lack of national and/or institutional guidelines regarding perinatal bereavement care creates challenging situations in cases of perinatal death events.

In the institutions where no local protocol is available perinatal bereavement care is the effort of the healthcare professionals who are open and sensitive to provide it, having identified its significance. Nevertheless, it may be a source for conflict if the general

attitude and recognition for bereavement care in the department is not favourable, or, in better cases, it may result in 'one-person care' solutions in which providing bereavement care belongs to one single healthcare operator, thanks to his or her awareness and empathy. The fourth hypothesis gains its validation this way.

5. The fifth hypothesis argued that the management of the perinatal death cases depends on the attitude of the healthcare professionals, resulting in differences of available support for involved families.

The management of adverse outcome perinatal cases has proven to be professionally and personally challenging, as well. When bereavement care is conditioned by the sensitivity of healthcare professionals and thus becomes a 'one-person care' solution, the provided care will only be available when the HCP is on duty, otherwise it will not be available. The support families may receive will, therefore, show recognisable differences. This way the fifth hypothesis can be validated, as well.

6. The sixth hypothesis argued that healthcare professionals do not receive satisfactory communication and psychological formation during their education and continuous trainings to adequately help the related patients, or to elaborate their own feelings of loss and grief.

The interviews with the HCPs have revealed how the lack of practical knowledge, adequate communicative skills and social expectations render case management a professional task where personal efforts and individual solutions must be utilised to find some, not standardised means to support families. Courses regarding bereavement care or self-care are not part of the formative education, it depends on the individual interest and intention of the healthcare professionals to find educative and competency development opportunities. In general, though, what and how to do in cases of perinatal death, beyond the medical tasks, have remained difficult responsibilities without proper guidance. The results of the research have thus confirmed the prior assumptions.

7. The seventh hypothesis made the assumption that the lack of communication and psychological skills influences the previously mentioned factors and strengthen the healthcare professionals' avoidance behaviour patterns.

The management of perinatal death events, especially when no bereavement protocol measures are at hand, are not part of the perinatal professional expectations. The lack of skills and competences in case management and self-care may create difficulties for the

care-providing professionals. The recurring, even singularly demanding situations enhance behaviour patterns of avoidance, moreover, the elaboration of their own feelings of loss and grief has not so far been foreseen among institutional frames. Therefore, avoidance behaviour and escape from loss situations may seem available solutions when the emotional involvement is rather demanding. The assumptions of the seventh hypothesis can be confirmed this way.

8. Finally, the eighth hypothesis established a possible link between the emotional effect of the loss event and the healthcare professionals' private life, presuming that the emotional effect of a perinatal loss event can be identified in the healthcare professionals' private life, as well, with consequences regarding their physical and mental wellbeing.

Figure 5.1 in 5.2 outlined by the primary, deductive coding structure regarding the HCPs' personal experiences have indicated in how many different modes personal experience of perinatal death events can be described in their private life. It affects how they evaluate their own professional competence and behaviour, leaving sensations of incompetence, self-conflict and doubt and making them realise their own fragility. It may create personality changes in self, both positive and negative, furthermore, it penetrates their family life, seeking ventilation opportunities, support. It may also manifest itself in sleepless nights, eating problems, an elevated level of anxiety that accompanies the HCPs home. All these findings indicate that the emotional effect of the perinatal loss event has repercussions outside the working environment, manifesting itself in diverse ways, therefore, the eighth hypothesis can be validated, as well.

### **5.7 Strengths and limitations of the research**

The research activity was always planned to be a qualitative one, focusing on the phenomenon how HCPs in perinatal context experience adverse outcome events. This is the first research in Hungary of this nature, providing also literature, legal and policy – guideline for perinatal bereavement care background to the understanding of the research topic. The applied method, IPA works with the subjective reports of the participants, for which certain conditions, calm and undisturbed meeting opportunity, intimate conversation are required. While it provides a detailed picture of the phenomenon, it cannot offer general, large scale tendencies and prevalences.

Therefore, though professionals with different specialisations were included in the sample, due to the relatively low representation of each field, it is not possible to formulate general statements regarding identified characteristic difficulties of the single professions, neither is it possible to differentiate on the basis of the work experience, competencies or responses to loss for the same reason. Further research, using the findings of the present one, should be implemented, with quantitative and qualitative methods, to investigate these potentially noteworthy and informative aspects.

At the same time, the research was not limited to a single healthcare institution, in both Hungary and Italy the practice of more organisations, on various care levels, could be seen through the reports of the interviewed HCPs, thus an intercultural reference for the analysis could be established. A comparative analysis in this field, with this focus has not been completed before, in which both the participants and the related institutions could be seen together.

The topic of the semi structured interviews was difficult to think and to talk about. Apparently, not everybody was open to the possibility to share personal thoughts or private, or even professional experiences related to loss, recruitment for the interviews was clearly a limitation. The obtained results reflect the subjective statements of the HCPs who were willing to dedicate time and attention to the emotionally demanding questions and demonstrated a high level of awareness regarding perinatal bereavement. Presumably it is only part of a larger, unknown spectrum. A more general and inclusive representation may be achieved via less personal and emotionally less absorbing research methods.

The conversation itself, nevertheless, proved to be an opportunity to ventilate everywhere, to find means to express subjective concerns, emotions and difficulties, demonstrating the importance of staff support for perinatal loss cases. The personal reflections of the participants required openness and trust as much as emotional and psychological involvement. Therefore, it can firmly be claimed that providing a possibility to share experiences in informal or formal organised ways, as a part of guidelines and educational programmes likewise, may bring significant benefits for the healthcare staff both professionally and personally.

