
**Good mothers/bad mothers: Grief, morality and gender inequality
in care encounters following perinatal death**

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TESIS DOCTORAL

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Buenas madres/malas madres: Duelo, moralidad y desigualdad de género en la atención sanitaria tras una muerte perinatal

MEMORIA PARA OPTAR AL GRADO DE DOCTOR

PRESENTADA POR

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Presentado por

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DECLARACIÓN DE AUTORÍA Y ORIGINALIDAD DE LA TESIS PRESENTADA PARA OBTENER EL TÍTULO DE DOCTOR

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Abstract

Introduction and objectives: When a baby dies during pregnancy or shortly after birth it can be devastating for women and their families. In Spain, perinatal bereavement care is a relatively new concept and there is a significant lack of information and research on practices in hospitals, women's experiences of care, and the interactive processes that produce social meaning and impact grief. The research set out to address these issues. From a conceptual perspective the study views grief and concepts of pregnancy and motherhood in an interactive, socio-relational, material and historical paradigm, which draws on continuing bonds and narrative reconstruction theory, as well as micro-sociological concepts.

Methods: The study population was defined as women who had experienced a pregnancy loss or neonatal death in the Spanish health system. The research used an ethnographic methodology that combined participant observation with quantitative analysis of survey data with a practice-based narrative/linguistic analysis of stories of care. The fieldwork took place over a three-year period, during which time 10 narrative style qualitative interviews were conducted and 796 women responded to an online survey.

Results: The research found that in general terms perinatal bereavement care is significantly underdeveloped in all aspects of care studied and at least half of hospitals fail to adequately meet the needs of the women they cared for. However, the research also identified significant improvements in care practices between the first and final years of the study. The most significant problems with care related to highly asymmetric decision-making and the absence or tight control of practices related to bereavement. Lack of compassion during care was a less severe issue, but still highly significant. Positive accounts of care related to *compassionate* health professionals (HPs) who contextualised loss within a grief-oriented frame. Contrarily, *cold* and *inhumane* HPs activated a medical frame that silenced grief by focusing care on the body or through the use of gendered discourses of women being overly emotional. Lack of agency in decision-making was sustained by women's situational vulnerability, lack of knowledge and discursive resources about perinatal death, deficiencies in information provision, coercion and dominance gestures, and the naturalisation of paternalism amongst both health professionals and patients. The research also identified specific instances of obstetric violence associated with verbal and physical abuse and lack of informed consent. Significant dissonance was found in the way that women positioned their babies as persons/children compared to how HPs tended to avoid assigning personhood and/or objectified the baby. The findings also found that the denial of access to the body or tight control of 'viewing' events restricted parents' capacities to engage in bereavement rituals and reinforced stigma. When care and bereavement rituals were positive, social practice was consistent with social roles, responsibilities and moral obligations between the mother and child. On the other hand, lack of access to the baby and 'viewing' events could often result in regrets and women questioning their social status and moral standing, subsequently positioning themselves as 'bad' mothers.

Conclusions: Perinatal bereavement care in Spanish hospitals is highly deficient and has a detrimental impact on many women, who represent a highly vulnerable group in the time immediately after the death. Care and grief is heavily shaped by and sustained on gendered inequality. Systemic changes and investment in training are required if care is to aspire to best-practice.

Keywords: Mixed-methods, perinatal grief, gender, morality, care, decision-making, rituals, obstetric violence

Resumen

Introducción y objetivos: La muerte de un bebé durante el embarazo o poco después del parto puede tener un impacto particularmente duro en las mujeres. En España, la atención sanitaria al duelo perinatal es relativamente nueva y existe una importante falta de información e investigación sobre las prácticas en los hospitales, las experiencias de las mujeres y los procesos interactivos que producen el significado social e influyen en el duelo. El objetivo de la investigación fue abordar estas problemáticas. Desde una perspectiva conceptual, el estudio considera el duelo y los conceptos de embarazo y maternidad en un paradigma interactivo, socio-relacional e histórico, aplicando conceptos de duelo como la continuidad del vínculo y la reconstrucción narrativa dentro del marco de la microsociología.

Métodos: La población se definió como las mujeres que habían experimentado una muerte perinatal en el sistema sanitario español. Se utilizó una metodología etnográfica que combinó la participación-observación con el análisis cuantitativo de los datos de una encuesta y el análisis lingüístico de las historias acerca de la atención. El trabajo de campo duró tres años, durante el cual se realizaron 10 entrevistas cualitativas y 796 mujeres respondieron a un cuestionario online.

Resultados: En términos generales, la investigación halló que la atención al duelo perinatal está significativamente infradesarrollada en todos los aspectos estudiados y al menos la mitad de los hospitales no llegaron a un nivel de atención adecuado. Sin embargo, se percibieron mejoras significativas en la atención entre los primeros y los últimos años del estudio. Los hallazgos más significativos se relacionaron con falta de compasión, asimetría en los procesos de toma de decisiones y con ausencia de prácticas relacionadas con el duelo. Los relatos positivos referidos a la atención se relacionaron con profesionales empáticos que contextualizaron la pérdida dentro de un marco orientado al duelo. Por el contrario, el silenciamiento del duelo estuvo asociado a profesionales *fríos* e *inhumanos* que actuaron conforme a un marco médico enfocado exclusivamente en el cuerpo, y que, además, activaron discursos de género que situaron a las mujeres como excesivamente emocionales. La falta de agencia en la toma de decisiones estuvo sostenida por la vulnerabilidad situacional de la mujer, la falta de conocimientos y recursos discursivos acerca de la muerte perinatal, la falta de información procedente de los profesionales, la coerción y manipulación del proceso de toma de decisiones, y la naturalización del paternalismo entre profesionales y pacientes. La investigación también identificó casos específicos de violencia obstétrica, incluyendo abuso verbal y físico, y falta de consentimiento informado. En cuanto a la producción social del significado de la muerte, hubo una disonancia importante en la forma en que las mujeres posicionaron a sus bebés como personas/hijos en contraste con la forma en que los profesionales tendieron a objetivar al bebé. Los resultados también muestran cómo los hospitales a menudo negaban o controlaban el acceso al cuerpo del bebé fallecido, lo que restringió las prácticas relativas al duelo y a menudo reforzaron el estigma. Cuando los rituales fueron positivos, la práctica social fue coherente con las posiciones sociales y las obligaciones morales. Contrariamente, la falta de acceso al bebé tendió a generar remordimientos y cuestionamientos sobre la identidad moral (de los profesionales y de las mujeres mismas) además de sentimientos de considerarse "malas" madres.

Conclusiones: La atención al duelo perinatal en los hospitales españoles es deficiente y tiene un impacto perjudicial en las mujeres, las cuales representan un grupo muy vulnerable en el tiempo inmediatamente posterior a la muerte del bebé. La atención sanitaria y el duelo están fuertemente marcados por la desigualdad de género. Se requieren cambios sistémicos e inversión en formación.

Palabras claves: Métodos-mixtos, duelo perinatal, género, atención sanitaria, toma de decisiones, rituales, moralidad, violencia obstétrica

Section 1.

Introduction

Chapter 1.

Background to the study

1. Jillian, Juan, Uma (manita) and I

My sister Jillian has lived in Spain since 1998. I moved here in 2005. I was taking photographs for a client a few miles outside Madrid in late December 2007 when she called. I went outside. I've forgotten her exact words.

"Uma's dead." Jillian was 39 weeks pregnant. Her voice sounded strange: soft, controlled, not quite right.

"What?" "Yeah, she's dead." The sun glistened on the frosty wild grass. There wasn't a cloud in the sky. "Can you get the camera and bring it to the hospital?"

Juan, her partner, met me at the door. "I'm ... sorry, what happened?" "We don't know. She just died." Following a medical induction, Jillian gave birth to Uma the next day.

Family and friends from Ireland advised Jillian and Juan to see Uma, but they were told that they couldn't. The midwife said it would have a terrible psychological impact, because of Uma's appearance. She also said that by law the father could see her if he really wanted to. No such law exists. The camera wasn't used. Later, Jillian said she found it hard to forgive herself for not fighting to see her.

Most of the health professionals were nice or at least courteous, but there was no talk about the loss, no information about grief or what to expect once they left the hospital. The day after discharge Jillian called and asked for hand and footprints, which she got from a pathologist.

I didn't see her until she was back home. She and Juan looked completely devastated and did so for a long, long time. You try to be there. We didn't talk about it much, although later we did.

On leaving the hospital they started to read about causes of stillbirth and recommended care on English language websites, they couldn't find any in Spanish.

There, they discovered another way of understanding the death of a baby. Other possibilities for more compassionate care that encourages active engagement with the baby after birth. An

approach that stresses a continuation of the social roles and responsibilities developed during pregnancy rather than absence and silence.

Too late for them, if not for others.

In 2008, Jillian and Juan set up a [website](#) where they posted Spanish translations of English information on grief and best practice care. In 2010, they formally established the first national Spanish stillbirth and neonatal death charity: Umamanita [*Uma + little hand in Spanish*]. They set up self-help grief support groups and started an annual commemorative event. They wrote a guide for hospital care, which became widely influential (Umamanita and El Parto es Nuestro 2010). Now, the website has over 7,000 visits a month from Spain and all over the world.

When Umamanita was established, very little was known about perinatal bereavement care in Spanish hospitals beyond the anecdotal. The prevailing ideas were that Jillian and Juans' experience was not untypical, but also that many women experienced care that was significantly worse. Conducting research became a priority for the association.

My own background in commercial research in Ireland led Jillian to ask me to help her with a 'small questionnaire' she was trying to develop. And that was the seed from which this thesis and other research work was germinated. It was what brought me back into research and why I decided to do a Masters in Research Methodology and a Doctoral programme in Anthropology and Sociology at Universidad Complutense de Madrid. Why I've collaborated with the association as a voluntary researcher for the last eight years.

And that's how Jillian and I ended up talking about Uma, grief and death, quite a lot in fact.

Although Jillian didn't see Uma in the hospital and they didn't take any photographs, about five years later she managed to get a copy of the photographs that were taken before the autopsy. They weren't nice. They weren't intended to be seen by a parent. Uma was naked, unwashed, discoloured, and set out in various positions on a slab of marble that had cut marks from use. But there she was. After five years, Jillian got to see what her little girl looked like.

She asked me to retouch the photographs so that she could show them to the family and put a photograph of her up in the house with her two younger sisters Miah and Abby.

Even if I had talked about her many times with Jillian, I never grieved for Uma, it wasn't that way for me. But it was a gratifying experience to spend so many hours with her, studying her features, working out how to retouch the photograph in a way that Jillian and Juan would like. Digitally caring for someone I had never met. An uncle doing something for his niece, I realised. A personal connection with her five years after she was born, dead?

Over the last 5 years there is one question that I have come to dread, or at least I did for quite a while: what's your thesis about?

Well, there's nothing like baby death to kill a conversation.

I have often felt guilt or shame when I see the look on my companion's face, the awkwardness, the silence, the occasional look of horror and even a few "uggghs!" Although there was always the occasional surprise and some wonderful conversations.

So I changed to saying my thesis was about grief and death. That was better, at first: “oh, that’s interesting, death is such a taboo!” But then you mention its about babies dying during pregnancy and you’re straight back to the funny faces and awkward silence.

But, it takes two to tango. How did I say what my thesis was about? Did I avert my eyes when I said it? Look down? Signal some shame or embarrassment?

How is it possible that dead babies can influence the living in such diverse ways? Like I said, it takes two to tango, the living *and* the dead. So, what does this tell us about the nature of social relationships, culture and the seemingly ambiguous beginnings and endings of life?

As well as addressing very specific questions about hospital care, I hope this study also sheds some light on why one our cultures most elevated and protected social figures can also be one of its most maligned.

2. Why is this an important area of study?

In 2018, there were 372,777 live births in Spain. Of those 711 died in the first 28 days of life. Around 1,500 babies were stillborn¹ after 22 weeks gestation (Cassidy 2018a; Instituto Nacional de Estadística 2018a, [b] 2018). No statistics exist on pregnancy loss before 22 weeks, but it is estimated that more than 15% of all pregnancies end in miscarriage (Wilcox et al. 1988). Additionally, in more than 11,000 women in Spain had a pregnancy termination due to risk to the mother’s health or because of severe foetal anomalies (Ministerio de Sanidad 2018). This represents many thousands of women. When extrapolated across a reproductive life, the possibility that a woman will experience some form of pregnancy loss is even higher. Stillbirth also disproportionately affects those with lower educational levels and immigrants by a factor of 1.5 to 4.9 (Cassidy 2020).

Clearly, though, all women don’t experience grief or a sense of loss after the death of a baby during pregnancy; for some women it may be a relief, for others it may bring mixed feelings (Corbet-Owen and Kruger 2001a; Murphy and Merrell 2009). However, research consistently shows that many women do live through significant grief, including at early gestational ages and for terminations of pregnancy for medical reasons (Gerber-Epstein, Leichtentritt, and Benyamini 2009; Hutti et al. 2017; Kersting et al. 2004; Lasker and Toedter 2000). Yet, society tends to minimise these experiences, containing and constraining them within women’s experiences of reproduction and gendered ideas of emotion (Layne 1999; Malacrida 1999; McCreight 2007, 2008).

Most women and their partners adapt well to loss and grief, but for a significant proportion the impact is quite severe. Population studies find that between 10% and 30% of women suffer from clinical symptoms of anxiety, depression, posttraumatic stress and complicated grief during the months and even years following the death of a baby (Boyle et al. 1996; Gold et al. 2016; Jind 2003; Thearle et al. 1995). This is consistently, although not uniquely, linked to low social support (Gold et al. 2016; Kroth et al. 2004; Murphy, Shevlin, and Elklit 2014). Although the majority recover from mental health effects within a period of 2 years, some suffer problematically for longer (Bennett et al. 2008; Boyle et al. 1996; Cacciatore, Froen, and Killian 2013; Christiansen, Elklit, and Olff 2013; Chung and Reed 2017; Kersting et al. 2005). Many women feel high levels of guilt, and blame

¹ Equivalent to “muerte fetal” in Spanish

² Those born dead or those that died shortly after birth.

³ Until 2011, when Article 45 of Civil Code was amended, the infant had to survive more than 24 hours. Most likely this

themselves for the death (Gold, Sen, and Leon 2017; Kersting et al. 2007), and research also points to increased risk of suicide (Weng et al. 2018).

Pregnancy loss and perinatal death affects men too, although this is also largely hidden within gendered ideas that positions them as strong and less emotional than women; their prescribed role being to support their partner (Korenromp et al. 2007; McCreight 2004; Samuelsson, Rådestad, and Segesten 2001; Vance et al. 1995). Siblings and grandparents are also affected, yet this is often not recognised (Aho, Inki, and Kaunonen 2018; Leon 1986; O'Leary and Gaziano 2011; Willer et al. 2018; Youngblut et al. 2015).

Witnessing perinatal death and caring for women and their families can also be extremely hard on health professionals. Research shows that midwives, nurses and doctors can suffer from secondary trauma, stress, anxiety, guilt and worry about being blamed (Andre et al. 2016; Farrow et al. 2013; Gandino et al. 2017; Gold, Kuznia, and Hayward 2008; Hutti et al. 2016; Mizuno et al. 2013; Nuzum, Meaney, and O'Donoghue 2014; Pastor-Montero et al. 2011).

So, beyond the biologically obvious, why is it that women bear the brunt of the burden for pregnancy loss and neonatal death? The aforementioned 'effects' of perinatal death are wrapped up in worldviews, discourses, practices, social history and certain configurations of pregnant and birthing bodies and dead babies. Investigating perinatal death from the perspective of anthropology and sociology provides us with an opportunity to take intersubjective social positions as a point from which to gain important insights into the social, political, and cultural values that dominate healthcare, death and dying, pregnancy and childbirth, motherhood and personhood, gender and reproductive inequality.

3. The origins of stigma and taboo

Grounding this study in a genealogical approach is to assume that what we understand to be a 'person' or 'thing', *now*, is in fact an unstable entity, a product of a set of relations produced through the interactions of discourses, practices and materialities over time; brought into being, modified, and maybe also silenced (Foucault 1972, 1978). From this perspective it is useful to locate the social processes that have configured stillborn and dead neonatal infants within different forms of taboo and stigma and to consider how this history materially affects current social practice.

The historical background to the story of stigma and silence in the context of pregnancy loss stretches back many millennia but it has two watershed moments. Firstly, at the meeting of the leading Catholic theologians at Carthage, in the 5th century AD, it was proclaimed that unbaptised infants, those born dead or that died before christening, had not been cleansed of original sin and were consequently condemned to hell, although they were only to receive a mild form of punishment (International Theological Commission 2009). Secondly, the progressive medicalisation of pregnancy and maternity from the 18th century onwards, which culminated in the shift of childbirth from the home to hospitals throughout the 20th century.

Archaeological and anthropological studies of Neolithic and Bronze Age burial sites in Europe, the northern Mediterranean and Spain tell a very different story to developments after the emergence of Christianity. These studies indicate that stillborn infants and those that died shortly after death

were regularly given ritualised burials. Neolithic graves and burial practices of perinates² in southern Spain have been found to be similar to adults (Ayala-Juan et al. 1999). However, later Bronze Age burials in central and northern regions of Spain were differentiated from adults and older children. Rather than being cremated, very young infants were buried in domestic spaces such as house walls or floors, often close to the hearth, or in contiguous horticultural or workspaces. Based on the grave formations, locations, burial positions and occasional funerary goods (such as protective amulets), the authors of these studies propose that there was no evidence of associated stigma (Chapa-Brunet 2008; Crespo, Subirà, and Ruiz 2011; DeMiguel Ibáñez 2010; Fernández-Crespo 2008; Jesús Torres-Martínez, Domínguez-Solera, and Carnicero-Cáceres 2012). Rather, the question of differentiation appears to have related to social categories and status related to age, dependence, or cultural beliefs. In recent years there has been a reconceptualising of the social status of the foetus in historical societies (Han, Betsinger, and Scott 2018; Thompson, Alfonso-Durruty, and Crandall 2014). This mirrors the challenges by authors such as Pollock (1981) to the prevalent ideas that childhood is a modern invention, that parent's had little affect for children before the 18th century, viewing them merely in economic terms or distancing themselves because of high mortality rates (Ariès 1962:128; Stone 1977:405).

By the high medieval period in Christian Europe it became common for unbaptised infants to be buried on unconsecrated ground, along with other stigmatised members of the community, such as mortal sinners and those that had committed suicide (Betrán 2015; Gilchrist 2005; Lewis and Gowland 2007; Scott and Betsinger 2018). Serving a political function to ensure initiation into the Christian community, infants that died before baptism became a source of considerable fear and were associated with punishment, sterility, errant souls and malign folklore (Gélis 1984:25–26; Gilchrist 2012:209; O'Connor 2012). Live unbaptised infants were thought to be a target of witches and sorcerers, such that newborns wore protective amulets and talisman (Horcajo Palomero 1999; Macky 2009:24,85). The death of a woman while pregnant was such a vexing problem that for a time *post mortem* caesareans were conducted so that women could be given a proper burial (Carmona-González and Saiz-Puente 2009; Debreyne 1858:181).

However, this positioning of the infant who died before baptism was not hegemonic and was met with institutional and lay resistance. Opposed by conservatives in the Church and never a formal doctrine, the Limbo of Infants (Aquinas n.d.:Q69, Art. 6) emerged as a theological alternative that conceptualised a less severe fate for the unbaptised child: an eternal state of happiness, although not in the beatific presence of God (International Theological Commission 2009). A more practical solution to the problematic was the training of midwives in emergency baptisms if the infants life was in danger (Carmona-González and Saiz-Puente 2009; French 2008:69). In medieval Galicia, pregnant women would conduct preventative baptisms by making a nocturnal visit to a bridge with a *cruciero* [holy cross], where they would ask a passer-by to perform the sacraments; practices that were repeatedly condemned by the Church hierarchy (Bande-Rodríguez 1997; Fuentes-Alende 1988).

The omission of unbaptised infants from burial in consecrated grounds also saw a diverse range of responses from parents. In central and northern Spain, house burials of stillborn infants and dead neonates persisted until the middle of the 20th century (Fernández-Crespo 2008; Gómez-Osuna et al. 2018; Jordán Montés and Jordán de la Peña 2019; Jesús Torres-Martínez, Domínguez-Solera, and Carnicero-Cáceres 2012). In Galicia they were buried at the foot of *crucieros* until at least the early 1930s (González-Pérez 1992). Ethnographic work in rural Murcia, Spain, has heard testimony that surreptitious night-time burials of unbaptised infants in Church cemeteries took place until the

² Those born dead or those that died shortly after birth.

mid 20th century (Jordán Montés and Jordán de la Peña 2019). Comparable practices have been found throughout Europe (Daniell 1997:117; Gilchrist 2005; Väisänen 1999), as well as ornate cemetery burials of perinates that appear to defy Catholic doctrine (Scott and Betsinger 2018).

Research from Ireland and Australia shows that churches began to permit the internment of unbaptised infants in common graves in the late 19th and early 20th century. The demand for these burials was so great that they soon had dedicated plots, where many thousands of babies were interred (Garattini 2007; Thompson 2008:65). These burials were extremely modest affairs, with no formal funeral service and often only attended by the father or one other male family member (Cecil 1996; O'Leary and Warland 2013; Thompson 2008:66). In Spain, burial in large common plots also seems to have been common in the early 20th century, but evidence comes from more recent exhumations carried out as part of investigations into the *stolen babies* scandal (Rendón 2012). The stigmatised burial of unbaptised infants continued until the Catholic Church amended Canon Law in 1980s to permit their burial on consecrated grounds, if it had been the parents intention to baptise the child (Catholic Church 1983).

These discourses and practices also have to be contextualised within the gendered discourses that associated women with lust and the sinful inheritance of Eve (Gilchrist 2005). The female body was considered to be more changeable than males; colder, wetter, prone to decomposition, both voracious and a source of nutrition for foetuses and infants (Bynum 1995:221). Like menstruation, pregnancy and childbirth were polluting. After giving birth, the woman was considered to be contaminated and required to stay at home, in the dark, during a lying in period of 30-40 days until reintegrated to the community through 'churching' (French 2008:59; Reider 2006:61). Nevertheless, it is important to consider that birthing rooms, along with other parts of home, and practices related to mortuary rituals were social spaces where women retained substantial power (Gilchrist 2005).

Hence, the progressive medicalisation of pregnancy, childbirth and infant care from the 18th century onwards resulted in a weakening of women's social positions and power. They became objects of social surveillance that had to be educated by a new class of male doctor-expert (Ehrenreich and English 2005:106; Fajula Colom 2013; Nash 1993). In the early 20th century, pseudoscientific discourses understood pregnancy and other female bodily functions as the sources of both physiological and psychological problems (Ehrenreich and English 1974:29, 2005:231-232). Women, particularly from the middle and upper classes, were also positioned as emotional and fragile, in opposition to rational man, and so required paternalistic protection (Lutz 1996).

Childbirth was reconfigured as pathological and a traumatic experience for both the mother and the baby (DeLee 1920), which provided a justification for heavy technological interventionism (Doherty-Turkel 1995:35). The prophylactic use of forceps, episiotomies, enemas, sedation and pubic hair shaving, amongst other dubious obstetric technologies, became widely used (García-Arregui 2019; Tew 1990; World Health Organisation 1985). Although women undoubtedly played an important part in demanding safer and less painful births (McIntosh 2012:64; Tew 1990:18), much evidence suggests that mortality rates were not lower, at least initially (Loudon 2000; Tew 1990:26). Under the new model, the consequences for autonomy were severe. Women were no longer accompanied by other women during birth, they were obliged to adopt a passive position, lying down rather than sitting or at an angle, and were often sedated as the obstetrician performed an 'operation' (Franco Grande, Álvarez Escudero, and Cortés Laíño 2005; Hodnett et al. 2011; Katz-Rothman 2007; Ruiz-Berdún 2014; Tew 1990). It was also common for mothers and newborns to be separated immediately after birth (Klaus and Kennell 1970).

Davis-Floyd's (1993) research with obstetricians shows how women's experiences of labour were completely disregarded in the totalising focus on delivering a live infant. The doctor and technologies became the interpreters of birthing bodies and those best placed to care for newborn babies, subordinating women's own knowledge and embodied experience (Martin 2001:57). As such, over the period of a century, childbirth changed from being an event attended exclusively by women and midwives (Leavitt 1986:36; Ruiz-Berdún and Martín-Alcaide 2018) to a medical practice in which the parturient became a disempowered patient, establishing a new form of gender-based inequality through the abuse of technology (Rothman-Katz 1982). Despite condemnations and calls for change since the 1980s (World Health Organisation 1985), this model of childbirth is still in practice in many countries, including Spain, and is evident in high levels of unnecessary medicalisation (Ministerio de Sanidad 2012; Zeitlin, Mohangoo, and Delnord 2010). Recently, the concept of 'obstetric violence' has emerged to account for gendered practices in childbirth that include verbal, physical and sexual abuse and the practice of surgical procedures and administration of sedation without consent (Goberna-Tricas 2019; McGarry et al. 2017; Sadler et al. 2016).

In the context of perinatal death, medicalised childbirth has had significant implications for women and their families. One of the most important consequences was the widespread introduction of sedation during labour, which has also been commonly reported in cases of stillbirth and neonatal death (Giles 1970). Although there are no contemporary studies that have published accounts of Spanish women's experiences of perinatal death during the 20th century, we can draw on narratives of older women's experiences in Australia and the United States between 1940 and 1970. Their stories tell how many of them woke up, having been heavily sedated during delivery or just afterwards, to discover that their baby had been born dead or died shortly afterwards. The use of sedation went hand in hand with the practice of immediately removing the baby from the delivery room, such that many women never saw their child, including in cases of neonatal death, seemingly because health professionals judged that it would be too upsetting. Some women have said that they were happy that they didn't see their babies, others did see their them after insisting, but it was more akin to a quick glimpse and they generally weren't allowed to touch or hold them (O'Leary and Warland 2013; Thompson 2008:105). No medical grounds existed for such practices, rather they appear to have been the result of a confluence of longstanding discourses and practices related to the social status of the dead infant in the institutional settings of religion and medicine, paternalism in medical practice and the positioning of women as emotionally fragile.

Conversely, these women's testimonies also reveal detailed memories of the loss many decades later. Many recalled significant grief and in some cases lifelong impacts on mental health, others framed the loss within the stoicism that was culturally valued at time (Cecil 1996; O'Leary and Warland 2013; Rosenblatt and Burns 1986; Thompson 2008). Jolly (1976) notes that he received an avalanche of letters when he published an article in an English national newspaper about the experiences of a mother in the 1940s who had always been troubled by not knowing where her son was buried. Jolly observed that the tone of the letters was that these women felt like "unnatural" mothers due to the social processes of exclusion around the death and the burial. In this respect, the intersection of patriarchal institutions of religion and healthcare in the 20th century resulted in an intense period of the most oppressive form of stigma and taboo, whose effects are still felt today.

4. Out of the shadows: A reconfiguration of healthcare

A paradigmatic fracture in the medical practices surrounding perinatal bereavement began in many Northern European and English-speaking countries in the 1970s and 1980s at a time when new concepts of care began to challenge the dominance of the biomedical model at a general level (Engel 1977; Illich 1976) and within childbirth (World Health Organisation 1985). Changes in bereavement care were driven by the concurrent emergence of a relaxing of Church doctrine that prohibited funerals for unbaptised infants (Catholic Church 1983), a growing recognition within obstetrics that there was an obligation to care for women in death as well as life (Bourne 1968; Bruce 1961; Elia 1959; Jolly 1976; Yates 1972), scientific recognition of the bond between mother and intrauterine infant and the possibility of grief (Kennell, Slyter, and Klaus 1970), and the establishment of a new social movement that advocated for bereaved parents and the need to put new legislation in place (Gensch and Midland 2000; Lovell 1997; Moulder 1998:15).

That said, foregrounding all of this was the institution of psychoanalytic and psychiatric grief theory in the early 20th century. In the 1960s and 1970s this provided a 'scientifically' acceptable explanation for the apparent distress of women through the application of attachment theory. Crucially, prevalent obstetric practices, such as not allowing the mother to see the baby, could now be challenged as promoting an unhealthy form of bereavement (Cullberg 1972; Giles 1970; Kennell et al. 1970; Lewis and Page 1978; Lewis 1972). As there had been no affective or 'actual' relationship with the object (baby), the difficulty of grief following pregnancy loss and neonatal death was thought to be due to the lack of proper 'identification' (Furman 1978). Compounded by care practices and the 'unreality' of the situation (Lewis 1976), it was thought that this led to problems in the various phases of grief: excessive denial of loss, yearning and disorganised mourning and complicated reorganization and restoration to normal life (Furman 1978; Kirkley-Best and Kellner 1982). These factors, along with an unsympathetic cultural context, were believed to create a high risk of pathological grief (Cohen et al. 1978; Condon 1986; Kirkley-Best and Kellner 1982).

Collectively, these social changes played a major role in supporting the rhetoric of the 1970s and 1980s that reconstructed perinatal grief as "silenced", "forbidden", "forgotten", "taboo" (Kirkley-Best and Kellner 1982; Kowalski 1980; Layne 1997; Lewis 1976). This reconfiguration gave rise to a series of recommendations for the care of women in cases of perinatal loss that focused on 'reality based grieving', which promoted 'memory making' acts as a way to overcome the difficulty with identification (Ransohoff-Alder and Berger 1989:312). Diametrically opposed to previous practice, women and their partners were encouraged to see, touch, hold and spend time with their baby, to name it, to take photographs, to keep 'mementoes' such as a lock of hair or a footprint, and to have a funeral (Estok and Lehman 1983; Furman 1978; Lewis 1976). By the early 1980s the term 'perinatal grief' was in use (Evans 1980; Kellner et al. 1981) and a new form of bereavement had been established and formed the basis of research and medical practice.

Underpinned by these concepts, and pushed by parent activists, such as Sands in the United Kingdom/Australia and Share and Unite in the United States, a more humanistic, patient-centred and sophisticated form of bereavement care became established in the hospitals of Northern European and English speaking countries over the following 20-30 years (Sands 1995). In contrast to male-centred, rationalised and biomedical obstetrics, new care models stressed the need to create space for emotion, self-determination and control over decision-making (Davidson 2008; Lovell 1983; McCreight 2008). Care began to emphasise the establishment of a trusting relationship, effective communication of evidence-based information, and personalised care. Primarily, healthcare professionals were encouraged to engage with and affirm the personhood of

the child and maternal/paternal identities (Cacciatore 2010; Kavanaugh and Paton 2001; Leon 1992). These new practices appeared to be popular with women and their partners, and advanced rapidly. Studies in the United States and Sweden found that by the mid 1990s, for example, almost all parents saw and spent time with their child following a late miscarriage, stillbirth or neonatal death (Rådestad, Nordin, et al. 1996; Toedter, Lasker, and Janssen 2001); a radical change from just 20 years earlier.

5. Perinatal death in Spain: Research demand and general questions

Without doubt, there has been considerable improvement to perinatal bereavement care in many western countries over the last 50 years. 'Silence' is no longer one of the major tropes in the narratives of parents and healthcare professionals, though many critiques of care persist as expectations have changed (Ellis et al. 2016; Peters et al. 2014). However, when we turn our attention to Spain, where this form of care has only recently come on the national agenda, we find a quite different picture. *Break the silence* is the unifying slogan for the national social movement of activists that are attempting to gain institutional recognition for perinatal death and bereavement, as well as lobbying for the improvement of care standards (Umamanita et al. 2017).

While Spain does have good maternity leave legislation when a baby dies during pregnancy after 180 days gestation, public health policy in the area of perinatal death and bereavement is highly underdeveloped at state and regional level. Unlike countries such as the United Kingdom, Holland and Australia, since the closure of the National Institute of Puericulture a number of decades ago, there is no national strategy or target for the reduction of perinatal mortality. The national statistics on pregnancy loss are not fit for purpose; they suffer from underreporting and are replete with missing socio-demographic data, particularly amongst those that have the highest mortality rates (Cassidy 2018b). In fact, the major preoccupation seems to be with collecting detailed statistics on pregnancy terminations, which appears to reflect the ideological interest of both sides of Spanish politics. The idea that bereavement care following perinatal death might be a necessity for women only appeared for the first time in a national strategy document on reproductive health in 2011, in a very brief section (Ministerio de Sanidad 2011:131).

When the first Spanish lay associations such as Umamanita, Superando un Aborto and Petits amb llum set up in the mid to late 2000s, only five pieces of empirical research had been conducted. Two studies addressed healthcare professionals and one was a quasi-experimental study on care interventions. The other two addressed women's experiences of grief, but none specifically studied women's experiences of care (Carrera et al. 1998; Gálvez-Toro, Amezcua, and Salido Moreno 2002; Gálvez-Toro 2006; Pastor-Montero et al. 2007, 2011). No survey research on practices at regional or national level had been conducted. The discourses and views of the healthcare professionals in these studies seemed to corroborate anecdotal evidence from parent testimonies that care was highly medicalised with little space for loss/grief. So, despite the fact that the perinatal mortality rate in Spain was similar to other high-income countries (Zeitlin et al. 2010), it was apparent that both the figure of the bereaved woman and the dead perinate had not acquired a social standing beyond that defined in biomedicine.

In identifying an urgent demand to conduct research on the situation in Spain, the definition of the research questions was at first very broad. Primarily, the requirement was to establish data that would permit an evaluation of care in terms of the prevalence or availability of practices related to technical and bereavement care, such as how many parents saw their babies after the birth and the mode of delivery. From a different viewpoint there was an interest in investigating the social

mechanisms that lead to such outcomes (humanistic care and decision-making) and women's views on positive and negative aspects of care, and how this influences grief. Through the emerging process of the exploratory research and the development of the conceptual framework, these broad questions became more defined and are specified at the end of Chapter 2.

6. Structure of the study and preview of the chapters

The thesis is organised in four sections and nine chapters. Chapter 2 completes the introduction by providing a theoretical and historical framework for the study by addressing three broad areas of concern. Firstly, the chapter considers the historical, social and dialectical ways that mothers and babies are brought into being through socio-relational practices within medical and consumer frames. Secondly, the chapter addresses grief theory from a social perspective in order to conceptualise a view of bereavement that can be applied in care contexts. Finally, the chapter proposes that care following perinatal bereavement can be understood as both a communicative process, based on language and speech, which centres on providing support and making-decisions, and also a material performance with bodies (the pregnant and postpartum woman and the dead baby). The chapter concludes by specifying appropriate research questions.

In Section 2, Chapters 3 to 5 set out the research design, based on an ethnographic approach that employs mixed-methods. The study population is defined as women who experienced the death of a baby in the second and third trimester or shortly after birth, including terminations of pregnancy for medical reasons, in the Spanish health system. From a methodological perspective, I use participant observation, qualitative narrative style interviews, and an online survey as the primary research tools. Following three years of fieldwork, 796 women from every autonomous community and over 200 public and private hospitals participated in the survey. For the qualitative part of the methodology I conducted ten qualitative interviews and extracted 622 entries to open-ended questions from the survey.

The results are presented over three chapters in Section 3. Chapter 6 examines humanistic aspects of women's encounters with health professionals, and how the alternate modes of interaction that they adopt are used as a means to contextualise the death within grief or medical frames. Application of the medical frame is interactively achieved by emphasising care on the body and technologies and rekeying expressions of 'negative' emotion, such as crying. Chapter 7 focuses on concepts of agency and autonomy during care and identifies that care is highly asymmetric during decision-making encounters, which is sustained by a number of factors, such as vulnerability and communicative disadvantage, lack of information, coercion and women's own collusion in paternalism. Chapter 8 centres on the baby and its body and the way that care practices and discourses revolve around it, specifically how meaning is constructed through talk and performance. Of special interest is the idea that the categories of son/daughter sit in tension to the threat of the dead body, its cultural unfamiliarity and perceived potential to cause harm. Additionally, the chapter examines the processes around the treatment of the body, in particular how the institution controls and constrains access to the body, often invoking discourses of taboo and stigma. The final chapter draws together the main ideas from the thesis and engages in some broader discussion and considers some points for future research.

7. Some questions of terminology

My primary concern in this study is with learning about grief its social production so that we might consider how to reduce the cost to individuals. In so doing, the study participants, their wellbeing and voice, are my primary responsibility. As such, when I consider local intersubjective experiences I generally use terms that have been naturalised through participation in fields of practice, such as *mother, father, baby, son, daughter, child*, while drawing attention to the fact that these are not hegemonic and are culturally and historically situated. If the context shifts to a broader socio-cultural sphere I prefer the term *infant or foetus*, understanding the former to be very broad and the latter to be a specific biological and socio-cultural meaning. On occasion I may also use a composite such as *loss/death or foetus/baby* to signify that neither individually seems appropriate or because I want to avoid essentialising social experience. Additionally, when I use perinatal loss/ death, I do so in a flexible sense that is not restricted to the biomedical definition that sets a lower gestational age limit around 22 weeks. Rather I use it to refer to all pregnancy loss and neonatal death.

8. Declarations

I have no declarations of competing interests to make. The research was undertaken on a voluntary basis with some small funding support from Umamanita. This support covered the purchase of some electronic recording equipment, online survey hosting costs and transcription fees that totalled around €600.00.

Chapter 2.

Conceptual framework and research questions

1. Introduction

This chapter develops the conceptual framework for the analysis by concentrating on three key areas of social practice and how they frame the death of an infant during pregnancy or shortly after birth. To start, the chapter asks: what is a foetus/baby and pregnancy/motherhood in historical and contemporary perspective? How is the foetus/baby and mother brought into being through alternative discourses and practices and positioned with and against each other? How does this relate to perinatal death? Taking these social positions and relations as the basis for grief, the second part of the chapter examines grief theory and proposes a social, cultural and relational view of grief that contrasts to psychological models and anthropological perspectives that focus on categorical transition. Both of these sections are strongly based on recognising the complexity of social relations, rejecting nature-culture dualisms, and provide a conceptual framework for interpreting the social meanings of healthcare encounters following perinatal death. In the final section, I examine the current model for perinatal bereavement care and recommended practice. By formulating a framework for analysing care encounters between women and health professionals in terms of communicative speech events and performative material practice I establish a basis for investigating the socio-relational process through which grief becomes manifest.

2. Pregnancy, maternity and foetal personhood

2.1. Essentialist perspectives

Before looking at what the death of a foetus means, it is necessary to contemplate what a foetus is, in a biological, social and culture sense. There are two primary, yet oppositional ways, to look at this: essentialism and relationality. The former is founded in objectivism and views personhood as temporally linear and defined by biological markers, most notably gestational age (Rutherford 2018). To start, we can consider perspectives that view life/personhood as equated to precise biological moments. The Catholic Church and some pro-life movements claim that life begins at conception or as in the case of recent antiabortion legislation in the State of Alabama, United States, when the foetal heartbeat can be detected (Benagiano and Mori 2007; Mazzei and Blinder

2019). However, no technological or other method can accurately state a precise moment for any of these positions, interacting as they do with subjective cultural and technological interpretations (Degnen 2018).

