

Engaging in perinatal loss in the Czech Republic: Keen community and haphazard institutionalisation

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Keywords: *perinatal loss, sociology of death and dying, bereavement care, community care, professionalisation, Czech Republic*

Implications for practice

- Care centred around its recipients and involvement of the bereaved and their experiences can be critical in reshaping understanding of expert knowledge
- Community involvement can be the foundation in the institutionalisation of perinatal bereavement services where they are not pre-existing
- Unprecedented synergy in collaboration among palliative care medical specialists, health and social care professionals as well as engaged community helps 'reinstitutionalise humanity' in bereavement care

Introduction

In the Czech Republic (CR), community and professional care for the bereaved after pregnancy loss, and specifically perinatal loss, is a recent

Abstract

In the Czech Republic, community responsibility for care of the bereaved after pregnancy loss, and specifically perinatal loss, is a recent phenomenon. Using a sociological, qualitative, explorative framework, the paper analyses practices and contexts for establishing community care as emerging bottom-up initiatives. The research, funded by the Czech Science Foundation 2016–2019, traces the significant change in the status quo of Czech practices of perinatal loss and associated bereavement care. Grassroots initiatives address these challenges rather than the public health system of the post-socialist past. The paper reflects risky or random as well as synergic effects of the changing environment in perinatal bereavement care provision.

phenomenon (Šmídová, 2019a). This paper reflects on the institutionalisation of community care services documented during three years of intensive fieldwork. This was a pioneering social science inquiry into perinatal loss, an

understudied phenomenon in CR. The core analytical focus of this paper is the engagement of ‘the community’ in changing the status quo in the practice of perinatal care provision. Community here is understood as a serial social collective (Young, 1994) of actors in physical proximity, in some form of relationship and engagement with the experience of perinatal loss for whom such practice was not part of their professional training, workload or expertise. Community care has developed alongside insufficient (or absent) routine professional services provided in the CR. These professional healthcare services are also now being transformed creating new arenas for cooperation with the community care, though this is not the focus of this paper.

Since 2014, community approaches to perinatal care have emerged in the CR. The transformation of community support into a professional organisation providing bereavement care is detailed in this paper. The paper presents and situates such care in a broader context of the CR, and the processes, relationships and practices involved in the establishment of this previously non-existent sector of care provision. Thus far published papers from this study concentrated on other relevant perspectives within the topic, such as the competitive environment for the newly established services, the details of the Czech context of death at birth, or the moments in re-institutionalisation of humanity in the Post-Socialist period (Šmídová, 2019b, 2019a). Promising developments as well as haphazard moments of the community support institutionalisation process were grasped and unveiled by the research and are presented below.

Project background

Perinatal loss, or late pregnancy loss, has been intensely studied in the international social-science context in recent decades (Earle *et al*, 2009; Komaromy *et al*, 2016, Layne, 1997, 2003, 2009; Letherby, 2009; Murphy, 2012; Malacrida, 1998). However, in the CR scientific study has only emerged since 2014, alongside a change in practice. The first funded project to provide assistance to bereaved families after perinatal or late pregnancy loss was the Empty Cradle¹ which started in 2016 and was led by the non-governmental organisation (NGO) Long Journey.

Detail of emerging initiatives, especially the difficulty of establishing them in the strongly

bio-medicalised setting for perinatal loss in the post-socialist CR transformation in last rites, has been presented elsewhere (Šmídová, 2019b; 2022). The shift towards more intimate approaches, practices, and availability of has been described by the author as the ‘re-institutionalisation of humanity’ (Šmídová, 2019a). The term refers also to a shift from the approach to dying and death under state socialism (Něšporová, 2011, 2013; Kepřt, 2017, Kotrlý, 2012). After 1989, practices changed, challenging the socialist legacy and practice of public last rites. This change reflects the experience of the individuals interviewed in this study. Šmídová (2019a: 97) refers to the turbulent transformation process after the collapse of the totalitarian, state-paternalist regime’s rigid collective-oriented social services, a time when institutions formed on democratic principles were yet to be established. It is in the last decade that there have been attempts to understand socially-recognised grief, with ‘a good death’ or ‘better dying’ being discussed. Better understanding of a dignified, humane approach to pregnancy loss is embedded in empowerment and respect of individual choice (and indeed needs), and the plurality of potential new orthodoxies or institutional protocols resistant to routines and stereotyping’ (Šmídová, 2019a: 97).

This paper reflects on the change in emerging practice with the ‘re-institutionalisation of humanity’ at the time when new services of perinatal care provision emerged in the CR aiming to change the status quo. It analyses aspects of the transformation of waning last rites and the so-called ‘expatriated death’ (Šiklová, 2013) where death and dying was displaced from everyday lives and experience. The topic of displacement of death relates to the medicalisation of childbirth with its normative picture of healthy pregnancies, mothers and babies (Šmídová, 2015a).

