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CE 36 - Santé publique, santé et société		

“Words Fail Me”: Naming the Unnamable (PERINAT)

I. Proposal’s context, positioning and objective(s)

a. Objectives and research hypothesis

This research project investigates the discourse on perinatal death, which is a broad term encompassing stillbirth (*ante partum* and *intra partum*), induced abortion following the diagnosis of lethal anomaly or rare disease, neonatal death¹ and cases of palliative care for newborns with a life-limiting condition.

The suffering that a family struck by perinatal grief has to endure is exacerbated by the silence and ensuing isolation that surrounds this event, widely associated with stigma and taboo in Western societies (Heazell 2016; Markin & Zilcha-Mano 2018), to the point that perinatal death is also referred to as the “silent” or “invisible” loss (Lang *et al.* 2011). This taboo remains deeply entrenched in private and public communication, despite the fact that perinatal death is not uncommon. According to statistics from the World Health Organisation (WHO), in 2018, 10.6 in every 1000 pregnancies in France ended with stillbirth or death in the first week of life, 6.06 in every 1000 in the UK, and 6.86 in every 1000 in Belgium².

The non-recognition of perinatal grief and bereavement in society leads parents to feel isolated, hindering their psychological adjustment after the loss (Layne 2003; Markin & Zilcha-Mano 2018). Because of its specificities, perinatal mourning entails different psychological mechanisms compared to other forms of bereavement (Weiss 2008), such as a deep sense of loss of parenthood status and a feeling of biological failure (Wallerstedt *et al.* 2003). Perinatal death can have detrimental long-term effects on parents’ lives, sometimes as long as 5–18 years (Gravensteen *et al.* 2012), with a higher likelihood of complicated grief (Lundorff *et al.* 2017) and predictably negative consequences on professional performance (Hazen 2009) and on social roles in general.³ In the light of these issues, increasing social visibility of perinatal loss (Keeble *et al.* 2018) and improving bereaved parents’ experiences of care and communication seems to be crucial to lessen the risk of dysfunctional grief and the consequences that the latter may trigger at personal and socio-economic level.

For most bereaved parents, their first communication experience about the loss takes place at the hospital. Patients are influenced from the onset by healthcare professionals’ discursive practices, which have a profound effect on their overall bereavement experience (Miller 2010; Semino *et al.* 2018). However, complex and emotionally-charged experiences, such as pregnancy loss, may lead to a feeling of “epistemic injustice” (Fricker 2007) on the part of the patient: the idea that the absence of appropriate words and concepts to express one’s experience interferes with the ability to understand this experience and make it intelligible to the larger community. In this respect, metaphors play an important, and potentially beneficial, role in the experience of people facing emotionally challenging events (Semino *et al.* 2018) as they facilitate understanding and promote patients’ adaptation and positive self-regard (Reisfield & Wilson 2004). By developing higher awareness of metaphoric speech among bereaved parents, physicians may gain insight into the cognitive and affective underpinnings of their experience, and this may help make sense of their needs and their emotional responses to an unshared experience. Conversely, using the ‘wrong’ metaphors in patient-directed communication can have far-reaching negative effects on the healing process (see, among others, Semino *et al.* 2018).

¹ This study embraces the WHO’s (2016: 19) extended definition of perinatal death, which includes both early neonatal death (occurring during the first seven days of life) and late neonatal death (from 7 days to 28 completed days after birth).

² https://gateway.euro.who.int/en/indicators/hfa_84-1170-perinatal-deaths-per-1000-births/ (Last accessed: March 8, 2022).

³ In addition to a decrease in the quality of life (Ryninks *et al.* 2014), parents facing perinatal loss may also experience mental health problems such as anxiety (Hunter *et al.* 2017), depression (Gravensteen *et al.* 2018), suicidal ideation (Yilmaz & Beji 2013), and post-traumatic stress disorder (Chung & Reed 2017).

This project seeks to further public understanding of the linguistic choices made by bereaved parents in order to improve their communication experience in socio-medical contexts. To pursue these aims, the study is carried out in two steps:

- i. the observation and identification of a number of linguistic aspects that characterize the narrative of bereaved parents, with specific reference to metaphorical constructions and cases of lexical innovation (neologisms);
- ii. the development and promotion of a set of open, correct and respectful discursive practices among (para)medical practitioners, as well as in the workplace, that will facilitate these parents' grieving process and post-traumatic re-integration in society.

The study will be conducted by means of interviews and questionnaires submitted to bereaved parents in France and Dutch-speaking Belgium⁴. The outputs from this project will be used to inform and improve the support offered by healthcare practitioners who are likely to come across a bereaved parent in their professional capacity. This aspect is perfectly in line with the increased salience that has been given in the past few decades to the meaning of "patient centredness" (Bensing 2000) and "patient centred discourses" (Pluut 2016) in medicine and in healthcare discourse. For this purpose, we will need to establish a network of contacts with the hospital (para)medical team, including neonatologists and pediatricians, also relying on the mediation role played by the charities participating in the project, which are all involved in the support of bereaved parents and whose members are also medical doctors⁵. The project further aspires to bring the results of the research to the larger public, to raise general awareness to, and consideration for, these issues in society at large.

For the purpose of our linguistic analysis, the project will focus on two elements in the discourse of perinatal death: a) **metaphor** as a commonly-used resource for expressing the inexpressible in the narrative of bereaved parents and b) the use of **neologisms** to denote bereaved parents and their prematurely deceased babies. The reason for this dual focus is that while metaphors provide insights into people's extant conceptualisations of their experiences, neologisms are a powerful means of creating and voicing *new* concepts by giving them a linguistic label (reification). These two elements are closely related as neologisms themselves often have a metaphorical basis.

Metaphor. From the perspective of metaphor analysis, this project is intended as a continuation of the scientific project "Death Before Birth: Understanding, informing and supporting the choices made by people who have experienced miscarriage, termination, and stillbirth"⁶ (henceforth DbB) carried out in 2016-18 by Jeannette Littlemore and colleagues at the University of Birmingham. The DbB project focuses on metaphor analysis (where one thing is described in terms of another) as an effective tool in providing insights into the complexities and tensions of emotionally-charged experiences (Gibbs, 2016) that are not widely shared or that are otherwise difficult to express (Semino, 2010, 2011), such as pregnancy loss and neonatal loss. The focus of the DbB project was on the metaphors that parents, especially women, used when talking about key moments at the time of their loss and during their bereavement process. The hypothesis, which also underpins the "Words Fail Me" project, is that metaphor use is prevalent in individuals' recounts of their experiences of perinatal death, and that it sheds light on the ways in which they construe these experiences, facilitating a deeper understanding of what they are/were going through and how this impacts/impacted upon their decision making. These insights into the experiences of people who go through pregnancy and neonatal loss can help counsellors support parents through the difficult aftermath of perinatal death. The purpose of the "Words Fail Me" project is to extrapolate from the DbB project (centred on the English language) and conduct research in two linguistically and culturally different contexts (France and Dutch-speaking Belgium).

Neologisms. From a lexical perspective, the culture of denial around perinatal grief (Markin/Zilcha-Mano 2018) translates into the lack of a specific term to designate either bereaved parents or their lost babies, as opposed to, for example, children without parents for which most languages have a word (e.g. *orphan* in English), or (married) adults who have lost a partner, e.g. *widow(er)*. The use of new identifying terms to designate the lost baby and their parents would allow the father/mother to feel recognised in their role as parents, thereby giving substance ("conceptual reification") to their emotionally challenging experience, but

⁴ The data from the interviews will be compared to the results of the earlier DbB project in the UK (see below) for female respondents, whereas this comparative aspect will not concern the questionnaires as they were not part of the DbB.

⁵ In the case of the *Nos Tout-Petits* charity in France, the current vice-president, Maryse DUMOULIN, is a retired medical doctor in Ethics and Public Health at CHRU Lille. The charity is also composed of perinatal care practitioners working for the hospitals of the Hauts-de-France region and in turn supporting the charity's volunteers, such as Dr. C. MORISOT and L. STORME (pediatricians and intensive care specialists), Dr. A-S VALAT (gynecologist-obstetrician), Dr. I. PAUCHET (psychiatrist), Dr C. PERROT MILLET (occupational health physician), Dr M. BONNIERE (fetopathologists), D. MERG ESSADI (midwife and psychologist), E. LEDUC, L. COTTENCIN, M. RUIZ SUAREZ, L. LETREZ, B. SERGENT, (psychologists).