On the other hand, legal personhood is normally awarded at birth, as is the case in Spain since 2014 (Gobierno de España 2011)³, which also presents a number of difficulties. Firstly, although personhood is awarded at birth, legal protections for the foetus as an individual entity stretch back to various points in the gestation, whereby pregnancy termination is only permitted beyond 15 and later 22 weeks in specific circumstances, such as congenital anomalies or life limiting health problems (Cazorla González-Serrano 2018; Gobierno de España 2010). Secondly, awarding personhood at birth disrupts the supposed temporal linearity associated with gestational age. To give an example: a 3500g baby born dead at full term (after 37 weeks) is not considered a person while a prematurely born 300g baby at 20 weeks, with little to no chance of survival, but who breathes (independently or not) for a short time is a full legal person. From the standpoint of bereaved parents who wish to register their children with a full name, such systems seem contradictory and unfair. On the other hand, establishing legal personhood before birth presents very clear dangers to women's reproductive rights (Kevin 2018).

As already intimated, classification systems based on gestational age (and other biomarkers) provide us with the other primary mechanism for determining personhood. When the reformist social health and hygiene movement brought infant and later foetal mortality within the scope of social policy in the early 20th century, it also demanded a reliable classification system for the development of healthcare indicators and statistics. Over the period of a number of years a new system for infant mortality was developed, which eventually led to the institution of the 'perinatal' period (Armstrong 1986). Firstly, 'infant death', which occurred between birth and the end of the first year of life, was restructured to reflect the fact that many deaths occurred shortly after birth. This resulted in the definition of the neonatal period, up to 28 days post-birth, and the post-neonatal period, up to one year. Until this point, stillbirth [*muerte fetal*] had been ambiguously defined as any foetus born dead that was fully formed (Morgan 2002), but three factors led to its definition as ranging from the 28th week of pregnancy to birth: firstly, many of the problems associated with neonatal death were known to have begun during pregnancy; secondly, many neonatal deaths were due to preterm births (before 37 weeks); thirdly, 28 weeks seemed to be the gestational age at which a baby was potentially viable if born prematurely. Thus, by the mid 1940s, three statistical categories had been developed: 1) stillbirth [*muerte fetal tardía*] occurred in the third trimester or from the 28th week; 2) neonatal death was from birth until 28 days postpartum; and 3) perinatal death conjoined foetal death and neonatal death. Aside from the latter expansion of the lower limit to 22 weeks pregnancy, the perinatal death classification first used by Peller (1948) remains the standard system used by most countries and international organisations. The term 'mortalidad perinatal' appears in Spanish publications as early as 1951 (Villar-Salinas 1951).

This new system had implications that reach far beyond mortality statistics, forming the basis for a whole series of legislation, research and care practices that affect the social organisation of perinatal loss and bereavement. In England, the Stillbirth Definition Act 1992 was a defining piece of legislation that resulted in significant improvements to the institutional treatment of women and their babies after intrauterine death, but only for deaths of 24 weeks or more. In Spain, 26 weeks (180 days) was adopted as the key determinant in the 1957 Civil Register law (Gobierno de

³ Until 2011, when Article 45 of Civil Code was amended, the infant had to survive more than 24 hours. Most likely this condition originated in historical religious and statistical practices related to births not being registered until baptism and because of high mortality rates in the first day of life. This practice had important consequences for parents as an infant that didn't survive could not be officially named (*only referred as foetus of [mother's name]*) nor registered in the family book.

España 1957). Despite the fact that pregnancy duration cannot be precisely specified (Lynch and Zhang 2007), this legislation subsequently informs other laws related to statistical recording systems (Instituto Nacional de Estadística n.d.) and maternity leave rights; including when a baby dies (Umamanita n.d.). It has also been used as the basis for burial regulations and autopsy protocols (Arce Mateos 2013; AsturSalud n.d.; Puras Gil, Teijeira Alvarez, and Balana Asurmendi 2009). Consequently, the difference of a day in the measurement of the duration of a gestation can mean that a death is classed as a stillbirth or a miscarriage. It may mean that a formal burial licence cannot be issued, that maternity leave cannot be accessed, or that a death is counted within the national statistical system.

The arrangement of pregnancy into trimesters can also be extrapolated into social practice as it relates to grief. Common cultural perceptions that experiences of grief and loss correlate to the temporal advancement of gestation mean that support offered to women by health professionals and within their social milieu varies accordingly (Lovell 1983). However, research does not support a linear, biometric arrangement of how support and care should be socially organised, at least not as a primary factor. Psychometric testing suggests a small positive relationship between gestational age and grief intensity (Cuisinier et al. 1993; Goldbach et al. 1991; Kirkley-Best 1981; Lasker and Toedter 1991; Theut et al. 1989), but the variance between cases tends to be high and other variables such as time and social support are stronger predictors (Janssen et al. 1996). Hence, an early miscarriage is often perceived as just one of those things, despite the fact that for many women it might be lived as the death of a person or at least a major life event (Gerber-Epstein et al. 2009; Rajan and Oakley 1993; Swanson 1999). On the other hand, as the possibility of grief following pregnancy loss has become increasingly recognised, there has been a tendency to label all pregnancy loss in terms of bereavement. This may create a moral imperative to grieve and the possibility of a reverse stigma, particularly in early pregnancy losses where there may be a greater diversity of interpretations and meanings (Corbet-Owen and Kruger 2001a; Moulder 1998:218; Murphy and Merrell 2009).

In this sense, the use of supposedly objectivist classificatory systems within healthcare institutions or category terms like baby, foetus, viable, non-viable, live, dead are in actuality social rather than biological definitions, which create composites such as “dead/alive foetus” or “dead/alive baby” (Kovit 1978). Legal personhood, conception, stillbirth, perinatal and even ‘trimesters’ are in reality imprecise and unstable constructs brought into being by configurations of biology, social and culture values, political ideologies, technologies, and history (Degnen 2018:29). Hence, as we attempt to define the foetus, or the mother for that matter, it is apparent that there are no easy definitions, no clear points of differentiation between nature and culture, the biological and cultural, human and non-human (Haraway 1987, 1988). This points to the need for a more subtle and complex approach that can incorporate essentialism, as a social component or discourse, while examining the way that foetuses and mothers are relationally produced through practice.

2.2. Vulnerable foetuses and moral mothers

The origins of the contemporary cultural object that is the *foetus/infant* and *mother* can be traced to shifts in biomedical practices between the 18th and early 20th century when medicine became specifically interested in pregnancy and infancy. The embryo, foetus and human reproductive process, for example, became discrete objects of scientific investigation, in particular through the work of embryologists, who had begun to collect and study them, as well as to produce drawings and models (Dubow 2011:1; Morgan 2002). As mentioned above, the foetus and infant became a focus of attention under the biopolitical (Foucault 2008) social hygiene movement in the early 20th

century. However, it is important to recognise that this modernising movement was primarily driven by political ideology related to the deterioration of the state, poor economic performance, low fertility and racial quality, as opposed to any interest in women's experiences or reproductive lives (Loredo Narciandi 2014; Nash 1993; Rodríguez Ocaña 1986). In Spain, which had some of the worst maternal and infant health indicators in modern Europe (Instituto Nacional de Previsión 1928:3–7), the State set about introducing new social institutes, statistical studies, healthcare training, insurance schemes and education campaigns on infant nutrition, hygiene and sleep (Bernabeu-Mestre and Gascón-Pérez 1999; Colmenar-Orazes 2009; Galiana-Sánchez and Bernabeu-Mestre 2011; Martínez-Navarro 1994; Rodríguez Ocaña 1986).

Under this new social model, mothers required education and surveillance by a new class of male doctor-expert (Ehrenreich and English 2005:106; Fajula Colom 2013; Nash 1993). In contrast to the 'Angel of the Home' of the 19th century, the 'Modern wife' was glorified as a heroic and patriotic figure dedicated to her biological mandate of rearing morally upstanding citizens (Álvarez Peláez 1990; Colmenar-Orazes 2009; McIntosh 2012:14; Sohn 1993). Her foil, though, was cruel and unnatural, the cause of infant mortality through ignorance, moral weakness, and working outside the home. If a child became ill or died it was because of women's moral failings or inability to follow expert advice, making them a danger to themselves, family and, therefore, the nation (Ehrenreich and English 2005:195; Loredo Narciandi 2014; McIntosh 2012:14).

Infants changed from being a simple heir of patriarchy to a biological and social symbol of a nation's future (Ehrenreich and English 2005:108). In Spain, advice pamphlets from doctors constructed infants as requiring specific forms of regimented lifestyles, disciplined education and care from the moment of birth. They were also portrayed as pure and emotionally weak, susceptible to being frightened and the possibility of irreparable mental damage (Loredo Narciandi 2014). The consolidation of paediatrics in the early 20th century also saw the development of a range of infant health indicators and comparative statistics, such as weight charts, muscle tone and neurological tests, which developed into standardised notions of 'ideal' babies (Katz-Rothman 2007; Stern 2002; Zafra Anta and García Nieto 2015). Through these mechanisms infants emerged as having very specific characteristics, needs and *rights* to a certain type of upbringing and care (Colmenar-Orazes 2009). Indeed, ideal babies were also positioned against abnormal, disabled and 'monstrous' babies through the obstetric field of teratology (Yang Costello 2006).

These moralising discourses and practices around women and infants foreshadowed subsequent developments in the 20th century and the materialisation of the foetus as a public figure. A key moment was the development of biotechnologies such as high definition photography and obstetrical sonography in the 1960s, which meant that the intrauterine baby could be socially perceived as an individual and discrete entity (Petchesky 1987). By temporally freezing the image of the foetus, it became disembodied from its social history, its mother and the process of growth, change and transformation that is a pregnancy (Lupton 2012:5–6; Sasson and Law 2008:5).

For different motives, both medicine and the pro-life movement used these images to represent the foetus as a subjective and vulnerable 'individual' who needed to be protected. Pro-choice activists adopted an essentialist standpoint diametrically opposed to anti-abortionists, believing that any recognition of bonds during pregnancy would weaken their argument. Hence, in many respects women's experience of pregnancy loss became invisible, lost between two competing ideologies (Layne 2006; Lovell 1997). Within the new fields of maternal-foetal medicine and neonatology, biotechnological advances consolidated the position of the foetus as a 'patient' (Williams 2005), independent of its mother - who was often relegated to the status of an environment or vessel for

the baby (Casper 1994a; Young 1984). The development of new reproductive technologies, such as ultrasound, foetal size and growth charts, heart tests, non-stress tests, amniocentesis, foetal blood tests, contributed to ideals of 'perfect babies', which became further translated into normative constructs. Davis-Floyd's (1993) research showed how the technocratic emphasis of obstetrics was on medicalisation and the production of the 'perfect baby', over and above women's experience. There is, though, great variability in how these perspectives are practiced and embedded in local cultures, some women find intensive monitoring of pregnancy intrusive, others welcome it, demanding new reproductive technologies and more predictable pregnancies (Petchesky 1987). In this regard, it is important to take into account that positioning technologies as good or bad is unhelpful. Rather it is important to observe how they are used or combined with clinical practice and discourses to produce certain meanings and relations (Gordo López and Sábada 2011).

With the advancement of these positionings and interests in medicine, the maternal-foetal relationship became increasingly viewed as one of conflict. The maternal body and womb were reconfigured as permeable and subject to contamination, a source of risk (Copelton 2007; Longhurst 1999; Lupton 2012; Oaks 2000). The 'good mother' is now highly knowledgeable of a huge range of risks to the foetus. They know their bodies intimately, follow a disciplined, aseptic lifestyle and assume responsibility for the outcome of the pregnancy (Beck and Beck-Gernsheim 1995; Georges and Mitchell 2000; Kukla 2010; Landsman 2008:17; Lupton 2012). Not too dissimilar from the 'modern mother' of the early 20th century, but in a context of lower fertility rates, older age of conception, and significantly lower foetal and maternal mortality rates, which contribute to a belief that pregnancy is relatively controllable and predictable after the first trimester (Georges and Mitchell 2000). Most importantly, though, reflexive and risk society lies on self-governance (Beck 1992; Giddens 1991), which increases the burden the individual assumes for the social.

Reproductive technologies such as ultrasound had other unintended consequences, particularly in the development of the social positions of intrauterine babies, parents and their social connection within wider kin relations (Draper 2002; Mitchell and Georges 1997; Sandelowski 1994; Taylor 2000). Now considered a form of portraiture, of individuals and families (Hockey and Draper 2005), ultrasounds are consumed, publicly displayed, widely shared with friends and family as physical objects or on social media. Research also shows how sonographers collaborate with parents to translate and code ultrasound images into cultural norms and family narratives, thereby bolstering foetal individuality and family and social networks (Mitchell 2001:108; Roberts 2012).

Studies in consumer and gift culture also disclose the mutually constitutive process by which mother and child are embodied and brought into being through the purchase of other consumer objects during pregnancy (Clarke 2004). Receiving gifts, purchasing a pram, a new car, maternity clothes, or having a baby shower are social and material practices that make mother, father and child (and other family members) socially prescient and imbued with cultural values long before birth. It also entangles parents in a series of symbolic and moral decisions (Clarke 2004; Taylor 2000). The variability of these decisions and the individualising processes of consumption permit parents to develop highly personalised social positions that are rooted in local histories. The importance of these consumer objects after perinatal death testifies to the strength of embodied personhood and the position of the intrauterine child in local social networks (Cassidy 2018c; Layne 2000; Murphy and Thomas 2013).

Collectively we can see the diverse and collaborative ways that mothers can assume social roles and related moral responsibilities at any point before birth and how personhood refers not so much to autonomous individuals who are established in law or by other essentialist means, but as persons that are 'done' through a complex web of social relations (Degnen 2018; Strathern 1988:13).

In the following section I consider the implications of these social and moral positions when a baby dies and examine contemporary grief theory as a means to understand how people and society manage relationships between the living and the dead.

3. Death and grief: from the private and transitional to the social and relational

Grief, as opposed to death, has traditionally been studied and defined within psychology and psychiatry, at least up until the beginning of the 21st century. Within these disciplines, it has been understood as a psychological process, that first focused on object theory, attachment and detachment as its central thesis (Hagman 2001) and has latterly stressed processes of adaptation and coping with stress (Horowitz, Bonanno, and Holen 1993; Payàs Puigarnau 2014; Stroebe, Schut, and Boerner 2017; Worden 2008). However, in this section, I draw on constructivist psychology, materialist anthropology and sociology to argue for a fully social and relational approach to bereavement and therefore eschew, more or less, the grief theory that centres on adaptation and coping. First, though, I address some important anthropological theory, as related to rituals, that provides a framework for understanding the social processes of death.

3.1. Rituals: categorical transition and liminality

As psychology was exploring grief as a transition from attachment to detachment (see Chapter 1), anthropology also gave attention to transition as a concept to help understand how societies managed the movement of members between social categories, such as unmarried/married and alive/dead (Van Gennep 1960:10–11; Hertz 1960). Under this functionalist conceptualisation of social practice, the role of rituals, funerals in this case, is threefold: the creation of a social space free of the usual social structures; the safe transition of the deceased into the world of the dead; and the reintegration of the bereaved into the world of the living. One of the main ideas in this theory is that failure to ensure safe transitions results in a polluting effect or danger to the social order because members (or the dead) become stuck in a liminal state (Douglas 1966:95; Van Gennep 1960:147; Turner 1967:93–111).

In the context of perinatal death, various authors have drawn on concepts of ambiguous loss (Brierley-Jones et al. 2015; Cacciatore, Defrain, and Jones 2008; Lovell 1997; Malacrida 1999) and transitional liminality (Bigelow-Reynolds 2016; Layne 2003:59–64; Peelen 2011:37–38, 86; Reiheld 2015) to explain stigma and silence. Layne (2003) proposes that, as pregnancy and birth are liminal statuses for women, the lack of reintegration rituals following a perinatal death results in a loss of identity. On the other hand, the dead foetus exists in a type of superliminality, as ‘foetus’ and as ‘dead’, which enhances its capacity for pollution and danger. Falling outside of established cultural classifications, pregnancy loss, as such, represents a double danger to the mother and baby in that they may remain permanently liminal, trapped in ambiguous social identities (Layne 2003:60; Malacrida 1999; Peelen 2011:86).

Despite the popularity of transitional rituals and liminality as tools for social analysis, in relation to understandings of death and mourning, they have also been criticised on a number of fronts. Firstly, the functional thinking behind Van Gennep’s and Hertz’s ideas has been challenged. One critique is that they assume that social life is best understood as a linear narrative, setting out from a discrete beginning and arriving at a discrete ending, where transition bridges a gap between the

two states (Semeretakis 1991:47). Howarth (2000) takes this a step further and argues that liminality is in fact an artefact of interpretative frameworks developed to explain their own analytic problems. Similarly, Semeretakis (1991:48) draws on Aries' (1981) view that the natural and social, life and death are "not rigid and oppositional but intertwined", arguing instead that life is significantly more complex and that processes of death reach far beyond the death event and associated funeral ritual (Semeretakis 1991:48). From this perspective we can understand 'rites of passage' and transition rituals as reinforcing the ideas of boundaries between life and death, nature and culture (Howarth 2000).

This is particularly important because if classical psychoanalytic grief theory reduces the experiences of grief to the private and intrapsychic and focuses on detachment from the dead (Hagman 2001), transitional rituals similarly preclude the idea that the dead may also become (re)integrated into the lives of the living, rather than just into the world of the dead. Hence, it is necessary to turn to more complex concepts of grief and death that consider social relations in terms of unfixed beginnings and endings that take less categorical views of life, death and the meaning of grief. This isn't to say that rituals or rites of passage are not important, far from it, but it does mean that they represent only one aspect of social practice and how society and people manage death and grief.

3.2. Continuing bonds, narrative reconstruction and disenfranchised grief

Viewing life and death as intertwined, contemporary understandings of grief recognise that the dead maintain an active and dynamic presence in the lives of the living (Hockey and Draper 2005; Klass, Silverman, and Nickman 1996; Valentine 2013). Continuing bonds theory observes that, contrary to the idea of detachment, many of the bereaved benefit from maintaining relationships with the dead long beyond what would have been considered pathological in classical grief theory. Integral to continuing bonds are social actions such as talking about the dead, collective remembering, and biographical and narrative reconstruction (Howarth 2000; Klass 1993; Neimeyer 2001; Silverman, Nickman, and Worden 1992; Walter 1996). Practices, such as mundane rituals and maintaining connections and presence through objects, photographs and memorials, have also been found to play a highly important role (Cadell et al. 2020; Gibson 2004; Godel 2007; MacConville and McQuillan 2010; Peelen 2011; Romanoff and Terenzio 1998; Turley and O'Donohoe 2012; Valentine 2013).

Hence, in the sense that death manifestly alters the social space, grief relates to the ongoing nature of the relationship between the bereaved and the deceased in the context of the wider social network and culture. A key question becomes: how do the bereaved go on living while managing their relationship with the dead in a way that is consistent with its specific history, associated cultural roles, responsibilities and social obligations (Charmaz 1997; Klass 2006; Valentine 2008:163–177)? As such, relationships with the dead can be viewed as an integral part of efforts to make sense of death and one's place in the world through the (re)construction of culturally coherent individual and joint biographies. This also disavows any ideas of *post mortem* relationships as static, meaning that the inter-relational social positions of the living and dead are open to change (Van den Hoonaard 1999; Klass et al. 1996; Klass 2006; Seale and van der Geest 2004; Valentine 2013).

Although continuing bonds and narrative reconstruction have not been explored in significant detail in the context of perinatal death, existing research suggests that parents are faced with the same challenges as any other bereaved person. It is evident that parents attempt to make sense of

the death, fulfil their moral obligations, and that they find solace in continuing bonds. Many parents like to talk about the child with family and friends, to maintain a connection through culturally situated performance and practice, by way of spaces (home shrines), places (graves and cemeteries), objects (such as those related to the pregnancy or birth) and formal and mundane ritual (Brownlee and Oikonen 2004; Cacciatore and Flint 2012; Grout and Romanoff 2000; Layne 1992, 2000; Lovell 1983; McCreight 2007; Murphy and Thomas 2013; Peelen 2011).

As these ideas lead us further away from an intrapsychic or personality based conceptualisation of grief to a more culturally situated, intersubjective and relational understanding (Charmaz and Milligan 2006; Klass 2006; Valentine 2008:124), they also imply that the right to grieve and the possibilities for grieving are socially negotiated or regulated (Charmaz 1997; Fowlkes 1990). Research has shown that many bereaved people are regularly excluded from mourning practices or denied social support because they are not kin (as in lovers, ex-spouses, carers, friends, work colleagues), because they or their loved ones were members of stigmatised social groups (criminals, drug addicts, LGBT+) or because of diminished social status, such as Alzheimer victims and the mentally disabled (Doka 1989; Fowlkes 1990).

Through the denial of social bonds and status of both the dead baby and the mother / father, perinatal grief is also considered to be a socially regulated and disenfranchised form of bereavement (Nichols 1989). As we saw in Chapter 1, this status has continued in different forms in western society since at least the emergence of Christianity. So, despite improvements to hospital care in many countries, parents' experience with their families and communities is often one of silence and inadequate social support (Lovell 1997; Malacrida 1999). This can make it very difficult to fulfil the basic functions and roles of bereavement, such as the social aspects of continuing bonds or collective remembering and narrative. Furthermore, attempts to subvert oppressive social regulation can often bring the bereaved into conflict with their social milieu. Just as importantly, though, it may also bring them into conflict with the dead if they feel that they are unable to fulfil their obligations (Cassidy 2014). This may make continuing bonds stressful rather than ameliorating, compressing grief into a tight private space, where feelings of guilt, anger and powerlessness become protagonists (Doka 1989).

Whereas the aforementioned mechanisms relate to the cultural values and discourses associated with social positions, grief is also influenced by the circumstances of the death and how it correlates to broader cultural expectations and normative life narratives. When people die young, when children die before their parents, when doubts persist about the death, when moral obligations to the dead can not be fulfilled or when death is the result of negligent or criminal actions, it can be viewed as a 'bad death' in contrast to normative expectations of a 'good death' (Bradbury 1996; Seale and van der Geest 2004). Historically, pregnant women probably had some expectation of perinatal death given the high levels of mortality, however, after the 1970s the perinatal mortality rate dropped to very low levels (less than 10/1000 births). This has a number of highly important consequences when a baby dies. Firstly, death can come as a great shock, and feel totally unexpected; particularly once the pregnancy has passed the first trimester (Kelley and Trinidad 2012; Malacrida 1997). Secondly, social practices and gendered discourses place the responsibility for pregnancy outcomes on the shoulders of women. Research consistently shows that more than half of women feel some guilt for the loss, while about 15-30% experience high levels of guilt (Gold et al. 2017; Rådestad, Steineck, et al. 1996). Furthermore, around one-in-four women blame themselves for the death (Cacciatore et al. 2013) or believe that members of their social milieu see them as being responsible (Gold et al. 2017). The absence of a cause of death, which is relatively common in perinatal loss (Korteweg et al. 2012), may also exacerbate these feelings (Heazell et al. 2012; Horey et al. 2014; Meaney et al. 2015; Sullivan and Monagle 2011).

Nevertheless, even in cases where a cause of death is evident, such as congenital anomalies, women may still feel that it was their choices during pregnancy that influenced the outcome (Landsman 2008:87, 155). Samantha Murphy's qualitative work in this area shows how bereaved women often feel that they must distance themselves from the 'immoral mother' through justifications of having behaved well and followed the rules during pregnancy (Murphy 2012).

The fact that in Western society the vast majority of pregnancy loss and perinatal deaths take place in hospitals makes it unsurprising that experiences with health professionals form significant parts of narratives of loss, often being present in such stories as principal characters along with mothers, fathers, babies, family and friends (Kohner and Henley 2001:35). As both the primary space for socialisation into the world of perinatal loss and for the practice of rituals, it is of particular interest to observe the role of healthcare systems in the processes of grief described above and the way that social positions are constructed during care. In the following section, I address the key thinking on the role of healthcare and establish some specific questions for the research.

4. Configuring healthcare following perinatal loss

4.1. The contemporary model of bereavement care

As I outlined in Chapter 1, the concept of perinatal bereavement care was introduced into obstetrics and neonatal care in the 1970s and 1980s when biomedical care models were first challenged and the maternal-foetal bond was accepted as being a basis for grief. In its present form this new model of care could be said to have four primary pillars: emotional support, decision autonomy in relation to care of the baby and medical decisions, memory-making rituals related to care of the body after birth, and evidence-based clinical practice related to the diagnosis, birth, puerperium and investigation of the cause of death.

Attending to emotion is seen as a counterpoint to the rationalist model of care, where emotion is viewed as out of place, unhelpful or a problem to be solved (Davidson 2008; McCreight 2008). As opposed to silence, distance and insensitivity, carers are expected to express empathy, warmth and to acknowledge the loss and the baby's existence (Downe et al. 2013; Erlandsson, Säflund, et al. 2011; Gold 2007; Kelley and Trinidad 2012; Säflund, Sjögren, and Wredling 2004). In talking about loss, health professionals should not minimise its significance and avoid using clichés or medicalised terminology to refer to the baby, when appropriate (Umamanita and El Parto es Nuestro 2010; Williams, Alderson, and Farsides 2001). Rather, health professionals are encouraged to listen and to try to understand the subjective meaning of the loss in order to personalise care (Lovell 1983). Ensuring that women are accompanied at all times and not made to feel alone or abandoned is also of utmost importance (Erlandsson, Lindgren, et al. 2011; Gold 2007; Malm et al. 2011; Trulsson and Rådestad 2004).

As discussed in Chapter 1, until the 1980s, it was common for health professionals to assume total control over decision-making in the context of perinatal loss (Kowalski 1980). Addressing this power imbalance formed a major part of the new model of care (Moulder 1998:222) as exclusion from decisions related to the treatment of the baby after birth appeared to cause long-term problems with grief (Benfield, Leib, and Vollman 1978; Estok and Lehman 1983; Lasker and Toedter 1994). Assuming at least some degree of control over care was also thought to reduce distress, anxiety and confusion (Fenwick et al. 2007; Malm et al. 2011). Now, various medical bodies and parents' associations recommend that women, and where appropriate their partners,

make all decisions related to care, including those related to clinical practice (Health Service Executive 2016; PSANZ 2019; RCOG 2010a; Sands 2016; Umamanita and El Parto es Nuestro 2010). Implementing such a vision requires health professionals to recognise that they don't necessarily know what is best (Moulder 1998:222).

Three areas of practice are central to bereavement and memory-making rituals: creating a safe context and supporting parents to interact with and spend time with the baby following the birth (holding, washing, dressing); taking photographs and collecting other significant objects (locks of hair, hand and footprints, clothing, etc.); and ensuring a respectful disposition of the body, regardless of the gestational age, be that by private means or organised through the hospital (PSANZ 2019; Royal College of Nursing 2018; Sands 2016). As already outlined in Chapter 1, the concept of 'memory making' was born out of the idea of women having no real memories, but more recently the focus is on social validation and the affirmation of parent and infant identities, through the continuation of culturally normative parenting (Cohen et al. 1978; Lovell 1983; PLIDA 2008b; Rådestad et al. 2009; Säflund et al. 2004). In this sense, these practices represent a fulfilment of cultural obligations to the dead, as well as the commencement of processes of continuing bonds, (re)construction of social identities and making sense of loss and death.

In terms of clinical practice, a series of evidence based recommendations are published in the guidelines of professional organisations, support associations and national care strategies (Health Service Executive 2016; PSANZ 2019; RCOG 2010; Sands 2016). There is little point in going into the details of each aspect of care, but it is useful to consider labour/birth as an example. In this area of care, the recommendations state that in the absence of clinical indications there is no rush to induce a birth following a diagnosis as almost all women will give birth naturally in a period of two-three weeks (ACOG 2009; Chakhtoura and Reddy 2015; Dudley 2011; RCOG 2010a). Likewise, unless medically necessary, vaginal birth is recommended over a caesarean section (ACOG 2009; NICE 2008; RCOG 2010a; SEGO 2008), as it has no benefits for the baby and is associated with short and medium term morbidity in the mother (Al-Zirqi et al. 2016; Lydon-Rochelle et al. 2001; Silver 2012; Singh, Sharma, and Chaudhary 2017). It is also recommended that prior to the commencement of the birth that women be provided with a full birth plan in relation to posture, mode of delivery and pain-relief, and that they be accompanied by their partner or other person of their choice at all times during the birth (Cassidy et al. 2018; Sands 2016:169).

4.2. A socio-relational view of perinatal bereavement care

From a socio-relational and materialist outlook, how to understand this model of care and locate it within the ideas of grief presented in the previous section? To facilitate the analysis it is useful to group these four areas of practice into two, although just temporarily. Firstly, we can consider emotional support and decision-making as a form of verbal and non-verbal communicative interaction. Secondly, the practices related to bereavement, such as ritual and treatment of the body, or clinical care, such as that practiced during the birth (which includes technologies of care), can be considered performative material action. I will deal with each of these separately, before drawing them back together.

To consider care as communicative symbolic interaction (Mead 1934) is to say that during intersubjective encounters between a woman who has just lost her baby and a health professional both parties will draw on linguistic resources and rhetorical devices to contextualise the situation as they attempt to collaboratively and reflexively achieve something: communicate information, reach a decision, conduct a diagnostic examination (Greenhalgh, Robb, and Scambler 2006;

Heritage and Maynard 2006; Mishler 1986:54). As such, they adopt social positions, attempt to position others and thereby represent themselves and the world in specific ways, bringing meaning to social phenomena (Gumperz and Cook-Gumperz 1982:1; Potter 1996:43). To do this they may use discursive resources, category systems (constructs), common sense knowledge or 'member resources' that permit them to engage in practical reasoning, to act and to understand the intentions of others (Fairclough 1989:80–81, 1992:72–82; Goodwin and Heritage 1990; Potter and Wetherell 1988). By evaluating these linguistic mechanisms it should be possible to see how carers, bereaved women, mothers, babies and dead babies are positioned and how this establishes associated rights (e.g. to grieve, to access the body, to make decisions), responsibilities and moral obligations (e.g. to provide particular forms of care, etc.) (van Lagenhove and Harré 1999; Wetherell 1998).

Social disjuncture may exist if there is tension at different levels: in the intent either party brings to the interaction, in the taken-for-granted meanings accessed from broader culture, or how objects (such as the baby) are referenced (Pollner 1975; Wortham and Rhodes 2015). If the interpretative frames and meaning applied to the situation differ to such a degree that co-operativity is called into question then we would expect certain communicative mechanisms to be used to repair the situation (Gumperz and Cook-Gumperz 1982:17; Pollner 1975). If not, either the health professional's or the woman's standpoint will dominate through unequal relations of power, limiting or redrawing rights and entitlements. Imbalances in power may be a function of rhetorical competence, access to resources and knowledge, or authority to contextualise (Blommaert 2005:71; Greenhalgh et al. 2006; Gumperz and Cook-Gumperz 1982:9–10). In the context of stigma or taboo, it is also useful to consider how silence (avoidance) or silencing and sanction (Hazen 2006; Huckin 2002; Jaworski 1997; Sobkowiak 1997; Zerubavel 2006) are employed in interactions as a way of establishing meaning or exercising power.

From the perspective of bodies and the material world, there has been increasing efforts to refocus social research on the body as a site of intersubjectivity, social practice and the materialisation of power (Butler 1993:33–34; Csordas 1994; Farquhar and Lock 2007). At a local level, the way that embodied phenomenological experience acts to condition "being-in-the-world" is a crucial aspect of care and the self as a social agent (Crossley 2012); even more so if silence is an important aspect of social interaction. With respect to perinatal death, it is useful to consider that much of the experience of grief, loss and care takes place beyond the realm of talk. Women must go through the full physical experience of giving birth, and all that entails. All of this must be experienced concurrently to the embodied experiences of grief and its various physical manifestations. It has also been observed that the feelings of shock, confusion and fear, common following diagnosis of perinatal death, impact women's sense of self in the world, capacity to communicate and make decisions (Kavanaugh and Moro 2006; Kelley and Trinidad 2012; Kellner, Donnelly, and Gould 1984; Malm et al. 2011; Peters et al. 2014; Samuelsson et al. 2001; Ujda and Bendiksen 2000). At the same time, bodies as the objects of medical practice are handled, measured, moved and manipulated with instruments, technologies and chemicals, becoming, as Csordas (1994) says, both the subject and object of care.

From a material culture perspective, we can also consider how the fleshly materiality of dead bodies demands appropriate action, be it bereavement and mortuary rituals, *post mortem* examinations or disposition, such that they are both a site for social practice and express object agency (Hallam, Hockey, and Howarth 1999; Harper 2010; Hockey 1996; Langer 2010). From this viewpoint, how bodies (pregnant or the dead) are located, treated and observed during care tells us much about how bereaved women and dead babies are culturally positioned and how identities

are produced through social practice (Csordas 1994; Farquhar and Lock 2007; Frank 1991; Hockey, Komaromy, and Woodthorpe 2010).

Technologies too are important in medical care. But like any relationally engaged material they are not benign and passive or only symbolic of social action (Olsen 2010:154). Technologies are materials that make different forms of the social possible and vice versa (Leonardi 2012). They represent a coming together of the material capacities and social, political and cultural values that may exist at anyone one time in history and in multiple possible forms (Mol 2002). Hence, feminist scholars have frequently critiqued the ideas of neutrality and objectivism that masculine controlled science claims when employing technologies. They argue that it results in dominant/subordinate relations between masculine/feminine, nature/culture, human/non-human, etc., which perpetuates inequality (Fox Keller 1985; Haraway 1987, 1988), much as I have described in the historical and contemporary 'social' practices of childbirth in Chapter 1.

As such, it would seem to make little sense to consider how social positions are negotiated in talk-in-interaction without considering women's embodied intersubjective experiences and the role of the various objects and technologies that they come into contact with during care. Collectively, these ideas provide some important guidelines for the study. It means that the social and intersubjective positions (identities) of actors are done not ascribed. There is no private or cognitive self, nor any overarching or essentialist sense of identity to which the experiences of the person are integrated, although that does not mean that there cannot be attempts to impose them. In contrast, a non-essentialist understanding of identity, or better said, social position, is based on the idea that the self and morality is a product of interaction and the continual negotiation of cultural positions (Fairclough 1989:102–104; De Fina 2015; Hall 1996). To be a bereaved mother (or not) is not a fixed concept, but one that is continuously negotiated and modified at local level including during hospital care and is shaped by the broader cultural values that influence how society views mothers, women, foetuses, babies and the dead. From a materialist perspective, bodies, objects and technologies are not passive participants in how the social is brought into being but are actively and influentially entangled in the socio-relational (Barad 1996:132; Csordas 1994; Keane 1997; Law 2009). Applying these concepts to care and how grief is socially produced, the objective is to consider how care influences the relationship between the living and the dead and women to the world.

5. Research questions

The primary objective:

Specifically the study is concerned with how talk, rhetoric, medical practice, bodies, history and materialities come together to produce specific configurations of grief in hospitals. As such, the primary interest relates to investigating how the social practices of care produces particular configurations and understandings of grief and positions women/mothers in relation to the institution and the world. Within this objective, it is important to establish how experiences of loss are framed within care encounters. Furthermore, it is necessary to consider how such meaning is achieved and what social mechanisms sustain, modify or challenge distinct forms of social reproduction. Finally, it is of interest to examine how rights to grieve or not grieve are established during care encounters on the basis of social roles and positions. And, how such meaning and practices shape experiences of grief, continuing bonds and narrative meaning-making.

Secondary objectives:

In evaluating care following perinatal loss in Spanish hospitals it is of concern to establish the specific characteristics of the local care model. Within this objective, the research will have to focus on determining the values that hospitals place on providing support and creating a social space for loss and grief vis-à-vis other forms of care. It is also relevant to establish how health professionals, as principal actors, are portrayed and characterised. Do they affiliate or disaffiliate from their patients and if so, through what mechanisms? Additionally, what are the characteristics of care in terms of decision-making and symmetry? Do health professionals promote agency or sustain asymmetry? Finally, for the purposes of comparative statistics it is important to establish the prevalence of a range of practices in relation to the diagnosis, labour/birth, sedative administration, *post mortem* contact, disposition of the body, amongst others.

In terms of women's experiences of care, it is important to consider, what kinds of 'mothers' emerge from the interactive processes of care in hospitals? In this respect, it is relevant to establish how women construct themselves in terms of rights, roles and moral responsibilities. For example, in considering the transition from pregnancy to pregnancy loss, do women's constructions of the self represent continuities or discontinuities in social position before and after death and to what are such changes attributed? Do they position themselves as agentive, autonomous individuals? Do they emerge as having a 'voice' in processes of care? On the basis of these processes, it is necessary examine how they position themselves within their relationship to their dead children and their own moral identity.

As key actors (if material) in the process of care and a key object of social negotiation it is particularly important to focus on the social position of the baby as it emerges from care processes. From this perspective, the study is interested in exploring if and how dead babies are positioned as a source of stigma and taboo or as persons that require specific social treatment and conventions in ritual after loss. Relatedly, what rights and responsibilities are they associated with in relation to parents in contrast to the hospital/institution?

Section 2.
Study design
and research
methods

Chapter 3. Study design: ethnography and mixed methods

1. Introduction

As a childless cis-gender male who has never lost a child, during a partner's pregnancy or any other time, I set out to address the research questions specified in Chapter 2 from a standpoint on women's experiences of perinatal death that really couldn't seem more distant. Although my sister lost her child during pregnancy and I have had a privileged vantage point in terms of observing what that meant for her, her partner, and other family members, I am still an 'outsider'. I have found myself repeatedly asking what that means for my position in the study and to what degree such distance can really be bridged? Sprague (2018) proposes that there are two common myths about what it means to stand outside or be distant from a social location. Firstly, she points out that being an 'insider' can be both an advantage and a disadvantage. While it may enhance empathy and encourage trust with research participants it may also make taken-for-granted meanings harder to detect. Secondly, she observes that standpoint as a research process is not a given, already occupied position, but one that is achieved. In this respect, it is less a place from which to begin an inquiry than a methodological process that seeks to arrive at a location, although there is no one place to arrive, no heterogeneity of experience or essence of meaning. As a researcher, I can only attempt to achieve an approximation to the particular place that bereaved women occupy, which may be better or worse, more or less useful to the goal of social change, depending on the success of the methodology and resources at hand.

Starting from this position, the chapter sets out a mixed-methods research design based on an ethnographic approach that tries to ensure a strong ethical commitment to the research participants and social change. The specifics of the qualitative and quantitative research are described in Chapters 4 and 5, respectively.

2. Some reflections on epistemology, ontology and the object of inquiry

The analytic framework proposes that it is the interaction of women, their families, health professionals, discourses, bodies, technologies, and care systems that dynamically bring certain configurations of grief into being. Viewing bodies and materialities as active in social relations, along with discourses, requires a perspective that doesn't view the objects of inquiry as ontologically passive. This also means a rejection of any divide between nature and culture, or any

privileging of the semiotic over matter (Barad 2007:132; Hallam et al. 1999; Haraway 1987; Latour 1993:4).

In attempting to overcome such dualisms, Barad (1996, 2007) proposes that all phenomena are physically and socio-culturally contextual and that all scientific observations are inseparable from the observer. Research, therefore, represents a 'view' that contains the inbuilt values of the investigative effort, but which is never complete nor reaches any essence of reality. Rather, knowledge production is the result of the entanglement or interaction of discourse, matter and the researcher (Barad 2007:139–140). Similarly important, standpoint theory, formed out of Haraway's (1988, 1991) proposal for feminist embodied objectivity, proposes that all knowledge is partial and limited, a coming together of physical location, history and culture (Sprague 2005:41). From Haraway's viewpoint this permits the researcher to attend to "specificity and difference", and learning to see from another's point of view (Haraway 1988:583).