The analysis presented in the paper explores significant changes in practice, provides context for such changes, and suggests promising and problematic areas for further developments of these new practices in perinatal loss community care. The involvement of ‘keen community’ and potentially arbitrary ‘haphazard moments’ or trends in the institutionalisation of this care forms the core focus of the paper.

The Czech context is introduced, followed by a methodology section and analysis presenting key findings describing the transformation of perinatal

loss (community) care. The analytical section opens with data from research interviews presenting the ‘point of departure’ situation that motivated actors to initiate change. The core section focuses on the (keen) community initiatives and their potential and effects. It recognises the bottom-up initiatives as significant innovations, points out their strengths and weaknesses, and concludes by stressing their integrative and synergic potential for the public healthcare system (PHS) in the Czech context.

The country context

The CR has a generous public healthcare system which is free at the point of contact for Czech nationals. This includes maternity and neo-natal care, which is covered by the public health insurance system. The country ranks highly in international bio-medicine; neo-natal mortality is very low (2 per 1000 live births) (World Bank, 2021) especially early neo-natal mortality (ČSÚ/CZSO, 2020; World Bank, 2020; OECD, 2021). However, recipients of care report low levels of satisfaction with care and wellbeing. Complex care services beyond medical care are lacking in the PHS (Takács and Seidlerová, 2012; Hrešanová, 2014; Šmídová-Matoušová *et al*, 2017) as reflected here.

The biomedical service is provided by gynaecologists and obstetricians and associated staff in outpatient clinics or hospitals. Midwifery, banned from 1950s through to 1989 (Tinková, 2014; Hrešanová, 2014; Lenderová *et al*, 2014), under the socialist/communist regime, is now a legitimate profession yet continues to face significant resistance in the PHS and among influential representatives.² The debate on competences and funding from the public budget is ongoing. Bereavement and undertaking services face similar challenges. The formalised, unsatisfactory services of the latter (funeral homes) were privatised after 1989 with regulation following later (Kotrlý, 2012; Nešporová, 2013; Gajdoš, 2012; Šmídová, 2019b) and bereavement services developed outside state or public health/social care. Hospital perinatal palliative or bereavement teams did not exist at the time of the research study, but were founded later.

Such practice is a part of the bigger picture. The social order, trends and post-socialist context of centralised, paternalistic healthcare provision (in a medicalised and gendered setting) emerge out of broader historical consequences (Šmídová *et al*,

2015; Slepíčková *et al*, 2012). After the centralised planning and ideological backdrop of the socialist/communist regime in CR, the fall of the Iron Curtain in 1989 brought long-needed transformations and dismantling of the systemic giant of the PHS. Nevertheless, death and dying, especially in human reproduction, is still understood as a failure of medical science and practice, both by the care provider and receiver (Šmídová *et al*, 2015; Slepíčková *et al*, 2012). This was reinforced by the erosion of rituals associated with death during the decades of socialist regime and marked by routinisation, uniformity, centralisation, formalisation and general lack of choice and individualised services, including those for the bereaved or dying (Bártlová, 2005; Kalvach *et al*, 2004; Kepřt, 2017; Nešporová, 2011, 2013; Kotrlý, 2012, 2014).

Czech PHS practices in the area of perinatal loss lack national co-ordination, and collaboration with social services and other care providers is non-existent (Šmídová, 2019b). Most initiatives challenging the status quo come from the bereaved and their communities scattered around the country (Šmídová 2019b, 2022). Healthcare lacks co-ordination with social services and other departments, and there is no critical debate about death, dying and the disposal of remains (Nešporová, 2011; Kotrlý, 2014; Šmídová, 2019a, 2022). However, change is slowly happening.

A few pilot projects were carried out in the Czech Republic by NGOs, covering palliative care for children and perinatal loss. These were supported by private foundations or the project funding schemes of the European Commission. Such initiatives include Avast Foundation supporting palliative care for children and more recently a children’s hospice (March 2021), and the perinatal palliative care online portal to support professions, which includes teambuilding measures (www.perinatalniztrata.cz/). These transformations legitimise inter-disciplinary and multi-paradigm approaches rather than strict bio-medical authoritative knowledge (Šmídová, 2022; Jordan, 1997). Yet there is still a lack of recognition of expert knowledge from other specialities and medical fields of expertise because of resistance, obstacles or marginalisation (Šmídová, 2019a; Illich, 2012; Jordan 1997).