⁶ <https://deathbeforebirthproject.org/> (Last accessed: March 8, 2022).

also breaking the taboo in private and public communication. As defended by hypostatization theory (Schmid 2008), originating from language philosophy and linguistic semantics, words have a “concept-forming power” (Leech 1981) in the sense that the existence of a unique and/or special term renders what is denoted conceptually real to language users, creating the impression that there is a corresponding entity to which the word refers. This is what is concretely happening in Dutch-speaking Belgium, where use of new Dutch words/compounds (*sterrenkind* ‘star child’ and *sterrenouder* ‘star parent’) has become a conventionalised practice in discourse on perinatal death and has proved helpful to break the taboo and bring the topic into conversations with others⁷. This reduces the “epistemic injustice” Fricker (2007) talks about: the absence of a word implies the absence of a unified concept (in Fricker’s terms a “social meaning”), which makes it extremely difficult for this meaning to enter into, or get accepted in, the larger community. In addition, neologisms often build on particular metaphorical concepts, such as “star” in the Dutch neologism, or “angel” in the English *angel baby*. Describing and understanding these metaphors is important to explain the acceptance or rejection of the neologisms by bereaved parents or society at large.

For this project, the impact of the use of metaphor and of hypostatization (the latter through the use of neologisms) will be measured through careful analysis of people’s testimonies via interviews and questionnaires, as illustrated in the methodological Section I.c below. Our study will be informed by the following Research Questions:

1) What metaphors are used by bereaved parents and in which ways are they used?

The project investigates the metaphors used in French and Belgian Dutch by parents describing their experience of perinatal death, with a view to comparing them to the English data from the ‘Death before Birth’ (DbB) project.⁸ We will: 1) identify the metaphorical themes and the conceptual metaphors used in parent’s accounts; and then 2) conduct a thematic analysis by observing which metaphors are used (and how) to describe the different stages of the bereavement experience, for instance: a) receiving the news about their baby’s death; b) opting for the type of funeral; c) leaving the hospital; d) communicating their loss; e) returning to work. It is commonly believed that metaphors are mere rhetorical devices or just the way we speak; however, as convincingly argued by Conceptual Metaphor Theory (see, among others Lakoff & Johnson, 1980; Grady 1997; Dancygier & Sweetser 2014) metaphors are conceptual, which means that we *think* metaphorically. Consequently, metaphor analysis can be useful in understanding the thought process of an individual and can provide insights into: their mental state following an emotional experience of trauma and bereavement; and the ways in which they are coming to terms with it. Identifying and understanding these metaphors can help those who have not been through similar experiences (e.g. counsellors), and who therefore lack the relevant “experiential knowledge” (Borkman 1976), to at least acknowledge what cannot be understood.

2) Do metaphors used by bereaved parents depart from conventional usage? If so, what creative metaphors do they use, what do these metaphors reveal, and what neologisms do parents produce?

Many of the metaphors that we use are conventional and are simply the way that something is expressed. In order to get at the distinctive nature of perinatal loss, in addition to examining conventional metaphors used, it is useful to identify and analyse metaphors that depart from conventional usage and that thus appear to distinguish this kind of loss from other more ‘everyday’ experiences. Concerning neologisms, we will see to what extent parents create their own (and if so, on what conceptual basis) or use existing word formations (see also Research Question 5).

3) In what way do the metaphors used in French and Belgian Dutch differ from the ones used by the British parents interviewed as part of the “Death before Birth” project?

Culture plays an important role in people’s experiences of trauma and bereavement, and one’s native language shapes the metaphors conventionally used to frame experiences in a given culture. This then has a knock-on effect on the ways in which these conventional metaphors are extended. The contrastive and interlinguistic nature of our study will therefore prove to be particularly insightful in this respect.

⁷ <https://anndecraemer.be/2017/05/19/het-nederlands-had-geen-woord-voor-ouders-die-een-kind-verliezen-vanaf-nu-wel/> (Last accessed: March 2022).

⁸ Since the DbB project data only focused on the responses of female participants, the comparison with the “Words Fail Me” project will be circumscribed to female subjects.

4) To what extent and in what ways do the metaphors and neologisms used by men to describe the loss of a baby differ from those used by women?

The voice of men is less frequently heard in debates surrounding perinatal death as pregnancy is still arguably considered primarily a ‘women’s issue’ (O’Leary & Thorwick 2006). Men are usually construed as mere ‘supportive partners’ and fewer studies have considered the impact of pregnancy loss on their health and wellbeing (Due *et al.* 2017) whereas men describe feeling “overlooked, alienated and marginalised in comparison to their female partners who had suffered the physical experience and whose pain was more visible” (McCreight 2004: 6). One of the novel aims of our project is to identify ways in which male grief resembles or differs from female one in terms of the metaphors used to describe the experience. This will help to acknowledge the impact that avoidance and coping behaviours as a result of a pregnancy loss may have on men, on their health and socio-professional life. In order to address this RQ, women and men will be interviewed individually (as described in the methodological notes in the Work Packages in Section I.c below). This gender difference is an important complement to the UK “Death before Birth” project.

5) What is the social and cognitive impact of neologisms denoting the deceased baby and their parents?

One of the functions of neologisms, as pointed out by Sablayrolles (2000), is a stabilising or demiurgic function, i.e. it provides the idea of a stable existence of the referred entity (see also Murano 2019). The idea that words stabilise what is named is also found in Schmid (1998:3) referring to Talmy (1991) who talks about “conceptual encapsulation” and the reification of an experience (the “ascription of entityhood”). In reference to hypostatisation, Schmid (1998:3) mentions that one of the effects of neologisms is that they allow the cognitive content to be “stored as an experiential *gestalt* in long-term memory”. In other words, neologisms accord (conceptual) unitary status to an enormous variety of different experiences. They thus have the potential to serve a powerful function in the context of pregnancy loss. In the “Words Fail Me” project, we will observe how the use of certain words (e.g., *sterrenkind/sterrenouder* in Dutch) can help parents better conceptualise and accept their condition. These novel forms are informationally relevant not only in allowing the father/mother to identify themselves as “parents”, thereby giving existence (“reification”) to the baby they have lost, but also breaking the taboo. The hypostatisation effect is not restricted to people who have experienced the denoted concept. For people who have not experienced perinatal death, the existence of a word to designate the bereaved parents and their deceased baby insinuates the existence of such experience, but also that there are people for whom this experience is worth encapsulating in a new word. The existence of novel/*ad hoc* created lexical items is so crucial in the process of conceptualizing and processing the events that new words are spontaneously and randomly making their first appearance in French- and English-speaking ‘bereaved communities’ (e.g. *mamange/parange/parent désenfanté* in French, or *angel baby* in the UK).

6) How do parents themselves evaluate existing terms and neologisms? And to what extent do neologisms spread beyond the close-knit circle of the bereaved?

By means of questionnaires, we will inquire, for French, about bereaved parents’ evaluation of existing (or newly created) terms to refer to themselves and their deceased baby, and measure specific variables in the selection of a set of possible neologisms considered fitting; respondents will also be asked to suggest possible alternatives to existing ones. Part of the questionnaires will be devoted to how people react to a set of different terms used to designate the deceased baby or the parents themselves. The aim will be to identify a selection of linguistic expressions that can better accommodate bereaved parents’ emotional needs. These expressions would be used to replace some infelicitous lexical items currently in use to refer to the deceased baby (e.g. “remains of pregnancy”). For Dutch, whose neologisms *sterrenkind/sterrenouder* are more conventionalised in official documents and the media, the questionnaires will be different, as they will explore the degree of conventionalisation of these already existing terms, among bereaved and non-bereaved parents. We also plan a corpus study to measure their degree of conventionalisation in Dutch.

Among the **technical barriers** to be lifted during this project, there is a risk that respondents may become distressed during data collection because of the sensitive nature of the topic under discussion in interviews and questionnaires. Recalling the experience of loss will evoke various emotions in the person telling their story even though they may well find the experience of sharing that story to be cathartic or validating of that experience. If an interviewee requires a break during the interview or would like to end or postpone the interview, these options will be made explicitly available to them. If the researcher senses that an interview should end or be postponed because of the participant’s level of distress, then they will suggest that the interview should stop for a break, or stop completely. To make sure that the respondents are not left in distress at the end of the interviews, debriefing sessions will be proposed and a list of contact information will be

shared with parents (e.g. *Association Nos Tout-Petits, Dispositif d'écoute « Mieux traverser le deuil »* created by Christophe Faure⁹).

All members of the research team responsible for conducting the interviews will be able to contact another member of the research team on the day of the interview for immediate debrief if required. We will also be holding a group debrief at weekly intervals in order to support each other. As further support measures to safeguard the well-being of research team members, the project coordinator will guarantee that:

- interviewers and transcribers undertake condensed bereavement support and sensitivity training (2 days) offered free of charge by the French and Belgian charities involved in the project.
- a dedicated budget line is added to pay for the support of an external supervisor working for the charities involved in the project who will offer psychological support to the researchers and non-permanent assistants involved in the interviews and their transcription during the 12-month period of data collection (see Work Package 1). Per language involved in the project (French and Dutch), psychological support sessions will take place on demand over the 12 months, and at least once every 2 months for a duration of 2 hours (hourly rate: approx. 122 Euros). For the *Nos Tout-Petits* (NTP) charity, the expert on perinatal bereavement in charge of psychological counselling is Bruno Fhon, who also offers regular support to the volunteers of the NTP charity.