## 6 CONCLUSIONS

The main objective of the PhD research has been the study of the emotional involvement, impact and encumber of healthcare professionals when facing perinatal events with adverse outcome, by exploring the underlying practice-related ethical, legal and guideline factors together with the personal psychological challenges.

The analysis of currently applied institutional practices regarding perinatal and intrauterine death events in Hungarian and Italian healthcare organisations could identify the legal measures providing the legal framework of the death events during pregnancy and child-bearing. In both studied realities the same possibilities are available for the families who lose their children in the early periods. Perinatal bereavement care guidelines on a national level are not available in Italy, while institutional protocol measures provide a frame in some healthcare institutes. At the same time, in Hungary a policy formulated in 2010 is waiting to be revised, yet it is still not widely known among the professionals working in perinatal fields. The possibly harmful, negative impact of the adverse outcome events on staff has already been acknowledged, however, the available guidelines do not formulate recommendations for support and self-care. Due to multifactorial differences, in relevant knowledge of legal possibilities, guideline recommendations, theoretical knowledge regarding death and dying, in the recognition of the importance of perinatal bereavement care and in facilities, institutional practice differences can be identified in perinatal or intrauterine infant death, especially in burial and bereavement opportunities. No general PBC frameworks are available in the studied countries, however, good examples and growing awareness of its importance can be identified.

The experience of perinatal and intrauterine death is an emotionally and professionally demanding task for HCPs, with challenges in providing adequate care, being able to say the right words at the right time, moreover, in coping with their own feelings. Especially traumatic experiences (intrapartum death or stillbirth, losing a twin, while the other survives) generate intense professional and psychological requirements. A better case management could be provided with proper skills and competencies development, thus easing the mental and psychological burden. Referential bereavement care team or specialist with defined tasks and responsibilities could potentially ease staff's emotional impact and facilitate care providing.

The institutions with a local protocol for PBC, with the contribution of their own personnel, have adequate support means, whereas where no local protocol or national guidelines are followed, support options are largely limited by the attitude and attention of the HCPs, with important inadequacies. A regional or national framework, which also allows local adjustments on the basis of available facilities, a minimum standard may guarantee optimum care potentials on all levels of healthcare. With organisational support and continuing education opportunities local bereavement care teams, with clearly defined tasks, could enhance the provided care. The identified 'one-person care' examples represent the core of the support. In both countries the lack of organisational responses to support staff, in both formal and informal channels, limits the self-care measures of professionals, they need to find own strategies of elaborations and coping, in adaptive and maladaptive ways, depending on their own personal choices and possibilities. The psychologist's presence at the department may offer help, in the context of a friendlier collegial relationship. Informal discussions between colleagues are limited by the available time and busy schedule.

Personal loss experiences precondition the attitude and the provided support healthcare professionals demonstrate in perinatal death cases, the non-elaborated private grief may negatively impact the required professional behaviour patterns, regardless of working experience, specialisation or nationality. Education programmes in thanatology and individual support solutions may proposition alternative means to resolve the conflict between personal life and professional self-standards. Moreover, personal loss experiences, especially if not elaborated, can be of high influence as a component of personal element in secondary trauma for HCPs. The elements related to professional and personal attitudes mutually affect each other, enhancing each other's effect as well. The experienced secondary trauma will bear more serious consequences regarding higher risks of compassion fatigue and burnout.

On the basis of the research results, international guideline measures, and formative training programmes proposals to a continuing education programme, to future research activities and to national guidelines of minimum standards in perinatal bereavement care regarding the required up to date information, skills and competencies and support for staff could be made, offering alternative ways for personal and professional development and optimum care.

## 7 SUMMARY

How healthcare professionals react to perinatal death events will have a direct impact on the provided care and on their professional and private lives, as well. Yet, it is only recently that international research interest has been directed to the phenomenon. The focus of the doctoral thesis has been on the emotional involvement and professional challenges of healthcare professionals in perinatal context, in Hungary and in Italy, with the aim to explore the underlying practice-related factors with ethical, legal and guideline focus, together with the personal psychological modes, individual solutions and present the results so that they could serve as a starting point for improvement.

To this end the doctoral dissertation has

- (1) presented an overview of the international research activity and achievements in the topic which later can serve as a starting point and reference for future research interest,
  - (2) outlined the presently valid and applicable legal measures and institutional regulations applicable in cases of pre- and perinatal death events with a focus on bereavement options,
  - (3) collected relevant recommendations of national and organisational guidelines, where available, with the focus of support and attention to healthcare professionals' needs in adverse outcome pre- and perinatal events,
  - (4) studied the presently applied institutional practice in the relevant Hungarian and Italian healthcare institutions, comparing the applicable and valid guideline recommendations with the effective support provided to the patients,
  - (5) analysed how the adverse outcome events and losses affect the care-providing personnel, what professional and personal challenges, difficulties they encounter when facing these situations, how they manage to cope with the experienced challenges and emotional involvement,
- and, on the basis of all the findings,
- (6) proposed interventional strategies, an educational programme, guideline focus areas for perinatal bereavement care and staff support, and a further research scheme aimed at providing adequate individual and team development opportunities and support for the involved care-providing personnel.

## 8 ÖSSZEFOGLALÁS

### **A perinatális veszteségek és intrauterin magzati halálozások gyásztámogatása jelenlegi szakmai gyakorlatának, valamint a szakemberekre gyakorolt hatásainak vizsgálata**

Az egészségügyi szakemberek perinatális haláleseteket illető reakciója és eljárás módja közvetlenül érinti a családoknak nyújtott támogatást, valamint hatással van hivatásukra és magánéletükre is. A problémát érintő érdeklődés ugyanakkor meglehetősen új a nemzetközi kutatásokban. A doktori értekezés fókuszában a magyar és olasz perinatális szakemberek szakmai és érzelmi nehézségei állnak, a szakmai gyakorlatot érintő etikai, jogi és szakmai irányelvek, az individuális megfelelési és megküzdési módok vizsgálatával.