Some (PHS) hospitals started moving away from the narrowly medicalised model of care, too, thus transforming ways of dealing with death, dying

and bereavement. Physicians, midwives and nurses are involved in new palliative care teams and multi-disciplinary units that include social workers, social scientists/researchers, and psychologists. Such grassroots initiatives (institutionalised as NGOs) together with so-far sporadic changes coming from within the existing PHS challenge the status quo in practice apparently blind to (perinatal) death.

Ideological shifts in practices call for reflection on potential collaborative and random situations impacting the care providers and recipients of care. The demand to restore 'last rites' to perinatal loss has risen among the bereaved, which has translated into several civic, state administration and political initiatives. The New Funeral Act (2017) transformed everyday grief practices such as how the infant remains are treated after pregnancy loss with the last rites returning towards the individualised, dignified re-institutionalisation of the eroded humanity of the past (Nešporová, 2013; Kepřt, 2017; Kotrlý and Vališová, 2014; Šmídová 2019a).

Methods

This study used explorative, sociological research methods to grasp the multiple layers of Czech perinatal (and pregnancy) bereavement care. Qualitative research approaches were applied to understand the complexity of engagement with perinatal loss by different groups of actors and services.

The paper draws on data collected and analysed from 2013 to 2019. The fieldwork comprised in-depth research interviews, observation and participation at topical events, ad hoc as well as systematic meetings with those involved in the transformation of perinatal loss care in the CZ, and document analysis. See Table 1 for an overview of the analysed data – interviews, personal encounters and documents.

Research participants

Participants were recruited through gatekeepers from previous research studies in reproductive medicine and practises of childbirth or approached directly following the snowball sample method. I made contact and interviewed a broad spectrum of people regarding late pregnancy loss. Altogether 50 personal individual interviews were carried out. Twenty of the participants had experienced late

pregnancy loss, eleven of which (9 mothers and 2 fathers) were approached because of this loss; the others took part primarily as care professionals but had incidentally suffered such loss. Eleven women who had experienced pregnancy or perinatal loss were approached through initiatives and organisations dealing with the issue of perinatal loss. The women came from urban and well as rural areas, reached middle or high levels of education, and had experienced at least one late pregnancy loss in recent years.

The participants thus included (besides the bereaved) care providers (lay and professional), policy makers, health professionals and various experts (funerary professions, NGO representatives, psychotherapists) and private stakeholders. An analysis of publicly available, written personal narratives on perinatal loss complemented sensitive data from the bereaved. Document analysis included: academic, legal and media coverage, web and social media pages and discussion forums. I met with some participants several times and took part in individual and group meetings with the various sectors involved and, on occasions, went beyond the original research design. These included, planned meetings and attending topical events. These were supplemented by attending research conferences which provided valuable feedback.

The sample is from a community which can be characterised as rather homogenous regarding their (higher) education, gender and professional involvement in humanities and/or social affairs. Ethnic composition of the secular (atheist) CR society is largely homogenous. For socially excluded Roma and other minority women (and citizens) access to services is complicated which can lead to them being excluded from or participating in the newly formed services; they were thus also difficult to access for this research. This pioneering research and fieldwork thus targeted accessible, mainstream experiences to provide an initial sketch.

The research process and collaboration

The research fieldwork formed reciprocal research partnerships providing mutually beneficial outcomes and reflection. The author of this study presented members of community initiatives with international context on perinatal loss (care) in Czech, their native language, offered statistical overviews and comparisons, discussed types of

Research participants and fieldwork data*allocation based on main selection criteria (each participant figures only once)*

Individual research interviews – recorded, transcribed and/or with detailed fieldnotes

A	bereaved parents		9
	<i>of which mothers (plus most of those in B)</i>	7	
	<i>of which fathers</i>	2	
B	volunteers/NGO actors (most of them with own experience of pregnancy loss)		11
C	health professionals		13
	<i>of which physicians (incl. pathologist, coroner)</i>	9	
	<i>of which midwives, nurses, other (some with own experience of pregnancy loss)</i>	4	
D	other involved professionals (state administration, funeral homes, psychotherapy, social work)		9
E	experts (researcher, lawyer, biostatistician, ethicist)		8
	Total		50

Supplementary fieldwork data (fieldnotes)

F	unique personal contacts during fieldwork: observation and discussions at topical events, face to face; national conferences, seminars, workshops		39
	<i>of which 2-day seminar on perinatal loss</i>	22	
	<i>of which discussions at palliative and hospice care, perinatal loss professional events</i>	17	
G	unique written narratives of pregnancy loss in CZ: stories collected online and published in existing books (parental guides, handbooks)		78
H	membership in relevant working groups and advisory teams (Czech Government Office working group on childbirth practices; NGO on perinatal hospice care, affiliated member to a new project on perinatal loss care provision for professionals); number of teams (unique new contacts – one each)	3	3
I	expert forums: international conferences, topical teaching presentations with discussions, final project workshop (number of events 17 – estimate 2 new contacts each)	17	34
	Total (including individual research interviews)		204

Documents and texts analysed

J	<i>78 narratives of perinatal loss (see above)</i>
	legal documents, such as The Funeral Act, documents relevant for the definition of pregnancy loss and perinatal loss, body disposal etc.
	web sites of the relevant organisations – state administration department, professional associations, NGOs, and topical events
	relevant leaflets, guides and handbooks for parents and general public, social media and online forums, media presentations and articles – ad hoc, informed selection sample (2013–2019)

good practices and exchanged contacts. Research participants reciprocally provided rich descriptions of their everyday practices and coping strategies fuelling the complex picture of Czech perinatal loss.