These ideas can be complemented with relational ontologies that view the social as produced in a network or assemblage of social objects, be they human or non-human (Barad 2007:132; Latour 2005:1–15; Law 2009). These approaches are fundamental because of how they address the issue of agency and incorporate human and non-human actors into social inquiry. Instead of focusing on intentionality, the effect that is produced in the interaction between different elements in the assemblage is the key consideration for the researcher. In other words, they collapse the subject/object duality and are concerned with local 'doings' or enactments, which are in a constant process of change and never complete.

Under this conceptualisation, a view of grief emerges as an affect produced by complex interactions and relations between the bereaved and the dead, healthcare professionals, the social milieu, socio-cultural and historical discourses, technologies, medical practices, objects and the spatio-temporal environment. This places the object of inquiry as something real in the sense of a doing, without assuming that it represents the only possible reality. The main idea is to investigate from different perspectives, to bring different research strategies to play so as to consider many alternative and partial accounts. This permits a study of the differences that can be observed as alternative doings. For example, why does one form of care and grief come into being and how is it sustained or modified at local level and shaped by wider competing discourses or cultural values?

3. The study population

Although the most widely accepted definition of the perinatal period stretches from the 22nd week of gestation to the seventh day post-birth (Zeitlin et al. 2010), based on the arguments outlined in Chapter 2, gestational age is not an appropriate delimiter of experience or the socio-relational dynamics of pregnancy, foetal personhood and loss/grief. However, for the study to include all cases of pregnancy loss does have some practical implications, particularly for the quantitative research. The divergences in care between the first and second trimesters and between stillbirths and neonatal deaths are so great that it was concluded that it would be far too complex, and beyond the available resources, to construct an instrument that could adequately capture all the processes of care. Hence, for the survey research the population was limited to intrauterine deaths occurring between 16 weeks gestation and birth, including *intra partum* deaths. On the other hand, the qualitative interview research included neonatal deaths as a sampling category.

In terms of what classes of perinatal death to include in the population, the literature presented in Chapter 2 also suggests that the type of death is not an important discriminating variable in terms

of grief or how care should be practiced. For this reason, the population included spontaneous intrauterine deaths (stillbirths in single or twin pregnancies), *intra partum* deaths, and terminations of pregnancy for medical reasons (Pector 2004; RCOG 2010a, [b] 2010; Sands 2016).

Clearly, the loss of a baby can deeply affect fathers as much as mothers (McCreight 2004), however the population was limited to women for a number of reasons. Firstly, including men/ fathers in the study population would have increased the intricacy of the research instruments, the requirements for fieldwork and recruitment in the quantitative and qualitative research, and increased exponentially the analytic complexities. The project simply didn't have enough resources for such an undertaking. Secondly, this study was the first national research programme in Spain to address care practices following pregnancy loss and it was felt that the priorities were to address the concerns of women first and foremost as those who bear the main social burden. Finally, only cases that occurred within the Spanish National Healthcare System were permitted to take part.

Table 1. Number and rates of perinatal deaths in Spain from 1996-2016, data elaborated by the author based on statistics available in the National Institute of Statistics

	1996	2001	2006	2011	2016
Live births	362,626	406,380	482,957	471,999	410,583
Perinatal deaths					
≥22 weeks gestation to 27 days post-birth	2,689	2,667	2,725	2,528	2,103
≥22 weeks gestation to 6 days post-birth	2,338	2,285	2,317	2,172	1,862
≥28 weeks gestation to 6 days post-birth	2,103	2,056	2,058	1,905	1,622
Perinatal mortality rate (22 weeks to 27 days)	7.36	6.52	5.61	5.33	5.10
Perinatal mortality rate (22 weeks to 6 days)	6.41	5.59	4.77	4.58	4.51
Perinatal mortality rate (28 weeks to 6 days)	5.76	5.03	4.24	4.02	3.93
Perinatal deaths adjusted for underreporting*					
Total ≥22 weeks gestation to 27 days post-birth (+5.0%)	2,959	2,961	3,040	2,836	2,366
Adjusted perinatal mortality rate per 1,000 births (22 weeks to 27 days)	8.09	7.23	6.25	5.97	5.73
% change between 1996 and 2016					
Change every 5 years (%)	—	-10.6%	-13.5%	-4.5%	-4.1%
Absolute change 1996-2016 (%)	—	—	—	—	-29.2%
Perinatal deaths adjusted to include terminations of pregnancy for medical reasons (2016 only)					
≥22 weeks gestation (+ 214 cases)	—	—	—	—	3,080
Perinatal mortality rate adjusted to include underreporting and terminations of pregnancy (22 weeks to 27 days post-birth)	—	—	—	—	6.2

* + 5,0% on the basis of the analysis of the data available in the Registro de Mortalidad Perinatal de la Comunitat de Valencia between 2011 and 2015 and argued in (Cassidy 2018b)

Calculating a precise size for this population is difficult, if not impossible, as no data is collected for intrauterine deaths between 16 and 21 weeks and the data between 22-27 is especially poor, due to underreporting. It is also unclear from national data if terminations of pregnancy are included or excluded. To try to overcome this problem, an analysis was undertaken of the national data for the years 1996 to 2016 (Cassidy 2018b). This required a significant manipulation of the

dataset to adjust for missing data and underreported cases, which has been estimated by various national studies at 5-50% depending on the gestational age group (Bosch Sánchez et al. 2006; Cirera Suárez and Garcia Rodriguez 2000; Cirera Suárez et al. 2008; Freitas Ramírez et al. 2008; Martínez López et al. 2007; Mosquero Tenreiro and González-Rico 1994; Registro de Mortalidad Perinatal de la Comunitat de Valencia 2015; Revert et al. 1998; Río Sánchez et al. 2009). If terminations of pregnancy are included (around 700 cases), the analysis estimated that there were about 3,000 deaths between 22 weeks gestation and 27 days postpartum for the year 2016. In terms of deaths between 16 weeks and 21 weeks, there is no way to estimate the number of spontaneous intrauterine deaths, but it is known that there were around 5,000 terminations of pregnancy between 15-22 weeks for congenital anomalies in the years 2015 and 2016 (Ministerio de Sanidad 2015, 2016). See table 1 for perinatal death calculations.

4. Methodology: Ethnography with mixed qualitative and quantitative methods

4.1. Introduction

As a philosophical and methodological approach to research, ethnography views human action as both meaningful and contextual. In other words, to understand such action is to comprehend the meanings that constitute it (Atkinson and Hammersley 1994; Schwandt 2000). Critical ethnography, however, occupies a position somewhere between realism and idealism (San Roman 2009), in that it rejects the idea that knowledge production can be value free. Rather it sees it as a dialogic that draws the researcher into the field of social action and implicates all research in ethical and moral choices (Erickson 2018; Madison 2019b; Tedlock 2000), which requires reflection on how interests and positions influence research (Biglia and Bonet i Martí 2017; Harding 1992; Kohler Riessman 2015; Lincoln, Lynham, and Guba 2018; Sprague 2018). As part of a moral commitment to research participants, this method is also concerned with exposing social processes of oppression, control, inequality and power imbalance rather than the generation of neutral descriptions of the world. In other words, the production of knowledge that has the capacity for social change and restorative justice (Callén et al. 2007; Lincoln et al. 2018). In undertaking such an endeavour, the objective is to generate data that sheds light on social practice and to locate taken-for-granted meaning in historical, economic, gendered and other social structures (Lincoln and Guba 2000; Thomas 1993:9). Hence, from a feminist perspective, a critical approach means to be concerned with asking questions such as who gets to determine what knowledge is legitimate, and the processes that marginalise the views and experiences of women or other social groups (Hesse-Biber 2012). The purpose of social critique therefore is positive change and an ethical commitment to human and social wellbeing in collaboration with rigorous scientific method (Madison 2019b; Thomas 1993:2).

4.2. Mixed-methods design

The research objectives establish a need to investigate what type of care is practiced in Spanish hospitals and how social positions and grief are interactively produced during encounters between bereaved women, healthcare professionals and other social actors. This means that, on the one hand, it is of interest to know relatively straightforward pieces of information regarding the prevalence of certain practices, such as *post mortem* interaction with the baby, use of sedatives or the caesarean section rate. This type of data is useful if it is gathered at a population level and has

some credibility in its capacity to provide an overarching view or barometer of the object of study. On the other hand, this information doesn't necessarily tell us how care and certain forms of social reality are achieved during social interactions. For this purpose traditional dialogic methods employed in ethnography, such as participant observation and qualitative interviews (Atkinson and Hammersley 1994; Thomas 1993:3) are more suitable as they are grounded in the local and intersubjective (Lincoln and Guba 2000; Madison 2019a). However, participant observation of care practices on maternity wards following perinatal loss is not a feasible data collection method as seeking informed consent in a situation of mental distress would be unethical due to the potential for doing harm. Qualitative interviews are a more feasible option as they can be done some time after the loss and may represent a superior strategy in that they can provide perspectives on past events and their impact in the present day.

Mixed-methods design is a viable way to research from within feminist epistemologies (Oakley 1998), new materialism (Fox and Alldred 2015) and pragmatism (Creswell 2009; Johnson and Onwuegbuzie 2004). Although care has to be taken in the way that values are integrated across methods (Bericat 1998; Davis and Craven 2016; Denzin 2012; Lincoln et al. 2018), these three epistemologies find common ground in a practical approach that centres on collecting the data that provides the most suitable evidence to address the research questions, rather than being constrained within a philosophical viewpoint. While a mixed-method strategy is normally advocated for its capacity to triangulate and validate data, it also provides a number of other advantages. Firstly, by converging multiple sources of evidence on a single object of interest it is possible to address the weaknesses of individual methods. It can also permit a dynamic interplay through the concurrent development of theory, methods and instruments (Bericat 1998:37; Bryman 2001; Teddlie and Tashakkori 2008:38; Yin 2006). And, from a less purposeful or pragmatic outlook, but of specific interest to this research, disconfirmation between data also opens up the possibility of examining divergence and the exploration of partial truths and phenomena (Hesse-Biber 2012; Sprague and Zimmerman 1993).

Many types of data can be used in mixed methods, including discourses in traditional and social media, statistical population data, geo-spatial data, secondary data, interviews (in various forms), Delphi studies, survey data (including close-ended and open-ended questions), architectural and design analysis of spaces, participant observation in offline and online contexts, amongst many others. For example, Gordo López and Megías Quirós' (2006) study of young people and messenger culture employs documentation, analysis of secondary survey data and various types of qualitative interview data (semistructured personal interviews, structured and unstructured group data) to explore discourses from different social perspectives and to attend to the particular dynamics and cultures of the object of study and research participants (2006:23–30). On the other hand, Serrano and Arriba's (1998) study of poverty and income wished to address how exclusion is produced in the interaction of social service provision. In their study they used exclusively qualitative methods but analysed historical user files, conducted participant observation of service user interviews and qualitative interviews with service professionals (front-line and management staff) and users. Hence, both of these studies used mixed methods to compare, contrast and triangulate, and used statistical or documentary data to inform and support other methods and procedures such as method design, fieldwork and analysis.

From within the framework of critical ethnography this study employs three primary strategies for collecting data or evidence:

- Participation/ observation in ethically acceptable settings
- Qualitative unstructured narrative interviews

- An anonymous online survey on healthcare practices and experiences of care, which collected both quantitative and qualitative data

Each of the methods is described in more detail in the following section. Beforehand, I'd like to consider some important ethical considerations when conducting research with the bereaved and how this informs research practice.

4.3. The ethical considerations of conducting research with the bereaved

The ethics of doing research with the bereaved, notably qualitative interviews, has been somewhat controversial for a number of years (Dyregrov 2004; Sque, Walker, and Long-Sutehall 2014). As in other forms of research with sensitive subjects, there is a concern that the distress caused by the interview, or potential for retraumatising, is too high a price to pay for the benefits of the research (Lee and Renzetti 1990; Rosenblatt 1995). One of the primary objections is the argument that the lack of structure in qualitative interviews makes true informed consent to participate impossible; neither researcher nor participant can know for certain how the interview will proceed (Buckle, Dwyer, and Jackson 2010). Nevertheless, a great majority of research participants find the process in some way beneficial or at least innocuous, although they may also find the process in some way distressing, which is to say that distress in itself is not necessarily negative (Biddle et al. 2013; Gekoski, Gray, and Adler 2012; Hynson et al. 2006; Omerov et al. 2014). That said, it is also notable that a very small amount of participants find the process in some way negative or unhelpful (Brabin and Berah 1995). Research with parents who had experienced a perinatal loss has made similar findings (Brabin and Berah 1995; Kavanaugh and Ayres 1998).

As such, conducting research of this type presents moral and ethical dilemmas for the researcher, but also for the participant. On the one hand, doing nothing could mean that an opportunity to change harmful social conditions or stigmatised bereavement goes unchallenged. Similarly to the experiences of other researchers (Buckle et al. 2010; Corbin and Morse 2003; Hynson et al. 2006; Riches and Dawson 1996), I have found that many participants expressed that they enjoyed the opportunity to talk about their children, particularly as they felt silenced by their social milieu. Some said it was the most they had ever talked about the death to anyone. In many respects, qualitative interviews seemed to function as a source of social validation (Corbin and Morse 2003), and this was also evident in comments at the end of the survey. Most of the women appeared to be motivated to participate for altruistic reasons, but one mother, Elisabeth⁴, seemed to participate because she needed to unburden herself. In the three years since the death of her son, she said she had hardly ever spoken about her traumatic experiences in the hospital. Although she was very distressed during parts of the interview, she insisted on continuing despite offers to stop. However, it was also apparent that this distress was not related to the fact of doing the interview, but was something she had been carrying for a long time and was related to the context of the death and the social circumstances of her grief. Elisabeth subsequently went on to participate in support groups and to attend counselling and has said that it has helped greatly. The question then is not necessarily one of distress, such as crying or becoming distraught when talking about the loss of a loved one, but of whether or not the process is harmful. In fact, the research results from this study suggest that it is the very lack of willingness of other social actors to engage with distress that contributes to problems during grieving, continually forcing 'negative' social emotions into the private sphere.

⁴ Pseudonyms are used for all study participants.

Taking Elisabeth as an example, it is possible to see how ethics and morals are often co-constructed during interviews, and it is important to allow for the fact that participants retain significant control before and during interviews (Corbin and Morse 2003). When recruitment processes are ethical, fully informed and unpressured, participants can refuse the offer to participate. If the approach to the interviewing is non-interrogational, the participant retains significant control over what is said. This is not to say that no power dynamics are at play, but it is undoubtedly one of the major skills of the researcher to help create an environment for the interview that is conducive to such control.

Finally, it is important to take into account that many bereaved people, like a number in my study, participate in research for altruistic reasons, precisely because they believe that there is a need for change to social and institutional practices (Corbin and Morse 2003; Dyregrov 2004; Gekoski et al. 2012; Hynson et al. 2006). To deny them this possibility is paternalistic and limits their agency in a way that is similar to care practices. In this sense, from an ethical perspective, the key issue is to have a proper ethics and participant safety plan in place so that support and follow-up care are available post-interview (see Chapter 4, Section 3.2 for details).

As the research demand came from a parent support association, concern for participant safety was the primary consideration in conducting this research, both in terms of anonymity, data protection, how the survey questions were worded and the mechanics of the qualitative interviewing process. Although, at the time of starting the research, the Universidad Complutense de Madrid did not require ethics approval for studies not involving clinical trials, a comprehensive participant safety plan was put in place. At a global level this included:

- Parent oversight (through Umamanita)
- The participation of other parents' associations in the research design
- Consultation with parents at all stages of the research design (exploratory interviews, post-interview consultations and feedback, extensive piloting)
- The involvement of expert psychologists in the development of the survey research questionnaire
- Ethical recruitment practices
- Attendance at perinatal grief training for the principal researcher prior to conducting qualitative interviews (Paul Cassidy)
- Informed consent
- Strategies for providing support post participation

Chapters 4 (qualitative methodology) and Chapter 5 (quantitative) each contain specific details of the measures taken to ensure participant safety for their respective methodologies.

5. Methods

5.1. Observation/participation: immersion in the community

Traditional participant observation was not feasible for ethical reasons, however, as a researcher there were a number of other ways that I could both observe and participate within the community in such a way as to become better informed and prepared for conducting other aspects

of the research methodology, such as interviewing and interpreting data. The observation and participation, as such, provided a backbone and support to the entire research project that stretched from the development of instruments to the analysis and interpretation of research results. In total, I completed over 50 ‘participations/observations’ that have allowed me to develop my knowledge of technical aspects of obstetric care, engage with healthcare professionals and discuss preliminary research results, observe parents in other settings, and engage with them in informal talk.

Observing and engaging with parents

Every year in Madrid, around the beginning of October, the support association Umamanita holds a commemorative event called *El día del recuerdo* to coincide with International Babyloss Day (see figure 1). The event involves various activities, symbolic rituals and commemorative acts, as well as providing a safe place for parents to gather and talk. I have attended this event every year as both a family member, a member of the association and as a researcher. It gives me an opportunity to talk informally (no recording or note taking) to parents about their experiences of grief and care and on one occasion led to a qualitative interview.

Figure 1. Photographs of El día del Recuerdo, October 2017.



Left: Homemade flags displaying messages to babies from parents and other family members. Right: The reading of names that takes place as part of the main commemorative event.

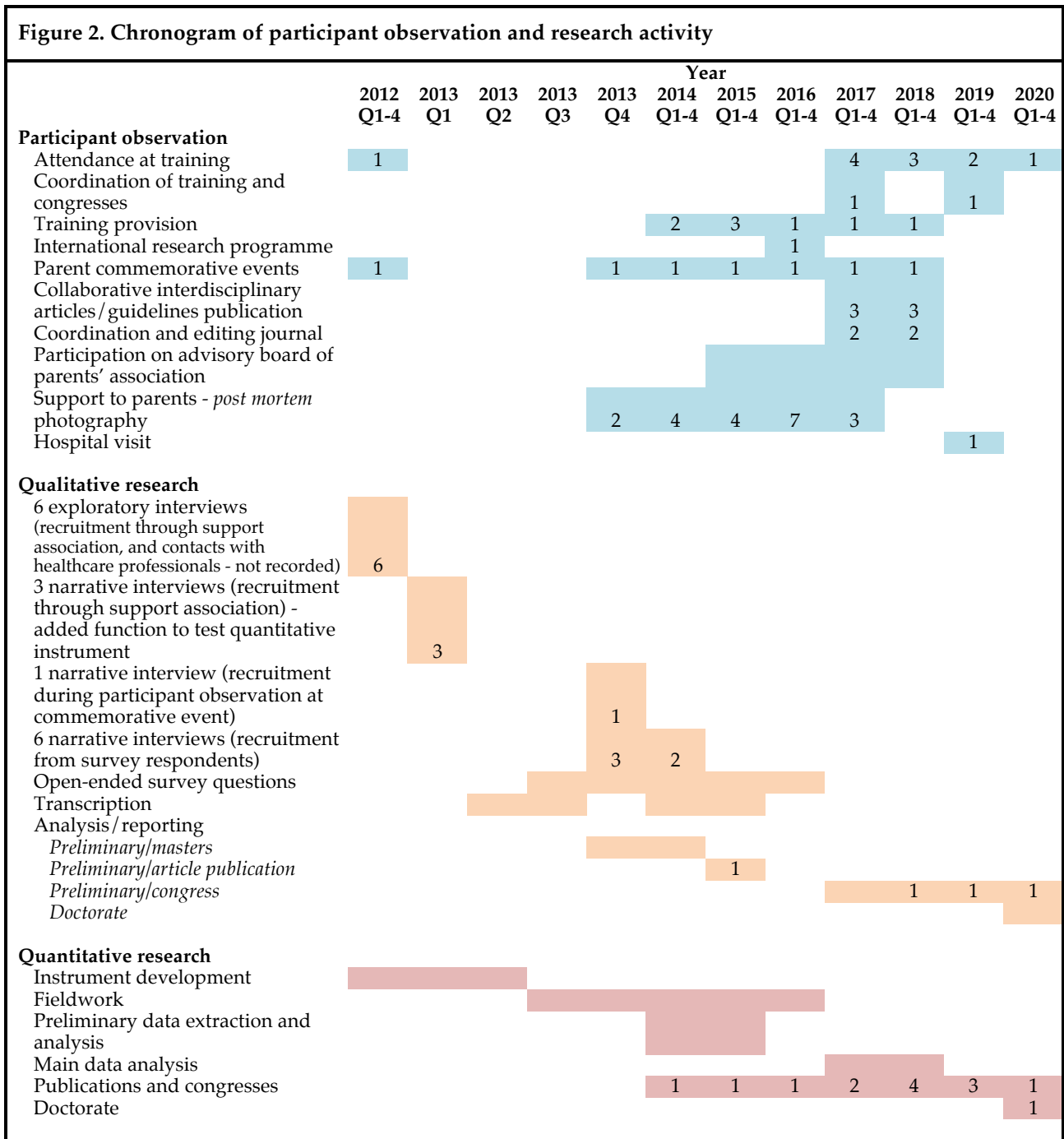
I also had occasion to provide support to parents on specific topics where I have developed in-depth knowledge of hospital practices, such as burial and autopsy protocols, and also provided support to a number of parents to help when retouch photographs recovered from autopsy files.

Although specific results of the observation are not presented in this study, I undertook a virtual ethnography of a pregnancy loss forum called *Superando un Aborto*, where I observed the entries of 22 members. The analysis was presented as part of my masters project (Cassidy 2014).

Education and training

As part of the ethics and participant safety programme, I attended a perinatal grief workshop in Madrid in January 2012 to learn about grief, care practices and techniques for engaging with

bereaved parents, as one way to prepare myself for conducting one-to-one interviews. I also attended more technical and medical focused workshops such as IMPROVE and an information workshop on *post mortem* examinations for parents (September 2017), an advocacy workshop and a pathology workshop (June 2018), and a support group workshop for moderators and health professionals (October 2018). These workshops broadened my knowledge and experience related to clinical/ medical aspects of bereavement care, which helped to understand and interpret accounts of care related to clinical practice.



Observing and engaging with healthcare professionals

Although direct research with healthcare professionals does not form part of the research methodology, I engaged with them at a number of levels. Firstly, I conducted exploratory interviews with three healthcare professionals and subsequently another eleven healthcare professionals were involved in the development of the quantitative research instrument. Additionally, collaborating with Umamanita, I helped to develop and provide a number of training sessions and an international congress⁵ for healthcare professionals in Spain. During these training sessions I could present general analytic concepts related to the research and some preliminary results. It was always fruitful to listen to how health professionals viewed the role of care and their perceptions of what women and their partners experience. Their views often coincided and diverged from the results of the research, and by talking to health professionals I gained a greater respect for the complexities of care provision and institutional dynamics. As part of the process of preparing the analysis I felt the need to see a hospital maternity unit, pathology and mortuary area, so I organised a visit to a hospital (in conjunction with a support association), which involved a discussion and conversation with three health professionals (midwife, pathologist and gynaecologist) and a tour of the facilities. This was very beneficial as a process of 'visualising' the physical dimensions of a delivery unit. Finally, I also collaborated with healthcare professionals in Spain and internationally on the production of perinatal care protocols and the development of interdisciplinary care guidelines.

A full list of 'observations' are detailed in Appendix 1 and a chronogram of activity in Figure 2.

5.2. Qualitative narrative interviews and open-ended survey responses

Narrative as theory, sense making or analysis has proven suitable to the study of life experiences following bereavement (Neimeyer 2001; Valentine 2008; Walter 1996) or illness (Bury 2001; Frank 1995; Hydén 2008). While recognising that all stories are told within cultural conventions, the strength of narrative lies in its ability to devolve as much power as possible to the research participant to tell their story as they feel inclined, giving space to their sense of self, 'voice' and experience of the world (Chase 2018; Polkinghorne 1991; Sandelowski 1991). Consequently, narrative is proposed to be particularly suitable to exploring grief and the disrupting force of death to one's sense of self and ontological security (McCreight 2007; Neimeyer 2001; Riches and Dawson 1996; Walter 1996). Within the field of perinatal bereavement, it has been employed to study broad cultural or historical discourses (Layne 1992; Thompson 2008) or thematic type analysis of group or subjective life experience of grief and care (Jones 2014; McCreight 2007; Umphrey and Cacciatore 2011; Willick 2006).

In this study, though, the interest lies not just in identifying broad themes related to grief and social position but also to exploring the taken-for-granted meanings and social mechanisms that produce meaning during encounters in healthcare. To this end, I avail of a practice-based interactional approach to narrative that provides a means to explore women's intersubjective experiences of perinatal loss and link these to cultural frames and discourses (De Fina and Georgakopoulou 2015). As in most discourse analysis this methodology views local speech events as contextual, action oriented and reflexive, spaces where the social world is transacted, negotiated and modified (Garfinkel 1967; Goodwin and Heritage 1990; Gumperz and Cook-Gumperz 1982; Mishler 1986). In employing narrative, we can also draw on certain conventions such as how

⁵ <https://www.isa2019madrid.com/es/>

stories always contain at least an account of a social action/event and often also orientations, evaluations and resolutions (Labov 1973:363; Mishler 1986:78). When applied to stories of care these characteristics can help us to understand what women attempt to achieve through their stories and the intersubjective and embodied experiences of encounters with health professionals and care systems. In terms of materialities and bodies I propose to take a 'located' view of materialities as they are brought into being as social actors within women's narratives of care (Heavey 2015) and the way that time and space condition and contribute to stories (Baynham 2015).

Unstructured narrative interviews

In total, ten qualitative narrative interviews were conducted, including three with couples and seven with women. The sampling followed a purposive and snowball procedure that attempted to ensure an even distribution of participants across gestational ages, type of death (spontaneous intrauterine death/ termination of pregnancy/ neonatal), socio-economic status and nationality. The interviews lasted from 2 to 3.5 hours and were transcribed verbatim following a pre-designed protocol. All interview participants were from the Madrid region.

Qualitative data from open-ended survey

The survey research (described below) included a number of open-ended questions on *post mortem* contact, autopsy, disposition of the body, and general impressions of care. In total, the responses of 622 respondents were extracted for analysis along with their socio-economic and loss related variables. The analysis initially concentrated on the entries of the 50 respondents who provided the largest amount of text (more than 2100 characters) and then explored the rest of the entries to check for saturation. In total, data from 52 respondents was used in the analysis.

The full qualitative methodology is described in Chapter 4.

5.3. Anonymous online survey

For the quantitative research an anonymous online survey was directed exclusively at women who had experienced an intrauterine pregnancy loss from 16 weeks gestation and up to and including *intrapartum* deaths occurring in the Spanish healthcare system. The questionnaire collected data on the prevalence of practices and women's subjective experience of care. The instrument was developed over the period of a year through an extensive process of drafting, content validation, and extensive piloting. Participants were recruited through a convenience 'snowball' sampling technique. The fieldwork was carried out over a three-year period from 2013 until 2016 and resulted in 796 completed interviews.

The full quantitative methodology is described in Chapter 5.

6. Mixed-methods in practice

At a practical level, the following examples give a better idea of the ways that the concurrent or parallel elaboration of the research design (Creswell 2009:213; Teddlie and Tashakkori 2008:123) was employed for instrument development, recruitment, exploration of preliminary data, validation and divergence in data analysis, and reporting. As illustrated in figure 2, instead of a lineal and sequential design, the development and implementation of the methodology permitted a constant process of feedback and (re)evaluation between the research strategies. I give some brief examples below:

Instrument development

The exploratory interviews (6), initial full qualitative interviews (3) and virtual ethnography (an observation in an online support forum) contributed to the development of the survey instrument, both in terms of understanding general care practices and care structures, but also for testing draft versions of the questionnaire (see Chapter 5, section 3). On the other hand, the preliminary results from the quantitative data provided points for exploration in the latter, more structured, phase of the qualitative interviews (see Chapter 4, section 3.4).

Recruitment and sampling

Both the participant observation and the survey were employed for the recruitment of participants to the qualitative data. One interview was organised following an informal conversation at a commemorative day event because the circumstances of the death were relevant to the sampling strategy. At the end of the survey questionnaire, respondents were asked to leave a name and email address if they wished to participate in further research. Based on their socio-demographics, the details of their loss (stillbirth, termination of pregnancy), previous contact with support associations (yes, no), care experiences (good, bad) and location (Madrid), a sampling frame was developed and the respondents were contacted by email, which lead to six interviews.

Validation and divergence in data

As mentioned above, triangulation has moved beyond its traditional remit of validating findings between different data sets to the exploration of difference (Hesse-Biber 2012). The triangulation of data in this study took place at various levels, both between qualitative and quantitative and between unstructured qualitative interviews and open-ended survey responses. The triangulation between data from the survey and qualitative interviews took place throughout the project, from the exploratory interviews and pilots to the development of the final conclusions. In general, the data converges on ideas about care and specific points of interest. For example, the qualitative and quantitative data coincide in the view that concepts of autonomy and agency are not of primary importance to the study participants, but tend to be backgrounded. However, each method also provides data that the other cannot. For example, the multivariate quantitative analysis was able to isolate care variables, which initially seemed to be of secondary importance, and demonstrate that they were in fact highly influential. On the other hand, the depth of data provided by the qualitative methods permitted the analysis to unpack interactive dynamics to establish how meaning is produced in action. This was critical to understanding how taboo and stigma are manifested and was beyond the capabilities of the quantitative research. Tensions also exist in the data. For example, a persistent discourse in the narrative interviews is that the majority of parents experience unempathetic care, yet the quantitative data suggests that this is not the case.

Integrated reporting

Rather than present quantitative and qualitative data separately, I have chosen to integrate the results in such a way as to illuminate specific questions and themes that emerge from the research. In doing so the qualitative research takes the lead with the survey data providing a supporting, contextualising and validating role. This approach centres the reporting on problems rather than on data, meaning that only the data and results that are useful are presented.

Chapter 4.

Qualitative research: Narrative discourse analysis

1. Introduction

The qualitative research specifically aimed to address questions related to how meaning and grief are socially produced within encounters between women and health systems (professionals, technologies, materialities). As such, it provides a more suitable means to undertake an in-depth exploration of how social positions, taken-for-granted meanings, power and control become manifest through a variety of social mechanisms. This chapter details the narrative and discursive part of the qualitative research from a theoretical perspective, as well as the implementation of the participant safety plan, sampling and recruitment, fieldwork and data collection, and analysis.

2. Qualitative data collection strategy 1: Narrative interviews

2.1. Introduction

Narrative style qualitative interviews formed the central plank of the data collection methodology. Within the approach adopted here, these interviews are understood as a social practice that produces a local or situated version of the subject through collaboration with the interviewer, as in any speech event (Kvale 1991:1–13; Mishler 1986:82; Rapley 2001; Slembrouck 2015). In this respect, the rest of this section describes the various aspects of interview as practice and how this relates to ethics and safety, sampling and recruitment, the fieldwork and conduct of the interviews, and the conversion of the recorded interviews to text.

2.2. Ethics and participant care

As detailed in Chapter 3 (Section 3.3), it is highly important to consider the potential harm or risk that participating in research on sensitive or traumatic events might suppose for an interviewee. In addressing this issue at the start of this chapter my intention is to establish ethics as both a moral and methodological concern that underscores the entire method. Based on a review of the literature on qualitative interviewing with sensitive subjects (Corbin and Morse 2003; Dyregrov

2004; Hynson et al. 2006; Kavanaugh and Ayres 1998; Riches and Dawson 1996; Rosenblatt 1995), a three phase ethics and participant safety plan was developed, which is described below.

Pre-interview

Interviews were only undertaken with parents who had been bereaved for a minimum of three months. If the recruitment was through a support association, an approximate profile of a suitable participant was provided (type of loss, gestational age of the baby, social class, nationality) and the support association subsequently made contact with a candidate they thought would be suitable and not in danger of being harmed by the interview. If the response was positive (in fact through this method all women that were asked agreed to participate), they passed the details to me and I initiated the next phase of recruitment. Phase two was conducted exclusively by email to reduce possible power imbalances. In the email I introduced myself, explained the nature of the project and advised potential candidates of their rights and protections (anonymity, right to withdraw at any point, etc.). In organising a location for the interview, participants were given a choice of having the interview in their home, at another venue of their choice, or at the researchers home. Whereas home interviews were my preferred option, in order for the interviewee to feel as comfortable as possible, it was important to offer other alternatives in case their homes weren't suitable for whatever reason. In total, seven interviews were conducted in participants' homes, two interviews in my home and one in a room at a participant's workplace. Prior to commencing the interview the participants were given a full explanation of the nature of the interview and required to read the informed consent document and to sign it. They were reminded that if they wished to stop or withdraw at any time during the interview they could do so and that they were guaranteed anonymity.

In-interview

The interview strategy was to attempt to give as much control to the interviewees as possible. The narrative style interview is suitable for this as it starts by asking the participants to tell their story in their own words and in the manner that they wished. This non-interrogational method meant that the participant set the agenda for how the story was told, requiring me to adapt to the way that they narrated rather than them having to construct answers that they thought would fulfil my needs. In this sense, the participant set the pace of the interview. However, in later parts of the interview (where questions required participants to reflected back on earlier parts of the narrative) it was important to try and ensure that the questions didn't push too hard for details that they did not wish to provide. This is a difficult balancing act, which can never be perfectly achieved. Regardless, being observant to verbal and non-verbal signs of distress during the interviews is important to establishing processual consent and ongoing negotiated ethics. It requires interaction and asking questions about how participants are feeling and giving them options to stop, take a break, or to not answer questions. While some participants became quite distressed during interviews, none of them chose to stop. Normally they just took a few seconds to breath, cry or compose themselves before continuing. In these situations I offered sympathy and tried to encourage them to take their time. In all cases, offers for a referral to a support association were made at the end of the interview. Only one participant specifically took this offer up.

Post interview

All participants were sent a follow-up thank you email with a scanned copy of their consent form. They were also asked how they were feeling and if they felt they needed any support that they should advise me or get in touch with a support association (whose details had already been

provided). After the first three interviews I requested any specific feedback that the interviewees had about their experience of the interview and if they had any recommendations for improvements for future interviews. They all responded that they found the process positive.

2.3. Sampling and recruitment

The sampling used a purposive procedure (Gobo 2007), which involved seeking out cases from as wide a range of situations as possible (gestational age, type of death, experience with care) so as to provide for the possibility of sampling an extensive variety of experiences and discourses. Based on a review of the literature, the procedure sought to interview parents, more specifically women, across a range of variables, including:

- Type of death (neonatal, *intra partum*, intrauterine, termination of pregnancy)
- Gestational age of the baby at the time of death (second and third trimester)
- Time since the death (< 1 year, 1-5 years, more than 5 years)
- Education level (primary, secondary, university)
- Nationality (Spanish, foreign national)
- Mother's age (under 30, over 30)
- Overall evaluation of care (good/bad)

Table 2. Characteristics of the narrative interview participants

Case ID	Recruit ment	Partici- pant(s)	Date interview	Tri- mester	Type of death	Months since loss	Nationality	Mother's age	Education level
A01	Supp. Assoc.	Couple	Jan-Mar, 2013	3rd	Intrapartu m/Neonat al	4-6	M: Spanish F: Nth. Eur.	35-39	University/ university
A02	Supp. Assoc.	Couple	Ene-Mar, 2013	3rd	Stillbirth	4-6	M: Lat. Am. F: Spanish	30-34	University/ university
A03	Supp. Assoc. Part.	Couple	Ene-Mar, 2013	2nd	Neonatal (Twins)	4-6	Spanish	40-45	Secondary/ secondary
A04	observ.	Mother	Oct-Dec, 2013	2nd	Stillbirth	4-6	Spanish	35-39	University
A05	Survey	Mother	Oct-Dec, 2013	3rd	Stillbirth	6-12	Spanish	30-34	University
A06	Survey	Mother	Oct-Dec, 2013	3rd	Stillbirth	4-6	Spanish	30-34	University
A07	Survey	Mother	Oct-Dec, 2013	3rd	Stillbirth	12-24	Spanish	30-34	Secondary
A08	Survey	Mother	Oct-Dec, 2013	3rd	Stillbirth	>60	Spanish	35-39	University
A09	Survey	Mother	Oct-Dec, 2013	2nd	Terminati on	24-36	Spanish	35-39	University
A10	Survey	Mother	Oct-Dec, 2013	2nd	Stillbirth	4-6	Spanish	30-34	University

In total, 10 interviews were conducted, all in 2013. In general, the interviews represent a good cross-section of the population based on the characteristics outlined above, although no women aged less than thirty were recruited. The circumstances of the deaths were varied in terms of

gestational aged (all between 20 weeks and 72 hours postpartum) and type of loss and type of pregnancy (spontaneous death, premature births, twins, IVF assisted, termination for medical reasons). At the time of the interview, all participants were in a heterosexual relationship with the father of the baby. Interviewees had diverse pregnancy backgrounds, some had experienced previous pregnancy loss (mostly in the first trimester), some had living children before the loss, others had had children since the loss, while some remained childless and some were pregnant at the time of the interview. The interviewees were largely, but not exclusively, educated to third level. Despite efforts, it proved difficult to access participants from working class backgrounds and those with lower/secondary level education - a sampling problem that is also evident in the survey research (see Chapter 5, section 3). In this respect, the use of open-ended survey responses as a secondary source of qualitative data compensates somewhat because the 52 cases included in the research include a proportion whose education level is secondary or lower (11 cases) and 6 foreign nationals.

The most significant weakness in the sampling relates to the total absence of immigrant women from Africa and Asia, both of which represent a significant proportion of the population of perinatal deaths in Spain. As a hard to reach group, within a hard to reach population, these women proved very difficult to access through existing referral chains and within the resources available to the project. Hopes of an interview with an immigrant from North Africa, for example, fell through at the last minute. Future studies should address these populations and put specific sampling and interviewing resources in place.

Table 2 displays a profile of interview participants.

2.4. Fieldwork and interview guide

The structural approach to the interview was based on a composite of methods recommended in narrative and bereavement research (Bauer 1996; Riches and Dawson 1996) and followed general theoretical concepts of narrative style interviews, such as those proposed by Mishler (1986) and Kvale (1991). The interview was 'relatively' unstructured in the sense that no questions were pre-prepared (Brinkmann 2018). Rather, I followed a format of 5-6 basic stages, including: a) initialisation, 2) main narration, 3) re-narration through open-ended questions, 4) direct questions on specific themes not addressed, 5) Conversational phase, 6) interview close. As per the participant safety plan, a follow up contact was made to each participant. The specifics of the guide are detailed in Figure 3. I conducted all of the interviews, which lasted between two and three and a half hours.

In practice, the format of the interview was highly dependent on the way that the participant chose to tell their story and my own developing skills as a qualitative interviewer. Quite often the phases became mixed as participants digressed, jumped between events and chronological order, offered extensive contextualising information for stories, and asked me questions. In such cases, I let the interview take a natural course, ceding as much power to the interviewee as possible. In terms of my own contribution to the interview, there were notable changes over the course of the fieldwork, but this was also dependent on the style of interaction of the participant. In particular, as I became more experienced, I learned to seek fewer clarifications and to resist the temptation to use a question to explore a topic in more detail and thereby interrupt the flow of the story.

As an interviewer, my greatest concern was to phrase a question in such a way that it might be hurtful or insensitive, or on the other hand, not to pick up on non-verbal signals and push too deeply into a topic that the participant didn't really want to go into. In reality, there were many awkwardly phrased questions or clarifications, but mostly these were resolved or repaired through talk or non-verbal communication and didn't seem to impact the interview too greatly (A few examples of these interactions are evident in the interview extracts presented in the results section). Finally, it's important to point out that as a non-native Spanish speaker, language was a more significant barrier in some interviews than in others. I found some participants more difficult to understand, sometimes due to an unfamiliar accent or because they used a lot of colloquial language, or in one case because of the intrusion of exterior noise. In these cases, it was sometimes necessary to make more clarifications than I would have liked.