A doktori disszertáció

- (1) áttekintést nyújt a releváns, nemzetközi kutatásokról, amely további kutatási tevékenységben kiinduló pontot és referenciát jelenthet,
- (2) felvázolja a pre- és perinatális halálesetekre vonatkozó kegyeleti törvényi és intézményi rendelkezéseket,
- (3) összegyűjti azon országos és intézményi szakmai irányelveket, amely fókuszában a perinatális gyásztámogatás és az érintett szakemberek szakmai és pszichológiai szükségleteinek támogatása áll,
- (4) vizsgálja a jelenlegi magyar és olasz intézményi gyakorlatban megvalósuló eljárás módokat,
- (5) azt elemzi, milyen hatással vannak a pre- és perinatális halálesetek az ellátásban érintett szakemberekre, milyen szakmai és személyes nehézségeket élnek meg, hogyan tudnak megküzdenni a nehézségekkel és az érzelmi érintettséggel, továbbá, a kutatási eredmények alapján,
- (6) intervenciós stratégiákra, továbbképzési programra, a szakemberek támogatását is fókuszba helyező perinatális gyásztámogatási szakmai irányelvekre, valamint további kutatási tervekre tesz javaslatot.

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Conference presentations related to the thesis topic

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**Zsak E.** Workplace Trauma and Loss and Personal Feelings in Perinatal Care (poster)

**11th EAPC World Research Congress 2020** Palermo, Italia, 7-9th Oct, 2020

**Zsák É,** Hegedűs K. Personal grief and professional trauma in perinatal care (poster)

**International Stillbirth Alliance's 11th Annual Conference on Perinatal Mortality and Bereavement Care** Madrid, Spain, 4-6th Oct, 2019

**Zsak E.** Dealing with secondary trauma and loss - personal and professional difficulties for caregivers (poster)

**2nd International Summit on Screening, Detection, and Assessment Tools for Maltreated Children,** Emili Sagol Creative Arts Therapies Research Center and the Sagol Research and Therapy Laboratory for Children at Risk, University of Haifa, Haifa, Israel, 4-6th Aug, 2019

**Zsak E.** Dealing with secondary trauma and loss - personal and professional difficulties for caregivers (oral presentation)

**16th Hawai'i International Trauma Summit Preventing Assessing And Treating Trauma Across The Lifespan** IVAT Honolulu, Hawaii, USA, 23-26th Apr, 2019

**Zsak E.** Supporting chronic trauma in perinatal loss and grief (poster)

**6th Annual Scientific Conference Of The European Association Of Psychosomatic Medicine EAPM Innovative And Integrated Approaches To Promote Mental And Physical Health** Verona, Italia, 27th-30th, June 2018

**Zsak E.** Supporting Hungarian Health Care Operators In Perinatal Loss And Grief (oral presentation)

**3rd ICPCN Conference: Inspiration, Innovation, Integration** Durban, South Africa, 30th May-2nd June 2018

**Zsak E.** Professional and psychological challenges of perinatal bereavement in Hungary (oral presentation)

**Magyar Hospice-Palliatív Egyesület XIII. Országos Kongresszusa**, Eger, 10-12th May 2018

1. **Zsák É.**, Geiszbühl-Szimon P. Emlékezési módok a perinatális veszteségben
2. **Geiszbühl-Szimon P.**, **Zsák É.** Nehézségek sodrában – az asszisztált reprodukciós eljárás folyamatának kihívásai a veszteségek tükrében (oral presentations)

**PhD Scientific Meeting 2018, PhD Scientific Days, School of PhD Studies, Semmelweis University**, Budapest, 19-20th Apr 2018

**Zsák É.**, Hegedűs K. Ways of remembering in perinatal loss – approaches and tendencies in Hungarian and Italian institutions (poster)

**Identity Agonies Congress Università degli Studi di Padova FISPPA** Padova, Italia, 3-4th Nov 2017

**Zsak E.** Professional and personal challenges and difficulties of the Hungarian medical/healthcare staff when facing pre- and perinatal infant death/ Le sfide e difficoltà professionali e personali degli operatori sanitari nei casi di morti pre- e perinatali (oral presentation)

**Magyar Pszichoszomatikus Szülészeti és Nőgyógyászati Társaság X. Kongresszusa** Székesfehérvár, 22-23rd Sept 2017

**Zsák É.** Communication dilemmas in pre- and perinatal care (oral presentation)

**15th World Congress of the European Association of Palliative Care**, Madrid, Spain, 18-20th May 2017

**Zsák É.**, Hegedűs K. Perspectives and Challenges of Perinatal Hospice Care in Hungary (poster)

**PhD Scientific Meeting 2017, PhD Scientific Days, School of PhD Studies, Semmelweis University**, Budapest, 11-12th Apr 2017

**Zsák É.**, Hegedűs K. Legislative and protocol measures in perinatal mortality and their applications in Hungarian institutions (oral presentation)

**17th World Congress of the Academy of Human Reproduction**, Roma, Italia, 15-18th March 2017

**Zsak E.** Professional and personal challenges and difficulties of the medical/healthcare staff in Hungary regarding pre- and perinatal infant death (oral presentation)

**Magyar Pszichoszomatikus Szülészeti és Nőgyógyászati Társaság IX. Kongresszusa** Szeged, 28-29th Oct 2016

**Zsák É.** Veszteségélmények és a belőlük fakadó pszichés és szakmai nehézségek a pre- és perinatális ellátásban (oral presentation)

**Összhang Közhasznú Egyesület, Születés Hete, Eger, 21-28th May 2016**

**Zsák É.** A ti veszteségeitek nekem is fáj – Gyász, krízis és trauma a pre- és perinatális ellátásban (oral presentation)