The fieldwork approach was informed by feminist research methodologies and inspired by studies of reproduction and reproductive loss (Letherby, 2009; Komaromy, 2016; Komaromy *et al*, 2016; Earle *et al*, 2009; Layne, 1997, 2003, 2009;

Rowling, 2009; Lovell, 2001; Paize & MacWilliam, 2020) stressing ethical and sensitive conduct. An expert advisory board was established for the study.

The collaboration that developed throughout the project between people dealing with death, dying, bereavement, and the disposal of bodies and foetal matter surpassed expectations.

Concerns and doubts raised in the process of applying for project approval included whether sociology as a discipline – and sociologists as the profession – are competent enough to explore perinatal loss; there is a dominance of medical expertise over life and death events (Seymour, 1999; Jordan, 1997; Illich, 2012) in the Czech research community. These questions were explicitly raised when obtaining the required Ethical Research Committee approval at Masaryk University. Disciplinary understandings of ‘no harm’ research were renegotiated on the spot, and unexpected allies (lawyers) defended the project against the natural and life sciences approach presented by other members of the board. The result of this surveillance and token study was yet more intense reflection that became integral to the research process.

Data collection and interpretation were conducted simultaneously. The analysis required planned reflection with analytical and methodological pauses in the research process which included impromptu periods of private isolation to reflect on the aspects of grief related to perinatal and pregnancy loss (Pearce, 2019; Malacrida, 1999; Davidson & Letherby, 2014; Davidson, 2018; Doka, 1989; Komaromy, 2016; Layne, 1997, 2003, 2007), various provisions of (hospice) care and lack of it (Boyle *et al.*, 2015; Carlson *et al.*, 2012; O’Leary & Warland, 2016) and caution around collecting anecdotal³ data on bereavement experiences of perinatal loss (Silverman, 2001).

All field notes and verbatim transcripts were revisited repeatedly in the search for relevant themes and clashing or missing events/accounts based on Silverman’s (2001) approach to text interpretation, all of which is grounded in thematic feminist research methods (Layne, 2009; Letherby, 2009; Rowling, 2009). As such, an emphasis on partnership and sensitivity to potential and practised power imbalances and adherence to research ethics was essential.

All data was collected and interpreted (coded) in Czech by; the author and the author has formal competences and experience with cultural translation.

The fieldwork challenged traditional claims of objectivity within the studied field by stressing the relationship between the selves and the studied fields (Brennan and Letherby, 2017). This approach is applied throughout. Towards the close of the research, questions about reciprocity and collaborative aspects in research on death, dying and bereavement became more intense (Borgstrom and Ellis, 2017). This study was not just a set of research exchanges driven by an ambition to grasp the status quo, acknowledge promising practices on the ‘community side’ and result in ‘publications’ by the researcher. Some of these research collaborations transformed into lasting relationships, continuing beyond the timeframe of the research study). These reciprocal, imaginative, reflexive and practice-oriented collaborations or friendships left their mark on the findings and knowledge in this area of expertise.

The interplay within the grassroots community influenced the complexity of experiences and analytical reflection throughout the fieldwork. Shared motivation as a team project aimed to improve perinatal loss treatment, care and experience. The engagement in the research process and lessons learned during the fieldwork are a significant contribution to better understanding the change in practice of Czech perinatal loss care provision.

This study takes on the relationship between the research theme and its proponents, where the community includes the researcher as well, which is not uncommon in topical feminist research (Cacciatore, 2009; Letherby, 2009; Komaromy, 2016; Komaromy *et al.*, 2016; Earle *et al.*, 2009; Layne, 1997 2003, 2009; Rowling, 2009; Radomska *et al.*, 2020). It considers the transformation and institutionalisation of targeted services in the context of the post-socialist CR and the transforming PHS. It points to the intensity (keen engagement) and potentially arbitrary (haphazard) moments brought about through these processes and relationships. The subject studied is contested in the CR and is very a sensitive subject for many participants representing varied PHS institutions. Identities of their hospitals or other organisations remain undisclosed in the paper.

