Analysis of the Currently Applied Practices Regarding Perinatal and Intrauterine Death Events and of their Effects on Healthcare Professionals

PhD thesis

Éva Zsák

Mental Health Sciences Doctoral School

Semmelweis University

Supervisor: Katalin Hegedűs, PhD

Official reviewers: Rachel Lev-Wiesel, PhD
Klára Horváth, MD, PhD

Head of the Complex Examination Committee: Beáta Pethesné Dávid, PhD

Members of the Complex Examination Committee:
Katalin Barabás, MD, PhD
Miklós Garami, MD, PhD
Péter Szeverényi, MD, PhD

Budapest
2021

1. INTRODUCTION

The analysis of the loss and grief experiences of healthcare professionals including the study of coping strategies and competencies to cope with work related loss events is a relatively new field of research at international and Hungarian levels, too. Although literature reviews and research studies on loss and grief have been produced extensively, assessments of the effect of loss and mourning on medical staff have seemingly been rather ignored so far, even though traumatic, adverse outcome events influence their professional and personal attitudes as well. This problem is all the more significant if one considers the fact that grief and trauma caused by perinatal loss, if not assisted and confronted properly, may easily develop into a phenomenon of complicated grief. As such, it represents an increased burden for the affected families, their immediate environment and also for the professional staff helping them. Yet this phenomenon remains an underrepresented field in analytical studies.

The above-mentioned complex issue deserves greater attention, which should result in the establishment of dynamic, up-to-date support programmes on all professional levels. The personal and professional challenges experienced by healthcare personnel when facing perinatal loss have only been acknowledged recently. The majority of the relatively few scientific publications in the field 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.

Perinatal loss in figures

On the basis of the available data it is well worth looking at the single numbers of the different loss events connected to the whole perinatal period, as indicated in the infogram below, to see how many families and through them, in connection with them, wavelike, a multitude of other people in their surroundings must face the difficulties of loss and grief.

Figure 1 **UNICEF, KSH data for Hungary (2019)**

Even ethical and sepulchral problems may arise at the loss of infants who die in the womb or are stillborn. Moreover, the impact of the loss events may take its toll on the personal lives of the healthcare specialists. The objective, therefore, is to systematically explore the influence of adverse outcome perinatal events on healthcare professionals affected by pre- and perinatal loss. The research aim has been to explore the potentially 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.

Ethical dilemmas

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. The ethical dilemmas of the pre- and perinatal periods include genetic screening, malformations, termination of pregnancy, the conditions of premature babies as well as curative treatment vs palliative care options. The generally applicable questions are related to the special moral status of the child to be born and the dilemmas of parental authority. The objective of perinatal palliative care is to find individually tailored solutions by understanding specific conditions and circumstances. All this can be the result of a high level, synchronised and outstanding professional and personal medical activity, which, at the same time involves an increased demand of professional and ethical responsibility in everyday practice, which may be defined as moral distress.

Legislative measures and guidelines for perinatal bereavement

Regarding sepulchral options and bereavement procedures, the conditions are largely defined by cohesive legislative measures in the studied countries. As for institutional regulations, in general, the situation is characterised by the option for the individual institutes to design their own regulations and proceedings within the limits of the national legislative frame.

The different, available national and organisational guidelines for perinatal bereavement care 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. 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 also be accentuated.

2. OBJECTIVES

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.

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.

The research material is a reflection of the personal narratives of the interviewees regarding experienced perinatal loss events. While the applied 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.

Hypotheses

To complete the research I formulated the following 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.

3. METHODS

Interpretative phenomenological analysis - IPA

Interpretative phenomenological analysis (IPA) is an approach to qualitative, experiential inquiry, used in psychology, human, social and health sciences. 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.

NVivo 12 Pro

To realize the study and the analytical steps the *NVivo 12 Pro* software was chosen, allowing thus the accomplishment of several research tasks, moreover, the whole research project can be carried out by using the programme. Thus it became 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 facilitated connection of the ideas and reflection on the results. The units of analysis, the core structural elements in the programme are *cases*, regarded as a specific instance of a selected phenomenon in correlation with anthropological and sociological literature. Attribute values (e.g. demographic and numeric data) were connected to each case, and classify the cases.

Research design, sampling, data analysis

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.

Research data was collected from individual interviews between Sept 2016 and Nov 2019 in Hungarian and Italian healthcare institutions. 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 semi structured 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. While the Hungarian healthcare context remained the main focus of the research, the Italian sample provided a background for an intercultural interpretation, too.