**18th ISPOG Congress, International Society of Psychosomatic Obstetrics and Gynaecology, Malaga, Spain, 12-14th May 2016**

**Zsak E.** Analysis of the effects of perinatal and intrauterine infant death on medical/health care professionals (oral presentation)

**Magyar Hospice-Palliatív Egyesület XII. Országos Kongresszusa, Kecskemét, 5-7th May 2016**

**Zsák É, Hegedűs K.** A perinatális és intrauterin magzati halálozások aktuális gyakorlatának jellemzői és szakemberekre gyakorolt hatásaik (oral presentation)

**PhD Scientific Meeting 2016, PhD Scientific Days, School of PhD Studies, Semmelweis University, Budapest, 7-8<sup>th</sup> Apr 2016**

**Zsák É, Hegedűs K.** Analysis of the Currently Applied Practices of Perinatal and Intrauterine Death and Their Effects on Health Care Professionals (poster)

**Magyar Pre- és Perinatális Pszichológiai és Orvostudományi Társaság XIII. Kongresszusa, Budapest, 12-13th Feb 2016**

**Zsák É.** A perinatális és intrauterin magzati halálozások jelenlegi alkalmazott gyakorlatának jellemzői és a szakemberekre gyakorolt hatásaiknak vizsgálata (oral presentation)

## 11 ACKNOWLEDGEMENTS

First and foremost, I would like to say thank you to my supervisor, Prof. Katalin Hegedűs for all that professional and personal support and attention with which she has accompanied my work. I am truly grateful for her trust in me, for all the opportunities and for our common work we have shared during the past years. Her dedication, academic and personal stance are and will always be an outstanding example for me.

I am thankful to the directors of the institute, Prof. Ferenc Túry, Prof. József Kovács and Prof. György Purebl for all their support. I would like to say thank you to the whole community of the Institute of Behavioural Sciences, for all their kindness, their interest and their support to my PhD studies.

A big thank you to all the members of the PhD research group, to Enikő Földesi, to Dr. Orsolya Horváth, to Dr. Adrienne Pálfiné Kegye and to Diána Sipócz for their constant help, advice and for their most valuable friendship.

I am sincerely grateful and thankful to Prof. Antonio Imbasciati, to Prof. Loredana Cena and to all the members of the Osservatorio di Psicologia Clinica Perinatale of the Università degli Studi di Brescia for the opportunities, for their kind hospitality, help and for the discussions, without which the doctoral thesis could not have taken this form. It is a privilege for me to be part of your activities.

I would like to express my most heartfelt thank you to Dr. Zsuzsanna Kovácsné Török, who has been a reference for me during all these years. Her guidance and support have been deeply appreciated and of great importance to me.

I owe words of gratitude to Prof. Ines Testoni at the Dipartimento di Filosofia, Sociologia, Pedagogia e Psicologia Applicata of the Università degli Studi di Padova for all her trust and for all the common work. Her dedication and passion has opened me horizons.

I would like to sincerely say thank you to all the healthcare professionals participating in the research who have shared their thoughts and feelings with me, thus contributing to the final outcome to a great deal. I am grateful for your honesty and for all your kind help.

To all my family goes my most heartfelt gratitude for all their love and support through which I have arrived to this significant milestone in my life.

The financial support of the *EFOP-3.6.3-VEKOP-16-2017-00009 „Az orvos-, egészségtudományi- és gyógyszerész képzés tudományos műhelyeinek fejlesztése”* project has meant significant help in my PhD studies as a predoctoral fellow, I am truly grateful for it.

Last, but not least, I would like to thank Andrea Finazzi for all the inspiration, for his encouragement and for believing in me.

*In loving memory of my little son, Péter.*

## APPENDIX

## Appendix 1. Perinatal post-mortem examination certificate

(Source: Erzsébet Hospital of Jászberény)

2. sz. melléklet

## Perinatális halottvizsgálati bizonyítvány C. 3110-52/V/új

Az adatszolgáltatás a statisztikáról szóló 1993. évi XLVI. törvény 10. §-a alapján kötelező!

II. ANYAKÖNYVI PÉLDÁNY

## PERINATÁLIS HALOTTVIZSGÁLATI BIZONYÍTVÁNY

Anyakönyvi azonosító		Folyószám		Az anyakönyvvezető tölti ki!	
1. Az elhalt családi és utóneve:		3. Anyja neve:			
2. Születés helye:		4. Neme: fiú (1) - leány (2), születési időpontja: év   hó   nap   óra   perc			
5. A hozzátartozó (temetési intéző) neve:		6. Lakcíme, irányítószáma:		7. Közelebbi megjelölése:	
8. A halálhöz helye:		9. Időpontja: év   hó   nap		10. Közelebbi megjelölése:	
11. A kezelőorvos neve:		12. Beosztása és munkahelye (rendelője, osztálya) címe:			
13. A halottvizsgálatot végző orvos neve:		14. Beosztása és munkahelye (rendelője, osztálya) címe:			
15. Kórbonctani vizsgálatot: nem tart szükségesnek - szükségesnek tart - hatósági eljárást tart szükségesnek (A kívánt válasz aláhúzendő!)					
16. A vizsgálat (eljárás) indoka és egyéb megjegyzések:					
17. A kiállítás kelte: év   hó   nap		a halottvizsgálatot végző orvos aláírása			P. H.
18. A halottasházba szállítás időpontja: év   hó   nap		19. Az eltemetésre engedélyezett idő: év   hó   nap			
20. A rendőrhatalósági szemlebizottság, az egészségügyi igazgatási szerv megjegyzése:					
21. A halál okát megállapító kórboncnak, igazságügyi orvos szakértő, illetve az elhalálozás helye szerinti illetékes egészségügyi igazgatási szerv tölti ki!		Boncolás után elhamvasztható. Boncolás után nem hamvasztható el. (A kívánt válasz aláhúzendő!)		P. H. _____ aláírás	