Findings

This section presents examples of recent practices before detailing the changes in Czech perinatal loss bereavement care. It recognises the brave few initiating the change, reflects the tension between the PHS and the grassroots initiatives and presents some synergic moments between the two. Such experiences enabled the broader community to change the status quo.

When the fieldwork started the PHS did not provide bereavement or perinatal loss support, and community care and other isolated initiatives were forming. Interviews revealed that private initiatives were often banned from hospitals by management, senior consultants or ward nurses. Independent midwives (and/or doulas) have limited access and authority in hospital hierarchies. There were isolated exceptions within the PHS pioneered by well-informed enthusiast individuals with broad knowledge, such as the case of the university hospital in Brno.

The intense experience of perinatal loss and lack of care as a point of departure for change

The parents among the study participants relayed their stories of horror and/or unpleasant experiences with shock, confusion and feeling that their voices were not heard and experiences not recognised by health professionals. The following conversations document a point of departure for many parents. One couple who had recently experienced late pregnancy loss (32+ weeks) recollected their hospital experience as follows:

‘If only the way of communication was a bit different, or they [hospital staff] called somebody else for assistance. Perhaps a chaplain or anybody at all (...) plus at the same time there is this master story of professional, top Czech medicine. Forget about that!’

Such recollections were typical rather than exceptional. A mother described her final experience as a pregnant woman, reacting to the attitude of health personnel in the hospital:

‘That was a trauma. They told me at the pre-natal screening that it was bad, seriously bad, and to be ready for the worst. And then

they just wrapped the conversation up neatly and told me to come back next week. And they just left me to leave the hospital with this brutal information.’

This was another account of failed communication; parents complained that there were no offers of help or signposting to other services. Under the conditions, they felt unable to ask for it:

‘It was all a great shock, and I do not think they managed it well. It was the manner we were told, how they communicated it. This was simply one big, bad, negative experience. No offer of any help, lack of empathy, I mean even just professional empathy.’

These quotes illustrate the shock and despair for the women and fathers after losing their babies. It depicts the power relations and emotional dynamics at play. Issues of life and death take place in real time for parents caught up in PHS with routinised protocols.

Parents’ well-being and patients’ attempts to communicate with hospital personnel was traumatising and exacerbated by the fatal diagnosis or the loss itself. One father pointed out:

‘It was weird that we had to repeat our story all over again once we were referred to the hospital after a regular pre-natal check-up that there was no heartbeat echo on the sonogram. We did this at the registration, then we were sent to several departments one after another... and then the shifts changed so we had to go through it all over again. Also, this was their regular routine shift for the maternity hospital personnel, so we heard nurses laughing in their office. We had this total feeling of inappropriateness, of being there and experiencing loss.’

These experiences and narratives were shared in the research interviews with the ambition of changing the status quo from the ground up. Similar narratives are shared in the bereaved community through online discussion and memorial sites (such as www.prazdnakolebka.cz) presenting accounts from an engaged community of volunteers as well as from (social and health) professionals mostly outside the PHS. This is the ‘keen engaged’ community around perinatal (and late pregnancy) loss. The research interviews

document how perinatal loss has been systematically overlooked and lacking in care provision for decades. The experiences of the bereaved parents led some of the participants to start changing such practice. Such grassroots initiatives of a few individuals with co-operation and assistance from the wider community started spreading new practices to a wider group of people affected by pregnancy loss.

Towards new practices in Czech bereavement care: changing the stage set

Individual midwives or other health personnel including a few physicians are open to progress too, yet institution rules and other professional bodies generally disapprove of change as the fieldwork analysis and research participants indicate. This was demonstrated earlier in (interventionist and patronising) childbirth practices in the Czech Republic (Hrešanová, 2008; Šmídová, 2011, 2015a) and in gendered and unequal arrangements within gynaecology and obstetrics (Šmídová, 2015b). The primary change envisaged is around attitudes and acceptance between recipients of care and professional caregivers; an equal and fair exchange and a professional/business approach. Professions within the PHS were/are suppressed by paternalistic, formalist and bureaucratic structures (Šmídová-Matoušová *et al.*, 2017; Heitlinger, 1987; Šmídová, 2016, 2015c). In the liberal pro-choice Czech context, pregnancy loss is played down within the medical profession. Strategies used by some medical professionals in regard to reproductive loss are denial and/or cynicism (Šmídová 2015a).