Figure 3. Narrative interview guide

Phase 0. Preparation

Establish pre-contact agreements and clarifying understandings about interview process, organising timing etc.; generally conducted by phone and email.

Phase 1. Initialisation

Start with small talk, introductions, reading and signing of the informed consent.

Explain the format of the interview, stress that it isn't a question and answer type interview. Invite the interviewee to tell their story in their own words in the detail and order that they wish. If the participant appears to have difficulty starting or expresses a preference for a question, suggest that they start by telling how they met their partner and some family history to ease into the narrative.

Phase 2. Main narration

While the participant tells the story, use active listening and non-verbal encouragement and reassurance. Only make interruptions for the purpose of clarifications that are necessary or because the interviewee solicited a response (verbally or non-verbally). Completion of the main narrative should be clearly signalled by the interviewee.

Phase 3. Questioning phase 1 and secondary narration

Address specific aspects of the main narrative that are of interest through open-ended questions such as "could you tell me about [...] again?" or "when you said [...], what do you mean?"

Questions should be designed to encourage re-narration of events or encounters first described in the main narration. No introduction of themes not specified by the interviewee.

Themes of interest include: diagnosis, post-diagnosis, labour/birth planning, accommodation, visits from family, dilation/childbirth, post labour care, *post mortem* contact, memory objects and photographs, disposition, sedative use, lactation and puerperal care, discharge and follow-up.

Phase 4. Questioning phase 2

Introduction of specific questions not covered phases 2 and 3.

Phase 5. Conversational phase

This is a more open phase similar to an informal conversation that can provide the researcher an opportunity to discuss ideas that were emerging in the research in an informal manner.

Phase 6. Closing phase

Ask the participant how they are feeling and if they are alone, if they feel ok to be alone. Confirm any follow-up actions.

2.5. Transcription

All of the interviews were transcribed verbatim according to a specified transcription procedure which was adapted from McLelland et al (2003). The procedure provided transcribers with instructions for interruptions, overlapping talk, pauses, trailing sounds, inaudible information, and other nonlexical and paralinguistic elements. The transcription guide is displayed in Figure 4 and a sample transcription can be viewed in Appendix 2.

The author transcribed four of the interviews, a volunteer transcribed two, and paid staff transcribed the remaining four. The author reviewed all transcripts for accuracy and they were also reviewed by participants on all but two occasions. One correction was made to a transcript based on feedback from a participant. Transcribers were required to confirm deletion of the audiotapes and related files once the transcriptions had been finalised. The transcriptions are stored on a password-controlled computer, only accessible to the author.

Figure 4. Transcription guide*
<p>Source ID is indicated with the first letter of their name</p> <p>Content Audiotapes are transcribed verbatim (i.e., recorded word for word, exactly as said), including any nonverbal or background sounds (e.g., laughter, sighs, coughs, claps, snaps fingers, pen clicking, and car horn).</p> <ol style="list-style-type: none">1. Nonverbal sounds are typed in parentheses for example ((Informant X. laughs))2. Mispronounced words are transcribed as the interviewee said them with the actual words in brackets if necessary3. Filler words are standardised and transcribed, for example ehm, hmm, ahum4. Word and phrase repetition are transcribed. If a word is cut off or truncated a > is placed at the end of the word <p>Inaudible information Inaudible or difficult to decipher sounds are to be identified. If a relatively small segment of the tape (a word or short sentence) is partially unintelligible, type (____) for each word that can be distinguished.</p> <p>Overlapping speech If individuals are speaking at the same time (i.e., overlapping speech) and it is not possible to distinguish what each person is saying, place a = followed by a (____)</p> <p>Pauses and trailing sounds If an individual pauses between statements or words use one, two or three "." to indicate the pause as short, medium or long (1 second, two seconds or 3 or longer). If the pause extends beyond 5-10 seconds, make a note and give an explanation if necessary.</p> <p>If the sound at the end of a word trails noticeably, use "." of variable length to indicate.</p> <p><i>* Adapted from McLelland et al. (2003)</i></p>

3. Data collection method 2: Qualitative data extracted from the survey research

3.1. Open-ended survey questions

The survey research included 796 responses from women who had lost a baby between 16 weeks gestation and birth, excluding neonatal death. Apart from closed-end questions, the survey included a series of open-ended questions related to: *post mortem* interaction with the baby, investigation of the cause of the death, the disposition of the body and overall comments on the care experience. Many of these open-ended responses display characteristics consistent with concepts of narrativity and take the form of ‘small’ stories or accounts of complicating actions (Georgakopoulou 2006; Mishler 1986:105) that are framed by the specific question, such as:

[If the respondent did see the baby] *In relation to seeing your baby, is there anything else you would like to tell us, that we haven’t asked about?*

The responses to the question can also be further contextualised by the questionnaire as a whole. The open-ended responses can be read individually or collectively, as well as in conjunction with other data from the questionnaire such as socio-demographics, the details of the death, etc. The translated versions of the open-ended questions and sample responses from one respondent (Eugenia⁶, Case ID. B19) are displayed in figure 5 (the original Spanish questions and the answers from Eugenia can be viewed in Appendix 3).

Figure 5. Open-ended survey questions and sample responses from one study participant

Post mortem interaction with the baby

Q48. [If a health professional explicitly stated that the respondent was not allowed to see the baby] *What reason were you given for not being allowed to see your baby?*

Example response: they didn’t give me reasons for saying no they looked surprised that I wanted to see her and they asked me 3 or 4 times if I was sure

Q49. [At the end of the section on *post mortem* contact - If the respondent didn’t see the baby] *In relation to not seeing your baby, is there anything else you would like to tell us, that we haven’t asked about?*

Example response: Filtered

Q54. [At the end of the section on *post mortem* contact - If the respondent did see the baby] *In relation to seeing your baby, is there anything else you would like to tell us, that we haven’t asked about?*

Example response: [The person] who prepared and evaluated me very well for seeing my baby was the [female] midwife in the health centre, not [the midwives] in the hospital. In the hospital at the time of the birth there were so many professionals around me and each of them had a different opinion only thanks to me being prepared they didn’t confuse me with their messages and actions

Investigation of the cause of death

Q74. [If an autopsy was conducted] *Is there anything about the autopsy or other medical test that we haven’t asked about that you would like to tell us?*

Example response: they also did blood coagulation tests and I asked to get the results of these tests by

⁶ Pseudonyms are used for all study participants.

email because the [female] doctor and [male] gynaecologist that attended me were so cold and distant in the first visit after the loss when they gave me the autopsy results

Disposition of the body

Q77. [If the respondent indicated that the disposition was organised through the hospital] *You answered that you choose to have the body cremated by the hospital without the possibility of recovering the ashes, please state why you choose this option:*

Example response: social services through the hospital organised for the burial in a common plot

Overall comments on the experience in the hospital

Q80. [To all respondents] *Thinking about your time in the hospital, what helped you most (something that someone said or did)?*

Example response: During the birth: the anaesthetist that SAW that I didn't want an epidural or anaesthetics as the pain that I was feeling was mostly not physically (it was in my soul) and he stopped the team that was pressuring me to put myself in a that posture and HE LET ME GIVE BIRTH calmly offering me a little sedative that I hardly noticed and I felt very good (I think it was propofol)

Q81. [To all respondents] *Thinking about your time in the hospital, what helped you least (something that someone said or did)?*

Example response: the lack of coordination amongst the professionals, I discovered that they wouldn't let me take the mobile in to take photos, we snuck it in, they didn't ask me if I wanted photos or memory objects. the weird scared faces, the pity that I saw in almost all the staff that cared for me in the delivery room, that they wanted to hide the baby in fact they took him away and they brought him back clean and wrapped but they didn't explain it to me. the [male] gynaecologist asked me "why" I was crying ????? I got very angry. And the [female] doctor who gave me the results was really on the defensive and said that maybe I had a bad "quality" placenta, I asked her what she wanted to say with that and she didn't explain it, she got annoyed with my questions, it hurt me a lot. it seemed that I couldn't cry or appear weak and I suffered a lot because I felt very fragile.

3.2. Extraction and sampling of the open-ended survey data

In total, 622 respondents provide at least some response across all 7 open-ended questions. This data was extracted along with basic socio-demographic information, the details of the loss and overall evaluations of care. The analysis first conducted a general thematic analysis of all the responses, creating around 300 codes that were grouped into areas of care and interactions with healthcare professionals.

Subsequently, a separate linguistic analysis of the 50 respondents with the largest entries (between 2100 and 4500 characters) was conducted. This procedure is described in detail in the next section. Once these 50 texts had been analysed the thematic analysis was used to explore the remaining texts to search for new discourses and to check for saturation. Data from two other respondents were used to supplement the analysis.

These 52 respondents formed the basis of the open-ended survey data presented in this study. A profile of the characteristics of these respondents is presented in table 3. Statistical analysis found that this subset corresponds broadly to the overall sample (n=796), with some small statistical divergences that showed very small effect sizes. In this respect, the qualitative sample contained more respondents from large urban areas (38.5% v. 26.0%), more women with first time pregnancies (69.2% v. 53.5%) and a higher rate of previous contact with support associations (69.2% v 55.1%). Importantly, there were no statistically significant differences in terms of their overall evaluations of care or grief intensity, as measured with a Spanish translated version of the Perinatal Grief Scale.

Table 3. Characteristics of the qualitative sample extracted from the survey

	n (%)		n (%)
Age at the time of the loss		Type of loss/death	
< 25 years	0 (0.0)	Spontaneous intrauterine	42 (80.8)
25 to 29 years	5 (9.6)	Termination of pregnancy	10 (19.2)
30 to 34 years	24 (46.2)	Intra partum	0 (0.0)
35 to 39 years	18 (34.6)	Gestational age	
≥40 years	5 (9.6)	16 to 19 weeks	10 (19.2)
Education level*		20 to 25 weeks	12 (23.1)
Up to second level or lower diploma	12 (23.1)	26 to 33 weeks	12 (23.1)
Diploma, university degree or higher	40 (76.9)	≥34 weeks	18 (34.6)
Nationality		Year of the loss/death	
Spain	46 (88.5)	2010-2011	10 (19.2)
Foreign national	6 (11.6)	2012	11 (21.2)
Geographic location*		2013	11 (21.2)
City, suburbs or large town	32 (61.5)	2014	9 (17.3)
Small town or rural area	20 (38.5)	2015/16	11 (21.2)
Pregnancy history*		Previous contact with support assoc.*	
First pregnancy	36 (69.2)	No	16 (30.8)
Not first pregnancy	16 (30.8)	Yes	36 (69.2)
Type of pregnancy		Satisfaction with care	
Singular	50 (96.2)	% 'agreeing'	31 (59.6)
Multiple	2 (3.8)	% 'disagreeing or neutral'	21 (40.4)
Total	52	Total	52

* $p < 0.5$, very small effect size (Φ)

4. Qualitative data analysis

As outlined above, the primary way of dealing with the texts (data from interviews or open-ended survey questions) is to treat them as 'stories' and as interactive examples of talk-in-action that recount narratives of care and encounters with healthcare professionals. Broadly speaking the analysis takes place at three 'levels' that collectively identify how meaning and positions are constructed and negotiated during social interactions in both the storied world and the storytelling world, as well as taking into consideration the context of production, broader cultural discourses and historical situatedness (Fairclough 1992:62–73; De Fina and Georgakopoulou 2015; Parker 1992:3–22; Potter and Wetherell 1994). The first two parts of the analysis took place at the level of the text or speech event, while the third level makes connections to wider cultural discourses and theory.

- The level of text or speech event 1. Grammar, form and narrative structure
- The level of text or speech event 2. Direct presupposition or intertextuality to discourses outside the speech event that can be directly inferred from the text, such as cultural norms, expectations, rights and responsibilities
- Indirect or inducted association to cultural and historical discourses and social theory

This approach assumes that the narratives will contain at the very least the story of an event or complicating action, and in many cases, an orientation, evaluation and resolution (Labov 1973:363; Mishler 1986:78). Following a review of the literature, a bespoke analytic framework was

developed that primarily concentrated on the negotiation of social positions and evaluations of care encounters and practices, with a keen interest in the dynamics of power and control that occur during such interactions.

Level 1. Text or speech event 1: Grammar, form and narrative structure

The text level analysis took place through multiple line-by-line readings and fulfilling simultaneous tasks that use grammatical techniques from conversation analysis to examine the textual form and to identify the subjects and objects enunciated in the stories, as well as what and how something is being said or communicated. The analysis addressed three primary components of narratives: orientations, complicating actions and evaluations/resolutions:

1) Orientations: Broadly speaking, the examination of orientations involved identifying *the when* (the time of day, duration of an action), *the where* (locations such as delivery rooms, emergency wards, surgery, etc.), *the what* (materialities and technologies of care) and *the who* (the characters in stories, such as doctors, nurses, family, the baby, mothers, grieving mothers) of narratives. This data provides the necessary contextualisation and background information to understand the story. Orientations can also relate to the state of mind or physical condition of the narrator, such as being 'in shock' or 'exhausted' during an interaction. Analysis at this level involved systematically identifying each of these actors and contexts, but not at an evaluative level.

2) Identifying the event or complicating action: A complicating action might occur at various levels. To give some examples, it might focus on: a) the overall story of the death; b) the story of the birth; c) the story of a specific inter-event interaction such as a 'move', for example a greeting (or lack of one), an offer, a request (e.g. to provide pain relief or to see the baby). In analysing events we can consider the overall content of the encounter, for example: in the interaction between a health professional and a bereaved mother we can consider in broad terms if the content is strictly medicine or includes content relevant to the bereavement. Is the content of the encounter rekeyed or reframed by a health professional or the patient? Are these attempts at framing successful or resisted? We can also consider if the content relates to affiliative actions (agreements, acceptance) or disaffiliative actions (disagreements, rejections). Do the interlocutors affiliate on the social categories (nouns and pronouns) used to denote the object of an interaction, e.g. referring to the object of loss as a 'foetus' or 'baby'? Do doctors disaffiliate patients from group membership by using technical language or body language? The analysis of verbs is also fruitful, such as identifying the way actors speak (loudly, aggressively, softly), use of subjectivity and equivocation ('I think', 'I guess'), lack of agency ('they left me', 'they put me', they 'allowed me'), consensus and communicative action oriented verbs (modal verbs such as 'can', 'could', 'would'). Other strategies attend to different types of silences and silencing, either referred to in the storied world or in the storytelling world.

3) Evaluations and resolutions: While evaluations can occur at various levels, some of the specific tools used to identify them include adverbs and associative adjectives (to be good/bad, very/really, only/even/always/none), passive nominalisation (absence of a direct social actor), distancing pronouns (he/she, 'that doctor'), sarcasm and irony, emotion (anger, despair, relaxed) dominance gestures (cut offs, interruptions). Other ways of examining resolutions may include examining differences between feelings in the storied world and the storytelling world, expression of possible alternative outcomes, impact of dispreferred actions, and repair or solutions to disaffiliative actions.

Level 2. Text or speech event 2: Presupposition, intertextuality and positioning

The second level of the analysis is closely integrated to the first but emphasises non-explicit social concepts and discourses that are embedded in language through presupposition or referential meaning. These can be identified through a variety of lexical devices such as evaluative indexicals or category terms. In the case of evaluative indexicals, for example, it is possible to establish if behaviour is evaluated as consistent with cultural norms or expectations, either generally or specifically, in relation to social categories, such as a doctor. Hence, it is possible to observe a difference between the following two statements:

He [the doctor] referred to him as a foetus

He [the doctor] even referred to him as a foetus

Although there is much more that could be said about these two statements, without any other contextualising information, the first statement is a fact, although the pronoun 'him' and 'foetus' stand in contrast. In the second statement, the inclusion of the evaluative indexical 'even' clearly presupposes social norms from outside the speech event, which signals that for this woman the use of the term 'foetus' breaks a social convention that contests the social position of her son. Therefore, category terms in general are inference rich. Mother, father, son, daughter, baby, doctor, nurse, and even 'no one' are all constructed out of social stereotypes (identities) that presuppose rights, entitlements, duties, responsibilities, capacities, and normative expectations of behaviour and social action. Category membership can be contested in local interactions through claims to membership, attempts to displace, reframing, and other linguistic forms detailed above. In this sense, one expects a 'mother' to behave in a certain way in relation to her baby/child or that a doctor will help someone when ill. Differences between expected social behaviour and actual, then, suggests disjuncture in meaning and contextualisation between social actors, which requires exploration. Speech patterns, such as hesitations, gaps and question tags can also be analysed to locate where mainstream discourses are inadequate to describe experience and possibly identify taboos or stigmatised objects.

Level 3. Association to wider discourses and rhetoric and theory

At the third level the analysis focuses on three areas of inductive reasoning:

- a) Further extrapolation from the social meanings embedded in member categories to consider the wider and longer term consequences of meaning constructed at local level.
- b) Associating with broader cultural discourses and theory, for example in relation to death, grief, pregnancy loss, motherhood, gender, and medicine, many of which have been identified in the review of the literature.
- c) Placing the present day discourses in historical context.

The analysis took place in Spanish. The data extracts presented in the results section serve a supportive function that is designed to make the analytic process more transparent and to give study participants a greater presence in the research. Each extract is presented in its original Spanish form and with an English translated version that only serves a communicative function. The translations of the survey extracts mimic the form of the entries, which means they include any grammatical errors or other stylistic deviations from standard vernacular. All translations

were conducted by the author, who has a number of years experience in Spanish to English translation.

Chapter 5.

Quantitative research: Anonymous online survey

1. Introduction

The objective of the quantitative research was to address three broad questions: the prevalence of practices in Spanish hospitals; perceptions of care and evaluations of interactions with healthcare professionals related to support and decision-making; and finally, specific questions of identity or social position, such as the terminology used to talk about the baby. This chapter describes the development process of the quantitative research, which follows a standard methodology.

2. The study population

As detailed in Chapter 3 (section 3) the study population for the quantitative research was defined as intrauterine deaths (spontaneous, termination of pregnancy for medical reasons, and *intra partum* deaths) from 16 weeks gestation onwards. The survey was limited to women and only those cases that occurred in the Spanish national health system.

3. Development of the questionnaire

The research instrument was developed over a period of almost 18 months. As this was the first time that a survey of this type has been conducted in Spain there was no local literature or other research instruments on which to base the development of the questionnaire. Therefore, it was necessary to conduct extensive investigation of background documentation (hospital protocols, research literature), exploratory interviews and a detailed validation process. The questionnaire was developed through the following phases:

1) Literature and documentation review: including perinatal bereavement care guidelines, academic articles on care and grief, as well as methodological guidelines for online survey research.

2) Exploratory qualitative interviews: conducted with experts (one support association, two midwives and one hospital psychiatrist) and parents (two interviews with couples in their home and one with a mother by Skype).

3) Content and face validation: On the basis of recommendations in the literature (Churchill 1979; Gerbing and Anderson 1988; Gill and White 2009; McGlynn 1997; Parasuraman, Zeithaml, and Berry 1985, 1988; Sitzia 1999), a content and face validation was conducted with eight bereaved women and eleven healthcare professionals (nurses, midwives, neonatologists and psychologists). Participants were sent an electronic copy of the questionnaire and asked to review it, rank items in the care quality scale, and make suggestions for exclusion of items or the addition of new content.

4) In-depth validation of the interviews: At the end of the first three narrative qualitative interviews (see Chapter 4), the participants were asked to complete the draft questionnaire while I observed them. As the participants completed the instrument, any questions or items that raised doubts were discussed and their meaning was clarified. Based on these interviews and participant suggestions, a number of significant changes were made to the wording of questions, filters and the addition of response items.

5) Development of the online instrument: The online version of the questionnaire was developed on the Limesurvey platform, which permitted the use of skip-logic, randomised presentation of question battery items (to avoid bias due to fatigue), and IP access control.

6) Piloting of the questionnaire, conducted in three phases:

- a) Initial piloting by three bereaved women to test the general functionality of the questionnaire.
- b) Main piloting by eighteen women who had experienced diverse types of pregnancy loss at different gestational ages. In the main piloting phase open-ended questions were added to the end of each section so that the participants could make specific comments and suggestions about the questionnaire.
- c) Three final pilot interviews to corroborate the changes made following the main phase of piloting.

The final questionnaire contained 106 questions and over 400 variables addressing different aspects of care, as well as questions related to socio-demographics, pregnancy history, and details of the loss. The questionnaire mostly employed closed-end questions, although a number of open-ended questions were included, mostly at the end of sections or as 'other' response options. The closed-end questions were categorical/nominal (yes/no/don't know), ordinal (e.g. Likert agreement scales) and continuous (e.g. age).

The introduction to the questionnaire explained the purpose of the survey, described the target population and the fact that participation was anonymous. At the end of the questionnaire participants were given the opportunity to leave their contact details (first name and email) if they wished to be kept informed of the publication of results and/or participate in further research. 82% of respondents requested that they be kept informed of the publication of results and left their contact details (name and email). Of these, 60% volunteered to participate in further research, far more than expected. All of these respondents received an email thanking them for their participation, explaining how, when and if any follow-up research would be conducted. They were also provided with the details of support associations.

The main areas that the questionnaire addressed were:

- **Personal details:** socio-demographics (Q1-9, Q97-102), details of the loss and pregnancy history (Q10-22)
- **Diagnosis:** location, health professional, accompaniment, perception of care and interaction with personnel (Q23-27)
- **Accommodation:** duration of stay, type of room, privacy (Q28, 29, 34)
- **Birth/labour:** mode of delivery, accompaniment, complications (Q30-33)
- **Administration of sedatives:** incidence, motive, informed consent, perceived impact on memory (Q35-42)
- **Post mortem contact with the baby:** incidence, location of contact, forms of interaction, duration of contact, reasons for prohibiting contact, open-ended question (Q43, 44, 46-54)
- **Memory objects and photography:** type of objects kept from the hospital, objects of special significance (Q57, 58)
- **Investigation of the cause of death:** types of studies offered and conducted, who communicated information, when the information was communicated, consent, duration of time to reception of results, communication of results, cause of death, open-ended question (Q63-74)
- **Disposition of the body:** who communicated information, disposition method, reason for a hospital disposition (Q75-77)
- **Two open-ended questions on general experiences in the hospital:** what most and least helped during the hospital stay (Q80, 81)
- **Perinatal Grief Scale:** 33 item scale (Q82)
- **Statistical documentation related to the birth:** completion of the statistical birth bulletin (Q83, 84)
- **Follow-up care from health system, professional and social support:** type, contact with support associations, rating of social support (Q85-90, 95)
- **Perceived negligence:** (Q91, 92)
- **Support oriented interaction with healthcare professionals:** role of health professionals during *post mortem* interaction with the baby (Q53, 3 items); language health professionals used when talking about the baby (Q55, 56); perceptions of interactions with health professionals such as feeling listened to, level of emotional support, etc. (Q62)
- **Decision-making interaction with healthcare professionals:** *post mortem* interaction with the baby (Q45 & Q53, 6 items), general information, control over decision-making (Q78, various items, Q79)
- **Coordination and organisation of care:** perception of (Q78, various items)
- **Overall evaluation of care:** competence of health professionals, satisfaction with care, willingness to recommend the hospital to other parents (Q62, 4 items, Q96)
- **Questionnaire close and support information:** An open-ended comment section was included at the end of the survey if respondents wished to add some information or make a comment on the questionnaire. They were also thanked for their participation, assured of anonymity, and provided with the contact details for three support associations if they felt that they needed support, generally or due to completion of the questionnaire.

The final questionnaire can be viewed in Appendix 5 (Spanish version).

4. Sample design and fieldwork

4.1. Sample design

Ideally, the study would have employed a probabilistic sampling procedure such as a hospital based population study, but ethics issues with access to patient lists, costs and the coordination requirements of such a strategy made it impractical. The only available option was to use an online convenience sampling or 'snowball' procedure, where subjects self-select for participation (de la luz Kageyama, Sanin-Aguirre, and Romieu 2010). This procedure had been successfully adopted for country-based studies in Sweden and England (Erlandsson, Säflund, et al. 2011; Heazell et al. 2012) and in international studies (Cacciatore, Rådestad, and Frøen 2008; Frøen et al. 2011) on parents' experiences of care following perinatal death.

Conducting survey interviews online has certain advantages and disadvantages. The main problem with online surveys is the impossibility of calculating a confidence level (error) for the data as the sample is non-probabilistic, due to self-selection by participants, which leads to errors in coverage (Couper 2000). On the other hand, the snowball technique is particularly useful for reaching subjects that are normally difficult to locate (Atkinson and Flint 2001), such as perinatal death where the population is relatively small and where the subject matter is stigmatised. Additionally, when the study began, the daily or weekly rates for internet use were between 79% and 94% for women aged 16-44 years, which, while encouraging, also meant that an online methodology automatically excluded between 6% and 24% of the population (Instituto Nacional de Estadística 2012). Most likely, this gap in coverage disproportionately affected population groups in lower socio-economic stratum, which have higher rates of perinatal mortality, and so represent a larger proportion of the study population. Hence, real coverage is lower than the Internet usage rate. On the other hand, the anonymity provided by the online methodology may be beneficial to the study of socially sensitive or stigmatised subjects, such as health, drug use or sexual behaviour, to give a few examples (Gosling et al. 2004).

4.2. The 'snowball' reference chain and fieldwork

To carry out the snowball sampling technique, a reference chain was developed that included healthcare professionals, parent support associations and support groups, and the administrators of popular forums, blogs and websites related to pregnancy and maternity. During the fieldwork the following tactics were used to reach the target population:

- Advertisements on the homepages of the two largest perinatal bereavement support associations, Umamanita and Superando un Aborto
- Periodic posts on the Facebook page of Umamanita, which were shared through the social media network
- Emails to Umamanita's lists of parents asking them to participate in the survey and to forward the email to any other parents they knew
- Emails to Umamanita's list of healthcare professionals asking them to forward the email to any parents they knew
- Requests to survey respondents to share the link with other women (at the end of the questionnaire)

- Publication of a press release that had a reasonable amount of coverage in national digital media (eleconomista.es, portalesmedicos.com, lainformación.com, alicanteactualidad.com, iberoamerica.net and elmundodigital.es).

The fieldwork lasted 3 years, from 24th June 2013 until the 29th June 2016. During this time, the sample profile was monitored for coverage errors and efforts were made to correct this if possible. For example, coverage was significantly lower in southern Spain, where there were fewer support associations, so efforts were made to increase promotion of the survey in that area.

5. Sample

5.1. Data extraction and purification

In total 1,082 interviews were completed during the fieldwork period. Following data purification and the elimination of invalidated cases (153), the final sample contained 929 cases. Of these, 796 cases related to deaths within the 5-year period prior to completion of the survey. The reasons for the elimination of 153 cases are displayed in table 4. They relate primarily to respondents from outside of Spain, neonatal deaths and some double entries. Table 5 presents the number of respondents according to the year that they completed the survey.

Table 4. Purification of the survey sample

	Time between the loss/death and completing the questionnaire		Total n(%)
	≤60 months n(%)	>60 months n(%)	
Valid cases	796 (86.0)	133 (85.3)	929 (85.9)
Non-valid cases - outside the definition of the population			
Neonatal deaths	45 (4.9)	7 (4.5)	52 (4.8)
Cases not in the Spanish health system*	25 (2.7)	4 (2.6)	29 (2.7)
Respondents whose baby had yet to be born	3 (0.3)	2 (1.3)	5 (0.5)
Cases, such as homebirths, where there was no healthcare provided by hospitals	2 (0.2)	0 (0.0)	2 (0.2)
Father or other family member	1 (0.1)	0 (0.0)	1 (0.1)
Non-valid cases - poor data quality			
Excessive amounts of missing data	27 (2.9)	9 (5.8)	36 (3.3)
Excessive time between starting and finishing (2 weeks)	2 (0.2)	0 (0.0)	2 (0.2)
Double entries	24 (2.6)	1 (0.6)	25 (2.3)
Total	926 (100.0)	156 (100.0)	1,082 (100.0)

*Exclusively from Mexico, Central and South America

Table 5. Year the questionnaire was completed according to the time lapsed since the death/loss

	Time between the loss/death and completing the questionnaire		Total n (%)
	≤60 months n (%)	>60 months n (%)	
Year			
2013	369 (45.6)	79 (59.4)	448 (48.2)
2014	160 (19.4)	12 (9.0)	172 (18.5)
2015	124 (16.7)	19 (14.3)	143 (15.4)
2016	143 (18.3)	23 (17.3)	166 (17.9)
Total	796 (100.0)	156 (100.0)	929 (100.0)

5.2. General characteristics of the sample

The final sample contained responses from cases that occurred between 2009 and 2016, while the average time between the death and completing the survey was 13.8 months (Std. dev.= 15.3). It is of note that the sample includes cases from more than 200 hospitals (public and private), all of the autonomous communities, and 50 of the 52 provinces in Spain, the exceptions being Palencia and Melilla. The details of the sample are presented in table 6.

Table 6. Characteristics of the final survey sample

	n (%)		n (%)
Age at the time of the loss		Type of pregnancy	
< 25 years	22 (2.8)	Singular	740 (93.0)
25 to 29 years	113 (14.2)	Multiple	56 (7.0)
30 to 34 years	364 (45.7)	Type of loss/death	
35 to 39 years	228 (28.6)	Spontaneous intrauterine	583 (74.3)
≥40 years	69 (8.7)	Termination of pregnancy	191 (22.4)
Education level		Intra partum	21 (3.3)
Up to intermediate second level	76 (9.5)	Missing data	1
Second or lower diploma	251 (31.5)	Gestational age at the time of the loss	
Diploma, university degree or higher	469 (58.9)	16 to 19 weeks	128 (16.1)
Nationality		20 to 25 weeks	193 (24.3)
Spain	755 (94.8)	26 to 33 weeks	151 (19.0)
Foreign national	41 (5.2)	≥34 weeks	323 (40.6)
Geographic location		Missing data	1
City, suburbs or large town	588 (74.0)	Year of the loss/death	
Small town or rural area	207 (26.0)	2009-2011	168 (21.1)
Missing data	1	2012	127 (16.0)
Type of hospital		2013	176 (22.1)
Public	593 (74.5)	2014	153 (19.2)
Private	203 (25.5)	2015/16	172 (21.6)
Pregnancy history		Previous contact with support assoc.	
First pregnancy	426 (53.5)	No	355 (44.9)
Not first pregnancy	370 (46.5)	Yes	435 (55.1)
		Missing data	6
Total	796	Total	796

5.3. Triangulation of the sample to national data sets

Type of pregnancy loss/death and gestational age

In total, 22.4% of losses in the sample were because of terminations of pregnancy due to health problems with the baby or because of threat to the mother's life. 74.3% of deaths were due to miscarriage / stillbirth and 3.3% due to *intra partum* death. In terms of deaths over 22 weeks gestation, the distribution of terminations to stillbirths, at 21.1% to 78.9%, appears to be a little higher than national data. Concerning gestational age distribution, 40.6% were greater or equal to 34 weeks and 16.0% were between 16 and 19 weeks. Regarding gestational age distribution for death over 20 weeks, 58.1% of the sample were deaths greater or equal to 34 weeks, compared to 52.7% in the national records (Instituto Nacional de Estadística n.d.)⁷.

Nationality

The distribution of the data according to nationality shows that only 5.2% of respondents were resident immigrants, compared to 25.4% in the national data (Instituto Nacional de Estadística n.d.), which represents a large bias to autochthonous women. Additionally, non-national respondents were exclusively European or from Mexico, Central or South America, which means that there was no representation in the survey from African or Asian women, who represent 11.6% and 1.8%, respectively, of annual intrauterine deaths in Spain. This skew in the data also has a knock-on effect to education level and age distribution, as autochthonous women (who have given birth) tend to have a higher education level and to be older⁸.

Age

The average age of women at the time of the death was 33.7 years (Std. dev.= 4.3), compared to 31.4 years (Std. dev.= 5.92) in the national dataset (Instituto Nacional de Estadística n.d.). The difference between the survey sample and the national data is largely related to the participation of women under the age of 30; 17.0% in the survey compared to 35.0% in the national data. However, it should be noted that participation of women under the age of 25, at only 2.8%, was very low.

Education

In terms of education level, the analysis found that the sample was sharply skewed toward higher education levels. For example, only 9.5% of respondents stated that they had achieved at least an intermediate second level education, compared to 46.3% in the national data. While this bias toward higher education levels can be partly explained by the other bias toward autochthonous women, an analysis of the national data (Instituto Nacional de Estadística n.d.) revealed that it couldn't account for a large part of the difference. Therefore, the logical hypothesis is to assume that the bias relates to sociocultural effects similar to that found in other countries, where studies have revealed that users of online support and respondents to online surveys on pregnancy loss tend to be skewed toward white, middle-class women (Barak, Boniel-nissim, and Suler 2008; Cacciatore, Rådestad, et al. 2008; Capitulo 2004; Gold et al. 2012; Zeanah et al. 1995). The fact that

⁷ Author's analysis of foetal death microdata from the National Institute of Statistics (INE) for the years 2010 to 2015.

⁸ An analysis of foetal deaths in the national register from 2010-2015 (Instituto Nacional de Estadística n.d.) found a significant association, with a strong effect size, between nationality and education level ($X^2(2, N = 5.651) = 416.51, p < 0.001, \Phi = 0.271$) and age ($X^2(2, N = 7.008) = 2888.85, p < 0.001, \Phi = 0.203$).

at least 55.1% of women who participated in the survey had at least some contact with perinatal bereavement support associations would, at face value, seem to explain this bias in the sample (see table 6). However, an analysis of this sub-group found no significant association between education level and contact with support associations ($X^2(2, N = 791) = 2.00, p = 0.368$). In conclusion, the significant biases in education level (a proxy for social class) remain partially unexplained. Any future studies should look at strategies to overcome this sampling issue.

Variables related to medical care

National data (Instituto Nacional de Estadística n.d.) contains details on the rate of caesarean sections in cases of intrauterine death, which, on average, was 22.2% between 2010-2015, with no significant difference between years ($X^2(4, N = 7,064) = 8.62, p = 0.071$)⁹. In the survey sample, the caesarean rate for cases over 20 weeks gestation was 20.7%, very similar to the national rate. Furthermore, an analysis of the autopsy rate found that at a countrywide level an autopsy was performed in about 71.2% of cases, compared to 70.5% of cases in the survey data. The closeness between the national and survey data on these two variables suggests that with regards to clinical interventions the survey is a near approximation to the reality of day-to-day practice in hospitals.

Contact with support associations

To finalise, we can consider if the 'snowball' sampling technique had any other effects on responses related to medical practices or women's experiences of care. Bivariate analysis found that there was no significant association between having previous contact with a support association (55.1% of respondents) and rates of caesarean section, autopsy, sedative administration or satisfaction rate. However, there was a significant positive association in terms of the number of women who saw their baby after the birth (57.8% vs. 46.8%, $X^2(1, N = 791) = 9.56, p = 0.002$) and those that left the hospital with at least one memory object (36.9% vs. 22.5%, $X^2(1, N = 791) = 19.13, p < 0.001$). In this sense, post-discharge contact with a support association would appear to positively affect some results as it seems unlikely that more than half of all women who have had a pregnancy loss would have been in contact with a support association.

6. Data analysis

The final data set contained nominal/categorical, ordinal (Likert type scales), continuous (e.g. age) and qualitative variables. Dummy categorical variables were also created for multivariate analysis by collapsing scales and separating variables with multiple response items into unique variables. The analysis generated univariate, bivariate and multivariate results, according to the needs of the research objectives. In all bivariate and multivariate analysis the alpha level for statistical significance was set at $p < 0.05$.

6.1. Non-parametric and tests of independence

In the case of bivariate and non-parametric (non normal distribution) analysis to test independence between categorical variables, the analysis used Pearson's Chi-squared or Yate's correction for continuity in the case of 2x2 contingency tables. In all cases, the minimum expected counts of 5 in each cell were checked (Gravetter and Wallnau 2014; Pallant 2010). As well as using an alpha level

⁹ Author's analysis of micro data from the National Institute of Statistics (INE) for the years 2010 to 2015.

of $p < 0.05$, all the independence tests that resulted in a rejection of the null hypothesis were analysed for effect size in the relationship according to the criteria set out by Cohen (1988). In the case of 2x2 contingency tables the Phi coefficient was used, while in larger tables Cr amer's V was employed. The criteria for interpreting effect size for both coefficients, as a measure of statistical power, are set out in figure 6.

Figure 6. Effect size interpretation criteria for statistical power (Cohen 1988)

Degrees of freedom (<i>df</i>)	Effect size		
	Small	Medium	Large
1	.10	.30	.50
2	.07	.21	.35
3	.06	.17	.29
4	.05	.15	.25
5	.04	.13	.22

6.2. Multivariate analysis

For the purpose of identifying predictor variables or explaining variance between groups, and for analysing the relationship between dependent variables (e.g. satisfaction or having seen the baby or not) and independent variables (socio-demographics, pregnancy history, care variables), the method of analysis varied according to the nature of the dependent variable. In the case of ordinal dependent variables, such as scale data (e.g. satisfaction), the analysis used multiple regression. If the dependent variable was dichotomous, the analysis used binary logistical regression. In both types of analysis, a number of criteria were taken into account in relation to sample size, the regression method, the relationship between the independent variables (correlation, multicollinearity, and singularity) and the existence of atypical values, normality and homoscedasticity.

In terms of multiple regression, the conditions for sample size depend on the requirements of power, alpha level, number of predictor variables and the expected effect size. Tabachnick and Fidell's (2007) formula recommends $N > 50 + 8m$, where m is equal to the number of independent variables (IVs), which is to say, if you have 5 IVs you need 90 cases. At 796 cases, the sample size was more than sufficient to meet these criteria (Pallant 2010). Binary logistic regression (BLR) provided a more suitable test to evaluate the probability that an IV, which can be categorical or continuous, belonged to one group or another. Additionally, BLR provides for the possibility of testing for the relative influence of each predictor variable in the model (Pallant 2010). In this regard, it is more flexible than multiple regression and the method doesn't make suppositions about the predictor variables, which don't have to be normally distributed, have a linear relationship, or equal variance between groups (Tabachnick and Fidell 2007). Calculating a suitable sample size for BLR is complex and there is little agreement on an appropriate method, but Peduzzi et al (1996) recommend $N = 10k/p$, where p is equal to the smallest proportion of negative or positive cases in the population and k is the number of covariates. In all the scenarios where BLR was used, these requirements were easily met. In the case of both forms of regression analysis a series of strategies were followed to ensure adequate levels of significance and valid interpretation of the data (Pallant 2010; Tabachnick and Fidell 2007).

The final multivariate technique used was segmentation/decision tree analysis, a predictive method that classifies independent variables into interrelated groups (Tufféry 2011). In this study, decision tree analysis was used for three reasons. Firstly, as a flexible method for exploring relationships between variables and for making decisions about which results to focus on when bivariate analysis rejected the null hypothesis for a large number of variables. Secondly, it was used for its capacity to distinguish between points on a scale (Tufféry 2011), helping to make decisions about the collapsing of 5-point scales into smaller groups. For example, the analysis found that the neutral point on a Likert agreement scale was typically, though not always, closer to disagreement than agreement, meaning that the creation of a dichotomous variable would group points 1-3 (disagreement and neutral) and 4-5 (agreement) on the scale. Although various types of algorithms for decision tree analysis exist, in this case I used CHAID, which is one of the older methods, but also easy to use and quite flexible (Tufféry 2011).