C. 3110-52/V/új r. sz. - Patria Nyomda Zrt. - (Tsz. 5-2923)

## Appendix 2. Interview template in Hungarian

Semmelweis Egyetem, Budapest  
Általános Orvostudományi Kar  
Mentális Egészségtudományok Doktori Program  
Magatartástudományi Intézet

### *A perinatális veszteségek és intrauterin magzati halálozások aktuális szakmai gyakorlatának, valamint a szakemberekre gyakorolt hatásainak vizsgálata*

#### Félig-strukturált interjú

##### 1. rész: Adatok

1. Név:
2. Életkor:
3. Képesítés, végzettség:
4. Intézmény:
5. Családi állapot:
6. Gyermek száma:

##### 2. rész: Szakmai tapasztalat

1. Mióta dolgozik ezen a területen?
2. Évente kb. hány beteget lát el?
3. Hivatásában előfordult már pre- és/vagy perinatális veszteség?
4. Ha igen, ezekből Ön mennyit látott el?
5. Hogyan szokott ilyen esetekben eljárni? Milyen szakmai ajánlást követ?
6. Mindig követi a szakmai ajánlást?
7. Az Ön intézménye rendelkezik saját, a pre- és perinatális veszteségekre vonatkozó szakmai ajánlással? (Ellátási, kegyeleti eljárás)

##### 3. rész: Szakmai készségek, képességek

1. A szakképzés során részt vett olyan kurzuson, ahol valamilyen módon foglalkoztak a pre- és perinatális veszteség problémakörével? Ha igen, milyen módon és mennyi ideig?
2. A kurzuson elsajátított információkat és készségeket tudja hasznosítani a hivatásában?
3. Ha nem, hogyan jut olyan információkhoz, megoldásokhoz, amelyek segítik a munkáját egy-egy ilyen esetben?
4. Pre- és perinatális veszteség esetén hogyan segítik a betegeket az Ön intézményében, és Ön milyen módon vesz ebben részt? Létezik Önöknél bármilyen kiegészítő segítség a veszteséget elszenvedők felé?
5. A pre- és perinatális veszteség ellátásában közreműködő kollégákkal jól tudnak együttműködni?

6. Ön szeretne-e másként tenni valamit a pre- és perinatális veszteségek ellátásában?

4. rész: Személyes élmények, tapasztalatok

1. Egy-egy pre- és perinatális veszteség milyen érzéseket vált ki Önből? Általában gyakran gondol arra, ami történt?
2. Idővel visszatekintve egy-egy veszteségre, milyen érzések, gondolatok merülnek fel Önben?
3. Milyen támogatást, segítséget vesz igénybe egy-egy veszteségélmény után, azért, hogy a saját elvárásainak megfelelően tudjon a hivatásában helytállni?
4. A megélt élmények bármilyen módon befolyásolják a magánéletét? Okoznak bármiféle problémát?
5. Hasznosnak tartana bármilyen külső segítséget azért, hogy jobban tudja a pre- és perinatális veszteségekhez kapcsolódó élményeit feldolgozni és hatékonyabban tudjon segíteni (pszichológus, kommunikációs stratégiák, specializáció)?

### **Appendix 3. Interview template in Italian**

Università Semmelweis, Budapest  
Facoltà di Medicina  
Scuola di Dottorato delle Scienze della Salute Mentale  
Istituto delle Scienze Comportamentali  
Eva Zsak

#### *Le analisi delle pratiche istituzionali attuali delle perdite perinatali e della morte intrauterina, e delle loro influenze sugli operatori sanitari*

#### **Intervista semi-strutturata**

##### 1° parte: Dati anagrafici

7. Nome:
8. Etá:
9. Qualificazione:
10. Istituto:
11. Stato familiare:
12. Numero di figli:

##### 2° parte: Esperienze lavorative

8. Da quando lavora in questa specializzazione?
9. Il numero dei suoi pazienti/anno?
10. Nella Sua prassi é già successa una perdita pre- o perinatale?
11. Se sí, quanti casi ne ha visti Lei?
12. Che cosa fa di solito in questi casi? Quale protocollo segue?
13. Segue sempre le linee guida?
14. Nel Suo istituto esistono le linee guida per queste perdite? (Procedimenti, sepoltura)

##### 3° parte: Competenze professionali

7. Durante la Sua formazione professionale, i Suoi studi Lei ha partecipato ad un corso in cui hanno parlato in qualche modo di questo problema? Se sí, in che modo e per quanto tempo?
8. Riesce ad applicare le informazioni e competenze studiate al corso?
9. Se no, dove riesce a trovare delle informazioni, pratiche per risolvere un tale caso?
10. Come sono seguiti i pazienti nel Suo istituto e Lei come fa parte di questa attività? Esistono da Voi le cure supplementari per la perdita pre- e perinatale?
11. Con le professioni coinvolte nella Vostra attività avete della buona collaborazione?

12. Lei cosa vuole fare in un altro modo per quanto riguarda le perdite pre- e perinatali?

4° parte: Effetti personali

6. Una perdita pre- o perinatale che emozioni provoca in Lei? Di solito pensa spesso a quello che é accaduto?
7. In retrospettiva Lei che emozioni, sentimenti prova pensando a queste perdite?
8. Che tipo di sostegno, aiuto trova Lei per Se stesso dopo una perdita pre- e perinatale perché possa continuare a lavorare secondo le proprie aspettative?
9. Le Sue reazioni personali hanno qualche effetto sulla Sua vita privata? Le causano dei problemi?
10. Lei vorrebbe ricevere qualche aiuto esterno per poter gestire meglio queste situazioni (sostegno psicologico, strategie di comunicazione, corso di specializzazione)?