The parents are the messengers and bearers of the experience of loss, which does not fit the purpose of a maternity hospital and is left to the PHS to manage. The motto and expectations of late modern bio-medical science is to protect, prevent and 'provide' life, as opposed to death (Foucault, 2009; Slepíčková *et al.*, 2012). The success story of Czech bio-medicine is, as elsewhere, demonstrated by charts and indexes of decreasing (neo-natal) mortality (Slepíčková *et al.*, 2012; Rieger, 2008; Komaromy, 2016; Layne, 2009). The spatial organisation of maternity hospitals (surgeries or birthing rooms) observed during the fieldwork and referred to in research interviews reinforces the image. In some rooms, pictures of new-born babies and families were displayed, contrasting sharply with the experience of perinatal loss as was

highlighted by some research participants. One university hospital attempted to overcome this by creating a separate birthing room for difficult pregnancy/childbirth incidences into a sub-basement floor. Here, parents are isolated, with a good intention, from the noise of a busy maternity ward. However, the space does not provide daylight, and hospital basements are associated with mortuaries. This situation further stigmatised and excluded those already suffering and is not fitting for the bereaved.

The high profile of Czech obstetrics, often demonstrated by diminishing rates of neo-natal mortality and technological advancements in pre-natal screening⁴ contrasts with interviewees' experience of the dysfunctions and mismanagement of the everyday hospital routine providing less than scant bereavement care after any death. The situation in Czech PHS hospitals originates partly in a rather cynical and pragmatic approach – the idea of late modern medicine as providing 'healthy populations' (Slepíčková *et al.*, 2012; Šmídová *et al.*, 2015; Šmídová, 2015a). It lacks professional competences when communicating death (Kalvach *et al.*, 2004) as well as time and organisational management.

The brave few: community of actors

The context from which the community of actors changes the stage set is reflected in the next section.

Those involved in building support networks in the CR are often mothers with personal experience of loss themselves. They engage in further and varied education/training for hospital personnel and better collaboration among professions. These initiatives launched the first NGOs to provide a range of specific care services for the bereaved after late pregnancy loss. Midwives joined parents individually or from a disaffected stock of trained, dedicated experts reflecting on unsatisfactory routine practices on the hospital wards. Social workers and other relevant professionals strengthen the team. Groups with overlapping objectives were formed to transform particular practices in individual hospitals. They aim to change the general social environment to prevent parents and personnel from poor medical practice documenting what the Czech sociologist Šiklová (2013) called the sequestered or 'expatriated' death.

This corresponds with internationally recognised initiatives (Layne, 1997; Earle *et al.*, 2009;

Komaromy, 2007; Caciatore, 2009; Pullen *et al.*, 2012). Some activities are framed as raising expectations of positive healing outcomes (Murphy, 2012; Capitulo, 2005; Malacrida, 1998, 1999) or normalising the new practice, thus forming new normativities, which Komaromy is wary of in her analysis (Komaromy 2007, 2016), and stand in contrast to complicated mourning (Malacrida, 1999; Pearce, 2019) and disenfranchised grief (Doka, 1989, Davidson, 2018) resulting from the loss. The field is competitive, institutionally vague and guidelines are unclear. These issues are explored elsewhere (Šmídová, 2022).

Any normalising practices such as various aspects of bonding, including cradling or washing and dressing the baby need critical attention (Komaromy, 2016). It is important to reflect what forms the normal process of grief after perinatal loss, which is being established in the process. Perinatal loss has not been seen as a real loss quite often. It causes difficulties in coming to terms with such a socially unrecognised grief, which sometimes transforms into complicated grief (Doka, 1989; Layne, 2009; Malacrida, 1998, 1999; Murphy, 2012; Davidson, 2018). Some women seek help in attending self-help groups even decades after their perinatal loss as they remained silent about it until such institutionalised opportunities to share their grief opened, the interviews evidence that. Thus, any normalising tendencies are reducing the diversity of experiences not reflecting that normalising the grief are performances that are always ‘incomplete’ Pearce, 2019: 201–206).

PHS care provision or other state or public insurance-funded services do not cover community initiatives in perinatal bereavement care in the CR. NGOs have established a dense, permanent network of services for this.

Emotional labour (Hochschild, 2012) in this context contributes to work overload and burnout for those involved. Precarious working conditions concerning both the formal and informal network of organisations involved in health and social care require recognition from the state for this invaluable work, yet research interviews indicate that until now such recognition is not provided. Although NGOs often substitute the state in care provision, their work is overlooked (Jacobsson and Saxonberg, 2013; Saxonberg, 2003). A majority of people involved in perinatal loss care provision are women but this perspective is not acknowledged or made explicit in the Czech context, which is

generally lacking sensitivity to gender relations (Šmídová *et al.*, 2015).