Section 3.

Research results

Chapter 6.

Contextualising loss/death in care encounters

1. Introduction

This chapter focuses on aspects of narratives of care that deal specifically with health professionals, and other material actors, relative to the humanistic qualities of their interactions with women following perinatal loss. While paying attention to technologies and materialities, the analysis draws on narrative and linguistic techniques as a 'way into' the texts in order to explore what form care interactions take and how this ultimately results in a particular positioning of women, care, perinatal death and grief. Based on the analysis, the findings establish two broad oppositional characterisations of healthcare professionals. At one extreme, they are positioned as compassionate and empathetic and at the other as cold, distant *and* inhuman. It is important to note that the analysis presented in this chapter does not address procedural elements of care interactions, such as decision-making (Chapter 7), or those that relate to the how the baby is positioned within care (Chapter 8).

2. Findings

2.1. Compassion and empathy

When talking about positive relationships with doctors, nurses and midwives, the women in the study used terms such as "respectful", "affectionate", "empathetic", "compassionate", "caring", and "human". To illustrate we can examine Clara's¹⁰ response (extract 1) to an open-ended question about what 'most helped' during the hospital stay. In the first line she states: "The respect, affection and empathy." It is notable that this statement acts like a title to the entry and refers to care in general, it is unqualified, and is emphasised by the emphatic full stop. Clara's response, however, also introduces four other ideas about appropriate and compassionate care, which are common across the narratives. Firstly, even though the female gynaecologist that gave her the news of the death didn't cry it is clear that there was an expression of sympathy or some communication of personal feeling that was positively received (lines 2-3). In general in the

¹⁰ Pseudonyms are used for all study participants.

narratives, emotional expression is relatively rare amongst doctors and mostly associated with female nurses / midwives and young (resident) female doctors.

Survey question: What was the thing that most helped you during the hospital stay? (something someone said or did)

1	El respeto, cariño y empatía.	The respect, affection and empathy.
2	Al obstetra	The [female] ¹¹ obstetrician
3	q me dió la noticia,	who gave me the news,
4	sólo le faltó llorar.	she did everything but cry,
5	El obstetra	The [male] obstetrician
6	q me atendió,	that attended me,
7	me dijo q,	he said that,
8	desgraciadamente,	unfortunately,
9	estas cosas pasan	these things happen
10	y q yo NO tenía culpa de nada.	and that I was NOT to blame at all.
11	La auxiliar	The [female] assistant
12	q me hizo la cama,	who made the bed for me,
13	me traía la comida...	she brought me the food...
14	me comió a besos y abrazos	she gave me lots of kisses and hugs
15	y me dió ánimos,	and she gave me encouragement,
16	mi hizo reír.	she made me laugh.
17	La enfermera de quirófano,	The [female] surgery nurse,
18	q sólo con su mirada,	with just a look,
19	me daba fuerza y seguridad.	she gave me strength and security.

Clara, third trimester stillbirth, survey respondent

Extract 1. Case ID. B24

Secondly, addressing feelings of guilt about the cause of the death is an important part of the relationship between health professionals and bereaved women (lines 5-10). The survey found that around two-in-three women felt a significant amount of guilt or blamed themselves for the death. Clara's text presupposes that the doctor, as an expert and the social figure responsible for the surveillance of the pregnancy, has the authority to assign fault. Thus, the doctor could also be a threat or source of shame. Clara's use of a capitalised "NOT" and "at all" (line 10) stands out because it signals that the doctor placed a significant emphasis on this and that this has subsequently served Clara as an important piece of technical information and/or as a discursive resource.

Thirdly, Clara's reference to how "just a look" from the [female] surgical nurse gave her "strength and security" is very significant (extract 1, lines 17-19). Being in shock, frightened or fearing for one's own personal safety is a central idea in the narratives, most notably in relation to the time just after the diagnosis, during induction and during the birth. This increases vulnerability and reliance on health professionals. In extract 2, below, Montse (an interview participant) responds to my question about why she requested a caesarean section. She emphasised how difficult it was to face the unknown (line 6), that she expected to suffer quite a lot and was "scared" and "terrified" of giving birth (lines 9,11-13). She also stresses that it was her first birth (line 10), which was also the case for more than half of the survey respondents. As such, we can understand the "look" the nurse gave Clara (extract 1) to have been a response to a non-verbal request for support.

¹¹ Translation note: All Spanish nouns contain the gender of the object, which is not the case in English. The speaker would have to make this information known. For this reason, I have decided to include this information in the translations for its potential relevance to the analysis.

This extract comes from the main narration phase, early in the interview, and an interruption to ask why Montse asked for a caesarean section.

1	P	Y, pero, ¿por qué preguntaste por [una] cesárea?	And, but, why did you ask for caesarean [sic]?
2	M	Pues porque quería acabar con eso.	Well because I wanted to be done with it.
3	P	Ya	OK
4	M	O sea, ehm.,	I mean, ehm.,
5		sabía,	I knew,
6		no sabía lo que me esperaba,	I didn't know what was ahead of me,
7		pero quería que terminara eso.. ya,	but I wanted to get it over with.. as soon as possible
8		no quería sufrir más de lo necesario,	I didn't want to suffer more than was necessary,
9		me daba miedo, ¿no?	I was scared, you know?
10		era mi primer parto.,	it was my first birth.,
11		bueno, ha sido,	well, it is,
12		y. me daba miedo,	and. I was scared
13		estaba aterrorizada	I was terrified

Montse, third trimester stillbirth, interview participant

Extract 2. Case ID. A05. Transcription lines: 330-335

In relation to fear of giving birth, which was a key theme in Gemma's interview (extract 3), we can examine an account she gave of an interaction related to the use of epidural analgesics. There are many notable elements in this account, but principally I want to highlight the sense of calm that Gemma conveys in the reported speech of the midwives and how they reassure her that they were fully focused on ensuring that the birth was not traumatic (lines 5-12, 25-36). In lines 25-36, Gemma describes how the labour evolved, drawing attention to how the epidural connection was set up (with her consent) just in case there was a need to administer it; in fact it wasn't used in the end. What I would also like to emphasise is the role that technology plays in providing security, how it acts collaboratively with the midwife in responding to Gemma's concerns and alleviating her anxieties. The midwives permit Gemma to equivocate and also set up the birth so that both possibilities are available and neither predetermined.

This extract comes from a section of the man narrative where Gemma talks specifically about the supportive and affectionate health professionals and specifically that she didn't want an epidural if it could be avoided, but also she didn't want to experience as much pain as in the birth of her son.

1	G	lo que no quería	what I didn't want
2		tampoco	though
3		es tener los dolores que tuve en el otro parto [de su primer hijo],	was to have the pain that I had in the other birth [of her first child],
4		entonces, [las matronas] me dijeron:	so, they [the midwives] said:
5		"tú tranquila,	"don't worry,
6		que en cuanto hayas dilatado lo más mínimo,	as soon you have dilated even a little,
7		si te duele,	if it hurts,
8		te ponemos la epidural	we'll give you the epidural
9		sin ningún problema,	no problem at all,
10	I	Ahum	Ahum
11	G	porque aquí la importante eres tú	because here you're what's important
12		y esto hay que hacértelo a ti lo menos traumático posible"	and we have to make this the least traumatic as possible for you"
13		[...]	[...]
14		entonces,	so,
15		como llegó el sábado por la noche	when Saturday night came
16		y yo seguía igual,	and I was still the same,
17		sin contracciones dolorosas	no painful contractions
18		ni nada,	nor anything,
19		tenía contracciones,	I had contractions,
20		pero a mí no me dolían,	but they weren't painful
21		y me dijeron que	they said that

22 para yo ponerme realmente de parto 23 me tenían que doler, 24 pues, me dijeron: 25 "mira, vamos a, 26 como la anestesista tiene ahora un hueco libre, 27 la vamos a llamar, 28 y te vamos a poner el catéter de la epidural, 29 sin conectártelo al, a la anestesia, 30 para que así, 31 en cuanto tú tengas el mínimo dolor, 32 lo único que hay que hacer es conectarlo	to start the birth properly they had to be painful so, they said: "look, we're going to, as the anaesthetist is free now, we're going to call her, and we're going to put the catheter for the epidural in, without connecting it to, to the anaesthetics so that, as soon as you have even a little pain, the only thing that we have to do is connect it and we don't have to wait.. if the anaesthetist is in surgery or with another.. mum or whatever, we won't have to wait" and I said: "well, ok"
---	--

Gemma, third trimester stillbirth, interview participant

Extract 3. Case ID. A06. Transcription lines: 421-433

From Clara's narrative (extract 1) we can also draw attention to the importance of non-verbal communication in a context where words might be difficult to find or seem hollow and insufficient. Camino's short response to the question on the things that 'most helped' her during the stay in the hospital contains two instances of compassion through touch from a female nurse and a young female doctor (extract 4, lines 1-6).

Survey question: What was the thing that most helped you during the hospital stay? (something someone said or did)

1 Que una enfermera 2 me secara las lágrimas con sus manos 3 y que la médico residente 4 que me hizo el legrado 5 me acariciara la mejilla 6 cuando me pregunto si tenía más hijos 7 y le dije que no. [...]	That a [female] nurse dried my tears with her hands and the [female] resident doctor who did the curettage caressed my cheek when she asked me if I had children and I said no. [...]
--	--

Camino, second trimester stillbirth, survey respondent

Extract 4. Case ID. B40

The other notable characteristic of "caring" health professionals is that they sometimes go beyond the requirements of their job to ensure that women are properly cared for at a humanistic rather than technical level. In Patricia's survey entry (extract 5) she replies that the most helpful aspect of her care was how "affectionate and understanding" everyone was (line 1), in particular "our" [female] midwives (line 2); the "our" indicating affiliation and closeness. But she draws specific attention to the trainee midwife who stayed with her beyond her shift and visited her in the room on the ward until she was discharged (lines 4-9). The exceptional nature of these actions is presupposed by the introductory conjunction "even though" (line 4), indicating that they were beyond what could be reasonably expected. Of note is the continuity of care that the trainee midwife provides at two points: during the birth ("stayed with us until the end", lines 5-6), and also by connecting care from labour to the ward ("until we were discharged", lines 7-9). These actions were constructed as being very helpful and therefore I would argue that they were also

necessary, particularly as the shift to ward care can mean a potential loss of continuity with the midwife or other professionals who shared the intimacy of the birth.

Survey question: What was the thing that most helped you during the hospital stay? (something someone said or did)

<p>1 Todo el mundo fue muy cariñoso y comprensivo. 2 Nuestras matronas nos ayudaron mucho. 3 Tuvimos matrona y matrona en prácticas, 4 a pesar de que la matrona en practicas había terminado su turno, 5 se quedó con nosotros 6 hasta el final, 7 y fue a vernos a la habitación 8 los días siguientes, 9 hasta que nos dieron el alta. [...]</p>	<p>Everyone was very affectionate and understanding. Our [female] midwives helped us a lot. We had a midwife and a trainee midwife, even though the trainee midwife had finished her shift, she stayed with us until the end, and went to see us in the room the following days, until we were discharged. [...]</p>
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Patricia, third trimester stillbirth, survey respondent

Extract 5. Case ID. B27

Almost one-in-three responses to the open-ended questions in the survey contained some mention of a health professional who was especially kind (compared to one-in-five that mentioned an specially unkind health professional). However, within these responses a particular figure that some women metaphorically referred to as an “angel” is also present. This is a carer whose exceptional kindness or sensitivity “saves” women from situations of particularly poor care or repairs the damaging actions of other health professionals. We can take an entry from Aida as a case in point (extract 6). The focal point of this story centres on lines 17-32, a highly medicalised and conflictive encounter with a group of gynaecologists that rudely enter the room and take over the birth. Aida found this very upsetting because it wasn’t the way she wanted to bring her “daughter into the world” (lines 25-26), but she also felt unable to resist (lines 27-28).

Aida specifies at the beginning and the end of the entry that the actions of the [male] midwife “saved” them [herself and her partner] “forever” and “it’s still saving us” them (lines 1, 44-45). She also says that she will be “eternally grateful” (line 13). These are extraordinary statements that are not related to the apparent kindness of the midwife (lines 6-7) but to the repair of the birth once the gynaecologists decide to abandon their attempts to accelerate the induction and leave the room. Clearly observing that Aida was unhappy, the midwife asked her: “you don’t want it to be like that, right?” (line 34). He then calms her: “He simply said ‘when you are ready call me, just relax’” (lines 38-39). Aida writes that she subsequently goes on to have a birth that was commensurate and appropriate to her ideal. A birth that, despite the death of her daughter, is positive in the sense that even though she is dead, she was still brought into the world in a dignified and respectful way. She finishes by saying “That saved us. And it’s still saving is.” (lines 44-45).

Survey question: What was the thing that most helped you during the hospital stay? (something someone said or did)

<p>1 Un matrono nos salvo para siempre. 2 Casualidad ingresamos con el. 3 Y casualidad tuvimos a la niña con el. 4 Aunque no era experto 5 en situaciones como la nuestra 6 simplemente mirandonos</p>	<p>A [male] midwife saved us forever. It was a coincidence that we were admitted with him. And it was a coincidence that we had our girl with him. Although he wasn’t an expert in situations like ours simply from the way he looked at us</p>
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7	supo que era lo mejor para nosotros.	I knew that he was the best for us.
8	Es verdad que las cosas se podrian haber hecho mejor	It's true that things could have been done better
9	(siempre me dolera no tener una foto de ella)	(Not having a photo of her will always hurt)
10	pero dadas las circunstancias	but given the circumstances
11	creo sinceramente	I sincerely believe
12	hizo lo que mejor supo	that he did the best he knew how
13	y se lo agradecere eternamente.	and I will be eternally grateful.
14	- No puedo decir lo mismo de las ginecologas,	- I can't say the same for the [female] gynaecologists,
15	simplemente frias.	just cold.
16	Nada humanas.	Inhuman.
17	A las 05.00 de la madrugada	At 5 in the morning
18	(cuando estaba casi totalmente dilatada)	(when I was almost completely dilated)
19	irrupieron en la habitacion	some 5 gynaecologists
	unas 5 ginecologas	burst into the room
20	y despues de hablar entre ellas	and after talking amongst themselves
21	le hicieron salir a mi pareja	they made my husband leave
22	y me hicieron empujar.	and they made me push
23	Asi, sin mas.	Just like that.
24	Necesitaba a mi pareja al lado	I needed my partner by my side
25	y no era el modo de traer a mi hija al mundo,	and it wasn't the way to bring my daughter into the world,
26	era consciente,	I knew,
27	y llore por dentro	and I cried on the inside
28	pero no dije nada,	but I didn't say anything,
29	de alguna manera me rendi,	somehow I gave up,
30	todo aquello era demasiado.	it was all too much.
31	Menos mal que lo debi de hacer mal	Just as well that I must have been doing it wrong
32	y decidieron posponerlo para ma tarde.	and they decided to postpone it for later.
33	-Entonces, el matrono me dijo	-Then, the [male] midwife said
34	"no quieres que sea asi verdad?"	"you don't want it to be like that, right?"
35	y yo le dije	and I said
36	que no.	no.
37	El simplemente me dijo	He simply said
38	"cuando estas lista llamame a mi,	"when you are ready call me,
39	estate tranquila".	just relax".
40	Y fue un parto "privado",	And I had a "private" birth,
41	con mi pareja, el matrono y una enfermera,	with my partner, the midwife and a nurse,
42	con poca luz en la misma habitacion donde me ingresaron	with light low in the same room where I was admitted
43	(en nuestro refugio).	(our refuge).
44	Eso nos salvo.	That saved us.
45	Eso nos sigue salvando.	And it's still saving us.

Aida, third trimester stillbirth, survey respondent

Extract 6. Case ID. B10

As a narrative, this story tells us a lot about care practices and culture in some hospitals. Most importantly it demonstrates how compassion, calmness and giving control to women can make good births possible (lines 40-43) in spite of the deaths of their children. But this also shows how the opposite approach can make matters worse, with the potential not just to undermine Aida's position as a woman capable of giving birth but also to introduce toxicity into the birth and between Aida and her daughter, a theme I explore more fully in the following chapters.

Additionally, it is notable that the subversive actions of the midwife only occur in the absence of the gynaecologists. Unlike the midwives in Gemma's story (extract 3), this midwife appears to occupy a weak position within the hospital hierarchy and has limited capacity to direct care for bereaved women - an idea that I have found to be commonly expressed during training sessions with midwives and nurses. Aida also makes it very clear that this positive outcome was only down to luck, observing that it was only "by chance" (lines 2-3) that this midwife attended the birth.

Hence, the figure of the angel or saviour emerges as an anomaly in a care system not prepared to provide good bereavement care, a form of resistance to common practices, or a vanguard in the movement or transition from one culture of care to another. This idea is supported by Aida's observation that "he wasn't an expert", that "things could have been better" (extract 6, lines 4-5 and 8-9). Consequently, another discourse in the narratives maintains that compassionate, humanistic care is *not* dependent on technical know-how or training in bereavement care. For example, if we look at an extract from Araceli's survey entry (extract 7), we find a similar notion related to humanistic aspects of care being positive (lines 1-3), but it is also qualified by a modifying clause, which clarifies that it was obvious that the midwives had no specific training (lines 4-5).

What was the thing that most helped you during the hospital stay? (something someone said or did)

1	En general	In general
2	el trato cariñoso de l@s matron@s,	the affectionate care of the [male and female] midwives
3	que	that
4	aunque	even though
5	era evidente que no tenían formación específica en duelo	it was clear that they had no specific training in grief
6	fueron tod@s muy humanos. [...]	they were all very humane [...]

Araceli, third trimester stillbirth, survey respondent

Extract 7. Case ID. B42

The conjunction "even though" (line 4) suggests that the carers were doing their best despite the limitations of a lack of training. It implies that many of these women value the humanistic aspects of care highly and are quite forgiving, if they feel carers are doing their best. Aida expressed something similar in lines 11-12 (extract 6). This also draws a clear line in responsibility for poor technical care between health professionals and their institutions.

Finally, I'd like to address another idea from Gemma (extract 8), which proposes that bad care results in bad grief and good care leads to good grief. This idea is based on meeting other women at a grief support group. Comparing her grief to the other women, Gemma links her positive experience of care to better grief and other women's experiences of poor care to more difficult and long-lasting grief.

This extract is an aside from a part of the interview where Gemma talked about how she found the Support Group, which came just after the completion of the main narration where she had been talking about the psychologist that she was seeing, when I asked her if she was still seeing her. Therefore the context is support after discharge from the hospital and her main point was more specifically related to the idea that many support group attendees are there because they have problematic grief as a result of poor hospital care.

1	creo que	I think that
2	de las reuniones [del grupo de apoyo]	in the [support group] meetings
3	somos de los que	we're [herself and her partner] the ones
4	yo veo por lo menos que	At least in my opinion
5	soy de las que menos mal está,	I'm one of the better ones,
6	que hay otras mamás mucho peor que yo	there are other mums worse than me
7	y hace mucho más tiempo que han perdido a sus bebés,	and they lost their babies much longer ago than I did,
8	pero yo creo que	but I think that
9	a nosotros	for us
10	nos ayudó muchísimo el trato que nos dieron en el hospital,	the care we got in the hospital helped a lot,
11	muchísimo,	really a lot,
12	porque,	because,

13	es que desde que entramos hasta que salimos,	from the moment we arrived until the
14	eh..,	moment we left,
15	todo fue apoyo	eh.., it was all support

Gemma, third trimester stillbirth, interview participant

Extract 8. Case ID. A06. Transcription lines: 796-801

Gemma, though, also introduces an important contextualisation related to the quality of care: good care is an exception rather the norm; she stands apart from other women in the group as “one of the better ones” (line 5). This is a notion that was present across the interviews, but the results from the qualitative and quantitative research contradict this finding. To illustrate, the survey found that, at a global level, women who received unempathetic care are in a minority, although a large one: between 20-40% depending on what parameters are used.

Table 7 shows that 74.5% of women ‘agreed’¹² that health professionals were always respectful and 71.4% ‘agreed’ that they felt emotionally supported by the nurses and midwives. On the other hand, only a little more than half (55.9%) ‘agreed’ that they felt emotionally supported by doctors and almost half (47.4%) ‘agreed’ that they had positive *and* negative experiences with different carers in the same hospital. On the other hand, these results have to be qualified at various levels. Firstly, women who suffered second trimester losses experienced significantly poorer care, although statistically speaking the effect sizes are small to medium. This indicates that while trimester does determine care to a significant degree it can’t be separated from a general culture of care in obstetrics that doesn’t offer unconditional support when women experience pregnancy loss. Secondly, even though 71.4% of women felt emotionally supported by midwives/nurses, less than half felt treated like a mother, showing how social position can be undermined in various ways. Finally, emotional support does not mean specifically addressing loss/grief; more than 80% responded that they received ‘none’ or ‘little’ information on grief.

Table 7. Evaluation of humanistic aspects of interactions with health professionals according to gestational age

	Gestational age		
	2nd trimester	3rd trimester	Total sample
% of respondents who ‘agreed’^{***} with the following statements:			
The professionals were always respectful to me and my family ^{*1}	65.4%	80.5%	74.4%
I felt emotionally supported by the nurses and midwives ^{*1}	60.9%	78.5%	71.4%
I felt that the professionals listened to me ^{*1}	56.4%	68.5%	63.6%
I felt that I could express myself emotionally in front of the professionals ^{*1}	47.3%	64.3%	57.5%
I felt emotionally supported by the doctors (e.g. gynaecologists and obstetricians) ^{*1}	45.9%	62.6%	55.9%
Some of the professionals treated me well and others poorly ^{*1}	53.6%	43.2%	47.4%
The doctors and nurses/midwives seemed to work well as a team ^{*1}	58.0%	68.0%	64.0%
Although I lost my baby I was treated like a mother ^{*2}	29.8%	57.9%	46.6%
% of respondents who rated information received on grief as ‘enough’ or ‘a lot’	10.2%	22.5%	17.5%
n	321	475	796

^{*}*p* ≤ 0.05; 1=Small effect size, 2=medium effect size, 3=large effect size (Phi)

^{**} Composite of points 4 (agree) and 5 (completely agree) on a 5-point Likert agreement scale

¹² Amalgamation of 2 points on the Likert scale: ‘agree’ (point 4) and ‘completely agree’ (point 5).

When we study longitudinal trends in the data (table 8) it is possible to see statistically significant increases in women's evaluations of carers, but only in third trimester losses. This is positive in the sense that it signals significant cultural change within maternity units, but it also stands in tension to the determinism that sees women who experienced a second trimester loss treated differently to women who experienced a third trimester loss.

Table 8. Evaluation of humanistic aspects of interactions with health professionals according to the year of the loss and gestational age

	Year of the loss			Total sample
	≤2012	2013/14	2015/16	
Second trimester (% agreeing**)				
I felt that the professionals listened to me	50.0%	57.2%	64.4%	56.4%
I felt emotionally supported by the nurses and midwives	55.0%	60.9%	69.9%	60.9%
I felt emotionally supported by the doctors (e.g. gynaecologists and obstetricians)	37.6%	47.8%	54.8%	45.9%
Some of the professionals treated me well and others poorly	52.8%	49.3%	63.0%	53.6%
n (second trimester)	109	138	73	320
Third trimester (% agreeing**)				
I felt that the professionals listened to me* ²	56.0%	73.7%	81.8%	68.5%
I felt emotionally supported by the nurses and midwives* ²	69.0%	84.3%	84.8%	78.5%
I felt emotionally supported by the doctors (e.g. gynaecologists and obstetricians)* ²	50.5%	68.6%	73.5%	62.6%
Some of the professionals treated me well and others poorly* ²	47.3%	44.5%	33.3%	43.2%
n (third trimester)	184	191	98	473
n (total)	293	329	172	796

* $p \leq 0.05$; 1=Small effect size, 2=medium effect size, 3=large effect size (Phi)

** Composite of points 4 (agree) and 5 (completely agree) on a 5-point Likert agreement scale

On the whole, the analysis establishes that, in the case of these study participants, affiliation to health professionals is characterised by communication of empathy, compassion and reducing anxiety through language, non-verbal communication, and positive use of technology. The apparent affiliation between health professionals and women indicates that the interactions unfold within common contextualisations or frames. This implies that empathy is associated with how carers address the experience of loss, directly or indirectly, and is separate from the technical practice of obstetrics.

In essence, the qualitative research chimes with the literature in placing humanistic aspects of care, such as expressions of empathy, at the forefront of positive care. As I discuss in Chapter 7, decision-making and autonomy are important but tend to occupy a position in the background of narratives. However, the quantitative analysis finds a certain tension or inconsistency with this result. A multiple regression analysis of the variables that most influenced satisfaction (see table 9), which explained 74.9% of the variance, found that emotional support from doctors was dropped from the model entirely and emotional support from nurses/midwives only occupied fourth position. The strongest predictor of satisfaction was "feeling listened to". This was followed by the "doctors and nurses/midwives seemed to work well in a team" and feeling that they were "kept well informed about all the steps and procedures during care."

This presents a significantly different picture. Feeling "listening to" is far less passive than receiving support. Its basis in equitable communication touches on support but also suggests

greater agentive capacity, as discussed in Chapter 7. This is supported by the inclusion of the variable about being kept informed of steps and procedures, which touches on information but may also refer to reducing anxiety or worry. However, the biggest surprise was the prominence of “team work”, which points to a significant observational capacity of women to evaluate the organisational dynamics of care. Collectively, this analysis positions women as placing far greater emphasis on the coordination and organisation of care, which is not to say that “emotional support” is not important, but that perhaps it marks a division between individual carers and the institution/organisation.

Table 9. Top 4 (of 9) predictor variables of satisfaction with care

	R ²	Est. of the stand. error	R ² change	F change	Sig.	B co-eff.
I felt that the professionals listened to me	0.585	0.855	0.585	817.328	<0.001	0.228
The doctors and nurses/midwives seemed to work well as a team	0.664	0.770	0.079	135.874	<0.001	0.210
In general I was kept well informed about all the steps and procedures during the care	0.699	0.730	0.035	67.293	<0.001	0.154
I felt emotionally supported by the nurses and midwives	0.720	0.704	0.021	43.840	<0.001	0.174
Constant						0.248

Method: forward

Durbin-Watson: 2.064

ANOVA: (F(8, 739) = 189,696, p <0,001)

2.2. Coldness, distance and inhumanity

In counter-position to compassionate carers are health professionals who, like the gynaecologists in Aida’s story above (extract 6), are described as: “distant”, “cold”, “impersonal”, and even “inhuman”. The use of the metaphors “cold/distant” in association with “inhuman” is clearly striking and, as we’ll see, central to understanding disaffiliation from carers and the social disjuncture that frequently occurs during care following perinatal loss.

Lourdes, who had a stillbirth in the second trimester, was very unhappy with the care she received and is a good starting point for the analysis. Her response in extract 9 is to question on what ‘most helped’ during the hospital stay. Through her use of “except” (line 1) and “one” nurse (line 4), she establishes a general absence of support and empathy from all the other health professionals by contrasting them to the only two instances of positive interactions with carers, a male doctor and a female nurse (lines 2-5).

Survey question: What was the thing that most helped you during the hospital stay? (something someone said or did)

[...]
 1 Durante mi estancia hospitalaria,
 2 salvo el médico que me atendió
 3 en primera instancia en urgencias
 4 y una enfermera de planta
 5 que demostraron empatía y humanidad,
 6 el resto de los profesionales que me
 atendieron
 7 tuvieron una atención deshumanizada,

[...]
 During the hospital stay,
 except for the doctor who saw me
 when I arrived in emergencies
 and a nurse on the ward
 who showed empathy and humanity,
 the rest of the professionals that attended me
 provided dehumanised and impersonal care.

	impersonal.	
8	Se limitaron a realizar un protocolo de actuación en cuanto a técnicas.	They limited themselves to carrying out a protocol focused on technical issues.
9	Los aspectos psico- emocionales no los tuvieron en cuenta.	Psycho- emotional aspects weren't taken into account.
10	Se mostraron fríos y distantes,	The were cold and distant,
11	haciendo más duro el doloroso proceso que es perder un hijo.	making the painful process of losing a child worse.
	[...]	[...]

Lourdes, second trimester stillbirth, survey respondent

Extract 9. Case ID. B28

Lourde's use of the adjectives "impersonal" (line 7), "cold" and "distant" (line 10) can be understood to coexist in one category. They are synonymous with persons that are uncaring, unfriendly, insensitive, and emotionless. Their aloofness and apparent disinterest in the feelings and opinions of the other party makes them difficult to communicate with. However, in this narrative, such characteristics (cold, distant) are intertwined with a questioning of the humanity of health professionals (lines 5 and 7). This introduces distinct meanings and a significantly more severe form of criticism and moral failing. Lourdes also specifically proposes that the only interest of the health professionals was in limiting interaction to the frame of physical, technical care at the cost of "psycho- emotional" care (lines 8-9). In fact, the idea that obstetric care following perinatal loss has a heavy focus on the physical dimensions of the body and technologies of birth is present across the narratives.

To illustrate, we can examine an extract from Ana María's response to the survey, in which she recalls how she felt "abandoned in a room" *until* there was some physical care to be provided: the administration of an epidural (lines 1-2). In using a metaphor of abandonment Ana María evokes discourses of being ignored, hidden away, cut off, and also neglected. She suggests that the health professionals themselves are only capacitated to provide biomedical care ("now we can do something", lines 3-4) and that they were uncomfortable with her "emotional pain" (line 5). Consequently, the neglect clearly relates to silence in relation to loss/ grief, and is unrelated to the quality of technical care. Nonetheless, we can also consider alternative narratives of an epidural as a technology, specifically those of Gemma in extract 3. Here, the epidural is synonymous with neglect, not of the body, but of the mind. But it could also be a metaphor for security, reducing fear of pain, increasing confidence in the technological process. Thus, the particular presence of this technology is one that signals absence of another form of security related to a need for interaction in the frame of grief and loss. Likewise, as the object of intervention, the body is bracketed with technology, one constituting the other in this configuration of care, creating a dualism between mind and body. One frame of social action is silenced while the other is activated.

Survey question: What was the thing that least helped you during the hospital stay? (something someone said or did)

	[...]	[...]
1	nos sentimos abandonados en una habitación	we felt abandoned in a room
2	hasta que ya pedimos epidural..	until we asked for the epidural..
3	es como si:	it was like:
4	ahora ya podemos hacer algo...	now we can do something...
5	se sentían muy incómodos con mi dolor emocional	they felt very uncomfortable with my emotional pain

Ana María, third trimester stillbirth, survey respondent

Extract 10. Case ID. B08

Regardless, the narratives also tell us that maintaining a social frame is an on-going and active process that must constantly employ social mechanisms to avoid engagement with expressions of grief/loss. Beatriz's baby Romina died in the late third trimester some 5 years before the interview. Below, she describes the moment that the gynaecologist tells her that her baby has died. In a concise and clipped reported speech of the [male] doctor's words we can see that he creates a biomedical frame in his use of technical terminology to communicate the death: "the gestation has terminated" (line 10). When Beatriz reacts by "shouting and crying" and attempts to get down off the bed (lines 13-14), which she describes as a natural reaction to such news (line 13), his response is to admonish her by saying "relax woman, you're going to fall on the floor" (line 17-18). The reported speech invokes a chauvinistic code rooted in sexism and paternalism.

This extract is drawn from the start of the main narration where Beatriz talks about the diagnosis. My question was to clarify who was present during the diagnosis, as Vicente (her husband) had initially been waiting outside. The nurse called the doctor who then didn't give Beatriz the diagnosis until after calling Vicente in, although she clearly knew something was wrong.

1	P	¿Porque nadie te había dicho nada?	Because nobody had said anything?
2		¿Porque nadie te había dicho nada hasta ese [sic] momento?	Because nobody had said anything, until this [sic] point?
3		[...]	[...]
4	B	entonces ya pasó Vicente [su marido]	so then Vicente [her husband] came in
5		y allí estábamos, una enfermera, el ginecólogo, mi marido y yo,	and there we were, a [female] nurse, a [male] gynaecologist, my husband and I,
6		cerraron la puerta	they closed the door
7		y entonces me volvió, me volvió a pasar el ecógrafo	and then he passed the, he passed the ultrasound over me again
9		y dijo:	and said:
10		"la gestación se ha interrumpido"	"the gestation has terminated"
11		digo:	I said:
12		"¿cómo?"	"what?"
13		claro, me intenté bajar de la camilla,	naturally, I tried to get down off the bed,
14		gritando, llorando	shouting, crying
15		y él,	and he,
16		lo único que supo decirme era:	the only thing he knew to say to me was:
17		"tú tranquila, mujer,	"calm down, woman,
18		a ver si te vas a caer al suelo"	you're going to fall on the floor"

Beatriz, third trimester stillbirth, interview participant

Extract 11. Case ID. A08. Transcription lines: 353-359

Through his response, the doctor rejects an explicit request for compassion, devalues Beatriz's response to the diagnosis as exaggerated, and sets limits to appropriate behaviour within the medical space. In effect, he silences. It is also notable that, in the storytelling world, Beatriz introduces the reported speech with an evaluation of her own "the only thing he knew to say to me was" (line 16). In doing this she communicates her humiliation and the inappropriateness of the doctor's remark, but she also recovers some face (in reference to me) by pointing out his limits as a person. Hence, both Beatriz and the doctor frame the encounter differently and a conflict exists in the way they access appropriate contextualisational cues. Needless to say, in this situational context, the authority to define the frame of reference, and therefore social control and power, lies with the doctor.

We also need to consider the male gynaecologist's use of the gendered/sexist trope 'hysterical woman' in line 17 ("calm down, woman"). While this is clearly belittling to Beatriz it is particularly interesting in this story because Beatriz's husband Manuel also had a very strong reaction to the diagnosis and ended up crying in the corner with his arms over his head, yet, within the story, received no similar admonishment. Other narratives, though, show that female health

professionals use similar mechanisms or discourses. Camino (Case ID. B40) recalled that the female doctor's response to her crying after receiving the diagnosis was for her to say: "well child, it's not that bad". The use of the infantilising mechanism in both of these cases draws on a rhetoric of women as overreacting and points to wider cultural values within obstetrics that are gendered, regardless of the sex of the administering professional.

The type of contextualisation disjuncture that is apparent in the two previous examples is evident in Eugenia's brief story, below. She uses multiple interrogatives "?????" (line 3) and sarcastic quotation marks to communicate her disbelief and anger that the male gynaecologist had asked her "why" she was crying (lines 1-2).

Survey question: What was the thing that least helped you during the hospital stay? (something someone said or did)

<p>1 [...] 2 que el ginecologo me preguntara 3 "por qué" lloraba 4 ¿¿??? 5 me enfadé mucho. 6 [...]</p>	<p>1 [...] 2 that the [male] gynaecologist asked me 3 "why" was I crying 4 ????? 5 it made me really angry. 6 [...]</p>
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Eugenia, second trimester stillbirth, survey respondent

Extract 12. Case ID. B19

The use of insensitive clichés or maxims that attempt to rationalise loss and death ("you're young, you'll have more", Patricia, B27) are also a feature of health professionals that lack compassion. In extract 13, below, it is apparent that the rude nurse is dismissive of Montse's physical complaints about not feeling well and the fact that she is crying. The nurse first tries to solve the problem through rational science, attempting to disprove Montse's lack of wellness by taking her temperature and glucose (lines 11-13). Then in response to Montse's crying she tells her that she will "end up wanting to have your tubes tied" with the number of children that she will have (lines 21-25).

This extract is taken for a section of the interview where Montse talks about experiences with different health professionals and comes in direct response to a prompt from me for any more examples.

<p>1 P ¿Y con algún otro.. profesional? 2 M [...] 3 el día siguiente 4 [...] 5 me encontraba fatal. 6 pues llamé a un, 7 llamé a la enfermera para que viniera, 8 [...] 9 y entonces, me acuerdo que me dice: 10 "a ver, ¿qué te pasa?" 11 dice: 12 "bueno, te voy a tomar la tensión, 13 te voy a hacer una glucosa, 14 te voy a hacer para que veas que no te pasa 15 nada" 16 y que tal, 17 [...] 18 y entonces, 19 yo estaba llorando y tal, 20 entonces me dijo que, 21 dice, 22 una frase que se me ha quedado ya para..</p>	<p>And with any other.. professional? [...] the next day [...] I felt terrible. [physically] so I called a, I called a nurse to come, [...] and so, I remember she says: "let's see, what's wrong with you? ((tone is impatient)) she says: "well, I'm going to take your temperature, I'm going to take your glucose, I'm going to show you that there's nothing wrong with you" and so on, [...] and so, I was crying and that, so she says to me, she says, a phrase that is etched on my memory</p>
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21	grabada, ¿no?,	forever, you know?
22	me dijo, eh., dice:	she said, she says:
23	“vas a acabar,	“you're going to end up,
24	“vas a acabar queriéndote	you're going to end up wanting to
25	hacer una, una ligadura de trompas	have your tubes tied
	de la cantidad de hijos que vas a tener”	with the number of children you're going
		to have”
26	me dijo eso,	she said that,
27	entonces, pues,	so, well,
28	no me pareció bien,	I didn't like that
29	porque ella no sabe si voy a tener más	because she doesn't know if I'm going to
	hijos,	have more children,
30	si no voy a tener hijos,	if I'm not going to have children,
31	si no sabe nada de mi vida	she doesn't know anything about my life

Montse, third trimester stillbirth, interview participant

Extract 13. Case ID. A05. Transcription lines: 784-794

Montse's unhappiness with this attempt to cheer her up helps to explain why women find such comments so hurtful. The offer of support is in fact designed to provide relief to the uncomfortableness of the speaker rather than the receiver. It expresses a desire to silence the encounter or reframe it in positive terms and communicates to Montse that she is overreacting and expresses little desire to know her at a personal level (lines 29-31). The severe disunity is event in Montse stating that the memory of the words remains etched in her memory (line 20). The fact that such interactions remain potent after the passing of a significant amount of time alludes to their social importance and impact. However, it also seems highly unlikely that the nurse's words, while careless, were designed to inflict hurt. Instead it points to a culture of care within the hospital and the existence of an alternative contextualisation of the significance of pregnancy loss. In effect, it reveals through the euphemism of positivity that pregnancy loss is taboo.

Other narratives make evident that sedatives are also used as a means to control bouts of crying. The survey data shows that 48.0% of women were given a sedative on at least one occasion. Given three options in a closed-end question, respondents indicated that health professionals were the principal drivers of sedative use: on 50.3% of occasions they advised women that “it would be better to take something to calm me down”, whereas on 17.1% of occasions they were administered without consultation, a theme addressed in more detail in Chapter 7. Women themselves requested something to help them ‘calm down’ on 32.5% of occasions.