## Appendix 4. Primary, deductive coding structure

<b>PRIMARY DEDUCTIVE NODES PD1</b>	PD1.1 Loss events in numbers	PD1.1.1 Number of losses a year			
		PD1.1.2 Number of losses total			
		PD1.1.3 Number of patients a year			
		PD1.1.4 Numbers as I see it			
	PD1.2 Personal experiences	PD1.2.1 Fragility			
		PD1.2.2 Changes in self			PD1.2.2.1 Control
					PD1.2.2.2 Personal development process
					PD1.2.2.3 Personal responses to loss
					PD1.2.2.4 Transformation
		PD1.2.3 Effects on private life			PD1.2.3.1 Adverse effects
					PD1.2.3.2 Emotional involvement
					PD1.2.3.3 Increased sensitivity
					PD1.2.3.4 Keeping balance
					PD1.2.3.5 No effect
					PD1.2.3.6 Self control
					PD1.2.3.7 Taking the loss event home
		PD1.2.4 Emotions, feelings			PD1.2.4.1 Feelings of grief
					PD1.2.4.2 Feelings regarding professional competence
					PD1.2.4.3 How to render a child's death
					PD1.2.4.4 Recurring thoughts, feelings
PD1.2.4.5 Some cases hit harder than others					
PD1.2.4.6 The difficulty of the loss event					
PD1.2.5 Problems	PD1.2.5.1 Doubt				

		with self	PD1.2.5.2 Guilt		
			PD1.2.5.3 Self conflict		
		PD1.2.6 Support solutions	PD1.2.6.1 Help at home		
			PD1.2.6.2 Individual solutions		
			PD1.2.6.3 Informal help from colleagues		
			PD1.2.6.4 No formal, institutional support		
			PD1.2.6.5 Private therapy		
	PD1.3 Present institutional practice	PD1.3.1 Guidelines and protocols			
		PD1.3.2 Particular features of institutional procedures	PD1.3.2.1 Individual case management		
			PD1.3.2.2 Memory making possibilities		
			PD1.3.2.3 No adequate attention		
			PD1.3.2.4 No dedicated ward or unit		
			PD1.3.2.5 'One-person' care		
			PD1.3.2.6 Protocol with staff involvement		
			PD1.3.2.7 Role of personnel defined		
			PD1.3.2.8 Special initiatives for PBC		
			PD1.3.2.9 Staff support (informal)		
			PD1.3.2.10 Support for family		
		PD1.3.3 Present way of help in perinatal loss			
		PD1.3.4 Present way of help in prenatal loss			
PD1.3.5 What happens after the department					
PD1.4 Professional experience	PD1.4.1 Years of practice				
	PD1.4.2 Collaboration with	PD1.4.2.1 Negative collaboration			

		colleagues	PD1.4.2.1 Positive collaboration	
			PD1.4.2.3 Potentials of collaboration	
		PD1.4.3 Professional difficulties	PD1.4.3.1 Accepting the death of a child	
			PD1.4.3.2 Chronic traumatic event	
			PD1.4.3.3 Different attitudes among staff	
			PD1.4.3.4 Emotionally demanding situation	
			PD1.4.3.5 Failure to manage own feelings	
			PD1.4.3.6 Fear	
			PD1.4.3.7 Incompetence	
			PD1.4.3.8 Lack of skills and competences	
			PD1.4.3.9 Sad tasks	
			PD1.4.3.10 Specially difficult cases	
		PD1.4.4 Required changes	PD1.4.4.1 Changes in attitudes	
			PD1.4.4.2 Formal support for the team	
	PD1.4.4.3 Individual support solutions in work context			
	PD1.4.4.4 Need for local protocol			
	PD1.4.4.5 Profound knowledge of BC			
	PD1.5 Skills and competencies	PD1.5.1 Empathy		
		PD1.5.2 Practical help		
		PD1.5.3 Satisfaction		
PD1.5.4 Sensibility				
PD1.5.5 Previous formation in pre- and perinatal loss		PD1.5.5.1 Basic formation		
		PD1.5.5.2 Books on grief		
		PD1.5.5.3 Continuing		

			education courses		
			PD1.5.5.4 Specifically dedicated material		
		PD1.5.6 Social expectations	PD1.5.6.1 Expectations regarding professional behaviour		
			PD1.5.6.2 Expectations regarding loss and grief		
		PD1.5.7 Training needs	PD1.5.7.1 Code of conduct		
			PD1.5.7.2 Elaboration of experiences		
	PD1.5.7.3 Skills, competencies to learn				
	PD1.6 Support and coping for HCPs	PD1.6.1 Coping and defensive means	PD.1.6.1.1 Adaptive coping strategies		PD1.6.1.1.1 Acquiring new knowledge in the field
					PD1.6.1.1.2 Elaborating feelings related to loss
					PD1.6.1.1.3 Finding a positive way to contrast, to keep the balance
PD1.6.1.1.4 Finding an explanation					
PD1.6.1.1.5 Individual therapy					
PD1.6.1.1.6 Involvement in a professional society's work					
PD1.6.1.1.7 Keeping a diary					
PD1.6.1.1.8 Physical activity					
PD1.6.1.1.9 Reinterpreting one's professional role and self					