Still, services and care organisations flourish on the enthusiasm and altruism from the few people engaged. Various interest groups, such as religious communities, further complicate understanding of the spectrum of choice already provided or imposed in a secular/atheist country like the CR (Nešporová, 2011, 2013; Halík, 2006; Kalvach *et al.*, 2004; Kepřt, 2017; Kotrlý, 2012). The bereaved and sympathetic communities, ie groups of actors supporting the bereaved, participating in care, have great expectations directed towards these individual grassroots initiatives. This adds to the burden of responsibility of these small teams working for the change often without any institutional support. The complexity of individual cases in such a setting affects the outcomes of the bereavement processes and the people involved: these entail complicated mourning (Pearce, 2019), disenfranchised grief (Doka, 1989), queer deaths (Radomska, Merhabi & Lykke, 2020), socially unrecognised types of grief where (even late) pregnancy loss belong (Dohnalová, 2014).

Implications for emerging perinatal bereavement care

Emerging practices in perinatal loss care provision and bereavement support have many layers that need a more detailed disentanglement in further research. The authoritative position of the medical professional associations in CR sometimes silences the work of civic initiatives and social work in the community (Šmídová-Matoušová *et al.*, 2017; Šmídová *et al.*, 2015). These associations administer incomparable resources, prestige and influence (Šmídová 2022). Their influence translates to other spheres of the social spectrum relevant to health, illness and death (Jordan, 1997; Davidson-Floyd; 1997, Speier *et al.*, 2015; Illich, 2012).

Community initiatives, together with a few newly established multi-disciplinary palliative hospital units, bring changes necessary for institutional transformation of the PHS in dealing with perinatal loss. They help dismantle the post-socialist eroded sense for empathy with personal loss in the Czech context, and they re-institutionalise and bring back dignity and ‘humanity’ (Šmídová 2019a) to individual mourning and grief as opposed to uniform,

depleted and generalised central organisation of last rites or even lack of them.

This change in practice presents a relevant perspective to help understand the process and environment for transforming the status quo. Such change include potentials as well as haphazard moments. At the time of the fieldwork, the community care initiatives were nowhere near enabling complex and systematic change to the existing models of care (or introducing one where it is missing).

The focus of this paper was on the role of experts, power relations and the authoritative position of medical experts involved in the process. The analysis targeted potential shifts in the relationships brought about by the institutionalisation of initiatives to improve an existing service. The outcome shows inter-disciplinary co-operation, sharing of good practices and respect for personal courage to deal with issues (of death, dying and bereavement); issues that are being generally left out both from 'parental courses curricula' or even medical and midwifery university training. These all challenge the otherwise guarded territories of professions. Community initiatives have stepped in to fill in the gaps of the PHS.

The experience of trans-professional co-operation and a revival of a community approach to bereavement care was clearly documented during the fieldwork. Such care did not exist in the paternalistic centralised regime of the state socialist/communist regime (1948–1989) and has not emerged in the confusion of the post-socialist state until recently (Dohnalová, 2014; Nešporová, 2011, 2014; Gajdoš, 2012; Kalvach *et al*, 2004; Trnka & Busheikin, 1993; Heitlinger, 1987). The cultural and historical roots of the situation may differ in the CR, yet participants in the study registered and described fragmentation and revival of community reconnection with death in their contexts similar to that described by Walter (1994: 191–197) who suggests the fragmenting of a bereavement experience results in discrete communities, which help reconnect with death. The stress on expert help in care provision is mixed with a recent individual approach in the CR. According to Walter (1994), critical reflections on professionalisation (with inherent routinisation) and bureaucratisation of death, stress on the importance of communities based on individuals. His observations are relevant to the practices in the CR.

Analysis shows the bereavement care community outside the PHS brings focuses on communication and the welfare of the bereaved. All this takes place in times of neo-liberal budget cuts affecting provision of care in various sectors of society even beyond the PHS (Speier *et al*, 2014; Slepíčková *et al*, 2012; Kalvach *et al*, 2004; Šmídová, 2022). Cost of such care (not covered by public health insurance at the time of the research study) contrasts to the free PHS services. The unsystematic funding, the combination of costs paid by recipients of care, privately funded (non-profit) and ad hoc services create a blurred landscape.

The potential to widen collaboration and the spectrum of care services in the PHS is hampered by structural obstacles (Šmídová-Matoušová *et al*, 2017; Kalvach *et al*, 2004; Slepíčková *et al*, 2012; Šmídová *et al*, 2015; Šmídová, 2011; Hrešanová & Glajchová, 2018). Such analyses point frequent distrust of physicians and other medical authorities in people with experiential knowledge (the bereaved), as lay or not professional. The fieldwork repeatedly showed that changes to combat poor practices in perinatal loss in Czech hospital settings and medicalized institutions were hindered as a result. The firm belief of those involved in changing the status quo of Czech perinatal loss care is that a range of expert knowledge deserves respect and recognition. This involves a unique understanding of perinatal bereavement, experiences of practitioners and other expertise brought about by professions not limited to bio-medicine. Choice and respect for the range of experiences and a need for complex care remain central for perinatal loss beyond old or new normative designs of its management. Attention to social structure (gender, class, ethnicity, religion, sexuality) and politics of identity should inform options offered and provided; frequently emerging practice does not reflect these, and more studies interrogating the structural issues are needed.