Another challenge will be to be able to recruit a sufficient number of parents willing to participate. The solution which ensures the feasibility of collecting the interviews is assured by the confirmed collaboration (in the form of a written agreement) with associations in France (*Nos tout petits*¹⁰, *NTP*) and in Flanders, Belgium (*Sterrenkinderen, Met lege handen, Berrefonds, Boven de wolken*¹¹). A call for participation has already been published via the social networks of the French charity *NTP* in March 2022 and parents have already been added to the list of future participants to the interviews. Some parents invited for the interview will be somehow more inclined to this kind of experience (interviews) as they have already participated in perinatal bereavement support groups organised by these charities. However, this will not be an inclusion criterion for the selection of the respondents.

b. Position of the project as it relates to the state of the art

The project “PERINAT: ‘Words Fail Me’: Naming the Unnamable” takes as its point of departure the findings from a study entitled: “Death Before Birth: Understanding, informing and supporting the choices made by people who have experienced miscarriage, termination and stillbirth” conducted by an interdisciplinary team of UK researchers (including Professor Littlemore and Dr Turner, also involved in this project) in 2016-2018. The study, funded by UK Economic and Social Research Council, was designed to investigate:

- how parents in England who have experienced pregnancy loss describe their experiences;
- the advice they were given regarding the cremation, burial and/or memorialisation of their baby;
- the extent to which the advice they received reflected guidance offered by the Human Tissue Authority;
- the ways in which friends, colleagues and healthcare professionals communicated with them about the loss.

The team conducted a series of interviews with: women who had experienced pregnancy loss (miscarriage, stillbirth and termination following a diagnosis of foetal anomaly) and their partners; midwives, funerary practitioners, and support agency workers. They also conducted textual analyses of patient information leaflets, consent forms, hospital protocols and other forms of documentation. Their analyses focused both on what was said and how it was said, paying particular attention to metaphor and other forms of figurative language, as these provide valuable insights into the ways in which people conceptualise life-changing experiences (Semino 2011). They found:

- More consistency is required in the range of information and support being offered to parents. Options around burial and cremation are not always made clear to the bereaved. Some Hospital Trusts do not offer the full range of memorialisation options because the Guidance produced by the Human Tissue Authority (2015) is somewhat unclear to them. Written and verbal communication of the options available to bereaved parents is sometimes euphemistic and vague in both content and delivery. As a result, parents often lack crucial information about the choices available.
- Parents exhibit a wide range of attitudes towards the foetus following pregnancy loss, with some viewing them as a ‘baby’ and others viewing them as ‘a pregnancy’. These views which reflect different kinds of

⁹ <https://mieux-traverser-le-deuil.fr/> (Last accessed: March 8, 2022).

¹⁰ <http://www.nostoutpetits.fr/> (Last accessed: March 8, 2022).

¹¹ <https://www.berrefonds.be;> <https://www.sterrenkinderen.be;> <https://metlegehanden.be;> [https://bovendewolken.be.](https://bovendewolken.be;) (Last accessed: March 8, 2022).

metaphorical thinking, do not map neatly onto the gestational period (so legal and care-based assumptions should not be made about the levels and types of grief experienced by people at these different stages), and not all of them are recognised in legislative procedures regarding memorialisation, registration and certification. Indeed, the registration itself was reported as having been a very difficult process. The need to engage in memorialisation activities, such as funerals, and a desire to receive the ashes of the body following cremation, can occur at any stage of gestation, as the metaphorical rituals associated with this can constitute an important part of the grieving process.

- A parent's world-view, as expressed through their use of metaphor, can be radically affected by the experience of perinatal death. When talking about the loss, they draw on conventional metaphorical scripts but supplement them with their own metaphorical experiences when they are trying to capture the individuality of their experience and their chosen memorialisation processes. For parents who opt for a cremation, the retention of the ashes is a particularly important outcome as it helps them retain a physical (albeit metonymic) attachment to their baby. It is important for funeral directors to take these needs into consideration.
- Parents who have experienced pregnancy loss sometimes develop paradoxical construals of time in which it is metaphorically displaced, expanded, or experienced in other non-conventional ways, and this affects their decision-making processes.
- As in other cases of bereavement, parents who have experienced pregnancy loss often use metaphor to report feelings of displacement and disorientation, a sense of a 'divided self' or 'mind-body separation' and a lack of 'ownership' over their thought processes. They want to be able to make decisions but to do so effectively they need appropriate support and guidance from professionals who understand their circumstances and their feelings of loss of agency. The quality of the communication is a determining factor in this respect in shaping whether or not they report a positive experience.

The findings from the DbB research project have been translated into national policy formulation by the Human Tissue Authority, improvement to the national bereavement care pathways, and the development of continuing professional development materials for midwives, registrars and funeral directors. They have thus had a direct impact on the wellbeing of people who have experienced pregnancy loss.

The project "Words Fail Me" is intended to build on the findings made in the DbB project. It seeks to further understand the experience of pregnancy loss in French and Belgian culture, as the cultural context in which the loss occurs is bound to shape one's experience and this is an as-yet unexplored phenomenon. However, since the DbB project data only focused on the responses of female participants, the comparison with the "Words Fail Me" project will be circumscribed to the data on female subjects. "Words Fail Me" will go beyond the remit of the DbB project by seeking to understand and reduce discursive practices that minimise the fact that parents of deceased babies are still parents. Not only do parents need to protect themselves against these practices but also challenge and change them. "Words Fail Me" aims to help develop alternative discursive practices and to investigate ways of having these practices more widely adopted. Through an additional focus on neologisms (and the resulting hypostatization), the project will also provide a potentially powerful way of shaping discourse around the issue of perinatal loss in France and Dutch-speaking Belgium. A final innovative aspect of "Words Fail Me" is that it will also consider the respective views of men and women and map their metaphor usage to express grief. There has been very little research to date on the ways in which people who have experienced the loss of a baby, or the agencies who offer support to them, use metaphor to frame the experience and come to terms with it. Metaphoric thinking underpins the decisions made by bereaved parents concerning disposal of the remains of pregnancy, the activities they undertake to come to terms with the bereavement, and the ways in which they talk about the experience. This is not surprising given that metaphor is prevalent in the language used to express emotionally charged, life-changing experiences (Semino 2011). Although there has been some research into the use of metaphor to deal with bereavement (Beder 2004; Crespo-Fernandez 2013; Young 2007), there has been no work on the use of metaphor and perinatal death, apart from the DbB project (dealing with English only). Capitulo's (2005) study shows that the use of symbols and rituals in perinatal bereavement counselling can help the bereaved, but does not explicitly deal with metaphor. Studying the metaphors used by the bereaved and those who support them when talking about this emotionally-complex, potentially isolating, experience and the decision-making processes that accompany it, will generate insights into their thinking processes and open up additional lines of communication with support agencies.

An innovative aspect of the "Words Fail Me" project is the focus on bereaved parents' 'return to work' stage, which seems to be particularly problematic (Hazen 2006). Research indicates that the workplace is one of the environments where perinatal bereavement is least recognized (Meunier *et al.* 2021), fostering the

perception of perinatal loss invisibility in both organizational practices and interpersonal relations with colleagues and immediate supervisors.

Another original element of our research is the analysis of the ways in which metaphors used by fathers to describe the experience of perinatal loss differ from those used by mothers. As anticipated in Section I.a (RQ 4), fathers are usually construed in discourse as mere ‘supportive partners’, and their grief is not openly acknowledged and socially legitimated. In this way, the “Words Fail Me” project presents an important complement to the UK DbB project, which focussed almost exclusively on the mothers’ narratives.