			PD1.6.1.1.10 Self-awareness	
			Self-control, balance	
			PD1.6.1.1.12 Sharing experience	
			PD1.6.1.1.13 Taking preventive measures	
			PD1.6.1.1.14 Using time, experience	
		PD.1.6.1.2 Maladaptive or avoidant strategies	PD1.6.1.2.1 Excluding emotions	
			PD1.6.2.2 Keeping oneself busy	
			PD1.6.2.3 Self- soothing habits	
		PD1.6.2 Existing organisational support	PD1.6.2.1 At home, within family	
			PD1.6.2.2 Experience	
	PD1.6.2.3 Individual, private support			
	PD1.6.2.4 Informal support between colleagues			
	PD1.6.2.5 No formal, institutionally organised support			
	PD1.6.2.6 Occasional professional help from the psychologist			
	PD1.6.3 Required help and support	PD1.6.3.1 Continuing education options		
		PD1.6.3.2 Grief elaboration possibilities		
		PD1.6.3.3 Group support		
		PD1.6.3.4 Guiding protocols		
PD1.6.3.5 Individual support				
PD1.6.3.6 Reference team or				

			person		
	PD1.7 Training and structural needs for best care	PD1.7.1 Specific courses			
		PD1.7.2 Specific needs for optimum care	PD1.7.2.1 Attention and empathy		
			PD1.7.2.2 Facilities		
			PD1.7.2.3 Knowledge		
		PD1.7.2.4 Staff			

## Appendix 5. Secondary, inductive coding structure

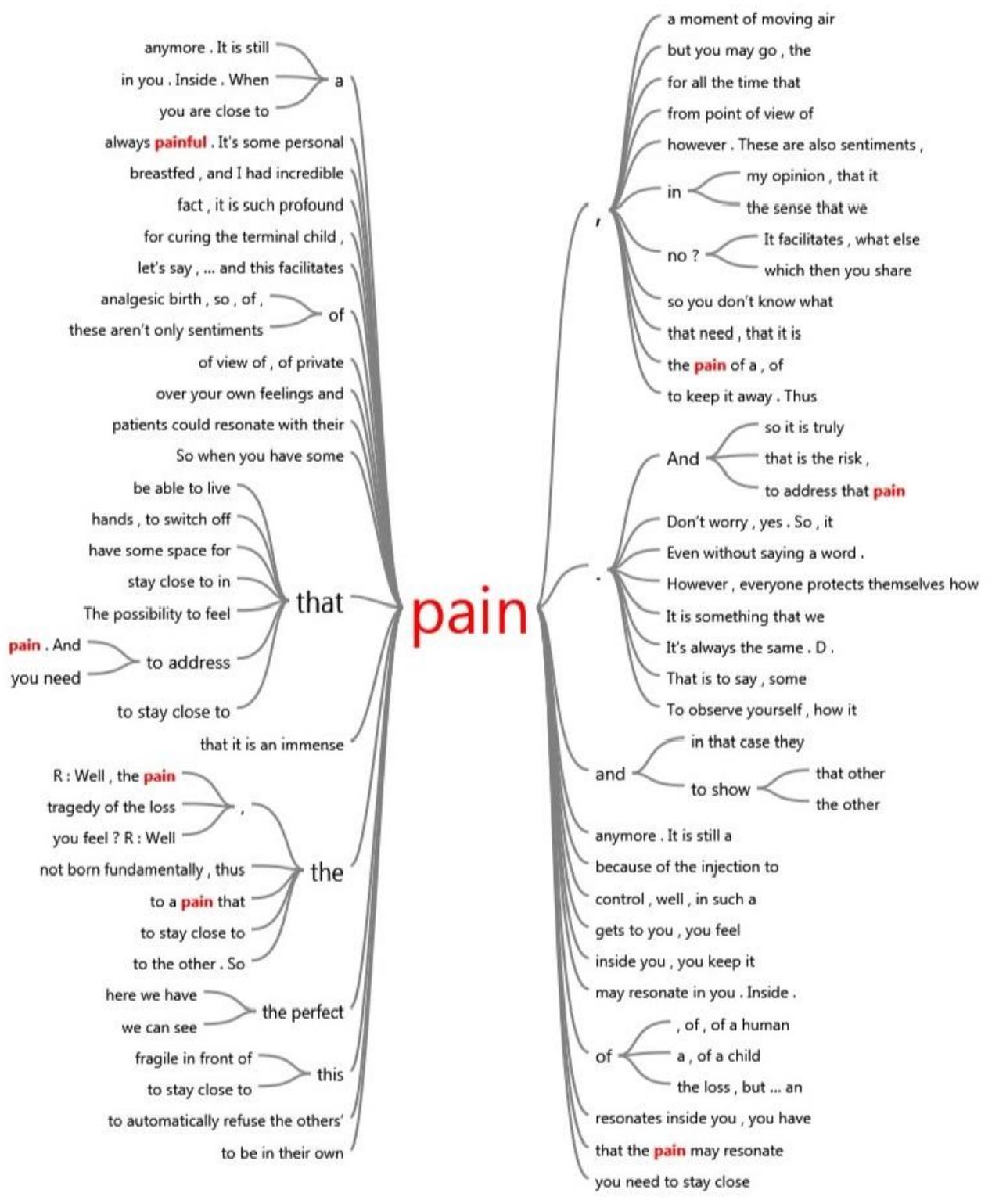
<b>SECONDARY, INDUCTIVE NODES SI1 - Conceptual framework of chronic professional loss experiences</b>	SI1.1 Perinatal death	SI1.1.1 Death - existential dilemma			
		SI1.1.2 Grief definition			
		SI1.1.3 Bereavement			
		SI1.1.4 Perinatal death events in words			
	SI1.2 Cognitive elements	SI1.2.1 Association			
		SI1.2.2 Dissociation			
		SI1.2.3 Explaining the incomprehensible	SI1.2.3.1 Expressions regarding perinatal death events		
			SI1.2.3.2 Reasoning		
			SI1.2.3.3 Verbal frames regarding loss situations		
			SI1.2.3.4 Why		
		SI1.2.4 Lack	SI1.2.4.1 Lack of new knowledge		
			SI1.2.4.2 Lack of openness		
			SI1.2.4.3 Lack of opportunity		
			SI1.2.4.4 Lack of recognition, awareness		
			SI1.2.4.5 Lack of skills, competences		
			SI1.2.4.6 Lack of support, supervision		
	SI1.2.4.7 Lack of time				
	SI1.2.4.8 Lack of tools, guidelines				
	SI1.3 Emotive elements	Open door and window SI1.3.1			
		SI1.3.2 Physical problems			
SI1.3.3 Tiredness					
SI1.3.4 Escape		SI1.3.4.1 Avoidance			
		SI1.3.4.2 Escape			
SI1.3.5 Fear					
SI1.3.6 Loss	SI1.3.6.1 Loss of a new life				
	SI1.3.6.2 Loss of faith				