The final number of interviews included in the thesis is 18. Out of the total, 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).

Template analysis was employed, with deductive and inductive approaches. The interview questions and the structure of the interview allowed developing a preliminary deductive code framework *a priori*, establishing nodes and coordinating major themes contemporarily. The primary coding arch covers a spectrum of the professional experiences of adverse outcome perinatal events to personal feelings and private life interferences.

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. From the secondary, inductive analysis, through abstraction and de-contextualisation, a concept framework of the studied phenomenon emerged as a result.

4. RESULTS

Primary, deductive coding

The primary, deductive coding structure 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 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.

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 in the following 7 principal parent nodes: *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.

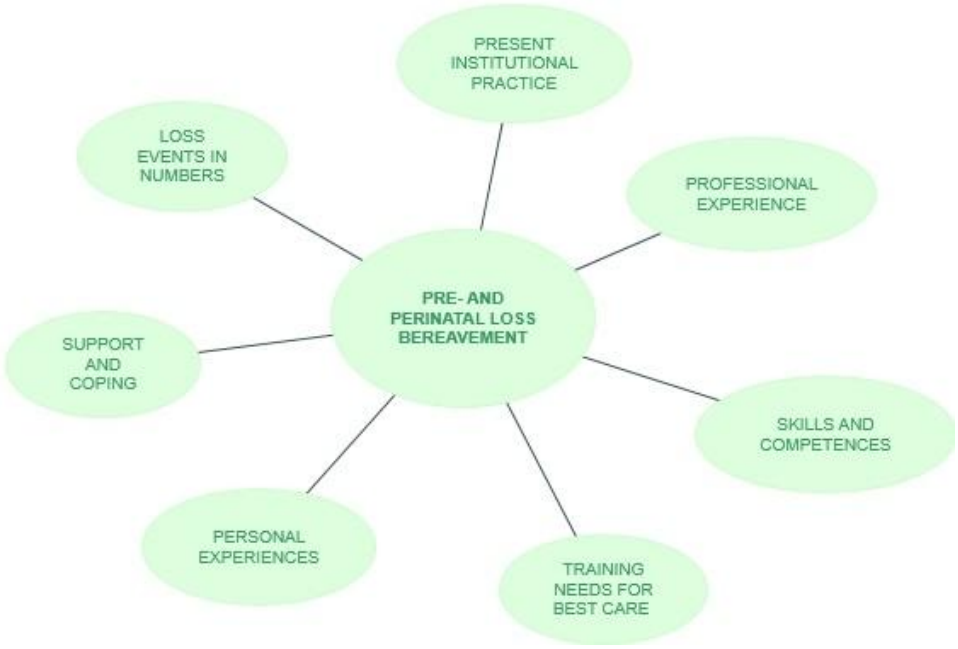

Figure 2. Deductive coding structure of the analysis

Secondary, inductive coding

The secondary, inductive code tree (SI1) emerged through a 'bottom-up' structuring from the hierarchy of the dynamically changing nodes, providing the concept framework to chronic professional loss experiences. 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. 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 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.