The paucity of studies from a linguistic perspective on perinatal death (Raschini 2011; Ruchon 2015, 2017, 2018b), a topic thus far mainly relegated to the fields of psychology and anthropology, underscores the highly innovative nature of the “Words Fail Me” project. Some existing research in linguistics explores the healing value of discourse in situations of vulnerability associated with infant loss (in utero or in the months following the birth) – an aspect of discourse which has been little investigated. This idea, which rests upon the performative value of lexis, is already present in Catherine Ruchon’s work, hence her participation in this project. In her PhD thesis on the subject (Ruchon 2015), she highlights a lexical gap for naming the parent who has lost their child, as previously already mentioned by Cazal (2009). The “Words Fail Me” project seeks to resolve this state of affairs by bringing together, probably for the first time, those affected by this loss and academic scholars, namely by including associations of bereaved parents in the research process, a practice which is not commonplace. The issue of perinatal bereavement is also extremely topical from a socio-political perspective, as it has gained momentum following the recent political turmoil on bereaved parents’ work leave, especially in France¹² and in the UK¹³. This is a subject to which linguists can and must offer a relevant and appropriate answer, which will be beneficial to society as a whole.

c. Methodology and risk management

One obvious way to improve our understanding of perinatal death is to ask people about their experiences and analyse the narratives that they produce. However, simply looking at what they say may not be enough. It is also important to look at *how* they say it. One analytical tool that is useful in this endeavour is metaphor. The ways in which people use metaphor to describe their emotional experiences can provide rich insights into what is inaccessible by means of a mere analysis of the content alone. Furthermore, when people describe intense traumatic experiences, they tend to make use of creative metaphor (Gibbs & Franks 2002). One reason for this is that metaphor allows us to say two things at once as it always works on at least two levels (i.e. the concept being described and the concept being drawn upon to describe it). It thus allows people to express the corporeal and the incorporeal elements of a lived experience simultaneously, in the same phrase. People may therefore reach for metaphors in response to a loss that is both physical and emotional. In their study of the narratives employed by women who had experienced cancer, Gibbs and Franks (ibid., 158) found that the women “embraced the power of metaphorical thought to make sense of the variety, even contradictory, aspects of their experiences”. Finally, metaphor has been shown to be a useful mechanism for exploring experiences that are not widely shared and provides an insight into experiences which may not otherwise be accessible (Littlemore & Turner 2019a, 2019b). The use of metaphor to describe such experiences may result in neologisms that help to reify experiences that might otherwise be underspecified. Such neologisms can serve a crucial function in situations where people’s experiences are literally ‘beyond words’, and it is therefore useful to explore their use and assess their impact within and beyond the bereaved community. Studying the metaphors and neologisms that parents use is thus a powerful way to improve understanding of the experience of reproductive loss, which though widely experienced, remains a social taboo (Layne 2003).

In the light of the above, the project will proceed in five different Work Packages (WPs, some partially overlapping in time) which will each come with their own methodology and specifications:

WP 1: Collection and transcription of data (interviews and questionnaires)

WP 2: Linguistic analysis of recounts (metaphor)

WP 3: Linguistic analysis of neologisms (questionnaires & corpus study for Dutch)

WP 4: Data management

WP 5: Impact and dissemination

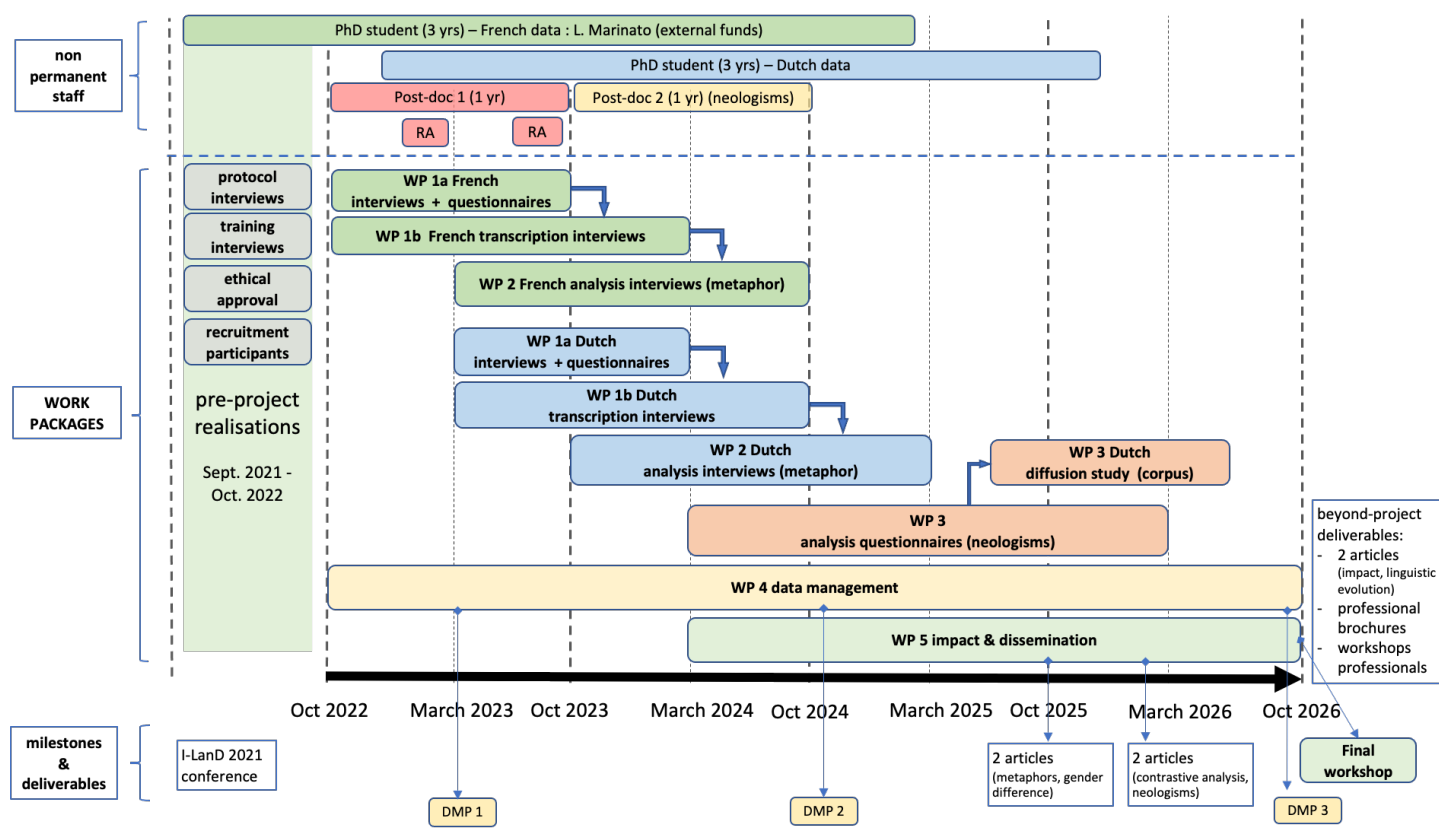
¹²<https://www.france24.com/en/20200204-cold-blooded-technocracy-bereavement-law-fiasco-plunges-macron-s-party-into-turmoil> (Last accessed: March 8, 2022).

¹³<https://www.theguardian.com/lifeandstyle/2020/jan/23/bereaved-parents-entitled-two-weeks-paid-leave-work-uk-jacks-law> (Last accessed: March 8, 2022).

Importantly, some of the work involved in the WPs above has already started in relation to the French language. Thanks to the PhD scholarship from the Région Hauts-de-France (obtained by Maarten Lemmens) we have been able to start the work on the French data collection (done by PhD student Lola Marinato, currently working on metaphors of perinatal loss in French and English) in 2021-2022 and various initial steps have already been undertaken: (i) elaboration of the interview and questionnaire protocols (with the help of the statisticians from the University of Lille, France and the University of Naples ‘Federico II’, Italy); (ii) approval of these protocols by the ethical commission of the university of Lille in February-March 2022 after a thorough revision process (pending minor revisions); (iii) confirmed collaboration agreement with the charity *Nos Tout-Petits* de Lille where Lola Marinato has already attended two bereavement training programmes to support bereaved parents (*Accompagnement du deuil périnatal*, and *Écoute de l’endeuillé.e*¹⁴); and (iv) recruitment of first French-speaking participants for the interviews and questionnaires by means of the charities and their (social) networks. In addition, the project coordinator (together with M. Lemmens & M. Lesuisse at the University of Lille) has already organised the 7th *Langaging Diversity* conference¹⁵ of the international research centre *I-LanD (Identity, Language and Diversity)*¹⁶ that took place at the University of Lille in October 2021 (held remotely due to the pandemic). The organisation of this event has been instrumental in presenting the project to colleagues for the first time and soliciting valuable feed-back from scholars working on topics that are closely related to the one of the conference “The Linguistic Construction of Emotional Challenges in a Changing Society”. The focus of the conference was also on the representation of emotional experiences (such as pregnancy loss) that are silenced because of taboo and on the need to name and represent them linguistically. The conference hosted a panel specially devoted to the “Words Fail Me” project¹⁷. These realizations importantly contributed to the successful start and elaboration of the project.

Gantt chart with WPs and (abridged) overview of milestones and deliverables

The Gantt chart below gives an overview of the planning and deliverables of the project; a more detailed description of each is given in the remainder of this section.



¹⁴ <http://www.nostoutpetits.fr/nos-activites/formations> (Last accessed: March 8, 2022).