Gloria, an interview participant, was quite happy with her care, especially from the midwives, she even returned to the hospital to give them a thank you gift a few days after the discharge. But she was not happy about the effects the sedatives had on her memory and her ability to take in information. Following a reference to sedatives as an aside to another part of the story, I asked her when the sedatives were administered (extract 14, line 1). She recalled how a midwife gave them to her (lines 15-18) just at the point when the reality of the death was sinking in (lines 5-7), when she had just started crying very heavily along with her partner (lines 10-14). In her narrative, the heavy crying and sedative administration are intimately linked. The administration of psychotropic medication is seen as an appropriate way to deal with strong emotional reactions like crying. Specifically, it communicates the idea that dampening these emotions or getting them under control is beneficial. The sedative as a technology serves a particular purpose, most likely the midwife understands that she is helping, it may even have positive symbolic value, but within the hospital culture it is associated with what might be termed negative emotion and its suppression rather than expression. In this respect, it is a way of controlling or silencing a socially normative response to loss/grief. Biomedical treatment rather than an alternative such as talk.

This extract is from the main narration and based on a (unnecessary) clarification about the timing of the administration of the sedative. The extract has a 20-line interruption due to a long aside related to Gloria's attempts to telephone her family.

1	P	<¿Cuándo te dieron los tranquilizantes?	<When did they give you the tranquillisers?
2	G	Pues al rato de traer [a Nacho, su pareja],	Shortly after bringing [Nacho, her partner]
3		eh, la verdad es que	eh, the truth is that
4		yo empecé a llorar cuando, cuando he	I started crying when, when I managed
5		conseguido hablar con esta amiga,	to talk to this friend
6		que se llama Paola	called Paola
7		fue cuando conseguí llorar la primera	that was when I managed to cry for the
8		vez,	first time,
9		hasta entonces	until then
10		mi estado de shock ha estado tan grande.	my state of shock was too great.
11		[...]	[...]
12		Y, y claro	And, and of course
13		entre que estaba ya con la gota gorda	between bawling my eyes out
14		cuando nos hemos visto,	when we saw each other,
15		entonces sí,	then, yes,
16		lloramos los dos juntos todo que	we cried all that we could,
17		podíamos,	str, straightaway
18		en, enseguida	the [female] midwife came in
19		entró la matrona	and, and, then
20		y, y ya que	the next thing was to give me a
21		el lato [sic] siguiente fue darme un	tranquilizer.
22		tranquilizante.	

Gloria, third trimester stillbirth, interview participant

Extract 14. Case ID. A02. Transcription lines: 426-429 + 449-452

These mechanisms of social interaction demonstrate how mild and severe social disjuncture in the contextualisation of pregnancy loss can be 'done' (brought into being) and why metaphors of cold and distant are associated with lack of humanity: for women the object represents a life and son/ daughter (see Chapter 8) and for health professionals it appears to represent a medical issue, at least that is how it appears from the perspective of the patient.

However, the narratives also contain more extreme versions of encounters with health professionals that might, under different circumstances or contextualisations, be properly classed as thoroughly dehumanising behaviour. Although not excessive in number, there are sufficient accounts of verbal abuse, physical aggression and humiliation to signal an important characteristic of obstetric culture in Spanish hospitals.

In her response to the question about what 'least helped' during the hospital stay, Diana outlined a long series of complaints, one of which addressed the use of violent and abusive language during the birth and threats of pain as a means to pacify her. Diana contextualises the narrative by stating that it was an extremely long natural birth (line 1), which we can later deduce to mean painful. She recounts that she was denied an epidural because her "shouting" was "annoying" and was threatened with being left in pain if she didn't "shut up" (lines 3-4). She was subsequently told that she was over reacting, "it hurts everyone", and is again told to "shut up" (16-17). Even her attempts to argue that her experience of pain is not exaggerated are dismissed and treated insensitively (lines 18-21). In this case, a highly stressful situation of an intrauterine death becomes exacerbated and highly conflictive.

Survey question: What was the thing that least helped you during the hospital stay? (something someone said or did)

<p>1 hay un parto natural muuuuuuuuu largo 2 y desagradable en el trato conmigo</p> <p>3 -Negarme la epidural 4 "porque tus gritos molestan, 5 si no te callas te dejo ahí con el dolor"</p> <p>6 (gritos de dolor por las contracciones). 7 -Decirme 8 "a todas les duele, cállate" 9 a lo que respondo, 10 el dolor con motivación se pasa mejor. 11 Y me dicen 12 "y tú qué motivación no tienes?" 13 .. 14 pues un hijo muerto no es la misma motivación que uno vivo. [...]</p>	<p>it was a veeeeeeery long natural birth and the way they treated me was [very] unpleasant</p> <p>-Denying me an epidural "because your shouting is annoying, if you don't shut up I'll leave you there in pain" (shouts of pain from the contractions). -Telling me "it hurts everyone, shut up" to which I respond, pain with a motivation is easier. And they say "and you, what motivation don't you have?" .. well a dead child isn't the same motivation as a live one. [...]</p>
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Diana, third trimester stillbirth, survey respondent

Extract 15. Case ID. B06

When we analyse Laura's response to the question about what 'least helped' her (extract 16), she talks about how, "every now and again four or five doctors came into the room together" removed her clothes below the waist and examined her, while she was naked (lines 3-6). The fact that she highlights this interaction means that the way that this procedure was carried out made her feel sexually violated ("I felt it was indecent", line 7) through the lack of recognition of female nakedness and the lack of social convention in the way that the examination is carried out. Her passivity is evident and she is dominated in numbers and through medical authority. In analysing this extract we can ask what social conventions were absent that would have avoided this situation: apologising, explaining why the examinations are necessary, explaining who is present and why they are there, asking for consent. Instead, the examination is performed as a systematic procedure that objectifies and violates her.

Survey question: What was the thing that least helped you during the hospital stay? (something someone said or did)

<p>[...]</p> <p>1 en la sala en la que estaba 2 me trataban como una enferma. 3 A veces 4 entraban cuatro o cinco médicos a la vez, 5 me desnudaban la parte de abajo</p> <p>6 y me miraban. 7 Me sentía en una situación indecente, 8 unida al dolor que tenía [...]</p>	<p>[...]</p> <p>in the room I was in they treated me like a sick person Every now and again four or five doctors came in together, they removed my clothing so I was naked below the waist and they looked at me. I felt it was indecent, on top of the [emotional] pain I was in [...]</p>
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Laura, third trimester stillbirth, survey respondent

Extract 16. Case ID. B12

Elisabeth, who was confined to complete bed rest because she had lost her amniotic fluid and spent two weeks in the hospital in the hope of saving the pregnancy, was also extremely unhappy with all aspects of her care. From her interview we can focus on her telling of an encounter with nursing assistants as they give her a bed bath. Prior to the transcript lines presented in extract 17,

Elisabeth described the vulnerability she felt at being bed bound and the indignity of being fully naked and bathed all over by others, but also said that “you” get used to it. Subsequently, though, she describes a day when a third health professional, not involved in the bed bath, comes and proceeds to have a non-work related conversation with the two assistants. For Elisabeth, it was highly indignant and humiliating that someone not involved in her care should see her naked. Of special interest in Elisabeth’s narrative is the impotency she felt and the lines where she imitates her own silent voice, using sarcasm: “hey, I can hear you, hey, there’s some girl seeing me naked who shouldn’t be” (lines 35-37) and “please, uhm, can you wait or something until they’ve finished washing me or something” (lines 40-41). From behind a screen of vulnerability, Elisabeth’s silent voice speaks to her apparent invisibility in the eyes of her carers and their dehumanising and objectifying actions. The power imbalance in the relationship is evident in Elisabeth’s justification for not speaking: she was worried that she would be categorised as troublesome and this would lead to even worse care (lines 32-33).

This extract is taken from an extended piece where I asked Elisabeth to tell me more about her interactions with the health professionals. This section comes after speaking about the doctors and nurses and relates to the nursing assistants.

<p>1 era como allí en bolas, 2 [...] 3 y estaban 2, 4 y viene otra, 5 amiga de otra compañera, 6 creo que era amiga, 7 que conocía a una 3ª que era del mismo 8 pueblo que una de ellas, 9 y se pone ahí delante, 10 o sea, 11 mientras, 12 vale, 13 si tú me estás lavando, 14 me tienes que ver en bolas, 15 pero una tercera, 16 uhm, 17 ¿qué quieres que te diga? 18 Pues, pues no me sentó bien, 19 ¿sabes? 20 pues es como, 21 he estado este fin de semana con tu 22 compañera, qué bien, no sé cuántos, 23 y yo ahí como, 24 o sea, 25 me volví a sentir como una mierda 26 ¿sabes?, 27 como oye, 28 que te estoy oyendo, 29 oye, que me está viendo en pelotas una tía 30 que no tienes por qué ver en pelotas, 31 [...] 32 que estuve a puntito de decirle: 33 "por favor, uhm, 34 ¿puedes esperar a que me dejen de lavar o 35 algo?" 36 pero esto de que y si luego me dicen: 37 "mira, la borde esta", 38 ¿sabes? 39 yo que sé, 40 estuve a puntito, 41 pero no tuve el agarre 42 [...]</p>	<p>I was there stark naked, [...] there were two of them, and another one came along, a friend of another workmate, I think she was a friend, she knew another friend from the same town as one of them, and she stands right there in front of me, I mean, while, OK, if you are washing me, you have to see me naked, but someone else, uhm what do you want me to say? Well, well I didn't feel good about that, you know? it's as if, this weekend I've been with your friend, oh that's great, bla bla bla and I was like, I mean, it made me feel like shit again, you know? like, hey, I can hear you, hey, there's some girl seeing me naked who shouldn't be seeing me naked, [...] I was at the point of saying something: "please, uhm, can you wait until they've finished washing me or something?" but then later they would probably say: "look at her, she's the rude one", you know what I mean? I don't know, I was one the verge, but I wasn't brave enough</p>
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Elisabeth, second trimester termination of pregnancy, interview participant

Extract 16. Case ID. A09. Transcription lines: 1017-1036

3. Conclusions and discussion

In examining narratives of interactions with health professionals it is important to start with how such stories are oriented. Similarly to other research (Adolfsson 2010; Ujda and Bendiksen 2000; Wojnar, Swanson, and Adolfsson 2011), many of the women in this study talk of fear and anxiety about having to give birth or of being alone. Not only does this refer to embodied experiences of childbirth and loss but also functions as a contextualisation for interaction with their carers, which leads to increased dependence or expectations of assistance. In facing the death of their infants in a context where belief in the capacity of medicine has been undermined, some women are also faced with their own mortality or the possibility thereof (see also Chapter 7). This conditions how women interpret health professionals' actions, be they compassionate, cold or cruel.

At an overall level, the main tropes of professionals as compassionate and empathetic vis-à-vis distant and cold coincides with other research (Gold, Dalton, and Schwenk 2007). While the figure of the 'angel' appears to be unique to this research, the 'aggressor' or perpetrator of violence has been noted in care following perinatal death in other countries (Romo Medrano 2019) but has yet to be documented. Compassionate carers are positioned as having a number of characteristics related to the expression of empathy, dedicated support and 'emotion' centred care, which is consistent with research in other high-income countries (Downe et al. 2013; Geller, Psaros, and Kerns 2006; Kelley and Trinidad 2012; McCreight 2007, 2008; Rådestad et al. 2011; Trulsson and Rådestad 2004; Ujda and Bendiksen 2000). In this study, compassionate professionals use verbal and non-verbal communication to transmit empathy and sympathy, to establish a non-threatening and safe environment, and a relationship based on trust. This capacity for empathising and offering sympathy can be thought of as enhancing intersubjectivity.

This form of communication helps to relieve pressure on women at a time of significant stress and when they have little knowledge of the social meanings of perinatal death. An important finding is that the positioning of carers as compassionate is not dependent on their expertise in bereavement care, but is generally associated with their 'humane' characteristics. Indeed, it was apparent that care was often substandard, but carers were rated positively. The strength and importance of these relationships is illustrated by the fact that even when women do acquire cultural capital (Bourdieu 1991:67) in relation to appropriate bereavement care, they are reluctant to alter their evaluations of these carers or their narrative resolutions. It is my opinion that this demonstrates how women's position is weakened by the dominating feelings of grief, anxiety and fear and lack of knowledge of appropriate care. In essence, context is everything and evaluations must be interpreted as such.

As discussed more thoroughly in Chapter 8, the diagnosis of the death of a baby can bring the social position of 'mother' into doubt through fear, taboo and self-protection. Compassionate carers not only reduce anxieties, they help to create concurrence (Gumperz 1999) in social encounters by reducing stigma and framing interactions within the expectations associated with pregnancy, motherhood and loss/grief. As this form of death is unexpected and largely unknown, for the woman this is not the application of a pre-standing socially known frame but one that is actively learnt, modified and reconfigured through interaction. There is, in effect, a rapid socialisation into the world of perinatal death. Hence, reciprocity and mutual understanding become the basis of the negotiation of context and new meanings (Goodwin and Heritage 1990), even if the full conditions of possibility for such meaning are not explored in the few short days spent in the hospital.

Nevertheless, the compassionate carer also has to be moderated somewhat because of the way that some health professionals discriminate between patients based on the gestational age at the time of

the loss/death. The employment of gestational age as an organising principle of care introduces an essentialising and simplistic mechanism that predetermines requirements for compassion, despite available research indicating that age is not a reliable indicator of the relationship between the mother and baby (see Chapter 2, section 2.1). The findings indicate that this differentiation is most significant before and after 26 weeks gestation (180 days), which also happens to be the gestational age at which legislation requires statistical registration of the death and inscription in the Civil Register (Gobierno de España 1957). Hence, institutional mechanisms influence hospital cultures and local practice in the way that meaning is socially negotiated in encounters between women and health professionals.

It is evident then that the outcomes of care encounters with *cold, distant* and *impersonal* health professionals are disaffiliative and appear to achieve a negotiated meaning that stands in opposition to compassionate carers. In these encounters, a barrier is constructed between women and their carers around a dualistic opposition of body and mind, a characteristic of biomedicine and its basis in objectivism (Borrell-Carrió, Suchman, and Epstein 2004). The almost singular focus of care on the body ignores or silences the complex social, cultural (Petersen 2012) and personal histories that give meaning to loss and grief. In the narratives of care in this study, this is illustrated in two forms: the prominence of technologies and the diverse range of social mechanisms that are employed to suppress and contain negative emotions, notably sadness and loss, as expressed through crying and sobbing.

Technologies of obstetrics, such as epidurals, induction medication, sedatives and protocols become metaphors for distance and separation *or* as mechanisms of control and conformity (see also Chapter 7) that define women in the ideal of the 'patient' they envisage (Davis-Floyd 1993; Fairclough 1989:103; Martin 2001). Technologies and bodies are conjoined while birthing women and doctors remain disconnected. This contrasts to the characterisation of technologies as they appear alongside compassionate health professionals, where they are much less prominent and tend to occupy a position that contributes to feelings of safety, security and control rather than being synonymous with neglect or domination. Hence, technologies do not appear in the narratives as bad or good, but as facilitating different types of capacities or possibilities. When they are retained within the control of the doctor and employed without consideration of the perspectives, beliefs and values of patients, they tend toward an amplification of biomedical power and a reduction of women's power.

Expressions of grief, sadness and distress, such as crying, can be understood as responses to a situation that disconfirms the actor's social position and sense of self. Communicatively, crying amounts to a request for help or compassion (Fields, Copp, and Kleinman 2006). By rejecting such requests, health professionals contravene expectations of reciprocity and normative responses (Potter 1996:59), in particular for their profession. This leaves women to fend for themselves and to attempt to comprehend why their request was rejected. I propose that in the context of medical authority, moral and responsible mothers, and feelings of guilt about the death (see Chapter 8), this can easily be interpreted as socially sanction.

These refusals to help are achieved through avoidance, minimising and devaluing, admonishment and counter requests to control emotions. These moves and counter moves, work to rekey or reframe the social interaction (Goffman 1974:40) and establish a medical contextualisation defined by absence of content related to loss or grief. There are a number of ways to look at this finding. Most commonly this is attributed to health professionals own fear of death, lack of training, or even burnout and secondary trauma (Gandino et al. 2017). It may also signify clumsy and counterproductive attempts to make bad deaths better through shielding and protection, which is

common within paternalistic cultures (Bradbury 1996). Undoubtedly these arguments hold weight, but silence that silences also has to be understood as deliberately produced for communicative purposes within a social encounter. To ignore something suggests a social or cultural pressure to do so (Sobkowiak 1997). Thus it can also be understood as a pragmatic and discursive strategy that silences talk and action related to a specific social object associated with taboo or stigma (Jaworski 1997). In the storytelling world, women attempt to hold health professionals responsible for these failures and establish the frame of loss/grief as appropriate.

Cultural tropes of health professionals, notably doctors, as cold, aloof and impersonal are not so unusual in a society that values their scientific rationalism. However, the disjuncture that occurs in the contextualisation of the object (Pollner 1975) helps to explain why metaphors of cold and distant become entangled with questions of humanity. In a context of vulnerability and asymmetry, the positioning of the loss/death (and therefore the social position of the dead baby) as insignificant or unworthy of compassion moves women to express moral disgust at the health professionals' behaviour (Rozin et al. 1999). In dehumanising women and their babies, even if unintentionally, they themselves are conversely positioned as cruel and inhuman, having failed to fulfil their basic duties as health professionals and even persons.

The lack of possibility for repair of this situation is probably why the discourses of extremely poor care are so dominant within the community of bereaved parents. It may also explain why support group moderators tell me that many parents return again and again to experiences of poor humanistic care, often expressing anger and frustration for many years after the loss. Hence, the positioning of 'angels' or 'saviours' as highly compassionate can only emerge from conflictive contexts. They represent a temporary, internal correction by an individual to the culture of the institution, even if they have little immediate power to create wholesale cultural change. Nevertheless, this subversive action can provide individual women with routes to escape from the territorialising effect of biomedical care and may also signal incipient cultural change.

On the whole, instances of resistance to mechanisms of silence by women are relatively weak or infrequent, existing largely in the storytelling world, in relatively safe social spaces. To an extent, this can be thought of as a collaborative silence, which is necessary for silencing to be successful (Zerubavel 2006:48). Undoubtedly, this is largely to do with institutional authority and interactive asymmetry, as well as state-of-mind, but it is also necessary to consider that if baby death is a cultural taboo, then it governs all participants and influences bereaved mothers too, encouraging them to remain silent, particularly if they feel guilt and shame for being responsible for the death. So, to a degree there is a partial or false symmetry, rather than dissonance, at least within the first few hours or days before women have the possibility of overcoming shock and accessing alternative discourses. This semblance of concurrence may therefore play an important role in health professionals perceiving that their interpretations and the mechanisms they use are appropriate and that women don't actually wish to talk.

Saying and not saying are also tied up in social practices that decide who can say and what can be said (Foucault 1978:27). Thus, we have to ask, how the power to contextualise (Blommaert 2005:42), and by consequence to constitute and materialise social bodies in one way or another, draws on broader social discourses (Butler 1993:34–35). Through rekeying and silencing that draw on gendered discourses women are portrayed as hysterical or overly emotional and requiring social control (Lutz 1996). This is consistent with historical and contemporary discourses that position women as being more prone to grief and hysterical or pathological reactions (Kanter 2002; Walter 2000). On this basis, the object of silence is not just a taboo associated with a dead baby, but is contained within emotional and infantilising discourses of women and specifically women in

obstetrics as opposed to other social domains (Martin 2001; Rothman-Katz 1982). I believe that the finding that “feeling listened to” was the single most powerful variable for predicting satisfaction with care and control over decision-making (see Chapter 7) relates directly to these dynamics and feelings of invisibility or powerlessness.

As I explore in more detail in the next chapter, symmetry in decision-making is severely imbalanced, which is attributable to many factors, but very specifically the cultural values of heavily medicalised care. Hence, that we discover instances of humiliation, verbal and sexual abuse that constitute only some of the various forms of obstetric violence (Sadler et al. 2016) consolidates the gendered-dimension of how care is provided. Such abuse and mistreatment has been identified as a characteristic of Spanish obstetric care (Bellón Sánchez 2014; Observatorio de la Violencia Obstetrica 2016; UN Committee on the Elimination of Discrimination against Women 2020), yet to find such examples in cases where women had lost their babies was quite shocking. The narratives coincide in the way that women feel humiliated and infantilised, making them feel invisible as persons before medical practices and shorn of any rights to dignity, privacy and autonomy. As adult human beings they are denigrated, verbally abused, objectivised and humiliated psychologically and physically. So, when care that creates a loss/grief frame validates loss and reinforces ideas of motherhood, biomedical frames make it clear that it is not just the social position of mother that is under threat but also that of person and woman.

Chapter 7.

Agency and autonomy in care encounters

1. Introduction

Whereas Chapter 6 focuses on the contextualisation of loss and Chapter 8 on the way that babies are positioned during care interactions, this chapter addresses questions of agency, autonomy and equity between women and health professionals in the social practice of care. The analysis considers women's accounts of interactive processes related to decision-making and how certain care procedures and outcomes are arrived at. The results address the social mechanisms and cultural values that result in highly asymmetric decision-making processes, as well as some examples of patient agency and resistance to medical authority.

2. Findings

2.1. Control over decision-making

One of the most striking results from the survey (n=796) was that only 42.0% of women 'agreed'¹³ that they 'felt in control of decisions related to medical care' and only 34.8% 'agreed' that they 'felt in control of decisions related to rituals and care of the baby's body after the birth. This is an important finding in its own right, but requires exploration of the social mechanisms that make it possible. To start, multivariate analysis (linear regression) of the survey data was used to determine which variables (related to information/communication, coordination of care and compassion) most significantly influenced women's sense of being in control of decisions related to medical and loss-related aspects of care. The analysis found that, in the case of medical decisions, 49.5% of the variance was explained by 8 variables, of which the top five were: 'feeling listened to'; 'the explanation of the birth process'; 'general information'; health professionals being 'sensitive' in their use of language (e.g., not using terms like 'foetus'); and having 'one health professional' that guided women through the process of care (see table 10).

In the case of control over decisions related to bereavement care, the final model contained 6 variables and explained 41.6% of the variance. Although information also features as important in this model, it is notable that 'feeling treated like a mother' is highly significant, as was women's

¹³ Amalgamation of 2 points on a 5-point Likert scale: "agree" (point 4) and "completely agree" (point 5).

perception that ‘the doctors knew how to treat cases of loss’. Together these models indicate that decision-making is fundamentally tied up in humanistic aspects of care relationships and the social positioning of the baby and mother during care encounters.

Table 10. Variables that predict feeling in control of decisions related to medical and bereavement care

	R ²	Est. of the stand. error	R ² change	F change	Sig. F change
Top 5 predictor variables of feeling in control of decisions taken in the hospital					
Medical care					
<i>I felt that the professionals listened to me</i>	0.342	1.152	0.342	384.405	<0.001
<i>They gave me a clear and understandable explanation of the birth process in cases of loss</i>	0.427	1.076	0.085	109.402	<0.001
<i>They gave me/us enough information to help us make the decisions we had to take</i>	0.455	1.051	0.028	37.267	<0.001
<i>The professionals were sensitive in their use of language</i>	0.472	1.035	0.017	23.671	<0.001
<i>There was one professional who guided us through the whole process</i>	0.484	1.023	0.013	18.078	<0.001
Bereavement care					
<i>I received enough information about the funeral or cremation and its organisation</i>	0.256	1.257	0.256	259.982	<0.001
<i>Although my baby died I was treated as a mother</i>	0.348	1.178	0.091	105.273	<0.001
<i>They gave me/ us enough help to keep physical memories of the baby, such as photographs, identification bracelet, etc.</i>	0.383	1.146	0.035	42.671	<0.001
<i>The doctors seemed to know how to deal with cases of pregnancy loss</i>	0.404	1.127	0.022	27.331	<0.001
<i>I received enough information about the decision to see the baby or not</i>	0.417	1.116	0.012	16.008	<0.001
<i>Medical decisions model:</i>			<i>Bereavement care model:</i>		
<i>Method: forward</i>			<i>Method: forward</i>		
<i>Durbin-Watson: 1.880</i>			<i>Durbin-Watson: 1.893</i>		
<i>ANOVA: (F(8, 740) = 91.529, p <0.001)</i>			<i>ANOVA: (F(6, 755) = 90.762, p <0.001)</i>		

2.2. Informational and communicative disadvantage

As the results of the analysis in the previous section show, information is a key element of feeling in control of decision-making. However, as only around half of the variance was explained this suggests that other factors came into play. Helena’s story, below, is a good starting point from which to explore the dynamics of power asymmetry. Helena didn’t see her daughter after the birth and regretted the decision, which appears to form the primary context of her answer to the open-ended question on what ‘least helped’ during the hospital stay. In lines 1 to 4 she states: “the lack of information for making decisions properly and not in the heat of the moment”. This response highlights two key issues. On the one hand, women are discursively disadvantaged as they have little knowledge of recommended care before they experience a perinatal loss. On the other hand, ‘state-of-mind’ reduces capacity to comprehend information due to “shock” (line 20), which results in poor decisions that are taken when judgement is clouded (line 4). For all intensive purposes, this denotes a form of temporary incapacity at a critical moment in care and is a major contextualising orientation in the narratives.

Survey question: What was the thing that least helped you during the hospital stay? (something someone said or did)

1	La falta de información	The lack of information
2	para la toma de decisiones	for making decisions
3	de forma correcta	properly
4	y no tomadas con el dolor del momento.	and not in the heat of the moment.
5	Sería muy importante	It's very important
6	antes de tener que parir	before giving birth
7	disponer de un psicólogo y especialista para	to have a psychologist and specialist
8	que te explique por todo lo que te tocara vivir.	to explain everything that you have to go through.
9	Como sera el parto,	What the birth will be like,
10	que sentiras o notaras,	what it will feel like,
11	que opciones hay,	what options there are,
12	inconvenientes,	what disadvantages,
13	como te sentiras antes, durante y después,	what you will feel like before, during and after ,
14	si es bueno o no ver a tu hijo,	if it's good to see your child or not,
15	si quieres parar la produccion de leche o no, etc.	if you want to suppress your milk or not, etc.
16	En definitiva	In short,
17	mas información	more information
18	y que sea explicada en un contexto favorecedor,	and explained in a favourable context,
19	no el mismo dia que recibes la mala noticia	not the same day that you get the bad news
20	que estas en estado de shock. [...]	when you're in a state of shock [...]

Helena, second trimester termination, survey respondent

Extract 1. Case ID. B38

We can also observe that the nature of care and information provision is also substantially more complex than it may seem. In proposing an alternative vision of care, a form of reflexive preference organisation (Goodwin and Heritage 1990), Helena also implies that the health professionals who provided information were not expert (line 7) and that the information she did receive was not broad enough in scope (lines 9, 14-15). But not only does she argue that the information she received contained insufficient detail to prepare her for decisions, in terms of advantages or “disadvantages”, neither did it address how she might “feel” at different stages. This is highly important because it speaks to state-of-mind and the how women are faced with an entirely new experience that is frightening and causes significant anxiety (see also Chapters 6 and 8). Thus, making decisions not only requires information, it requires the right information, delivered by the right person, at the right time and in a safe and secure context.

When we examine the survey results, we find that Helena’s view that information provision was a key deficiency is almost universally replicated across the study population. In comparison to evaluations of the humanistic qualities of health professionals (see Chapter 6), information provision is rated much lower. The results presented in table 11 show that less than half of women in the study (45.2%) ‘agreed’ with the statement: “they gave me/us enough information to help us make the decisions we had to take.” However, ratings of information received about specific aspects of care, such as pathology studies, seeing the baby, or disposition options, received evaluations that were lower still. Furthermore, in many aspects of care, women (and/or their partners) received no information or communication at all. On the whole, only one-in-three women received adequate information across all aspects of care. The fact that informational deficiencies in bereavement care are similar to medical care indicates that this is a feature of obstetric care in general rather than being an issue with perinatal loss.

The results presented in tables 11 and 12, below, also show that gestational age is an organising principle of information provision. Multivariate analysis found that gestational age was the strongest predictor of differences in information related practices and that socio-demographic and other pregnancy variables had statistically insignificant associations. For example, in second trimester cases, 81.3% of women responded that they received “no” information about the disposition of the body compared to 39.4% in third trimester cases (table 11). So, while lack of information is a transversal characteristic of care, practices are governed by an intersection with gestational age. This is to say that a positive linear relationship exists between the attribution of social positions of dead babies (person) and women (mothers) according to the advancement of the pregnancy.

Table 11. Ratings of information provision during the hospital stay according to gestational age

	Gestational age		
	2nd trimester	3rd trimester	Total sample
% of respondents 'agreeing'*** with the statement:			
They gave me/us enough information to help us make the decisions we had to take* ¹	38.3%	49.8%	45.2%
In general they kept me/us well informed about all the steps and procedures during the hospital stay* ¹	40.3%	57.3%	50.4%
They gave me a clear and understandable explanation of the birth process in cases of loss	48.4% ²	52.2%	50.7%
I received enough information about the funeral or cremation and its organisation* ²	7.1%	30.7%	21.3%
I received enough information about the decision to see the baby or not* ²	22.7%	52.7%	40.6%
% of respondents that rated information received as 'enough' or 'a lot'			
Information on pathology studies and autopsy* ¹	24.2%	36.7%	31.7
Information on lactation and puerperal care* ¹	22.1%	36.6%	30.8
Information on keeping physical memories/ memory objects* ¹	5.4%	16.0%	11.7
% of cases where no-one communicated information			
% of women who responded that “no-one” communicated options for conducting pathology studies to determine the cause of death* ²	34.9%	12.4%	21.5%
% of women who responded that “no-one” communicated options for the disposal of the body* ³	64.5%	13.9%	34.3%
% of respondents that rated information received as 'none'			
Information on the disposition of the body* ²	81.3%	39.4%	56.2%
Information on pathology studies and autopsy* ¹	39.9%	17.8%	26.7%
Information on lactation and puerperal care* ¹	40.5%	29.3%	33.8%
Information on keeping physical memories/ memory objects* ¹	88.0%	66.9%	75.4%
n	320	474	796

* $p \leq 0.05$; 1=Small effect size, 2=medium effect size, 3=large effect size (Phi)

** Composite of points 4 (agree) and 5 (completely agree) on a 5-point Likert agreement scale

When we examine longitudinal data (table 12), it is notable that evaluations of information provision increased significantly in the years of the study. While this is positive it is important to point out that it is from a very low base and is only statistically significant for third trimester losses. In the final two years of the study, around one-third of women rated general information provision as deficient and around two-thirds still rated the quantity of specific aspects of information (related to autopsy, disposition, lactation) as ‘none’ or ‘little’.

Table 12. Ratings of information provision during the hospital stay according to the year of the loss and gestational age

	Year of loss			Total sample
	≤2012	2013/14	2015/16	
Second trimester (% agreeing**)				
They gave me/us enough information to help us make the decisions we had to take	40.0%	37.0%	38.4%	38.3%
I general they kept me/us well informed about all the steps and procedures during the hospital stay	39.4%	40.9%	40.3%	40.3%
They gave me a clear and understandable explanation of the birth process in cases of loss	50.0%	48.9%	45.2%	48.4%
I received enough information about the funeral or cremation and its organisation	6.4%	7.0%	8.3%	7.1%
I received enough information about the decision to see the baby or not	20.4%	19.9%	31.5%	22.7%
n (second trimester)	109	138	73	320
Third trimester (% agreeing**)				
They gave me/us enough information to help us make the decisions we had to take ^{*1}	40.2%	52.9%	61.6%	49.8%
I general they kept me/us well informed about all the steps and procedures during the hospital stay ^{*1}	46.7%	61.3%	69.4%	57.3%
They gave me a clear and understandable explanation of the birth process in cases of loss ^{*1}	41.3%	57.6%	62.2%	52.2%
I received enough information about the funeral or cremation and its organisation ^{*2}	18.2%	34.6%	46.4%	30.7%
I received enough information about the decision to see the baby or not ^{*1}	41.8%	58.5%	61.6%	52.7%
n (third trimester)	184	191	98	473
n (total)	293	329	172	796

* $p \leq 0.05$; 1=Small effect size, 2=medium effect size, 3=large effect size (Phi)

** Composite of points 4 (agree) and 5 (completely agree) on a 5-point Likert agreement scale

2.3. Autocracy and lack of informed consent

The findings presented in the previous section show how autonomy and informed consent were simply not possible for many women in the study. This points to a culture of paternalism that positions women as passive participants in care, and is well illustrated by the following narrative from Laura, whose baby was stillborn in the second trimester (extract 2). Her narrative addresses the care process around the pharmacological induction of labour. Here, the verb forms she uses to describe the actions of the health professionals signal where agency lies in the encounter (emphasis added): “*they told* me I had to” (lines 2), “*they put* a medication” (line 4), and “*they decided* to back up” (Line 11). The story contains no mention of a particular reason for having to start the induction and gives a sense of contextual dislocation. It was clearly not her wish that they induce the birth at that time, which she communicates in a bracketed aside: “it was late and I was in a terrible state” (line 3). Laura makes three main points: one, she feels she suffered unnecessarily; two, the health professionals treated her as if she had no agency or capacity to make decisions and inform the technical, biomedical care that they provided but also seemed to be somewhat incompetent (“it was if they were experimenting on me”); and, three, her own state-of-mind inhibits her capacity (tiredness and the impact of the loss) for resistance and autonomy.

Survey question: What was the thing that least helped you during the hospital stay? (something someone said or did)

<p>[...] 1 - cuando llegué, 2 me dijeron que tenía que parir esa misma noche 3 (era tarde y yo estaba fatal). 4 Me pusieron un producto por la vagina 5 y unas horas después 6 vinieron a buscarme 7 (tenía muchos dolores) 8 y una enfermera estuvo hurgándome. 9 El dolor era insoportable. 10 Luego 11 decidieron dar marcha atrás, 12 parar todo. 13 Fue como si 14 estuvieran experimentando conmigo [...]</p>	<p>[...] - when I arrived, they told me I had to give birth that same night (it was late and I was in a terrible state). They put a medication in my vagina and a few hours later they came to get me (I had a lot of pain) and a nurse was prodding me [in the vagina]. The pain was insufferable. Later they decided to back up, to stop everything. It was as if they were experimenting on me [...]</p>
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Laura, third trimester stillbirth, survey respondent

Extract 2. Case ID. B12

Absence of informed consent was also a theme throughout Mar's interview. She was told that she "had to" have a curettage to remove the placenta after the birth (extract 3, line 3-4). However, based on a previous traumatic experience of a curettage following a miscarriage, she had told me earlier in the interview that she had really hoped to avoid another one. In this extract, she tells how she attempted to exercise some influence over her care by asking for an alternative option. When this was refused, she countered by proposing an alternative solution (lines 6-20), which was also rejected, with no reciprocal response, discussion or explanation (lines 9-10, 20).

Mar also contextualises the narrative by stressing that this happened early in the morning after a long difficult day (lines 22-29). So, in the story, she finds herself being brought down to the surgery for a curettage that she had not consented to (lines 30-38). She portrays herself as a passive or silent observer of unwanted actions on her own body from the people who are supposed to be caring for her. Now, in the storytelling world she even laughs sardonically (lines 44, 53, 55) to indicate how surreal the situation was and that this had a disarming effect. Mar's story provides insights into how the abuse of institutional authority and the imposition of medical practices can impact women's sense of self and social position. From line 43 onwards she communicates two principal ideas. Firstly, despite understanding herself to be a strong and capable person, the imposition of medical authority is so totalising that she loses her sense of self and feels utterly powerless and unable to draw on her own resources to defend herself and use reason to stop the process: "I had nothing to hold on to, to be myself, to impose myself" (lines 43-54). Secondly, the imposition of the medical procedure gave her the sensation that everything was spiralling out of control and led her to feel that it was possible that anything might happen to her (lines 67-71). In effect, she perceives her "carers" to be a serious threat to her wellbeing and experiences a form of violence against her person that encourages her to remain silent.

This extract is taken from an extended section in the main narrative about the birth and the process leading up to the performance of the curettage.

<p>1 en ese momento 2 me dijeron que, 3 que me tenían que hacer un legrado ((dicho con sarcasmo)) 4 para expulsar la placenta,</p>	<p>at that point they told me that, that they had to give me a curettage ((said with sarcasm)) to remove the placenta,</p>
--	--

5	((suspira con emoción))	((breathes out deeply with emotion))
6	y yo le dije a	and I asked
7	la ginecóloga	the [female] gynaecologist
8	si no había otras opciones.	if there were any other options.
9	Me dijo que no,	She said no,
10	que no había otras opciones,	there weren't any other options
11	le dije, digo:	I said, I say:
12	"yo sigo teniendo contracciones,	"I'm still having contractions,
13	y ¿no me puedo ir al baño,	can I not go to the bathroom,
14	igual que ha nacido mi hija en el baño,	and like my daughter was born in the bathroom,
15	cuando estaba sentada?"	when I was sitting?"
16	y digo:	I say:
17	"en otra contracción,	"with another contraction,
18	¿por qué no puede salir la placenta?"	why wouldn't the placenta come out?"
19	Me dijo:	She said:
20	"que no"	"no!"
21	((suspira con emoción))	((breathes out deeply with emotion))
22	y, claro,	and of course
23	a todo esto después de,	all of this after,
24	de todo,	such a,
25	de todo el día tan largo	such a long day
26	que habíamos vivido,	that we had been through
27	pues	well
28	yo me encontré	I found myself
29	a la una de la mañana	at one in the morning
30	con que me bajaban a, a un quirófano	being taken down to, to a surgery
31	a hacer un <i>legrado</i> ((con sarcasmo))	to have a curettage ((with sarcasm))
32	así,	just like that,
33	sin, sin darme ninguno tipo de opción,	without, without giving me any kind of options,
34	y bueno	and well
35	ya,	straight away
36	como,	like,
37	como ya después	like straight away
38	sin, sin un consentimiento informado,	without, without informed consent
39	o sea,	I mean,
40	hicieron algo que no deberían de haber hecho,	they did something they shouldn't have done,
41	que es hacer una intervención quirúrgica sin un consentimiento informado	performing a surgical procedure without informed consent
42	[...]	[...]
43	no tenía dónde agarrarme	I had nothing to hold on to
44	((ríe))	((laughs))
45	o sea,	I mean,
46	[...]	[...]
47	dónde agarrarme:	nothing to hold on to
48	para ser yo,	to be myself,
49	para imponerme,	to impose myself,
50	para...	to...
51	o sea,	I mean,
52	si me están llevando a un quirófano	if they are taking me to surgery
53	((ríe))	((laughs))
54	en contra de mi voluntad,	against my will,
55	((ríe))	((laughs))
56	no, no es,	it's not
57	o sea,	I mean,
58	no es el pensamiento consciente,	it's not a conscious thought
59	¿vale?	OK?
60	pero sí el hecho de decir,	but its like saying:
61	o sea,	I mean,
62	después de todo lo que ha pasado,	after everything that had happened,
63	terminar aquí sin yo quererlo,	to end up here without wanting to,
64	es como:	it's like:
65	"y ¿qué más puede pasar?"	"and what else might happen?"
66	era, era una sensación de, de desamparo total,	it was, it was a feeling of, of total defencelessness,
67	o sea,	I mean,
68	como que:	like:
69	estás en un,	you're in a,
70	te empiezan a pasar cosas sobre las que tú no	things start happening to you over which you

71	tienes ningún control y sientes que puede ir a más, no?	have no control and you feel like they might get worse, right?
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Mar, second trimester stillbirth, interview participant

Extract 3. Case ID. A10. Transcription lines: 1053-1095

The survey data provides us with another example of how consent is a weak cultural value within obstetric care. As mentioned in the previous chapter, sedatives were administered to almost half of women (48.0%), but in 17.1% of these cases (n=382) the respondents stated that they were given sedatives ‘without consultation’. Additionally, in 54.5% of cases the effects of the sedatives were not explained at all. Yet, research shows that powerful psychotropic medications such as benzodiazepines have significant impact on memory and cognitive ability (Buffett-Jerrott and Stewart 2002; Longo 2013).