			SI1.3.6.3 Loss of innocence
			SI1.3.6.4 Own loss experience
		SI1.3.7 Pain	SI1.3.7.1 Pain
			SI1.3.7.2 Pain of a dead child
			SI1.3.7.3 Perfect pain
			SI1.3.7.4 Suffering
		SI1.3.8 Wall	SI1.3.8.1 Resistance to new attitudes
			SI1.3.8.2 Self protection
	SI1.4 Own, personal loss experiences	SI1.4.1 Own loss experience	
		SI1.4.2 References to effect of previous loss experiences of colleagues	
	SI1.5 Functional behaviour patterns	SI1.5.1 Actions we do	SI1.5.1.1 Care and accompaniment
			SI1.5.1.2 Presence
			SI1.5.1.3 What I do in case of perinatal death
SI1.5.1.4 What others do in case of perinatal death			
SI1.5.2 Communication in loss situations		SI1.5.2.1 Communicative skills	
		SI1.5.2.2 How to say	
	SI1.5.2.3 What I say		

**Appendix 6. The result of word frequency analysis in tree structure for the node  
SI1.2.3.3 Verbal frames regarding loss situations**

always	difficult	find	seen	absolut	bad	comple	happene	like	painful	person	see	truly	asked	decor	brutal	coll	deal	die	etc	finger	goes	grief	happ	heart	
																									demanding
child	experience	place	time	back	come	happene	like	must	people	remain	situat	danothe	anyway	baby	breast	close	dead	devast	enough	fairly	give	howe	just	luckily	man

Appendix 7. Word-tree structure of PAIN (SI1.3.7) (context and combinations)



## Appendix 8. Perinatal Bereavement Care In Everyday Practice – A continuing education programme plan

<b>PERINATAL BEREAVEMENT CARE IN EVERYDAY PRACTICE – A continuing education programme plan</b>				
	<b>Title</b>	<b>Objectives, competencies</b>	<b>Time</b>	<b>Workform</b>
Part 1	<b>Introduction</b>	<ul style="list-style-type: none"> <li>➤ Objectives of the education programme</li> <li>➤ Schedule</li> <li>➤ Practicalities</li> <li>➤ Trainers</li> <li>➤ Participants</li> </ul>	30'	presentation  pair and groupwork
Part 2	<b>Perinatal mortality numbers and causes</b>	<ul style="list-style-type: none"> <li>➤ Provide an overview of perinatal mortality</li> <li>➤ Know the applied definitions of perinatal mortality</li> <li>➤ Understand the underlying epidemiology</li> <li>➤ Postmortem examination</li> </ul>	30'	presentation and short discussion, Q&A
Part 3	<b>Psychological and social aspects of adverse outcome perinatal events</b>	<ul style="list-style-type: none"> <li>➤ Provide the best possible psychological and social support in perinatal bereavement</li> <li>➤ Understand the importance of respectful care</li> <li>➤ Recognise the possibilities of bereavement support</li> <li>➤ Understand the effect on HCPs and the importance of support for them</li> </ul>	30'	presentation and short discussion, Q&A
Part 4	<b>Guideline recommendations for bereavement care</b>	<ul style="list-style-type: none"> <li>➤ Provide an overview of different recommendations</li> <li>➤ Understand the importance of framework options for optimum care</li> <li>➤ Recognise local possibilities and resources</li> <li>➤ Identify improvement options</li> </ul>	30'	presentation and short discussion, Q&A
Part 5	<b>Communication in perinatal loss events</b>	<ul style="list-style-type: none"> <li>➤ Compassionate communication principles</li> <li>➤ Outline relevant information</li> <li>➤ Identify elements of compassionate care when delivering bad news</li> <li>➤ Attention to settings, behaviour patterns, metacommunication</li> </ul>	30'	presentation  pairwork
Part 6	<b>Bereavement care solutions</b>	<ul style="list-style-type: none"> <li>➤ Provide an overview of relevant legal measures</li> <li>➤ Understand possibilities of bereavement procedures</li> <li>➤ Identify potentials of institutional bereavement care</li> <li>➤ Recognise the importance of parenting, of creating memories</li> <li>➤ Understand the effect of proper</li> </ul>	30'	presentation and short discussion, Q&A

		bereavement care and staff satisfaction		
Part 7	<b>Art therapy for coping</b>	<ul style="list-style-type: none"> <li>➤ Discover alternative ways to express own feelings and thoughts regarding important professionally experienced losses</li> <li>➤ Learn positive coping strategies to ease emotional burden in chronic trauma</li> </ul>	60'	<p>short presentation</p> <p>individual work evaluation and discussion</p>
Part 8	<b>Assessment and evaluation</b>	<ul style="list-style-type: none"> <li>➤ Provide an overview of the education programme</li> <li>➤ Individual evaluation</li> <li>➤ 'Take home' messages</li> </ul>	30'	evaluation and discussion, comments, Q&A