¹⁵ Abstracts and proceedings of the 2021 *Langaging Diversity* conference are openly accessible online on the portal of the remote event management company that hosted the event, *Underline*: <https://underline.io/events/183/reception>. Each paper and poster presented has already been assigned a DOI.

¹⁶ http://www.unior.it/index2.php?content_id=19031&content_id_start=1&titolo=il-centro-di-ricerca&parLingua=ENG, (Last accessed: March 8, 2022).

¹⁷ Recording available at: <https://underline.io/events/183/sessions?eventSessionId=7271> (Last accessed: March 8, 2022).

Work Package 1: Collection and transcription of data

Work Package 1 will consist of two parts which may to some extent overlap in time: (1) the collection of the interviews with bereaved parents and (2) the transcription of these interviews.

(1) Collection of interviews. In the first part of WP 1 (months 1-12), we will contact bereaved parents via the different charitable associations in France and Belgium and conduct semi-structured interviews with them for a duration of 60 minutes each. The use of metaphor and neologisms in parents' recounts will be observed and analysed by means of anonymised semi-structured interviews and questionnaires to be administered to a total of 200 bereaved parents (100 male, 100 female), 50 couples¹⁸ in France and 50 couples in Dutch-speaking Belgium. Bereaved parents will be contacted via: (i) a number of charitable associations made up of volunteers and health professionals who support bereaved families¹⁹; and (ii) a "call for participation" launched through the Social Network Sites of the above charities. Mothers and fathers will be interviewed separately in order to help us isolate answers provided by female and male respondents and thus devote the necessary attention to fathers, often neglected subjects in this kind of studies. The fact that the method of sampling of the population consists of couples proves also crucial from a statistical perspective as it will enable the analysis of dyads, an underexplored topic of great interest in statistics literature (Kenny *et al.* 2006). The testimonies shared by single parents will not be discarded, but simply constitute a subcorpus of data that will not be used in the statistical analysis of dyads. This type of study will be conducted in collaboration with Maria Iannario (University of Naples 'Federico II') by relying on her expertise on categorical data analysis.

To compare the results of our study with the earlier British study (DbB), the interviews will follow the template used for data collection of the DbB project, which also conducted a comparable number of interviews. The interviews serve to scrutinise the use of metaphor in parents' narrative with reference to a number of different key moments of their experience: getting the news about their baby's death; communicating their loss; opting for the type of funeral; leaving the hospital; returning to work. Due to the obvious constraints related to the sensitive nature of the subject under study, a specific sampling method will be adopted. A number of respondents (>30 couples per language involved) will be randomly selected by filled-out lists and each of them will be invited to recruit further subjects from their acquaintances by means of a chain sampling. Interviews will however include questions to classify respondents according to a number of socio-demographic variables to further control for some possible exogenous factors. Interviews will be conducted in France and Belgium on native speakers of respectively French and Belgian Dutch, with at least one of the two parents working at the moment of the pregnancy and thus going back to work after the loss.

We will complement this interview-based study by asking bereaved parents to complete a questionnaire to measure the need for and/or the utility of neologisms to designate bereaved parents and their lost baby. Following Kerremans' work (2015), this will allow us to measure the personal utility (degree of identification), the social utility (salience of the extra linguistic reality) or the holistic utility (informativeness and nameworthiness) of the neologisms under scrutiny. Part of the questionnaires will be devoted to how bereaved parents rate a set of self-designating terms, also extrapolated from different ancient and modern languages and presented as a gloss. This will allow us to collect metalinguistic feedback to evaluate the speakers' acceptability and what motivates it. Our final aim is to identify a selection of lexical items that meet both the emotional and social needs of bereaved parents. In order to be able to evaluate how neologisms are received outside the circle of the bereaved, the questionnaires will be presented to the same number of non-bereaved parents, who would serve as a comparison reference population. The overall reliability of statistics tests will be guaranteed by the statisticians involved in the project (see Section II below for more details).

Among the **technical barriers** to be overcome during this project, there is a risk that both respondents and interviewers may become distressed during data collection because of the sensitive nature of the topics under discussion. Support measures and solutions to lift these barriers have been already outlined in detail at the bottom of Section I.a.

In light of the current COVID-19 pandemic, a possible fall-back solution if in-person interviews are unauthorised will be to conduct them remotely using the Big Blue Button 3 via the University of Lille server.

(2) Transcription of interviews. The second part of WP 1 (months 3-18) consists of the transcription of the interviews in French and Belgian Dutch, for which we will recruit non-permanent research assistants. Recruitment of such assistants will be possible thanks to the availability of advanced MA students at the

¹⁸ Same-sex parents and single parents will be welcome to share their experience. While same-sex parents will also be included in the study of dyads, data from single parents will form a subcorpus that will not be used in the statistical analysis of dyads.

¹⁹ France: *Nos Tout-Petits*, with their five headquarters in Alsace, Nice, Normandie, la Réunion, Savoie; Flandres: *Sterrenkinderen*, *Met lege handen*, *Berrefonds*, *Boven de wolken*. All have confirmed their collaboration by means of a written agreement.

University of Lille (for French) and M. Lemmens' connections with the KU Leuven university (for Belgian Dutch).

Time plan: (1) collection: 1 year (Oct. 2022 - Oct. 2023);
(2) transcription: 1.5 year (partial overlap with collection of data; Oct. 2022 - March 2024)

Work Package 2: Linguistic analysis of recounts (metaphor)

The transcripts of the interviews will be uploaded into NVivo²⁰ for coding. NVivo is a qualitative research package which is used to assist in data organisation and annotation using a set of user-defined categories. For our analysis, we will focus on the main parts of the interviews where individuals were explicitly talking about their experience of the loss, their ways of dealing with it, the choices they made regarding memorialisation and remembrance, and people's reactions to their loss (also upon their return to work). For the analysis, we will be using the method that was used in the UK "Death before Birth" project; by using a method that has successfully been applied before, we will overcome the challenge of subjective analysis; this also vouches for comparability of the data. The analysis will start as the transcriptions are being delivered; hence the time overlapping between the transcription (WP 1) and the analysis in the planning (WP 2).

The analysis will proceed in different phases. First, we will identify the metaphors at the level of the phrase following a procedure produced by Cameron (2003). Within these phrases we will ensure that the metaphorically used items are genuinely metaphorical by using an adapted version of the PRAGGLEJAZ Group (2007) Metaphor Identification Procedure which obliges the analyst to identify a relationship involving similarity. Second, we will classify the metaphors into broad categories that reflect the semantic fields to which the vehicle terms belong. In our identification of these metaphor categories, we will not make any assumptions about conceptual metaphor or source domains, so not all of the categories of metaphor that we identify will be found in established metaphor lists (e.g. Lakoff & Johnson 1980; Grady 1997). In some cases, one linguistic metaphor will be assigned to more than one metaphor category and some categories will be more overarching than others. So that we do not miss any important information, we will adopt a maximally inclusive approach in which all categories are treated at the same level despite the fact that some categories may presuppose others. While metaphors will be a central element in our investigation, they do not exhaustively characterise the data. A third level of analysis therefore consists in identifying all the topics that parents talk about, and the key things that are said, even if no metaphors are being used. By doing so, we get a full view of what is being talked about, and how. Within the metaphors identified we will then mark up those that are creative (using an adapted version of the procedure employed by Müller, 2010) and those that result in neologisms (using the manual component of a procedure employed by O'Donovan & O'Neill in 2008). We will then group these data in different ways in order to identify the ways in which the parents conceptualise: their experiences of pregnancy and neonatal loss, and the communication they had with healthcare professionals and others. We will also use these data to identify key terms that are used by the parents and will test people's responses to those terms in WP3.

Time plan: 1.5 years (March 2023 – Oct. 2024)

Work Package 3: Linguistic analysis of neologisms (questionnaires)

The next step in our project aspires to measure the social impact of linguistic choices in the context of perinatal loss. To do so, we have designed a questionnaire to elicit responses from bereaved and non-bereaved parents on the neologisms used to designate parents having experienced perinatal death and their babies. Work Package 3 will consist of three parts: (1) Questionnaire design (partly completed, see Gantt chart), (2) Questionnaire implementation, and (3) Questionnaire analysis.