In this respect, it is useful to consider what Gloria said when talking about her state of mind when she was administered sedatives around 20-30 minutes after the diagnosis when she had started to cry for the first time (extract 4). By way of context, Gloria was not happy with the effect that the sedatives had on her memory and capacity to make decisions. Firstly, it is of interest that she recalls that the midwife gave only a cursory explanation of what the medication was for (“to relax”, line 4) and that she used a generic term “pills” (line 4), which disguises the content of the medication. However, I want to focus on lines 6-9. Here, to a degree, Gloria mitigates the health professionals’ actions, in the sense that she stresses that her deep state of anguish at the news of the death of her daughter meant that she would have taken anything to make it go away. In the metaphor of the “poison” (line 7) and self-harm or death we get an idea of the strength of her pain and how this conditions her worldview. This analysis helps us to appreciate that state-of-mind not only relates to exhaustion and shock, but also to the impact of grief and fatalism, which amplifies vulnerability and asymmetry. This emphasises why health professionals have an ethical responsibility to full and proper informed consent.

This extract comes from a part of Gloria’s interview when she was revising the draft survey questionnaire after completion of the narrative interview. In lines 1 and 4 she paraphrases the question and response option.

1	G	¿Me preguntaron si quería sedantes?	Did they ask me if I wanted sedatives?
2		No.	No.
3		Me han dicho: “toma estas pastillas para tranquilizarte”	They said: “take these pills to relax”
4		No?	Right? [directed to her partner Nacho]
5		me daba igual todo,	As I couldn’t have cared less about anything,
6		si me decían:	if they had said:
7		“tomar un veneno	“take this poison
9		para que se te vaya.”	to make it go away.”
10		¿Me aconsejaron?	Did they inform me?
11		pues, no	well, no
12		.. ((silencio))	.. ((silence))
13		¿o sí?	or yes?
14	N	Que yo recuerdo, no.	Not that I remember.

Gloria and Nacho, third trimester stillbirth, interview participant

Extract 4. Case ID. A02. Transcription lines: 1293-1296

Finally, Tania provides an example of lack of consent related to the disposition of body. Tania’s baby died in the second trimester, and we see that she only discovers that an autopsy has been conducted when she saw the “report from pathology”, which gave her a “shock” (lines 5-6). Tania stresses that the process that led to the autopsy being conducted

was absolutely unilateral: “Nobody asked me at any point” (lines 1-2). In the next lines she establishes that as the mother it is her agreement that is required to conduct such a procedure on *her* “baby”. I deal with the theme of possession and rights in Chapter 8 in detail, but here it suffices to signal how consent relates not just to medical practices on the mother, but to all aspects of care, including those related to the baby.

Survey question: Is there anything about the autopsy or other medical tests that we haven't asked about that you would like to tell us?

1	A mí no me preguntó nadie		Nobody asked me
2	en ningún momento		at any point
3	si estaba de acuerdo		if I agreed
4	hacerle la autopsia a mi bebé.		to having an autopsy on my baby.
5	Cuando vi el informe de anatomía patológica		When I saw the report from pathology
6	me dio un shock		I got a shock
7	al ver		to see
8	que se lo habían hecho		that they had done one
9	sin mi permiso.		without my permission.

Tania, second trimester stillbirth, survey respondent

Extract 5. Case ID. B52

2.4. Coercion in decision-making encounters

This section examines the social mechanisms used by health professionals during care encounters to impose, persuade or manipulate decisions toward the preferred institutional options. Specifically, how pressuring, single-option care pathways, the pace of care, invalidation of lay knowledge and physical dominance of interactive spaces sustains medical authority and undermines agency, although not always successfully.

In Mar's story above we found that she attempted to establish some equity in the encounter with the gynaecologist by proposing an alternative, reasoned option to a curettage, which was rejected without discussion (extract 3, lines 12-18). This introduces a theme across the study that lay knowledge is invalidated or at least viewed as inferior. Such negation of women's views, however, also stretches to knowledge of their own bodies. Examples from this study include the rejection of information about the advancement of dilation, contradiction of women's views on the existence of contraction pains or their degree of painfulness, denying that the amniotic sac had broken, and not listening to mothers' fears about reduced foetal movement.

Anabel, whose baby was stillborn in the second trimester, was extremely unhappy with the care she received in the hospital. In extract 6, which was offered as a contextualisation for why she didn't see her daughter, she narrates that she was especially upset with how she ended up giving birth in a bedpan and subsequently needed a curettage and blood transfusion (lines 1-7). She attributes blame for this outcome to the [male] midwife who dismissed the information she offered him about her contractions (lines 10-15). She uses sarcasm to question why a health professional's knowledge overrides that of a woman who has given birth twice before (lines 16-18). In Anabel's story, the authority to decide what information is valid rests with the expert, the health professional, and the birthing woman occupies an inferior position. For Anabel the most troubling outcome is that her daughter was born in a “bedpan, which people use to defecate”, a humiliating experience that pollutes any possibility of a ‘good’ birth and challenges the personhood of her baby. Hence, although women may have little knowledge of procedures and care in cases of perinatal loss, they do retain the capacity to interpret their own bodies and many are already

experienced in childbirth. As we see later, giving women control over their births can in fact lead to ‘good’ births in spite of the circumstances.

Survey question: Is there anything else in relation to not seeing your baby that we haven’t asked about that you’d like to tell us?

<p>[...] 1 Cuando nació mi bebé 2 yo estaba sufriendo una hemorragia 3 la cual me obligó a pasar por un legrado 4 y varias transfusiones de sangre. 5 Por como sucedió todo 6 tuve que parir 7 a mi hija 8 en la cuña 9 donde la gente suele defecar 10 porque 11 según el matrono 12 que me atendía 13 yo estaba equivocada 14 y no eran contracciones de parto 15 lo que tenía. 16 Se ve que 17 el era capaz de percibir 18 con más exactitud 19 lo que mi cuerpo sentía 20 a pesar de que 21 ya había dado a luz dos veces anteriormente. [...]</p>	<p>[...] When my baby was born I was having a haemorrhage which meant I had to have a curettage and a number of blood transfusions Because of how everything happened I had to give birth to my daughter in the bedpan which people use to defecate because according to the [male] midwife that was attending me I was wrong and they weren’t labour contractions that I was having. It seems he was capable of understanding more accurately what my body was feeling even though I had given birth twice before [...]</p>
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Anabel, second trimester stillbirth, survey respondent

Extract 6. Case ID. B18

Anabel’s story represents only one way that medicalisation dominates lay knowledge. From Mar’s interview, we can examine how single-option care pathways also create imbalances in decision-making (extract 7). Mar’s baby was diagnosed at 16 weeks with a chromosomal condition that results in physical development problems and abnormalities. The diagnosis meant that it was highly unlikely that her baby would survive the pregnancy, although it was a possibility. During the consultation with the doctors, when Mar and her partner were to receive the results of the diagnosis, she told me that the doctors automatically set up the paperwork to refer them to an abortion clinic the very same day (lines 1-10). Because this seemed strange, I interrupted Mar to clarify what the doctors communicated (lines 12-16). She confirmed that not only was a termination not discussed, it was just assumed to be a natural course of action. Neither was there any discussion of the prognosis or other options (lines 17-25).

As mentioned earlier, Mar was keen to avoid a termination because, based on a previous experience, she didn’t want a curettage. But regardless of this specific history, what stands out is the absence of alternative options to a termination and the speed with which the doctors expected it to proceed. In this case, for example, a number of other possibilities existed: delaying the termination for days or weeks in order to prepare for the death and get used to the idea; or carrying the baby until it died or was born alive (which is what Mar and her partner decided to do; her baby eventually died in week 22 and was stillborn). However, Mar’s decision, which was not taken lightly and with considerable trepidation (line 27-28), was met with incredulity by the health professionals, who gave her the impression that they thought she was somewhat unbalanced (lines 30-33). Hence, doctors can also exercise their authority by positioning non-conformist and non-medicalised treatment options as foolish and irrational.

This extract is taken from a part of the main narrative that deals with the diagnosis. The interactions are more conversational as they come at the end of the section and I had to make a number of clarifications because I wasn't sure if I was following the story properly.

1	M	básicamente	Basically
2		ese día, lo que,	that day,
3		lo que querían hacer era,	what they wanted to do was,
4		ehmmm,	ehmmm
5		derivarnos a una clínica de aborto	refer us to an abortion clinic
6		[...]	[...]
7		digamos que	I mean
8		ellos ya tenían el informe con lo que habían visto,	they had the report and had seen,
9		con los descubrimientos ecográficos de, del día anterior y el resultado del FISH ((prueba de ADN))	with the findings of the ultrasound from, from the day before and the result of the FISH ((DNA test))
10		para derivarme a una clínica a, para interrumpir el embarazo	to refer me to a clinic to, to terminate the pregnancy
11		[...]	[...]
12	P	pero,	but,
13		y antes de eso	before that
14		¿alguien te decía,	did anyone say:
15		ehmmm,	ehmmmm
16		Mar, igual vas a tener [que] pensar en, en interrumpir... el embarazo?	Mar, you might have to think about terminating... the pregnancy?
17	M	No, no..., no hombre,	No, no..., no
18		son cosas que obviamente	they are things that obviously
19		((ríe))	((laughs))
20		te,	you, ((plural))
21		tú piensas,	you ((the interviewer)) think
22		pero no,	but no,
23		nadie,	no one,
24		nadie se sentó 5 minutos a decírnos:	no one sat down with us for 5 minutes and said:
25		"el pronóstico es este, las soluciones son estas."	"the prognosis is this, the solutions are these."
26		[...]	[...]
27		cuando decidimos que no íbamos a interrumpir el embarazo	when we decided that we weren't going to terminate the pregnancy
28		((suspira fuerte))	((heavy sigh))
29		y bueno,	and well,
30		pues las miradas fueron como de, de:	well, the looks were like, like:
31		"pero ¿estás entendiendo bien lo que te estamos diciendo?"	"but, do you understand what we're telling you?"
32		o sea,	I mean,
33		como de que fuéramos tontos	as if we were stupid

Mar, second trimester stillbirth, interview participant

Extract 7. Case ID. A10. Transcription lines: 615-638

Similarly, we can observe that in Vanessa's story a medicalised labour/birth is so heavily favoured by the [male] gynaecologist that he used fear of pain to coerce the use of a particular analgesic before labour had even started. This story actually comes from a response to the survey question on what 'helped most' in the hospital. Vanessa wrote about how a [female] midwife helped her counteract this pressure. Specifically, she stresses the midwife's calm and unrushed approach to the labour (lines 1, 4) and her lack of intervention and respect for privacy (lines 2-3). She attributes having a "good birth" (line 6) to these characteristics. Comparatively, the [male] doctor is positioned as having an entirely different style: using anxiety and fear about a long and painful birth to coerce the administration of an epidural (lines 8-12). Given that many women already experience significant fear and anxiety about giving birth in general and even more so in cases of

stillbirth, this seems particularly callous. One has to consider whose interests the doctor had in mind.

Survey question: What was the thing that most helped you during the hospital stay? (something someone said or did)

1	[...] La comadrona que acompaño el parto estaba muy tranquila,	The [female] midwife who was with me during the birth was very calm
2	nos dejó a solos	she left us alone
3	(en el sentido bueno),	(in the good sense),
4	y no metió prisas con la inducción:	and didn't rush us with the induction:
5	así que	so
6	era un parto bueno y corto	it was a good birth and short
7	(2 horas)	(2 hours)
8	todo lo contrario de lo que el médico obstetra habia pronosticado	the complete opposite of what the [male] obstetrician had predicted
9	(que seria muy largo,	(that it would be long,
10	24 h o más,	24 hrs or more,
11	muy doloroso	very painful
12	y que deberia aceptar anestesia epidural).	and that I should accept epidural anaesthetic).

Vanessa, third trimester stillbirth, survey respondent

Extract 8. Case ID. B05

Table 13. Data related to the birth and labour

	Gestational age		
	2nd trimester	3rd trimester	Total
Mode of delivery (%)			
Vaginal* ¹	94.7%	86.8%	84.0%
Vaginal induced* ¹	78.4%	69.0%	72.8%
Vaginal not induced* ¹	13.4%	6.8%	9.4%
Instrumentalised	16.2%	12.9%	14.2%
Caesarean* ²	2.8%	23.0%	14.9%
Caesarean in public hospitals* ¹	3.0%	16.9%	11.3%
Caesarean in private hospitals* ³	2.4%	41.5%	25.1%
Accompaniment during the birth by a partner or other support persons			
Not accompanied* ¹	33.8%	26.4%	29.2%
Partner not permitted to enter / accompany during the birth	19.9%	15.6%	17.3%
n	321	475	796

* $p \leq 0.05$; 1=Small effect size, 2=medium effect size, 3=large effect size (Phi)

Data presented in table 13 about mode of delivery shows that the caesarean birth rate is more than double the recommended rate at almost one-in-four deliveries of all births in the third trimester. Although this is high, in private hospitals the rate is 41.5% compared to 16.9% in public hospitals. While it is clear from the interviews that a significant number of women ask for a caesarean following the diagnosis of an intrauterine death, the differences between public and private hospitals indicate that values other than appropriate clinical care of women are at play in obstetric practice.

Whereas fear is the principal method of coercion in Vanessa's story, we also find that 'protocols' are widely used as a means to manipulate and pressure. Esther, whose baby was stillborn in the third trimester, provided a long and detailed list of things that she found unhelpful during the

hospital stay. Specifically, she was unhappy that she only saw her baby very briefly. She attributed this to her own lack of bravery, but also to the actions of a female gynaecologist who constantly pressured her to make decisions. Of note in extract 9 is the idea that the professional invokes a protocol and third party as a superior force or authority who is obliged to act (“they have to” in line 7 and 10 and “pathology department” in line 11). In demanding an immediate decision, the doctor applies pressure that is additional to her own authority, which Vanessa seems to have resisted. The invocation of a third party and superior authority is also much harder to withstand, as they aren’t present. Regardless, there is no particular technical reason that the body would have had to go to cold storage immediately (Dahlstrom and Fitzgerald 2017). In this sense, the doctor’s focus is on advancement of the medical process of care, regardless of the distress of the patient.

Survey question: What was the thing that least helped you during the hospital stay? (something someone said or did)

<p>[...] 1 Esta misma profesional 2 es la que estuvo metiendo prisa 3 todo el tiempo 4 para que me decidiera a ver a mi niña, 5 llevándome a decir: 6 " Mira no podemos esperar más , 7 el cadáver se lo tienen que llevar a la cámara frigorífica 8 porque 9 se altera muy rápido 10 y tienen que coger las muestras 11 para anatomía patológica". 12 [...]</p>	<p>[...] That same [female] professional is the one that was rushing me all the time to decide if I wanted to see my girl, she even went so far as to say: " Look we can't wait anymore , they have to take the corpse to the cold room because it changes very quickly and they have to take samples for the pathology department". [...]</p>
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Esther, third trimester stillbirth, survey respondent

Extract 9. Case ID. B04

While pressure and coercion toward predetermined outcomes is present in each of the narratives presented in this section, it is also clear that time and the pace of care are formative. If we examine Gloria’s account (extract 10) of the time after the diagnosis, we can observe that she makes no explicit complaint about the way that the process of care moves from diagnosis to induction. Nonetheless, the principal idea that comes across in her story is that the transition is fast and happens when she is still confused and attempting to assimilate the news of the diagnosis that her baby is dead (lines 4-12). It is noticeable that her state of shock meant that she hardly showed any initial reaction to the diagnosis apart from disbelief. Presupposed within Gloria’s narrative is the doctors’ belief that an immediate pharmacological induction of the pregnancy is an appropriate course of action. In fact, they appear to proceed with her care as if it were a form of emergency, despite there being nothing in Gloria’s case that suggested that it was: in normal cases a dead baby poses no physiological threat to the mother and in 80-90% of cases will be born naturally within a period of one-to-three weeks (Chakhtoura and Reddy 2015; Dudley 2011; RCOG 2010a). We can also ask the question: was it really necessary to separate Gloria from Nacho (lines 15-17), her main source of social support?

The following extract is taken from an extended narrative about the diagnosis. When Gloria signalled the end of that section of the story and a turn change, I asked her if there was anything else they had told her after the diagnosis.

<p>1 G y me han dicho: 2 "es que no hay latido" 3 y yo:</p>	<p>and they said: "there's no heart beat" and I said:</p>
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4		"¿perdón?,	"what?
5		¿eh?,	eh?
6		¿qué no hay latido?,	there's no heartbeat?,
7		es que no puede ser,	that can't be,
8		no puede estar bien esto"	that can't be right"
9		y el:	and he said:
10		"que no, no hay latido"	"there's not, there's no heartbeat"
11		y yo:	and I said:
12		"Nacho, ¿estás escuchando lo que están	"Nacho [Gloria's husband], are you
		diciendo?"	listening to what he's saying?"
13		y tal	and so on
14		y me han llevado para poner la vía	and they took me to put in the drip
15		y Nacho ha pasado mal también del susto	and Nacho also felt unwell from the fright
		of it	
16		y de hecho	in fact
17		el se quedó en urgencias y yo fui,	he stayed in emergencies and I left
18		[...]	[...]
19	P	Vale, entre, entre que te decían	Right, so between telling you that
		que no había latido y	there was no heart beat and,
20		¿qué te contaban más en este	did they tell you anything else at
		momento?	that time?
21		[...]	[...]
22	G	vino todo el equipo de urgencias	almost the whole emergencies
		casi,	team came,
23		porque vino uno a, a meter la vía,	because one came to, to put in the
			drip,
24		los dos ginecólogos	the two [male] gynaecologists
25		y, y uno decía,	and, and one said,
26		el que era mayor decía,	the older one said:
27		"lloran, lloran, llora todo lo que	"cry, cry, cry all you have to cry"
		tienes que llorar"	
28		y yo:	and I said:
29		"¿cómo voy a llorar?	"how am I going to cry?
30		es que	I mean
31		no estoy entiendo lo que me	I don't understand what you're
		estáis diciendo",	saying
32		y, y empezaron:	and, they said:
33		"bueno,	"well,
34		vamos a empezar la inducción	we're going to start the labour
		del parto"	induction"

Gloria, third trimester stillbirth, interview participant

Extract 9. Case ID. A02. Transcription lines: 314-330

In this case, other possibilities existed, such as delaying the induction for a period of hours or days in order to allow Gloria and Nacho to get over the initial shock, to assimilate information and gather their support networks. It can also be noted that Gloria had a very difficult time deciding to see her daughter Fernanda and, after a 13-hour induction and labour did so only very briefly, without holding her or taking any pictures, which she deeply regretted. Would a delay to the induction have dramatically changed the course of Gloria's care and significant parts of her narrative of loss and grief?

Patricia, whose baby was stillborn in the third trimester, was also happy with the health professionals but regretted leaving the hospital manage the disposition of the body and not spending more time with her baby after the birth. In extract 11, her response lays fault for this situation at the use of closed-end questions, lack of options and lack of time to make decisions. Accordingly, it is important to take into account just how coercive closed-end questions are when asked by an authority figure. In a situation where women are unsure about appropriate social behaviour and searching for clues for how to act, they are highly susceptible to trying to establish the preferred option of the health professional (see also Chapter 8 for how these dynamics invoke stigma and taboo).

Survey question: Is there anything else in relation to seeing your baby that we haven't asked about that you'd like to tell us?

<p>[...] 1 Que no se hagan preguntas cerradas tipo: 2 ¿nos hacemos cargo nosotros del bebé? 3 ¿os hacéis cargo vosotros del bebé? 4 Sería mejor que nos dijeran todas las opciones posibles, 5 y dejarnos tiempo para pensar y decidir. [...]</p>	<p>[...] They shouldn't use closed-end questions: will we take charge of the baby? will you take charge of the baby? It would be better if they gave us all the possible options, and give us time to think and decide [...]</p>
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Patricia, third trimester stillbirth, survey respondent

Extract 11. Case ID. B27

Finally, we can also consider how the physical dimensions of interaction, such as the orientation of bodies and space, health professionals' mannerisms, and non-verbal language can compound asymmetry. Aida's account of care (extract 12) contains many of the characteristics of unequal relations that I have already discussed. Evident in the action and command verbs in lines 5 and 6 ("*they made my husband leave*", "*they made me push*"), is little consideration for the patient's views or the possibility of collaborative decision-making. However, we can also observe a number of dominance gestures in the first 4 lines. To start, the group of five gynaecologists "burst into the room" (line 3), aggressively asserting their authority over the social space and showing little regard for the time of the morning, the situation of loss, or the fact that the room might represent an intimate setting. Secondly, the patient and her partner are outnumbered five to two (line 3). It should also be taken into account, as was emphasised by another participant (Ruth, B01), that women are normally lying down in these encounters, already a weak position to someone standing up. Thirdly, the gynaecologists "talk amongst themselves" (line 4), excluding Aida, and her partner, from the medical decision-making process. Subsequently, the woman's partner is "made" to leave (line 5), creating further imbalance in the relationship by reducing her main source of support. In reality, this practice is systematic, almost one-in-three women were not accompanied during the birth, mostly due to the insistence of health professionals (see table 13). Weakening of such support networks has an important impact on care. When women were unaccompanied during the birth it led to lower levels of contact with the baby (37.3% vs. 59.4%, $p < 0.001$) and higher levels of sedative administration (54.1% vs. 45.6%, $p = 0.037$).

The truly sad aspect of this part of Aida's story is the effect it has on her as a mother and how this mirrors Mar's story (extract 3). She felt utterly defenceless and impotent, weeping on the inside and giving up because "it was all too much" (lines 11-14). Viewed in this way, the process of care, the context of loss, the associated stress and anxiety and physical effort of giving birth led to a form of exhaustion and a condition of feeling utterly overwhelmed. So, although Aida's silence is deliberate, in order to protect herself, it forces her to place her own needs before that of her daughter's. In this case, there was a happier ending, as the failure of the labour to proceed in line with the gynaecologists plans meant that they abandoned the birth and a [male] midwife stepped in and helped her have a calmer, less intrusive birth (see Chapter 6, extract 6, for more details).

Survey question: What was the thing that most helped you during the hospital stay? (something someone said or did)*

<p>[...] 1 A las 05.00 de la madrugada 2 (cuando estaba casi totalmente dilatada) 3 irrumpieron en la habitacion</p>	<p>[...] At 5 in the morning (when I was almost completely dilated) around 5 gynaecologists</p>
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<p>4 unas 5 ginecologas 5 y despues de hablar entre ellas 6 le hicieron salir a mi pareja 7 y me hicieron empujar. 8 Asi, sin mas. 9 Necesitaba a mi pareja al lado y no era el modo de traer a mi hija al mundo,</p> <p>10 era consciente, 11 y llore por dentro 12 pero no dije nada, 13 de alguna manera me rendi, 14 todo aquello era demasiado. [...]</p>	<p>burst into the room and after talking amongst themselves they made my husband leave and they made me push. Just like that. I needed my partner by my side and it wasn't the way to bring my daughter into the world, I knew, and I cried on the inside but I didn't say anything, somehow I gave up, it was all too much. [...]</p>
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Aida, third trimester stillbirth, survey respondent

Extract 12. Case ID. B10

**See extract 6, Chapter 6 for the full entry*

2.5. Naturalised paternalism

While analysing the responses to the open-ended survey questions, in particular the questions that asked women to talk about the thing that ‘most helped’ them during the hospital stay, it was notable how many responses made reference to being given permission for relatively simple acts such as being allowed to have partners and family in the room. The language choice in these entries signals a wider culture of subordination and acceptance of asymmetry in healthcare relations and within institutions such as hospitals. Silvia’s entry (extract 13) is a case in point and an archetypal response: as the governors of the social space that is the institution, health professionals grant permission for action. Implicit in this entry is the possibility that the institution can deny permission, and that Silvia or her family could do very little about it.

Survey question: What was the thing that most helped you during the hospital stay? (something someone said or did)

<p>1 Permitieron 2 que estuviera acompañada en la habitación por mi pareja, familia y amigos. [...]</p>	<p>They allowed my partner, family and friends to be in the room with me.</p>
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Silvia, second trimester termination of pregnancy, survey respondent

Extract 13. Case ID. B39

Ruth’s narrative provides an interesting example of what some women expect from care providers (extract 14). She was very unhappy with her treatment during a diagnostic consultation, where she found out that her baby had a severe chromosomal abnormality: the doctor was evasive, aggressive and she was left alone after the consultation. However, in reimagining an alternative outcome she exhorts deception and paternalistic behaviour. She proposes that the staff “should have” (line 3) created a pretence to get a family member to the consultation (lines 7-11). This expectation of paternalism contrasts to the possibility of being straightforward with her during the consultation, suggesting that she call someone to come and be with her, and not leaving her alone in the meantime.

Survey question: What was the thing that least helped you during the hospital stay? (something someone said or did)

	[...]		[...]
1	al ver que yo estaba sola		knowing that I was alone
2	[...]		[...]
3	tendrían que haberse inventado cualquier excusa		they should have made up any excuse
4	para hacer que alguien me acompañara,		so that someone was with me,
5	no sé,		I don't know,
6	por ejemplo,		for example,
7	decirme que me querían hacer una prueba		tell me that they wanted to do a test
8	y que después no podría conducir		and that after I couldn't drive
9	y que mejor si llamaba a alguien		and that it would be better if I called someone
10	para que después me llevara a casa		so that after they could take me home
11	o algo así,		or something like that,
12	¿no?"		right?"
	[...]		[...]

Ruth, second trimester termination of pregnancy, survey respondent

Extract 14. Case ID. B01

This expectation of kind or benevolent paternalism is a feature of the narratives. It helps to identify an intersection between compassionate care (two-thirds of cases) and lack of information and control over decision-making (over half of cases) and why lack of agency does not influence evaluations of care to the same degree as humanistic aspects of care, despite the fact that regrets about decisions taken in the hospital significantly influence grief. In sum, it seems that many women have only limited expectations of autonomy in decision-making, which when combined with informational and communicative disadvantage and coercion leads to very low levels of control over decisions. It alludes to a certain culture or expectation of paternalism and acceptance of medical authority tied up in the concept of care. Nevertheless, as we'll see in the next section, this is certainly not universal.

2.6. Agency, resistance and the acquisition of better care

Although, generally speaking, the narratives portray asymmetric care relationships and a type of cultural and contextual passive participation, they also contain a number of instances of women exercising their agency and attempting to take matters into their own hands. Two common ways that women attempt to do this is to ask for sedatives or to request a caesarean section. Often these technologies represent the only available knowledge that women have about how to deal with intrauterine death, but we can identify a number of other forms of agency and resistance. Firstly, we can look at some accounts where women characterise themselves as the most assertive force in the provision of care: asking questions and demanding information and appropriate support.

Rocío, in responding to the question on what 'most helped' her during the stay in the hospital, states, in extract 14 (lines 3-6): "they kept me at all times in a private room (including for the birth) and talking to my gynaecologist who I could ask all kinds of questions". But she then clarifies this and devalues the quality of the care received by stating: "even if its true that it was more my initiative" (lines 7-9) and "they only give it [information] to you if you ask questions" (line 19). While she recognises that the quality of the answers and information she received were very good (lines 10-13), her "sense" was that there was no protocol in place to care for women like her (15-16). In effect, Rocío proposes that the hospital was not prepared and staff not trained to deliver appropriate care. It also indicates that good care is only available if you know how to acquire it.

Therefore, she draws on a trope of public institutions that you have to know the system and how to manage it in order to access the services that you have rights to. In a very lucid analysis of this situation, she points out: “the problem is if you don’t know what’s going to happen to you there are questions that are not addressed” (lines 20-22). Hence, she arrives at the crux of the problem in perinatal bereavement care: many hospitals are not organised to provide information through trained personnel and women don’t know what questions to ask or are unable to do so because of temporary incapacity. Hence, we find that the communicative and informational disadvantage that women find themselves in results in a circular effect that perpetuates poor care. Effectively, circumstances result in a breakdown in the client driven service model.

Survey question: What was the thing that most helped you during the hospital stay? (something someone said or did)

<p>1 Que me mantuvieran 2 en todo momento 3 en una habitacion privada 4 (incluso para el parto) 5 y hablar con mi ginecólogo 6 al que pude hacerle todo tipo de preguntas 7 (si bien 8 es cierto 9 que fue más iniciativa mía). 10 Quiero decir, 11 en todo momento 12 me respondió a mis preguntas. 13 Con total claridad, 14 pero 15 no percibí que hubiera un protocolo 16 en el que la iniciativa partiera del personal médico 17 donde por ej. 18 anticiparan esa información 19 (solo se facilita si tu preguntas, 20 el problema es que 21 al desconocer que es lo que te va a pasar 22 hay preguntas que se quedan en el tintero. 23 Por ej. 24 A los días del parto 25 tuve una subida de leche, 26 nadie me había advertido)</p>	<p>That they kept me at all times in a private room (including for the birth) and talking to my [male] gynaecologist who I could ask all kinds of questions (even if it’s true that it was more my initiative) I mean, at all times he responded to my questions. With complete clarity, but I didn’t sense that there was a protocol where the initiative came from the medical staff where for e.g. they anticipated [the need for] that information (they only give it to you if you ask questions, the problem is if you don’t know what’s going to happen to you there are questions that are not addressed For e.g. A few days after the birth my milk came up, no one had warned me)</p>
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Rocío, second trimester stillbirth, survey respondent

Extract 15. Case ID. B33

Of critical importance in the outcome of Rocío’s story is the fact that she was being cared for by receptive health professionals who responded to her requests. However, the study also contains examples of more conflictive relationships where attempts to express agency or to use reason are not successful (like Mar in extract 3, above). In such encounters some women resort to the use of emotion displays as an alternative strategy of negotiation. Laura provides a relatively straightforward example (extract 16). After arriving at the emergency ward and telling them that her baby had died, the health professionals wanted to admit her without her partner. So, she started crying and refused to be admitted without him (lines 5-6), causing the health professionals to relent (line 7). That Laura resorted to such a tactic suggests that she thought that using reason would be unsuccessful. Instead she has to debase herself, and adopt the hysterical woman stereotype in order to negotiate a favourable outcome. As such, the negotiation, though successful, came with a high cost as she says: “it was humiliating” (line 8).

Survey question: What was the thing that least helped you during the hospital stay? (something someone said or did)

<p>[...] 1 - al llegar a urgencias 2 les dije que mi bebé estaba muerto 3 (venía del centro de salud) 4 y me dijeron que mi pareja NO podía entrar conmigo. 5 Me eché a llorar 6 y dije que no entraría sin él 7 y entonces me dejaron. 8 Fue humillante [...]</p>	<p>[...] - when I arrived at emergencies I told them that my baby had died (I had come from the Health Centre) and they told me that my partner could NOT go in with me. I started crying and said that I wouldn't go in without him and so they let me. It was humiliating [...]</p>
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Laura, third trimester stillbirth, survey respondent

Extract 16. Case ID. B12

Mireia though had less success attempting to see her baby after the birth, but was equally humiliated (extract 17). She provides a contextualisation that establishes her lucidity and capacity as an adult to make a decision that she wanted to see her baby (lines 1-4). Nevertheless, she says: “everyone around” her “said no” (line 6). When she wasn’t allowed to see her baby after the birth she said she “cried and got mad” (twice) in an attempt to convince the nurses (lines 10, 14), but they reject her request again (line 12). They offer the counter reason that the baby’s smallness meant that they couldn’t, invoking an institutional protocol (line 13). So, Mireia alters her tactic, reducing her request to a kiss, even if the baby is not visible, which a nurse eventually agrees to (line 20-25). In this sense, the emotion display was only partially successful as a negotiation device, but was also a sensible option when reason had failed.

I think it is also important to point out the sense of exhaustion that Mireia communicates in the coda: “I gave him three little kisses on the little cloth and *I fell asleep*” (line 28, emphasis added). This gives an idea of how exhausting conflictive relationships with carers can be, which comes on top of the energy that has already been expended in recovering from shock, grieving, anxiety and giving birth, and in this case the effects of a sedative. Hence, challenging medical authority can represent a certain amount of risk and can come at a significant cost, although for Mireia it was clearly worth it, as the coda “I fell asleep” also communicates a certain sense of peace with herself and her relationship with her baby.

Survey question: Is there anything else in relation to not seeing your baby that we haven't asked about that you'd like to tell us?

<p>1 Yo queria ver al bebe, 2 sabia que 3 con 18 semanas 4 era pequeñito pero formado. 5 [...] 6 Pero todo el mundo a mi alrededor me decia que no. 7 Una vez di a luz 8 lo busqué, 9 y no estaba, 10 llore y rabie 11 porque queria verlo 12 y las enfermeras me dijeron que no,</p>	<p>I wanted to see the baby, I knew that at 18 weeks he¹⁴ was small but formed [...] But everyone around me said no. As soon as I gave birth I looked for it and it wasn't there, I cried and I got mad because I wanted to see it and the female nurses said no,</p>
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¹⁴ In this case Mireia didn't actually know the gender of her baby, however no gender-neutral pronoun (it) exists in Spanish, so the gender goes to the default male. I feel that using “it” in this context would not be an appropriate translation. An alternative would be to substitute the pronoun for “the baby”, which she uses in the first line.

13	que era pequeño,	that it was small,
14	rabie y llore,	I cried and I got mad,
15	(me sedaron)	(they sedated me)
16	para que	so that
17	al menos	at least
18	me dejasen darle un besin,	they would let me give him a little kiss,
19	aunque fuese envuelto,	even though he was covered up,
20	y al final	and finally
21	vino una enfermera	a nurse came in
22	con él envuelto en un trapito,	with him wrapped in a little cloth
23	diciendo;	saying;
24	" es que no solemos hacerlo	" we don't usually do it
25	cuando son tan pequeños.."	when they are so small.."
26	Le di tres besitos	I gave him three little kisses
27	al trapito,	on the little cloth,
28	y me quede dormida.	and I fell asleep

Mireia, second trimester termination of pregnancy, survey respondent

Extract 17. Case ID. B07

3. Conclusions and discussion

The results of both the quantitative and qualitative data establish very clearly that severe asymmetry and lack of equity in decision-making processes are a dominant characteristic of care practices following perinatal loss in Spanish hospitals, affecting up to two-thirds of the study population to varying degrees, and in some cases very severely. While the findings indicate that power imbalance is independent of socio-demographics and pregnancy histories, it is more extreme in second trimester losses/deaths. Furthermore, although feelings of being in control are significantly higher in cases where women were positive about humanistic aspects of care, they are still very low overall. Even though it is not unusual for studies in this field to find that women feel a lack of control over decisions (Corbet-Owen and Kruger 2001b; Lundqvist, Nilstun, and Dykes 2002), it is surprising to see just how extensive and deeply embedded the problem appears to be in the Spanish health system. On the other hand, it is notable that imbalances in decision-making are much less influential on overall evaluations of care than humanistic aspects of interactions with health professionals; they tend to be backgrounded in narratives. In this respect, the interpretation of the results must take into account that concepts and expectations of autonomy are not homogenous (Thompson and Whiffen 2018).

The results suggest that asymmetry is grounded in five factors: i) women's pre-standing informational disadvantage with regard to what constitutes appropriate care in cases of perinatal loss, which weakens their capacity to direct and acquire care; ii) the varying degrees of mental incapacity and debility following a diagnosis of perinatal loss, which limits interactive capacity, and enhances communicative disadvantage; iii) health professionals lack of preparation and training for the provision of appropriate care and information following perinatal loss; iv) a general culture of care in obstetrics that devalues patient participation and rights to autonomy, which is sustained by a variety of social mechanisms employed by health professionals and by the naturalisation of patients in paternalistic cultures; and v) a dissonance between women's and health professionals understanding of the significance of the loss/death.

That women have to navigate care following perinatal death with little practical experience or knowledge to orient them towards appropriate action is perhaps a highly unusual circumstance in

western society and particularly in the context of pregnancy where such considerable planning and educational effort goes into preparing for the birth. From a knowledge perspective this represents a significant disadvantage in linguistic and rhetorical competence, or what Bourdieu refers to as cultural capital (Bourdieu 1991:67). As social actors, this limits women's ability to participate in decision-making encounters and amplifies inequalities by reducing their capacity to evaluate and judge carers' positions and negotiate or defend their own stance or position. But perhaps, more fundamentally, it undermines their knowledge of what exactly their own rights and entitlements are (Blommaert 2005:71; Gumperz and Cook-Gumperz 1982).

If we take this as our starting point, we can better appreciate the lack of equity that bereaved women bring to decision-making encounters with health professionals in these circumstances. This means women are highly dependent on health professionals to help them overcome informational disadvantage as well as to create a safe context for care (see Chapter 6). Nevertheless, a key finding is that women rated information provision extremely low: only around one-third received sufficient information to help when make appropriate decisions in all areas of care and many women received no information about some aspects of care. Comparatively, studies in other high-income countries have found that ratings of communication and information are often above 75% (Basile and Thorsteinsson 2015; Paton et al. 1999; Redshaw, Rowe, and Henderson 2014), which also shows room for improvement.

As informational deficiencies span both bereavement and technical care, the problem appears not to be specific to perinatal loss but to originate in a wider culture of care that doesn't value the involvement of patients in decision-making. In this respect, numerous contemporary studies (statistical, quantitative and qualitative) point to a model of obstetric practice in Spain that is still strongly rooted in biomedical values and practices (Biurrun Garrido 2017; Blázquez Rodríguez 2009:344; 2019; Zeitlin et al. 2010), despite efforts at humanisation (Ministerio de Sanidad 2007). Consequently, any analysis of care following perinatal loss must consider how it intersects with or is contained within the wider context of obstetric culture. At a very simple level, lack of information for making decisions, equates to lack of informed consent and autonomy, which in itself violates the basic charters of national and international legislation on human and patient rights (Gobierno de España 1986, 2002; UNESCO 2005).

Taking an interactive and relational view of the social is to understand that this situation must be continuously reproduced or 'done' at local level (Goodwin and Heritage 1990). Accordingly, when we look beyond basic statistics related to control and information we find a pattern of structural, cultural, linguistic and spatio-temporal mechanisms through which autonomy is undermined and asymmetry is sustained, which includes: the presentation of single-option medicalised solutions and a view of women's bodies as sites for medical intervention; the imposition of institutionally mandated/protocolised action that separates care provider from responsibility; unnecessarily treating cases as emergencies; pressured and manipulative decision-making; and member exclusion and dominance techniques.

In Habermasian terms this amounts to strategic action oriented to specific doctor or institutionally preferred outcomes rather than decisions based on communication as an equitable negotiated process (Edwards 2012). These dominance gestures are characteristic of instrumentally focused doctor-patient interactions and the manner in which health professionals socialise patients into medicalised culture (Mishler 1986:57). While positive relationships between women and their carers encourages communication (see Chapter 6), if information is not provided and options are not discussed, the decision-making process continues to be strategic and paternalistic, i.e. based on institutionally embedded assumptions about what is best, not the preferences of the patient.

However, it is important to distinguish between conscious and unconscious strategic action. Conscious strategic action is evident in explicit coercion and manipulation, browbeating, and the use of technical jargon to further imbalance and destabilise patient attempts at agency. On the other hand, unconscious deception can occur when neither patient nor doctor are aware and asymmetric practices may often be made as sincere acts in good faith (Scambler and Britten 2001). Both forms are clearly present in the research. Soft paternalism is intertwined with compassionate care and hard paternalism with dysfunctional relationships characterised by instrumentalism.