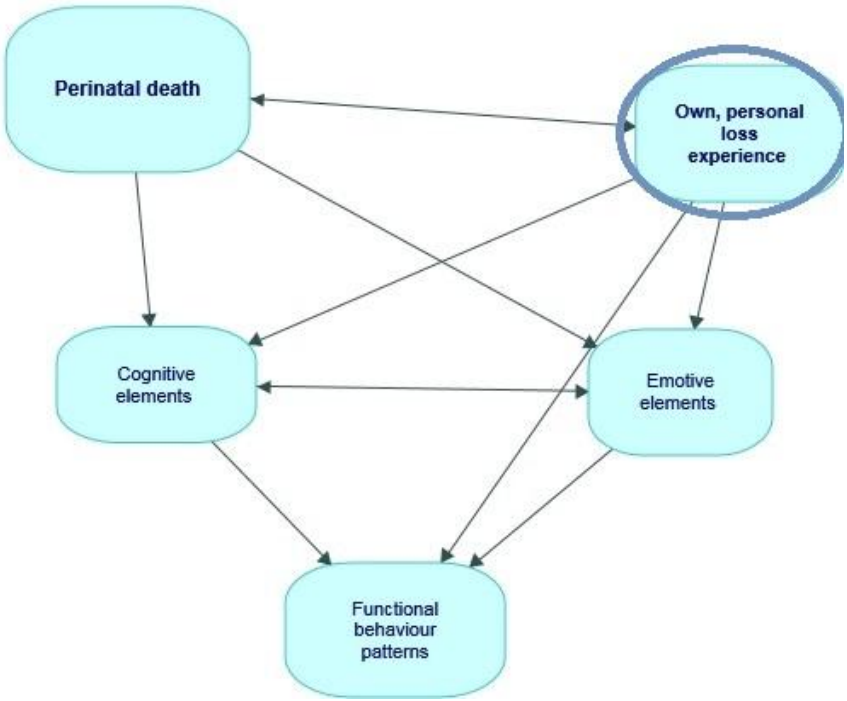

Figure 3. Conceptual framework of chronic professional loss experiences

Proposals for future education, research and policy making solutions

The research 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. On the basis of the findings, it is possible 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.

The overall objective of the proposed **Perinatal Bereavement Care In Everyday Practice** continuing education programme 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 planned 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.

Further research, using the findings of the present one, should be implemented, with quantitative and qualitative methods, to investigate the potential prospective aspects of the PhD research.

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. With the renewal and update of the currently available guidelines from 2010 national perinatal bereavement care minimum standard recommendations should propose measures regarding care characteristics and tasks, local, institutional facilities for care, perinatal bereavement care team or reference specialist among staff members, with definition of tasks and responsibilities, bereavement care options, administrative and social support and, last but not least, staff support (organisational formal and informal options, both educational and psychological skills and competencies development options).

5. CONCLUSIONS

The main objective of the PhD research has been the study of the emotional involvement, 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.

1. During the analysis in Hungarian and Italian healthcare organisations it was possible to identify the legal measures in both countries which provide the legal framework of the death events during pregnancy and child-bearing. In both studied countries 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, institutional protocol measures provide a frame in specific healthcare institutes only. 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.
2. Due to multifactorial differences, related to relevant knowledge of legal possibilities, guideline recommendations, theoretical knowledge regarding death and dying, and to the recognition of the importance of perinatal bereavement care and institutional facilities, differences can be identified concerning institutional practices in perinatal or intrauterine infant death, especially in burial and bereavement opportunities. No general perinatal bereavement care frameworks are available in the studied countries, but good examples and growing awareness of its importance can be identified.
3. For healthcare professionals, working in perinatal departments, the experience of perinatal and intrauterine death is an emotionally and professionally demanding task, they face 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 management of the cases 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.
4. The institutions which formulated a local protocol for perinatal bereavement care, 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 contribute to the provided care. The identified 'one-person care' examples represent the core of the support.

5. 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 presence of the psychologist at the department may offer informal help, in the context of a more friendly collegial relationship. The informal discussion between colleagues is limited by the available time and their busy schedule.

6. 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.

7. 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.

8. On the basis of the research results, the studied 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.

6. BIBLIOGRAPHY OF PUBLICATIONS

Publications related to the thesis

Zsák É. (2021) Kegyeleti kérdések perinatális veszteség esetén [Bereavement dilemmas in perinatal loss cases]. *Kharón Thanatológiai Szemle* 2021; 25(2):39-46

Zsák É. (2020) Etikai kérdések a perinatális palliatív ellátásban [Ethical dilemmas in perinatal palliative care]. *Kharón Thanatológiai Szemle* 2020; 24(2):15-29.

Zsák É, Hegedűs K. (2020) A perinatalis hospice-palliatív gondozás lehetőségei és kihívásai [Possibilities and challenges of perinatal hospice-palliative care]. *Orv Hetil.* 2020; 161(12): 452–457. DOI: 10.1556/650.2020.31636

Zsák É, Németh T, Hegedűs K. (2019) Personal Loss and Grief Experiences of Healthcare Personnel in Pre and Perinatal Care: A Review of Literature. *Cancer and Clinical Oncology*; Vol. 8, No. 1; 2019. 23-34. DOI:10.5539/ cco. v8n1p23

Testoni I, Cordioli C, Nodari E, **Zsak E.**, Marinoni GL, Venturini D, Maccarini A. (2019). Language Re-Discovered: a Death Education Intervention in the Net Between Kindergarten, Family and Territory. *Italian Journal of Sociology of Education*, 11(1), 331-346. DOI: 10.14658/pupj-ijse-2019-1-16

Zsák É, Hegedűs K: Szakemberek veszteségélményei, gyásza és megküzdési stratégiái a perinatális ellátásban. Szakirodalmi áttekintés [Experiences of loss, grief, coping strategies of the healthcare personnel in perinatal care. A review of literature]. *Kharón Thanatológiai Szemle*, 2019. 23 (2): 1-11.