(1) Questionnaire design. As far as the contents are concerned, we will administer questionnaires in which French and Belgian Dutch-speaking parents will, once again individually, be presented with a number of neologisms used to denote bereaved parents and their babies (as anticipated in WP1(1)). Respondents will be asked to express their opinion on existing or possible word choices by means of rating answers. In a more open section of the questionnaire, parents will also be asked to suggest alternative metaphors and neologisms that they feel would be better suited to refer to given situations or subjects ("To what extent do you think this term is useful?"; "How appropriate do you think this term is for...?"). The questions about neologisms will inquire about the parents' evaluation of existing (or newly created) terms to refer to the deceased baby and/or their parents; for Dutch, there already exist such neologisms (*sterrenkind/sterrenouder* 'star child/star parent') that

²⁰ <https://www.qsrinternational.com/nvivo> (Last accessed: March 8, 2022).

begin to be more widely used, also in the media and official documents, but this is not yet the case for French. For this reason, the questionnaires administered to Dutch-speaking parents will be different, as we they will explore the degree of conventionalisation of these already existing locutions.

The questionnaire has been designed with the support and expertise of statistician Aurore Lavigne, Associate Professor of Applied Statistics at the University of Lille (*Laboratoire de mathématiques Paul Painlevé*, UMR CNRS 8524), who has supervised the stages of questionnaire design and testing, as well as guaranteed the overall statistical reliability of the questionnaires administered to bereaved parents. The questionnaire format completed in this WP will also be conducive to a corpus-assisted language analysis when the data collected will be searched electronically and investigated using quantitative methods and statistical techniques. Maria Iannario, Associate Professor at University of Naples ‘Federico II’, will supervise the quality of data collection and the sample design whereas Rosa Fabbricatore, a psychologist who is currently also a PhD candidate in Social Sciences and Statistics at University of Naples ‘Federico II’, will evaluate the reliability of data by means of proper statistical methods. The participation of Rosaria Romano will concern data analysis.

(2) Questionnaire implementation. Since questionnaires had not been envisaged by the earlier “Death before Birth” project, this step will only concern France and Dutch-speaking Belgium.

For Belgian Dutch, the questionnaires will be geared towards the degree of conventionalisation of the existing neologisms, which will be complemented by a corpus-based lexical diffusion study measuring to what extent the term is being picked up by media and official instances.

Since we intend to compare the discursive choices of bereaved parents to society in general (i.e. also outside the circle of the bereaved, so as to address Research Question n.2 on conventional vs creative uses of metaphor), the choice of neologisms will be investigated by administering the same questionnaire to both the bereaved and to a control corpus of non-bereaved parents. The number of questionnaires will have to be sufficiently large if we intend to control statistical risks in the treatment of data; we will therefore administer questionnaires to 100 bereaved and 100 non-bereaved parents for each language involved.

For each subpopulation (according to the language [French and Belgian Dutch] and to the type [bereaved and non-bereaved parents]), respondents will be randomly sampled, but in the questionnaires there will be questions to classify them according to their age, ethnicity, gender, socio-demographic profile, political affiliation and religious orientation in order to further control for some possible exogenous factors. This will enable us to gauge the effect of factors such as age, sex, language, etc. on the choice of neologisms.

(3) Questionnaire analysis. The data will be analysed using adapted quantitative methods and statistical techniques, drawing again on the support and expertise of the statisticians in our research team.

Time plan: (1) design: 3 months (mostly completed in March 2022)

(2) implementation: 1 year (For French: starting October 2022; for Dutch: starting March 2024)

(3) analysis: 1.5 years (For French: starting March 2023; for Dutch: starting October 2023)

Work Package 4: Data management

As required by the French National Research Agency (ANR), a Data Management Plan (DMP) will be developed six months after the start of the project (DMP1), specifying all the necessary details about the project-generated data (methodology, documentation, storage procedures, ethical issues, dissemination, and so on). The University of Lille library will support us in drafting and implementing our DMP, which will be updated half-way through the project (DMP 2; M24) and finalized at the end (DMP 3; M48).

There will be two main types of data: recounts of experiences by bereaved parents (recorded interviews and transcriptions) and responses from questionnaires. We will get into touch with these parents via the associations with whom we have a written agreement confirming their participation. All the data will be anonymized, stored in a secured and encrypted way, and only members of the consortium will have access to them. All researchers who have access to the recordings and/or transcriptions will sign a non-disclosure agreement. Before data are collected, we will contact the Data Protection Officer of the University of Lille to discuss all relevant legal and ethical aspects. Participants will be asked to sign a consent form giving their consent that the data be used, in anonymous format, for research purposes only. We will make some of the research data available in an institutional repository such as the European data repository *Zenodo*, a platform of the European Commission where a corpus of data can be safely stored free of charge²¹. The coordinator

²¹ <https://zenodo.org/communities/ecfunded/> (Last accessed: March 8, 2022).

already has experience with data availability policies as she has already made the corpus of one of her studies freely available on *Zenodo*²². Anonymized interview transcripts will temporarily be held in encrypted Word and Excel files on the researchers' password protected computers. The recordings of the interviews will be digital and will temporarily be stored on the same computers and the University of Lille's secure data sharing facility *NextCloud*. The interview transcriptions and their codings will be stored on a secure repository with restricted access (*Zenodo* or UdL *NextCloud*) for ten years after the end of the project.

Time plan: 3.5 years (Oct. 2022 – March 2026)

Work Package 5: Impact and dissemination

To ensure that our work is impactful, we will provide input into the care pathways that are offered to people who have experienced pregnancy and neonatal loss. We will also feed into guidance and continuing professional development materials for medical doctors, midwives, funeral directors, registrars and employers. In order that the input reaches the largest possible number of people and that it is correctly targeted, we will work with the organisations that are responsible for providing continuing professional development for these groups of people. We will work with these organisations from the project's inception through to its end and beyond. To ensure wide public dissemination of our findings, we will publish papers in professional journals for midwives, funeral directors and registrars across France and Belgium and run a series of public-facing workshops. This is in addition to at least 6 academic publications (on naming and neologisms, the performative nature of language, contrasting metaphors in French, Dutch and UK discourse on perinatal death and gender differences in the experience of perinatal death) and to the 6 conference presentations (on the above topics) that we will produce and deliver. All peer-reviewed scientific publications will be made available through immediate open access. Following the ANR open access requirements, we will make the publications available in the French national repository HAL and in the UK open access platform PURE²³.

In addition to participating in international conferences to disseminate our findings, we will organise a final workshop where we will disseminate the results of the project. In addition to the project team members, we will invite academics working on perinatal death, metaphor, neologisms and healthcare discourse, and professionals who support people through the experience of perinatal death (support workers, midwives, doulas, registrars, funeral directors and counsellors) as well as representatives of the press including medical journalists. More information about the broader societal impact of our project on those affected and those who support them is provided in Section III.

Time plan: 2.5 years (March 2024 - October 2026)

II. Impact and benefits of the project

In addition to the academic dissemination detailed in Work Package 5, our project will have social impact through informing and improving care pathways of parents who have experienced pregnancy loss, termination, stillbirth, neonatal death, or palliative (end of life) neonatal care for newborns. As a societal challenge, this project intends to stimulate the political and professional debate on the consequences of perinatal death to make a transformational change in terms of the communication experience of bereaved parents, mainly by informing the communication choices of those who seek to support and advise them in medical and non-medical contexts.

We will mainly work with support agency/charities, such as *Nos Tout-Petits* in France and the Flemish associations (*Sterrenkinderen*, *Met Lege Handen*, *Boven de wolken*, *Berrefonds*), that strive to improve the

care for the bereaved in a range of contexts. By working with them, our research findings will inform best practice in supporting the bereaved since charity staff and volunteers play a key role in conveying information and guidance to them. Collaboratively with these organisations, we will create briefing documents on the different ways in which bereaved parents use metaphor to understand, come to terms with, and communicate their experiences, as well as outline ways in which this information can be used by counsellors. The above material could be distributed via the web page of the “Words Fail Me” project, also to be created for dissemination purposes.

In addition, the findings of our study will provide material for, and inform revisions to, these charities’ already existing training programmes for midwives and doulas, volunteers, counsellors, funeral directors, registrars, journalists and employment organisations. In particular, we will work in collaboration with the *Collège National des Sages-femmes de France*²⁷, the Flemish association for midwives (*Vlaamse Beroepsorganisatie van Vroedvrouwen*²⁸), The Doulas de France association²⁹ and the *Vlaamse Federatie van Doulas*³⁰ and the French and Flemish Registrars (*Etat civil; Dienst bevolkingsregistratie*). Thanks to our contribution as linguists and communication experts, the above training programmes will be improved by suggesting an open, ethical and respectful communication as standardised practice in the event of perinatal death, helping parents come out of the isolation that exacerbates their condition.

We will also encourage these charities to establish contact with Funeral Directors’ associations, such as the *Association Française d’Information Funéraire*³¹ and the *Flemish union of undertakers*³² to open up a dialogue with funeral directors and crematoria managers in order to provide support and guidance on the implementation of health-related regulations when arranging funerals and death rituals for bereaved parents.