No central authority at the state level provides guidance or care in perinatal loss; not even the Ministry of Health which represents the bio-medicalised authority, driven by the authoritative medicalised model of care provision. The Czech Medical Chamber (ČLK, 2021) identifies the terminology for legal matters, yet both the ČLK and the professional medical society, ČLS JEP (2021), represent and prioritise the bio-medical problems, and carry on both paternalist and post-socialist strong legacies (Šmídová, 2015c, 2019b).

The Ministry of Health needs to take account of other, more relevant voices, in forming its policies. Education for those involved in perinatal loss is decentralised and unco-ordinated and has not been included in the standard university curricula for medics and other health care professions. It was introduced only recently and ad hoc.

Conclusion: towards collaboration

Czech community bereavement care draws from various sets of expert knowledge and understandings of care provision. It also draws on a strong sense of reciprocity and solidarity. Towards the close of the fieldwork, there were synergic practices based on diverse expert knowledge in perinatal palliative and bereavement care. Perinatal and child palliative and hospice care found a way through the neglect of other medical specialisations (Šmídová 2022, 2019a) and started influencing the status quo alongside flourishing non-governmental initiatives. A shared approach and co-operation in the community and multi-professional involvement in care is emerging. The task is to co-ordinate and negotiate with potential authorities or responsible institutions to respond and recognise those in the community. The community substitutes the state and invests enormous amounts of work in this endeavour and the emotional labour required is heavy (Hochschild, 2012). Thus, institutionalised humanity is getting restored in the Czech post-socialist paternalist context, upgrading the political culture of (perinatal) loss.

These grassroots community practices in the CR resemble those recently described for the British and Western contexts (Brown and Walter, 2014; Pearce, 2019; Murphy, 2012; Woodthorpe, 2009, 2011; Borgstrom and Ellis, 2017). There are tensions between the institutionalised paternalistic mechanisms and incorporating informed community approaches enabling the revival of community care.

The fieldwork data reveal need for the empowerment of those receiving care. There is a call to move from the unifying institutional (absence of) care to personalised and individualised care provided by teams of relevant people including the community outside the bio-medical scheme. The potential to bring systematic solutions increases with collaborations, enthusiasm and sharing of good practices.

This paper presents changes and challenges in care surrounding perinatal loss in the Czech Republic between 2014–2019. The research reported substantial shifts in the community aspect of care provision. The sense of mutuality, community and common goals became an intense research experience beyond documented clashes and haphazard practices. The engagement with the topic thus formed an intense experience for the researcher (author of the paper). The community embraced sharing knowledge beyond a conventional research study.

Mutual understanding using a feminist research approach and lived experience of loss contrasted with the experience of oppression, inequality, sequestration or disenfranchisement of relevant topics and problems. This form of sisterhood or felt community reflects an affinity of values and ideals of civic engagement and helping others. Engaging in perinatal loss in the CR provided mutual support within the keen community. It also helped to analytically pinpoint the environment of blurred (open) boundaries within community engagement in perinatal bereavement care and between gated bio-medical authoritative expert knowledge protected by organisational practices within the PHS, with its adherence to tradition in expertise, force of habit and rigid routines. The practices and strategies of an engaging – keen – community involved in Czech perinatal loss bereavement care are a resource for change in the haphazard environment dominated by the stalled practices within the PHS.

- 1 The translations of local names and titles are used for better fluency and easier understanding of local terminology. The same applies for citations and references originating in the Czech language used throughout the text. However, the study was in the CR, not international; all material was collected and analysed in the Czech language by the principal investigator, who is the author of the paper.
- 2 The rivalry between the interventionist biomedical and assisting midwifery approach to childbirth present worldwide (Reiger, 2008; Jordan, 1997) is complicated in the CR by the decades of ban of the midwifery profession and establishment of strictly bio-medicalised approach to childbirth under the auspices of physicians in the era of Communism (Hrešanová, 2008; Šmídová, 2015a).
- 3 Silverman refers to anecdotal data when critically reflecting on sloppy data collection processes, such as unsystematic and unjustified attention to ‘interesting’ or ‘exotic’ cases instead of a systematic and grounded approach.

4 Presentations at the web page of the Czech Association of Gynaecology and Obstetrics (<https://www.cgps.cz/>) and repeated annually in opening speeches of their national conference (Šmídová 2015b).

Acknowledgements: This research study was supported by the Czech Science Foundation/Grantová Agentura České republiky (GA17-02773S).

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