Testoni I, Piscitello M, Ronconi L, **Zsak E**, Iacona E, Zamperini A. (2019) Death Education and the Management of Fear of Death Via Photo-Voice: An Experience Among Undergraduate Students *Journal of Loss and Trauma* 2019 Volume 24, Issue 5-6: Using Creative Arts Therapies in Survivors of Loss and Trauma: 387-399

Zsák, É; Geiszbühl-Szimon, P. (2018) Emlékezési módok a perinatális veszteségben [Ways to remember in perinatal loss]. *Kharón Thanatológiai Szemle* 2018; 22(3): 27-40.

Zsák, É; Hegedűs, K. (2017) Veszteségélmények, gyász, megküzdési stratégiák a prae- és perinatális ellátásban [Experiences of loss, grief, coping strategies in pre- and perinatal care]. *LEGE ARTIS MEDICINAE* 27: 3. 93-100.

Zsák É. (2017) Egy kisfiú halálára: fájdalmak és veszteségek Charlie Gard körül [Upon the death of a small boy: grief and loss around Charlie Gard]. *Kharón Thanatológiai Szemle* 2017; 21(3): 40-45.

Zsák É, Kovácsné Török Zs, Hegedűs K. (2015) A perinatális veszteségek és intrauterin magzati halálozások aktuális szakmai gyakorlatának, valamint a szakemberekre gyakorolt

hatásainak vizsgálata [Analysis of practices actually applied in perinatal and intrauterine infant death, and of their effects on medical personnel]. *Orv. Hetil*., 2015, 156(29), 1174–1178.

Zsák, É; Hegedűs, K. (2015) A perinatális veszteségek és intrauterin magzati halálozások kezelésének aktuális szakmai gyakorlata, és szakemberekre gyakorolt hatásuk [Analysis of practices actually applied in perinatal and intrauterine infant death, and of their effects on medical personnel] (2015)
Semmelweis Egyetem Orvos-, Fogorvos- és Gyógyszerésztudományi Diákköri Konferencia 2014/2015, Budapest, 2015. február 11, Magatartástudomány, pszichiátria szekció, III. díj

Book chapter

Zsák É. (2019) Szakmai és emberi nehézségek és kihívások a pre- és perinatális veszteségekben (Ch. 4) In: Varga K., Andrek A., Molnár J. E., eds. (2019) A szülés és születés minősége a perinatális tudományok megközelítésében. Medicina Könyvkiadó, 2019

Publications not related to the thesis

Zsák É. (2017) A kegyes halál olaszországi kálváriája: Dj Fabo hosszú útja a vágyott békébe [The Italian calvary of a death longed for: Dj Fabo's long journey into his desired peace]. *Kharón Thanatológiai Szemle* 2017; 21(2) 41-46.

Zsák É. (2015) A most significant experience: The patient who taught me the most. In Heide Otten – Ernst P. Petzold eds. *Ascona Balint Award Essays 2015 The Student, the Patient and the Illness.* International Balint Federation 2015: 155-161.

Zsák É. (2014) A halálhoz való jog kérdése Olaszországban - Eluana Englaro esete [How do people of Italy see the right to die? – through the case of Eluana Englaro]. *Kharón Thanatológiai Szemle* 2014; 18(3):42-46.

Zsák É. (2014) Michaela Murgia Accabadora A lélekanya. *Kharón Thanatológiai Szemle* 2014; 18(1): 43.

Zsák É. (2011) The Rood and Christ in Old English poetry. In Kathleen E. Dubs and Janka Kascakova ed. *Does It Really Mean That? Interpreting the Literary Ambiguous* Cambridge Scholars Publishers, Newcastle upon Tyne, UK: 2011. ISBN-13: 978-1443826617. 6-21.

Zsák É. (2006) 11. School life, 12. Teaching competencies. In: Furcsa L, Zsák É, Stefán I, Szaszkó R. *Szaknyelvi kommunikáció pedagógusok számára*. Budapest, Tempus. 2006.: 49-65.

Zsák É. (2003-2004) Notes on the usage of the word 'maintenance' in the morality play *Wisdom.* In Kathleen E. Dubs ed. *What does it mean? Pázmány Papers in English and American Studies, Vol. 3.* Pázmány Péter Catholic University. Piliscsaba: 2003-2004.: 100-106.