As for the dissemination of project results, our research group will participate and deliver project-related presentations within the framework of far-reaching initiatives to promote and popularise scientific culture, such as the *Fête de la Science*³³ et *The Pint of Science Festival*³⁴. Other dissemination initiatives to citizens will involve: setting up a web page of the project; organising seminars in high schools to meet pupils and teachers and raise awareness about the communication needs of bereaved young adults/peers; and the participation in radio programmes bridging between scientific research and citizen debate, such as *La Méthode scientifique on France Culture*³⁵ and *Nieuwe feiten* (“New facts”) on Radio1 (information programme on national Flemish radio). Research team members may also consider using podcast technology to reach a broad range of citizens in the dissemination of their results and increase the societal impact of their studies; possible outlets in this direction include *Un podcast à soi* (Arte Radio)³⁶ and *Universiteit voor Vlaanderen* (podcast on research topics on Flemish national radio)³⁷.

To conclude, achieving the main aims of this project will address a broader societal challenge in terms of public knowledge: the need to break the silence that currently surrounds perinatal death and raises awareness of an area of family life that is little talked about. Our project also intends to translate its results into practical recommendations for political reform, thus embracing a practice-based perspective on the study of metaphor (Reisfield & Wilson 2004). This perspective focuses on how metaphors can help communication in specific institutional settings (e.g. healthcare) with the final aim of making policy recommendations about which metaphors should be adopted or objected to in the light of the conceptual processes that they are associated to (Semino *et al.* 2018: 626). The insights we will gather on the use of metaphor will highlight the most difficult steps of this challenging experience and will be used to improve the quality of life of these parents at specific steps of their bereavement experience. For instance, we hypothesize that some stages of the perinatal loss experience can be particularly problematic for parents, such as the moment they have to give their farewell to their stillborn baby at discharge from hospital, as confirmed by findings in the field by Lindgren *et al.* (2014). In this study mothers describe the separation from the child when leaving hospital empty-handed as unnatural

²² <https://www.cnsf.asso.fr/> (Last accessed: March 8, 2022).

²³ <https://www.vroedvrouwen.be/> (Last accessed: March 8, 2022).

²⁴ <https://doulas.info/en/welcome/> (Last accessed: March 8, 2022).

²⁵ <https://dedoula.be/> (Last accessed: March 8, 2022).

²⁶ <http://www.afif.asso.fr/francais/> (Last accessed: March 8, 2022).

²⁷ <http://uitvaartunie.vlaanderen/> (Last accessed: March 8, 2022).

²⁸ <https://www.fetedelascience.fr/> (Last accessed: March 8, 2022).

²⁹ <https://pintofscience.fr/mondial> ; <https://pintofscience.fr/about/> (Last accessed: March 8, 2022).

³⁰ Émission sur les “sciences, et sur les problématiques éthiques, politiques, économiques et sociales qui font l’actualité de la recherche” <https://www.franceculture.fr/emissions/la-methode-scientifique> (Last accessed: March 8, 2022).

³¹ https://www.arteradio.com/auteurs/charlotte_bienaime (Last accessed: March 8, 2022).

³² <https://radio1.be/universiteit-van-vlaanderen-podcast-overzicht> (Last accessed: March 8, 2022).

and clashing against the biological instinct of motherhood and protection of the offspring felt during pregnancy. The findings of our study, with specific reference to the use of metaphor, will corroborate recommendations for national policy, for example for the introduction of routines for a dignified goodbye at the hospital, including designating a deputy guardian into whose arms a parent could place the baby to facilitate the separation (Lindgren *et al.* 2014), as it is already the case in countries like Sweden. The possibility of leaving the baby in the arms of someone known to the parents should be an option for parents who choose to take farewell of the child at the hospital.

III. References related to the project

- Beder, J. (2004). *The voices of bereavement: a casebook for grief counselors*. London: Routledge.
- Bensing, J. (2000). Bridging the gap: The separate worlds of evidence-based medicine and patient-centered medicine. *Patient Education and Counseling*, 39(1), 17–25.
- Borkman, T. (1976). Experiential knowledge: A new concept for the analysis of self-help groups. *Social Service Review*, 50(3), 445–456. <https://doi/abs/10.1086/643401>
- Caliendo, G. (2022). Vaccine nationalism or ‘Brexit dividend’? Strategies of legitimation in the EU-UK post-Brexit debate on COVID-19 vaccination campaigns. *Societies* 12(37). <https://doi.org/10.3390/soc12020037>
- Caliendo, G., Ruchon, C. (2020). La nomination des enfants décédés en bas-âge et de leurs parents. D’une analyse du discours située à une linguistique d’intervention. *SHS Web of Conferences* 78, 01019.
- Caliendo G., Iannario M. (2009). Communicating European Values in Institutional Discourse: a Statistical Model for the Analysis of Citizens’ Perception of the EU. *Glottology, International Journal of Theoretical Linguistics*, 2, 19-40.
- Cameron, L. (2003). *Metaphor in educational discourse*. London : Continuum.
- Capitulo, K. (2005). Evidence for healing interventions with perinatal bereavement. *The American Journal of Maternal/Child Nursing*, 30(6), 389–396.
- Cazal, Y. (2009). Une lacune qui fait parler : quand le discours spontané sur le lexique s’exerce sur la lacune lexicale : “mère-qui-a-perdu-son-enfant”. Dans Achard-Bayle G., Lecolle M. (éds.), *Recherches linguistiques*, 30, 105–121.
- Chung, M.C., Reed, J. (2017). Posttraumatic stress disorder following stillbirth: trauma characteristics, locus of control, posttraumatic cognitions. *Psychiatric Quarterly*, 88, 307–321.
- Crespo-Fernandez, E. (2013). Euphemistic metaphors in English and Spanish epitaphs: A comparative study. *Atlantis*, 35(2), 99–118.
- Dancygier, B., Sweetser, E. (2014). *Figurative language*. New York: Cambridge University Press.
- Due, C., Chiarolli, S., Riggs, D.W. (2017). The impact of pregnancy loss on men’s health and wellbeing: a systematic review. *BMC Pregnancy and Childbirth*, 17(1), 380. <https://bmcpregnancychildbirth.biomedcentral.com/track/pdf/10.1186/s12884-017-1560-9.pdf>
- Foubert, O. (2021). Institutionalisation, conventionalisation, and the social nature of neologisms. *Neologica*, 15, 117–132.
- Foubert, O., Lemmens, M. (2018). Gender-biased neologisms: the case of *man-X*, *Lexis*, 12 (special issue: *Lexical and Semantic Neology in English*). <http://journals.openedition.org/lexis/2453>
- Fuoli, M., Littlemore, J., Turner, S. (2021). Sunken Ships and Screaming Banshees: Metaphor and evaluation in film reviews. *English Language and Linguistics*. *English Language and Linguistics*, 26(1), 75–103. doi:10.1017/S1360674321000046.
- Fricke, M. (2007). *Epistemic injustice: power and the ethics of knowing*. Oxford: Oxford University Press.
- Gibbs, R. W. (2016). *Mixing metaphor*. Amsterdam/Philadelphia: John Benjamins. <https://doi.org/10.1075/milcc.6>
- Gibbs, R. W., Franks, H. (2002). Embodied metaphor in women’s narratives about their experiences with cancer. *Health Communication*, 14(2), 139–165. https://doi.org/10.1207/S15327027HC1402_1
- Grady, J. (1997). Foundations of meaning: primary metaphors and primary scenes. Unpublished PhD Thesis. University of California at Berkeley.
- Gravensteen, I.K., Helgadottir, L.B., Jacobsen, E.M., Sandset, P.M., Ekeberg, Ø. (2012). Long-term impact of intrauterine fetal death on quality of life and depression: a case-control study. *BMC pregnancy and childbirth*, 12(1), 1–9.
- Gravensteen, I. K., Jacobsen, E. M., Sandset, P. M., Helgadottir, L. B., Rådestad, I., Sandvik, L., Ekeberg, Ø. (2018). Anxiety, depression and relationship satisfaction in the pregnancy following stillbirth and after the birth of a live-born baby: a prospective study. *BMC pregnancy and childbirth*, 18(1), 1–10.
- Hazen, M. A. (2006). Silences, perinatal loss, and polyphony, A post-modern perspective. *Journal of Organizational Change Management*, 9(2), 237–249.
- Hazen, M. A. (2009). Recognizing and responding to workplace grief. *Organizational Dynamics*, 38(4), 290–296.
- Heazell, A. E. P. (2016). Stillbirth – a challenge for the 21st century. *BMC Pregnancy and Childbirth*, 16, 387–388.
- Hunter, A., Tussis, L., MacBeth, A. (2017). The presence of anxiety, depression and stress in women and their partners during pregnancies following perinatal loss: a meta-analysis. *Journal of Affective Disorders*, 223, 153–164.
- Keeble, C.J., Loi, N.M., Thorsteinsson, E.B. (2018). Empathy and the public perception of stillbirth and memory sharing: an Australian case. *Frontiers in Psychology*, 1629.
- Kenny, D., Kasy, D., Cook, W. (2006). *Dyadic Data Analysis*. London: The Guilford Press.
- Kerremans, D. (2015). A Web of New Words. *A Corpus-Based Study of the Conventionalization Process of English Neologisms*. Frankfurt am Main: Peter Lang.
- Lakoff, G., & Johnson, M. (1980). *Metaphors we live by*. Chicago: University of Chicago Press.
- Lang, A., Fleischer, A. R., Duhamel, F., Sword, W., Gilbert, K. R., Corsini-Munt, S. (2011). Perinatal loss and parental grief: the challenge of ambiguity and disenfranchised grief. *Omega: Journal of Death and Dying*, 63, 183–196.
- Layne, L. L. (2003). *Motherhood lost: a feminist account of pregnancy loss in America*. New York: Routledge.
- Leech, G. (1981). *Semantics. The study of meaning*. Harmondsworth: Penguin Books.
- Lemmens, M. (2015). Cognitive semantics. *Routledge Handbook of Semantics*. Riemer, N (ed), 90–105 London/New York: Routledge.
- Lemmens, M. (2021). *Usage-based perspectives on lexical and constructional semantics*. Shanghai: SFLE Press.

- Lemmens, M., Caliendo, G, Foubert, O., Marinato, L. (2021). Neologisms and metaphors applied to societal issues. Presentation held at the international conference *Language Diversity 2021*, October 13–15, 2021. doi: 10.48448/nctr-gw75. Available in OA: <https://underline.io/events/183/schedule?day=2021-10-13T22%3A00%3A00.000Z>.
- Lindgren, H., Malm, M. C., Rådestad, I. (2014). You Don't Leave Your Baby—Mother's Experiences after a Stillbirth. *OMEGA-Journal of Death and Dying*, 68(4), 337–346.
- Littlemore, J. (2019). *Metaphors in the mind: sources of variation in embodied metaphor*. Cambridge: Cambridge University Press.
- Littlemore, J., McGuinness, S., Fuller, D., Kuberska, K., Turner, S., (2020). Death before Birth: understanding, informing and supporting the choices made by people who have experienced miscarriage, termination, and stillbirth. *MIDIRS Midwifery Digest*.
- Littlemore, J., Turner, S. (2019a). Metaphors in communication about pregnancy loss. *Metaphor and the Social World*.
- Littlemore, J., Turner, S. (2019b). What can metaphor yell us about experiences of pregnancy loss and how are these experiences reflected in midwife practice? *Frontiers in Communication*, 4, 1–17. <https://doi.org/10.3389/fcomm.2019.00042>
- Lundorff, M., Holmgren, H., Zachariae, R., Farver-Vestergaard, I., O'Connor, M. (2017). Prevalence of prolonged grief disorder in adult bereavement: a systematic review and meta-analysis. *Journal of affective disorders*, 212, 138–149.
- Markin, R. D., Zilcha-Mano, S. (2018). Cultural processes in psychotherapy for perinatal loss: breaking the cultural taboo against perinatal grief. *Psychotherapy*, 55(1), 20.
- McCreight, B.S. (2004). A grief ignored: narratives of pregnancy loss from a male perspective. *Sociology of Health and Illness*, 26, 326–350. <https://onlinelibrary.wiley.com/doi/10.1111/j.1467-9566.2004.00393.x>
- Meunier, S., de Montigny, F., Zeghiche, S., Lalande D., Verdon, C., Da Costa, D., Feeley, N. (2021). Workplace experience of parents coping with perinatal loss: A scoping review. *Work*, 69(2), 411–421. DOI: 10.3233/wor-213487
- Miller, R. S. (2010). Speak up: 8 words and phrases to ban in oncology!, *Oncology Times*, 32(12), 20.
- Müller, R. (2010). Critical analysis of creative metaphors in political speeches. *Researching and Applying Metaphor in the Real World*. 321–332. Amsterdam/Philadelphia: John Benjamins.
- Murano M. (2019). La néologie dans les dictionnaires collaboratifs, *Neologica, La néologie à l'ère de l'informatique et de la révolution numérique*, 13, 143–162.
- O'Donovan, R., O'Neill, M. (2008). A systematic approach to the selection of neologisms for inclusion in a large monolingual dictionary. In *Proceedings of the 13th Euralex International Congress*, 571–579.
- O'Leary, J., Thorwick, C. (2006). Fathers' perspectives during pregnancy, postperinatal loss. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 35(1), 78–86. <http://doi.org/10.1111/j.1552-6909.2006.00017.x>
- Pluut, B. (2016). Differences that matter: developing critical insights into discourses of patient-centeredness. *Medicine, Health Care and Philosophy*, 19, 501–515. <https://doi.org/10.1007/s11019-016-9712-7>.
- PRAGGLEJAZ Group. (2007). MIP: a method for identifying metaphorically used words in discourse. *Metaphor and Symbol*, 22(1), 1–39. <https://doi.org/10.1080/10926480709336752>
- Raschini, E. (2011). *L'approximation en discours. Le débat bioéthique sur l'assistance médicale à la procréation*. Unpublished PhD thesis. Université Paris 13.
- Reisfield GM, Wilson GR. (2004). Use of metaphor in the discourse on cancer. *Journal of Clinical Oncology*, 1/22(19), 4024–7. doi: 10.1200/JCO.2004.03.136. PMID: 15459229
- Ruchon, C. (2015). *Des vertus antalgiques du discours? : L'expression de la douleur et de l'attachement dans les discours sur la maternité*. Unpublished PhD thesis. Université Paris 13 SPC.
- Ruchon, C. (2017). Identité numérique de parents endeuillés. Le pseudonyme comme pratique de deuil, In Guilbert, T., Lefort, P., (éds.), *Discours et (re)constructions identitaires*. Presses Universitaires du Septentrion, 133–148.
- Ruchon, C. (2018a). L'être et le nom : éthique de la nomination dans le cadre du deuil périnatal, *Langage & Société*, 163, 101–119.
- Ruchon, C. (2018b). Une situation d'interlocution spécifique: les discours numériques du parent endeuillé à son enfant décédé. *Semen*, 45, 115–145.
- Ryninks, K., Roberts-Collins, C., McKenzie-McHarg, K., Horsch, A. (2014). Mothers' experience of their contact with their stillborn infant: an interpretative phenomenological analysis. *BMC pregnancy and childbirth*, 14(1), 1–10.
- Sablayrolles J.F. (2000). *La néologie en français contemporain: examen du concept et analyse de productions néologiques récentes*. Paris: Champion, Lexica – Mots et Dictionnaires.
- Schmid, H.-J. (1998). Constant and ephemeral hypostatization: *thing, problem* and other shell nouns. In: Caron, B. (ed), *Proceedings of the 16th International Congress of Linguists (Paris, July 22-25, 1997)*, CD-ROM, Amsterdam: Elsevier.
- Schmid, H.-J. (2008). New words in the mind: concept-formation and entrenchment of neologisms. *Anglia*, 126(1), 1–36. <https://doi.org/10.1515/angl.2008.002>
- Semino, E. (2010). Descriptions of pain, metaphor, and embodied simulation. *Metaphor and Symbol*, 25(4), 205–226. <https://doi/abs/10.1080/10926488.2010.510926>
- Semino, E. (2011). Metaphor, creativity and the experience of pain across genres. In Swann, J., Carter, R., Pope, R. (eds.), *Creativity in language and literature: the state of the art*, 83–102.
- Semino, E., Z. Demjen, Demmen, J. (2018). An integrated approach to metaphor and framing in cognition, discourse, and practice, with an application to metaphors for cancer. *Applied Linguistics*, 39(5), 625–645.
- Talmy, L. (1991). Path to realization: a typology of event conflation. In: *Proceedings of the Seventeenth Annual Meeting of the Berkeley Linguistic Society*. 480–519. Berkeley: Berkeley Linguistic Society..
- Wallerstedt, C., Lilley, M., Baldwin, K. (2003). Interconceptional counseling after perinatal and infant loss. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 32(4), 533–542.
- Weiss, R.S. (2008). The nature and causes of grief. In: *Handbook of Bereavement Research and practice: Advances in Theory and Intervention*. American Psychological Association, 29–44.
- Yilmaz, S.D., Beji, N.K. (2013). Effects of perinatal loss on current pregnancy in Turkey. *Midwifery*, 29(11), 1272–1277.
- Young, E. (2007). Figures of grief: metaphors from a bereavement writing group. *Omega: Journal of Death and Dying*, 56(4), 359–367. <https://doi/10.2190/OM.56.4.d>