So, given that the quantitative research found that information and control were far less influential over evaluations of care, and that asymmetry is backgrounded rather than foregrounded in the narratives of care, we also have to ask to what degree is paternalism naturalised and taken-for-granted? In general, it is accepted that both soft and hard paternalism are sustained by collusion and trust in the voice of medicine (Charles, Gafni, and Whelan 1999; Coupland, Robinson, and Coupland 1994). Also, research in general healthcare has found that not all patients want to be fully involved in decision-making (Charles et al. 1999; Coulter and Jenkinson 2005; Coulter 1999; Elwyn et al. 2000). Undoubtedly, this plays an important role in sustaining asymmetric relationships, but I think it has to be unpacked a bit. The research shows that collusion can be both strategic and unconscious or cultural. For example, if carers are perceived as very powerful, women may be reluctant to express their views (Say and Thomson 2003). In this chapter and Chapter 6, there are various examples of women choosing to be silent as a form of self-protection or because of worry about repercussions. If resisting or expressing agency is perceived as risky, then women may choose not to, particularly if they are already physically and mentally exhausted. Conflict is taxing. In this sense, silence and lack of resistance may be superficially collaborative, but not represent consent or approval. Regardless of whether women want to fully participate in decision-making or not, that still has to be established as their choice, otherwise it is a violation of basic rights. Furthermore, there is no social education on perinatal loss that prepares women for how to manage and acquire the care that they have rights to. Hence, they have no way to know when an issue is not being addressed or information not provided, which makes it the ethical responsibility of the hospital to create the conditions of possibility for equitable decision-making.

Although the underlying values of the biomedical model would purport to be one of rationalism grounded in medical objectivity, the fact remains that many aspects of care do not conform to current evidence, either technically or in relation to bereavement care. To illustrate, we can evaluate practices in relation to caesarean sections and the use of sedatives. In cases of intrauterine death, in the absence of clinical indications, vaginal birth is recommended over caesarean section as there is no threat to the mother and the baby's health is no longer a concern (ACOG 2009; NICE 2008; RCOG 2010a; SEGO 2008). However, the caesarean section rate (for stillbirth) in this study is around 1.5-3 times higher than in England, Sweden and the United States (DiStefano et al. 2015; Gravensteen et al. 2013; Redshaw et al. 2014; Rossi, Hall, and DeFranco 2018). A comparison between live births over 28 weeks gestation using data from the Instituto Nacional de Estadística for the year 2015 (Cassidy 2020) shows that there is only a small difference between the caesarean section rate for live births (26.8%) vs. stillbirths (23.0%). This highlights how non-evidence based care has a significant presence in both types of birth, pointing to a monoculture of medicalisation, which is consistent with other research and government reports (Ministerio de Sanidad 2012). Additionally, that the caesarean section rate in private hospitals exceeds best practice guidelines by more than four times (World Health Organization 2015) is not arbitrary and explainable by the circumstances of an intrauterine death. This is not to say that women don't influence mode of delivery by asking for caesareans, but rather that private hospitals clearly provide the cultural and structural conditions of possibility for caesareans to be practiced.

The administration of sedatives has been considered highly inadvisable in cases of perinatal loss for more than 40 years (Benfield et al. 1978; Canadian Paediatric Society 2001; Gilson 1976; Kellner et al. 1981). In this study, around half of women were given sedatives, which was four-to-five times greater than that found in a U.S. study (Lacasse and Cacciatore 2014). Although they are often thought of as benign, sedatives have been reported by bereaved women to be associated with regrets about decision-making (Kellner et al. 1981; Malacrida 1997), and to negatively impact memory (Canadian Paediatric Society 2001; Condon 1986; Lewis 1976). This is consistent with the established retrograde amnesic effects of sedatives and cognitive impairment that can result from even a small dose of medications such as benzodiazepine (Buffett-Jerrott and Stewart 2002). Furthermore, in the aftermath of psychologically traumatic events they may actually worsen posttraumatic stress (Guina et al. 2015). Although not presented in this text, other analysis from this study found a highly significant association, but not causal, between sedative use in the hospital and complicated grief (Cassidy 2019).

Sedative administration during labour, childbirth and the puerperium is also a historical and contemporary marker of medicalised obstetric care with a basis in paternalism where the doctor protects the woman from the stress of childbirth, but also uses sedation as a form of pacification and control (Bellón Sánchez 2014; Myers and Myers 1979; Tew 1990:125). More generally sedative/ tranquiliser use is a feature of gendered practices in mental healthcare (Blum and Stracuzzi 2004; Stoppard 1999): women are more than twice as likely to be diagnosed with anxiety as men (American Psychiatric Association 2013) and to be prescribed tranquilizers (Rogers and Pilgrim 2005). In this respect, the research finds a clear intersection between biomedical practices and gendered ideas of women as overly emotional, requiring protection or control (see also Chapter 6). In conclusion, technologies are often employed in ways that only relate to the values and preferences of the doctor and the practice of orderly medicalised childbirth (Martin 2001:57), but as I have pointed out already in Chapter 6, they can be configured differently and devolve power and capacity to patients.

Much as we saw in Chapter 6, which highlighted verbal abuse and humiliation during care, in this chapter I have drawn attention to some disturbing stories of care that amount to very violent acts on women by their carers, including the practice of surgical procedures following browbeating or when women are in a state of exhaustion and incapable of providing consent. The stories I included from Mar and Anabel are harrowing and make for very uncomfortable reading, but they were not alone. While these cases represent very clear instances of obstetric violence or abuse (Goberna-Tricas 2019; Sadler et al. 2016), there is an argument to be made that they represent just the most extreme forms. Many of the more mundane practices of asymmetry, rooted in lack of information, coercion or socially accepted medicalisation, could also be considered institutionalised forms of abuse because they violate basic principles of human and patient rights and are rooted in gendered notions of women as incapable of being the protagonists of their own care (Castro 2014; Sadler et al. 2016). How widespread these practices are is difficult to say and dependent on how it is defined, but it is clearly not a minor issue associated with a few bad apples. Instead, it appears to be a structural problem rooted in institutional values and lack of training.

To conclude, the research findings show how perinatal grief is not just about mothers before loss/ death but also about women and their bodies before society, how they are positioned and configured as persons, women *and* bereaved mothers, and the social spaces into which they must fit. The research shows how totalising the dominance of care can be and the impact this can have on women's sense of self and security, increasing anxiety, loss of trust in healthcare and introducing highly toxic plots into narratives of self, loss and grief. Undergoing a radical shift from subject to object within childbirth practices, the powerless woman here stands in complete

contradiction to the self-determined and disciplined woman of pregnancy (Beck and Beck-Gernsheim 1995; Georges and Mitchell 2000; Kukla 2010; Landsman 2008:17; Lupton 2012). In undermining social position in this way their sense of being in the world is fundamentally alerted, the social stories assigned to their bodies out of sync with canonical narratives. Opportunities to restore a coherent sense of self and some control over the story of care and even to have a 'good' birth under very trying circumstances are lost. On a positive note, the research also shows that to a degree new models of care are already coming into place in Spanish hospitals and that when women feel listened to, safe, receive good information, are given adequate time and not pressured, they can take control of their own care.

Chapter 8. Doing death: babies in care encounters

1. Introduction

Chapters 6 and 7 address the interactive dynamics between women and health professionals in order to see how loss is contextualised and how the social positions of women and health professionals are established, modified or challenged. Chapter 8 shifts the analysis to the object of loss and attends to the social practice and mechanisms that reinforce or oppose cultural taboos related to dead babies in the time immediately after the death. By examining the tensions that exist around the production of social categories related to baby / dead and the way that the materiality of the dead body is treated, the analysis considers the corresponding production of mothers of dead babies and the manner in which this configures the social practice of grief and the relationship between the dead and the living.

2. Results

2.1. Naming the dead

To start, we can consider how women refer to or denote their babies in their stories. Most women use terms such as “my son” [mi hijo], “my daughter” [mi hija], “my boy” [mi niño] or “my girl” [mi niña], with occasional variants such as “our son/daughter” [nuestro/a hijo/a] or “our boy/girl” [nuestro niño/a], “my baby” [mi bebé] or “my little one” [mi pequeño/a]. During the narrative interviews, eight of the participants used their babies’ given names, one preferred a nickname, and another varied between “the baby”, a given name, and “the foetus” - the only example of a woman using the term ‘foetus’ to refer to her baby. In this case, ‘foetus’ was used when talking about medical/technical aspects of care or when referencing doctor’s talk, whereas the baby’s given name was used when talking about his ‘possessions’, such as a tree that was planted in the garden in his memory. These observations are supported by data from the survey which found that 89.1% of women knew the gender of the baby before it died and 81.5% had already chosen a name (n=796, table 14).

When we examine the terminology that health professionals use to talk about babies, we find that name use following intrauterine death is extremely low, occurring in only 17.1% of cases. Instead, terms such as ‘the baby’ (41.0%) or ‘the foetus’ (36.4%) were far more common. Also, differences

based on gestational age are statistically significant ($p < 0.05$): in second trimester losses only one-in-twenty women were asked for their baby's name and the term 'foetus' was used at least once in 56.4% of cases (see table 14). The importance of simple category term use as cues for contextualising social interaction is evident in their influence on women's rating of care. When health professionals used the term 'foetus', only 47.6% of respondents 'agreed' that they were 'sensitive' with their use of language, whereas this rose to 90.4% when they had used the baby's name ($p < 0.001$, small-medium effect size). Likewise, when at least one health professional referred to the baby as 'foetus', satisfaction was 52.4%, but when at least one health professional referred to the baby by their name it stood at 90.4% ($p < 0.001$, small-medium effect size), see table 14.

Table 14. Category terms used to refer to dead babies according to gestational age

	Gestational age		Total sample
	2nd trimester	3rd trimester	
% of women who knew the sex of the baby before the death* ²	75.4%	98.3%	89.1%
% of women who had chosen a name for the baby before the death* ²	63.2%	93.9%	81.5%
At least one health professional used the baby's name* ¹	5.0%	25.3%	17.1%
At least one health professional referred to the baby as "the baby"* ¹	30.8%	47.8%	41.0%
At least one health professional referred to the baby as "foetus"* ²	56.4%	22.9%	36.4%
Don't know / can't remember**	14.6%	16.4%	15.2%
% of women satisfied (% 'agreeing'**) with care:			
If at least one health professional used the baby's name	87.5%	90.8%	90.4%
If at least one health professional referred to the baby as "the baby"	79.8%	78.9%	79.1%
If at least one health professional referred to the baby as "foetus"* ¹	49.2%	57.8%	52.4%
Global satisfaction* ¹	56.6%	73.7%	66.8%
n	321	475	796

* $p \leq 0.05$; 1=Small effect size, 2=medium effect size, 3=large effect size (Phi)

**Amalgamation of 2 points on the Likert scale: "agree" (point 4) and "completely agree" (point 5)

Ana María illustrates this effect in extract 1 where she talks about her experiences of care just after the diagnosis and what 'least helped' during the hospital stay. Of specific interest is the connection that she makes between medicalised care that "dehumanises everything" (line 2) and the conclusion: "they called *her* dead foetus..." (line 9, emphasis added). By doing this she signals a link between care that lacks compassion and has a biomedical focus (see Chapter 6) and the positioning of dead babies as objects.

Survey question: What was the thing that least helped you during the hospital stay? (something someone said or did)

1	el protocolo...	the protocol...
2	lo inhumaniza todo:	it dehumanises everything:
3	hacerme una vía,	putting in a drip,
4	dejarme ingresada con una persona al lado,	admitting me and leaving me alone with someone else,
5	tenía tanto miedo de parir a una niña muerta...	I was so scared of giving birth to a dead girl...
6	las prisas..	the rushing..
7	de repente todos quieren hacerlo rápido	all of a sudden they all want to do something quickly
8	y ya no la hay no?...	and at that stage there isn't anything, right?...
9	la llamaron feto muerto...	they called her dead foetus...

Ana María, third trimester stillbirth, survey respondent

Extract 1. Case ID. B08

In contrast, when Ana María wrote about the things that ‘most helped’ during the hospital stay she describes a very positive encounter with the last midwife to attend the birth (which differed sharply with her experiences of other personnel). In her story of this encounter, she focuses on the presence of a number of social conventions that the midwife follows when she arrives: “she introduced herself” (line 3), “she asked for our daughter’s name” (line 4) and the midwife expresses her condolences for the death (line 6). In this sense, she establishes a frame of care that is constructed around respect, death and loss, placing the baby at the centre.

Survey question: What was the thing that most helped you during the hospital stay? (something someone said or did)

1	La última matrona llegó a las 21		The last midwife arrived at 9 pm
2	[...]		[...]
3	Se presentó,		She introduced herself,
4	nos preguntó por el nombre de nuestra hija.		she asked us our daughter’s name.
5	Se disculpó de antemano por si decía alguna cosa que pudiera molestarnos,		Se apologised in advance in case she said anything that might upset us,
6	que a ella también le afectaba que hubiéramos perdido a nuestro bebé		because she was also affected by the loss of our baby

Ana María, third trimester stillbirth, survey respondent

Extract 2. Case ID. B08

When we shift the focus to how health professionals are reported to talk about neonatal babies we can observe some important differences. In extract 3, Albert talks about the time just after his twin boys, Luis and Jorge, were born prematurely in the second trimester; they lived for 12 and 72 hours, respectively. Albert relates the doctors’ urgency in establishing the boys’ names as soon as they were born alive. Notable in the story is that the question comes after the birth and is conditioned by their status as alive (lines 1-2). The doctors also apply pressure to assign the boys names, emphasising an urgent requirement to do so, even though it is apparent that the names are not fully decided (lines 4-10). For Albert, and his wife Blanca, this was a very positive part of their care, but it also serves to contrast with how the names of babies of similar gestational age who die before birth are not used. Hence, alive / dead marks an important point of inflection in establishing personhood through name use.

This extract is from a very early part of the interview where Blanca [Albert’s wife] was talking about the birth, having rushed to the hospital with contractions, and Albert interrupts to assist Blanca when she stated that her memory of the time right after the birth when their twin boys were taken to the ICU was unclear.

1	Nacieron		They were born
2	y cuando vieron que estaban bien,		and when they saw that they were alive,
3	dijeron:		they said:
4	“¿cuales son sus nombres?”		“what are their names?”
5	“pues no lo sé,		“well, I don’t know,
6	espérate”		wait”
7	“pero, el primero,		“but the first one,
8	¿cómo se llama?,		what’s his name?
9	el segundo,		the second one,
10	¿cómo se llama?”,		what’s his name?
11	“oh dios mío, mi vida,		“oh my god, my word,
12	ahora si pongo mal los nombres yo”		what if I give them the wrong names”
13	((se ríe))		((laughs))

Albert, neonatal death of twins born prematurely in the second trimester, interview participant

Extract 3. Case ID. A03. Transcription lines 290-292

Amongst the study participants, therefore, the use of a dead baby's name or the term 'baby' is a marker of good, compassionate care and synchrony in the social encounter. On the other hand, the use of the term 'fetus' signals a biomedical frame and disjuncture between the ways women and health professionals understand the significance of the death. Regardless, this is not to be taken to mean that this is the case for all women, it must be established through interaction and not assumed.

2.2. Fear of the dead

While category term use provides us with a broad concept of the social space and framing that mothers vis-à-vis health professionals use to position babies, the narratives also show that the category of son/daughter doesn't override the fear that many women have of encountering the bodies of their children. This is evident when women talk about how they felt about the idea of seeing their baby after the birth, particularly their concern that the image of the body would cause a persistent perturbing memory and psychological damage.

A number of ideas are present in Olivia's story where she explains why she didn't see her daughter after the birth (extract 4). When she says she "thought she couldn't handle anything else" (line 1) we can appreciate the difficulty of transitioning from the news of the death to thinking about giving birth and seeing the body. But, it is also apparent that the category of daughter ("she was *also* my first daughter", line 2, emphasis added) clashes with that of 'dead' ("not alive", line 3) and the possibility of a dominant disturbing memory that might pollute the category 'daughter'.

Survey question: Is there anything else in relation to not seeing your baby that we haven't asked about that you'd like to tell us?

<p>[...]</p> <p>1 creí que no podía soportar más cosas,</p> <p>2 también era mi primera hija</p> <p>3 y no quería quedarme con el recuerdo de verla sin vida.</p>	<p>[...]</p> <p>I thought that I couldn't handle anything else, she was also my first daughter and I didn't want to have a memory of her not alive</p>
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Olivia, third trimester stillbirth, survey respondent

Extract 4. Case ID. B41

Mar's worry about seeing her daughter after the birth related to her physical deformities and the possibility that she might feel disgust or repulsed by her (extract 5, lines 17-18). In lines 13-15 she expresses that she was concerned that this would pollute her positive memories of the pregnancy and her sense of her daughter as a person ("a flesh and blood person", line 15). However, she also contextualises these apprehensions by locating them within the language of medicine that *only* talks about her baby in terms of her deformities (lines 1-8).

This extract comes from a part of the interview where we discussed whether or not Mar had prepared to see her baby after the birth.

<p>1 cuando a ti te están diciendo</p> <p>2 constantemente</p> <p>3 que tu,</p> <p>4 que tu hija es deforme,</p> <p>5 ¿no?</p> <p>6 Porque era,</p> <p>7 lo que a mí me transmitían era que</p> <p>8 mi hija tenía muchas deformidades,</p> <p>9 pues, uhm,</p>	<p>when you are being told constantly that your, that your daughter is deformed, right? Because it was, what they conveyed to me was that my daughter had a lot of deformities, so, uhm,</p>
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10	tú tienes miedo de,	you're afraid of,
11	de decir,	to say,
12	el día que ella nazca,	the day she is born,
13	no sea este concepto que tengo yo de ella	that she won't be this idea that I have of her
14	o estas patadas que yo siento,	or of those kicks that I feel,
15	un ser de carne y hueso,	a flesh and blood person,
16	uhm,	uhm,
17	tenía miedo de, de,	I was afraid of, of,
18	que me produjese repulsa o asco	that I would be repulsed or disgusted

Mar, second trimester stillbirth, interview participant

Extract 5. Case ID. A10. Transcription lines: 891-895

Hence, we find that discourses related to the physical appearance of dead babies occupy a place in narratives as contextualising orientations or justifications for actions based on the threat of the combination of the category terms 'son/daughter' and 'dead'. This power appears to come from the cultural unfamiliarity of the category combination 'dead' and 'baby'. Given the relative absence of such imagery in society, deciding to see a baby or not requires that women create such an image, which hints at why this subject is a social taboo: most people will have never seen a corpse, let alone images of dead babies.

In the context of this lack of knowing, the reference point for imagining dead babies is a contrast with idealised notions of live babies. This is evident in the way that health professionals talk about dead babies when attempting to encourage or discourage *post mortem* contact. In Yolanda's story of how the midwife succeeded in convincing her to see her daughter (extract 6), we see that two factors are central to the argument: firstly, the midwife says the baby is "gorgeous" (line 6) and secondly that Yolanda wouldn't regret it (line 7); meaning that the dead baby she would encounter would not cause her any harm. Hence, the midwife draws on normative 'baby' like qualities and mother-child discourse to overcome the parents' fear of engagement with the body.

Survey question: Is there anything else in relation to seeing your baby that we haven't asked about that you'd like to tell us?

	[...]	[...]
1	La matrona	the midwife
2	que nos asistió en el parto	that attended us during the birth
3	insistió	insisted
4	respetuosamente	respectfully
5	en que viéramos a nuestra niña,	that we see our girl,
6	nos dijo que era preciosa	she said she was gorgeous
7	y que nos alegraríamos mucho de haberla visto	and that we would be happy to have seen her

Yolanda, third trimester stillbirth, survey respondent

Extract 6. Case ID. B36

However, in attempts to dissuade women from seeing their babies, which are more common in second trimester deaths, health professionals paint an oppositional picture to the normative baby. Mireia, who specifically requested to see her baby but was prohibited from doing so, recalls that the reason she was given was that the baby was "very small" (extract 7, line 2) and that it wasn't going to be like she "imagined" (line 3). Hence, the health professional draws on imagery that contrasts dead babies to live babies, and specifically positions them as having the potential to cause lasting psychological damage (line 4).

Survey question: What reason did they give you for not allowing you to see your baby?

1	Que no me lo recomendaban en estos casos,	they didn't recommend it in these cases
2	que era muy pequeño,	because he was very small,
3	que el bebe no iba a ser como yo me lo esperaba	because the baby wasn't going to be like I imagined
4	y que no me iba a quedar buen recuerdo.	and because it was going to give me a bad memory

Mireia, second trimester termination, survey respondent

Extract 7. Case ID. B07

Apart from smallness, babies were also referred to as “very dark” (Cris, B11), “wrinkly like a raisin” (Camino, B40), and “deformed” (Mercedes, B48). Imagery that contrasts dead babies to idealised notions of babies as well formed, large (weight), light coloured and smooth skinned. Building on this idea of dead babies as powerful and threatening, in the following section, I examine stories that speak of the different mechanisms that hospitals and health professionals use to deny access to the dead and retain possession and control of their bodies.

2.3. Possession of the dead

In addressing how dominion and control of access is exercised, we can start by examining survey data related to *post mortem* contact with the baby and associated rituals such as seeing, holding, etc. The data shows that just over half of women (52.9%) in the study saw their baby after the birth, 34.5% held their baby and 30.4% kept at least one memory object from the hospital. This data, though, has to be considered in terms of gestational age and longitudinal trends. For example, 32.1% of women in cases of second trimester deaths saw their baby compared to 66.9% in the third trimester (see table 15, next page). When the data is analysed by year of the loss, we also find statistically significant upward trends (with small to medium effect sizes): *post mortem* contact in the second trimester rose to 42.5% in the final years of the study (from 19.1% in the first years), while in the third trimester it increased to 78.8% from a base of 60.5% (see table 16).

The analysis also found that only 6.7% of women were explicitly told that they couldn't see their baby, which suggested that other mechanisms were at play. To explore this finding, a binary logistical regression was used to identify predictors from all variables related to evaluations of health professionals, technical care (e.g. type of birth), socio-demographic, and pregnancy variables. Controlling for gestational age, the final model contained five variables that increased or decreased the odds of women having seen the baby after the birth ($p < 0.001$):

1. Provided with 'good information' to help make the decision (aOR¹⁵: +2.08, C.I: 95%, 1.43-3.01)
2. 'Advised' to not see the baby (aOR: -2.13, C.I: 95%, -3.12-1.43))
3. Felt 'pressured' to see the baby (aOR: -5.84, C.I: 95%, 12.4-2.78)
4. Use of the baby's name by at least one health professional (aOR: +3.15, C.I: 95%, 1.82-5.43)
5. Being accompanied during the birth by a partner or other (aOR: +2.07, C.I: 95%, 1.43-3.01)

¹⁵ Adjusted odds ratio

Table 15. *Post mortem* contact with the baby and evaluations of decision-making processes in relation to seeing the baby according to gestational age

	Gestational age		
	2nd trimester	3rd trimester	Total
% of women who...			
Saw their baby* ²	32.1%	66.9%	52.9%
Touched their baby* ²	19.4%	55.7%	41.0%
Held their baby* ²	15.3%	47.6%	34.5%
Dressed the baby ¹	–	–	16.6%
% of fathers who...			
Saw their baby* ³	29.6%	78.7%	58.9%
Touched their baby* ²	9.4%	47.2%	31.9%
Held their baby* ²	5.6%	32.2%	21.5%
Dressed the baby* ¹	1.9%	7.8%	10.6%
% of cases where a family or friend saw the baby* ²	14.6%	48.2%	34.7%
% of cases where the respondent was told that they could not see their baby	10.6%	5.7%	7.7%
% With memory objects and photographs			
% of cases where the respondent received at least one memory object or photograph* ¹	17.1%	39.4%	30.4%
% of cases where the respondent has a photograph of the baby from the hospital* ¹	5.3%	16.8%	12.2%
% of respondents 'agreeing'*³³ with the statement:			
I felt that I was in control of the decisions related to ritual (e.g. seeing/ holding)* ¹	19.7%	44.9%	34.8%
I received enough information about the decision to see or not see my baby* ²	22.7%	52.7%	40.6%
They advised me that it would be better to not see my baby* ¹	26.7%	18.0%	21.4%
I felt pressured to see my baby*	–	–	6.4%
Disposition method			
Donated to science	10.3%	12.4%	11.7%
Private disposition* ³	7.5%	60.2%	38.9%
Hospital managed disposition* ³	81.9%	26.6%	48.8%
% of respondents who stated that 'no one' explained the procedures and options for the disposition of the body	64.5%	13.9%	34.3%
Evaluation of information received (verbal or in writing) in relation to the 'disposition of the body (e.g. the funeral arrangements, cremation)*³			
None	81.3%	39.4%	56.2%
A little	12.7%	34.5%	25.7%
Quite a lot	4.1%	18.1%	12.5%
A lot	1.9%	8.1%	5.6%
% of women who didn't see their baby and the disposition was organised by the hospital* ³	55.7%	20.1%	30.5%
n	320	474	796
Reason for a hospital managed disposition			
No other option/hospital protocol	71.6%	24.6%	57.1%
Not possible to return the body in cases where an autopsy is performed	7.8%	21.1%	11.9%
There was no communication about the disposition/lack of information	9.3%	7.9%	8.9%
It was the best option for us	2.7%	24.6%	9.4%
Other (cost/ decision taken by family /in a state of shock/ rushed decision)	1.9%	7.9%	3.8%
No response/missing	6.6%	14.0%	8.9%
n	257	114	371

* $p \leq 0.05$; 1=Small effect size, 2=medium effect size, 3=large effect size (Phi)

**Amalgamation of 2 points on the Likert scale: "agree" (point 4) and "completely agree" (point 5)

Table 16. Post mortem contact with the baby and evaluations of decision-making processes in relation to seeing the baby, by gestational age and year of the loss

	Year of loss			Total sample
	≤2012	2013/14	2015/16	
Second trimester				
% of women who saw the baby* ¹	19.1%	37.0%	42.5%	32.1%
% of fathers who saw the baby	21.8%	33.3%	34.2%	29.6%
% who kept a memory object from the hospital* ¹	9.1%	20.3%	23.3%	17.1%
% of hospital managed dispositions* ¹	83.6%	84.1%	68.5%	80.4%
% that felt in control of the decisions related to ritual (e.g. seeing/holding)* ¹	9.2%	20.9%	33.3%	19.7%
% advised to not see the baby	28.0%	25.7%	26.4%	26.7%
n (second trimester)	109	138	73	320
Third trimester (% agreeing**)				
% of women who saw the baby* ¹	60.5%	67.0%	78.8%	66.9%
% of fathers who saw the baby	74.6%	80.1%	83.8%	78.7%
% who kept a memory object from the hospital* ¹	32.4%	37.2%	56.6%	39.4%
% of hospital managed dispositions	25.9%	28.3%	23.2%	26.3%
% that felt in control of the decisions related to ritual (e.g. seeing/holding)* ¹	36.1%	47.1%	57.1%	44.9%
% advised to not see the baby* ¹	22.8%	16.3%	12.1%	18.0%
n (third trimester)	184	191	98	473
n (total)	293	329	172	796
% of women who saw their baby where post mortem contact lasted more than 5 minutes				
2nd trimester (n=103)	28.6%	29.4%	22.6%	27.2%
3rd trimester (n=318)	35.7%	35.2%	28.2%	33.6%
Total	41.4%	43.0%	40.4%	41.8%

* $p \leq 0.05$; 1=Small effect size, 2=medium effect size, 3=large effect size (Phi)

** Composite of points 4 (agree) and 5 (completely agree) on a 5-point Likert agreement scale

Although the first three variables relate directly to decision-making processes, it is notable that the fourth variable is associated more closely with a positive relationship triad between mother-baby-health professional and the fifth variable with the mother-father dyad and social support during the birth. Collectively, these two variables can be said to form a social network, which, when positive, appears to provide a context that favours overcoming the fears and anxieties of seeing the baby. Further analysis found that when the positive variables were all present and the negative variables absent, 90.5% of women saw their baby after the birth. On the other hand, in situations where only one positive variable was present (n=51), only 19.6% of women saw their baby. Importantly, this indicates that care is not entirely determinant and that a significant proportion of women are capable of resisting coercion and pressure to not see the baby.

When we turn our attention to hospital practices in relation to the disposition of the body, we find similar dynamics, but sharper differences between second and third trimester deaths. In cases under 26 weeks gestation, 81.9% of dispositions were handled by the hospital, compared to just 26.6% in cases greater than or equal to 26 weeks (see table 16). When we examine the reasons for a hospital disposition, it becomes apparent that distinct criteria are applied for deaths under 26 weeks. In effect, this means that hospitals take possession of the body, and, in the great majority of cases, don't offer the possibility of a private disposition. Susana's response to a question in the survey (extract 8) helps to illustrate the institutional processes that govern disposition practices.

She recalled that “no one” spoke to them about the disposition options (lines 1-2), but when they asked about the possibility they were told that because the baby was less than 24 weeks old it was not “considered to be a baby” and therefore they couldn’t release the body (lines 5-6). Hence, through an asymmetric relationship, where the hospital retains all power to impose a protocol, the institution assumes proprietorship over the body. This regulation then acts to define ‘personhood’ and parental rights, through a concept of what constitutes a ‘baby’.

Survey question: Who explained the procedures and options for the disposition of the body? Response option: “other, please specify”

1	Nadie,	No one,
2	nunca nos lo ofrecieron,	they never offered it to us,
3	de hecho	in fact
4	lo solicitamos y nos lo negaron	we asked for it and they said no
5	al ser de menos de 24 semanas,	being less than 24 weeks old,
6	hasta entonces no lo consideraban un bebe....	until then they don’t consider it to be a baby....

Susana, second trimester stillbirth, survey respondent

Extract 8. Case ID. B35

During her interview, unresolved questions of possession and parental rights were the central component of Elisabeth’s story. When we met, it was three years after the death of her son Felipe following a termination of her pregnancy at 21 weeks, after the loss of all the amniotic fluid. Elisabeth was told not to look at her son when he was born, she called the doctors words: “don’t look, don’t look.” Neither was she spoken to about options for disposing of his body and had no idea what had happened to him. I’d like to highlight how, in lines 6-19 of extract 9 below, Elisabeth speaks directly to the institution and questions the basis of her exclusion from decisions related to the treatment of her son’s body. Although having difficulty speaking, she establishes her own ‘rights’ as superior to the institution by stating repeatedly “he’s mine” (lines 7,8,9,10) and then “he’s my son” (line 12). She contrasts this fact to the nature of the relationship between her and the hospital, which was to help her “resolve a health problem” (line 15). Hence, she questions why providing such a service results in her never seeing her son or not being consulted about what she would have liked to do, such as seeing or holding him (lines 17-19). She emphasises her point by saying that even though she doesn’t know how hospitals work, this doesn’t explain why an institution came to assume such rights (lines 21-24). In the eyes of the institution, the category ‘parent/mother’ is either not relevant, has diminished standing, or does what is ‘best’ for the ‘patient’.

The second part of the extract (lines 26-47) begins when I ask Elisabeth, with a somewhat awkward question, how she feels now about the idea of seeing Felipe. In answering she provides important insights into how this situation has affected her. While stating that she imagines that seeing Felipe wouldn’t have been “pleasant” (line 29), she proposes that she thinks it would have given her “closure” (line 31). When I ask why, she compares the way the health professionals took Felipe’s body away to someone disappearing (lines 37-38). She argues that when this happens those who are left behind don’t know if the disappeared are OK or not. It this doubt, the not knowing, the thinking the worst that is most troublesome (lines 36-41); in effect she worries that Felipe’s body might have been maltreated in the hospital or disposed of as biological waste, which it probably was. If we consider that the rights Elisabeth establishes earlier in the extract are founded in her role as ‘mother’, we also have to consider the responsibilities that she assumes for this situation, an important theme that I return to in the final section of the chapter.

This extract is from a section toward the end of the interview and deals with Elisabeth's primary concern, that she never saw her son's body and doesn't know what happened to the body. She is very worried that the body was used in experiments or disposed of as rubbish. Previous to my question she talks about having gotten the name of someone who works in the hospital and about the possibility of trying to resolve these questions.

1	P	Pero,	But,
2		quieres saber dónde, dónde fue su cuerpo o...?	you want to know where, where his body went or...?
3	E	= si, claro	Yes, of course
4		¿qué hacen?	what do they do?
5	P	después de patología o...	after pathology or...
6	E	porque, porque es mío,	Because, because he's mine,
7		es que es mío, ssst.	he's mine, ((heavy sigh with emotion))
9		es que es mío,	he's mine,
10		o sea ((suspira))	I mean ((sigh))
11		es mío	he's mine
12		es mi hijo,	he's my son,
13		tú me has quitado,	you've taken,
14		no me has quitado o	you haven't taken or
15		me has ayudado has resuelto una situación de salud,	you've helped me to resolve a health problem,
16		pero es mío,	but he's mine,
17		y no me has preguntado nada,	and you haven't asked me anything,
18		ni ¿quieres verlo,	not even, do you want to see him?
19		quieres cogerlo,	do you want to hold him?
20		[...]	[...]
21		yo no entiendo cómo funcionan los Hospitales,	I don't understand how hospitals work,
22		Ni no entiendo de protocolos	Nor, I don't understand protocols
23		ni, pero,	nor, but,
24		pero es mío, es mi hijo	but he's mine, he's my son
25		[...]	[...]
26	P	ahora ¿si piensas que te hubieras gustado verle o, o, o no?	now, do you think that you would have liked to have seen him or, or, or not?
27	E	ahum, uhm ((suspira))	ahum, uhm ((sigh))
28		hombre,	well,
29		creo que a lo mejor agradable como tal,	I don't think it would have been pleasant as such,
30		[...]	[...]
31		pero creo que me ayudaría a, a cerrar.	but I think that it would help me to, to get closure.
32	P	¿por qué?	why?
33		[...]	[...]
34		yo no he visto el fin a la situación, vale?	I haven't seen the end of the situation, OK?
35		es como cuando,	its like when,
36		es un duelo que, que. ahum, ssts	it's a grief that, that ahum, ((sighs))
37		no sé cómo decirte,	I don't know how to say it,
38		si desaparece una persona	if a person disappears
39		y no encuentras el cuerpo	and you don't find the body
40		y no sabes qué hace,	and you don't know what they're doing
41		pues puede estar bien o,	well, they could be fine or,
42		yo sé que está muerto,	I know he's dead,
43		[...]	[...]
44		pero no sé cómo decirte,	but I don't know how to say it to you,
45		no lo he visto,	I didn't see him,
46		o decirle,	or say to him,
47		no, no me he podido despedir	I wasn't, I wasn't able to say goodbye to him

Elisabeth, second trimester termination, interview participant

Extract 9. Case ID. A09. Transcription lines: 1318-1344

Within the concept of possession, Leticia's interview provides more insight into why this practice is also influenced by wider discourses and cultural values related to institutional rights. When I asked her how the idea of seeing her baby had come up, she replied that she asked the midwife first (extract 10, lines1-7). Although this was unusual in its own right, of interest is Leticia's

motivation for asking. She was concerned that the answer would be ‘no’, even though she “knew” she was her daughter (lines 8-10). When I asked her to explain why she felt that way, she finds it difficult (lines 16-18), but settles on the idea that she felt that there was a possibility that someone would come and tell her that she couldn’t see her daughter and take the body away “all of a sudden” (lines 20-26). It is apparent that Leticia felt that the death in some way annulled her rights as a mother, resulting in a transfer of possession to the institution. Although it is not entirely clear why from the interview, I would argue that Leticia draws on wider discourses of institutions as arbiters of fault who remove babies (children) from bad mothers. Hence, some women may have an expectation that death acts to transfer power and rights to the institution, as a form of social sanction, which may encourage them to not resist such action, even though in Leticia’s case she sought to proactively avoid this outcome.

This extract comes following the main narration, which finished quite quickly compared to other interviews, after about 40 minutes. My question (lines 1-2) is aimed at a renarration of the process leading up the decision to see the baby after the birth.

1	P	en el hospital después del... del diagnóstico, eh., te... cuando te hablaron de... de verla, ¿no?	in the hospital, after the... the diagnosis, eh, you.. when they spoke to you about.. about seeing her, right?
2			It was... it was me, us.
3	L	Fui... fui yo, nosotros.	I mean, it was me who said that I wanted to see her.
4		Vamos fui yo la que dije que quería verla.	<Before they sa.. they said anything I said:
5	P	<¿Antes que dij.. dijieran nada?	"Will I be able to see her?"
6	L	Yo dije:	Because I didn't...
7		"¿voy a poder verla?	I know she's my daughter,
8		Porque yo tampoco...	but
9		sé que es mi hija,	I didn't know what they were going to say,
10		pero yo tampoco	and Cynthia [the midwife] told us that we could [see her].
11		sé qué es lo que te van a decir,	Why did you ask yourself>, why did you doubt yourself?
12		y a nosotros nos dijo Amalia [the midwife] que sí.	Why did I doubt?
13	P	¿Por qué te preguntab>, poruqe te dudabas [sic]?	Why did you doubt it?
14	L	<¿Por qué dudaba?	I don't know
15	P	¿Por qué dudabas de... ?	I really don't know,
16	L	No lo sé,	I don't know
17		es que tampoco lo sé,	I said..,
18		no sé,	because
19		dije..,	if someone was going to come
20		porque	and they're going to tell me
21		si va a venir alguien	that I can't see her
22		y me va a decir	and they're going to take her off me
23		que no la puedo ver	and if all of a sudden they're going to
24		y si me la van a quitar	and they're going to take her away
25		y si rápidamente van a hacer	
26		y se la llevan,	

Leticia, third trimester stillbirth, interview participant

Extract 10. Case ID. A07. Transcription lines: 754-764

2.4. Viewing the dead

Viewing of the body emerges as a practice whereby women and their partners *do* see their baby after the birth but this event or interaction is highly constrained within medical practices at the expense of ritual related to loss/grieving. To begin, we can observe that, of the women in the survey who did see their baby, four out of ten estimated that this process lasted less than five minutes and very few (10.4%) responded that contact last more than one hour (table 17).

Furthermore, less than half of women (44.2%) ‘agreed’ with the statement: ‘I felt I could spend as much time as I liked with my baby’, and there was only a very slightly significant upward movement in this result over the years of the study. A useful contrast is to compare this finding to data from a Norwegian study which found that 27% of women spent between 1 and 11 hours with their babies and 48% spent 12 hours or more (Gravensteen et al. 2013).

Table 17. Evaluations of care related to *post mortem* contact with the baby according to gestational age

	Gestational age		
	2nd trimester	3rd trimester	Total
% of respondents ‘agreeing’** with the statement:			
The place where I saw my baby was private	65.0%	67.6%	67.0%
The professionals were respectful in their physical treatment of my baby* ¹	68.0%	85.5%	81.2%
I felt that I could spend as much time with my baby as I wanted* ¹	30.1%	48.7%	44.2%
My baby was presented to me in a respectful and affectionate manner* ¹	63.1%	85.2%	79.8%
The professionals participated in the process of seeing/holding/spending time with my baby	48.5%	51.9%	51.1%
It was a good decision to see my baby*	90.2%	98.4%	96.4%
Time spent with the baby*³			
1-2 minutes	35.9%	15.5%	20.5%
3-5 minutes	31.1%	18.3%	21.4%
6-20 minutes	19.4%	29.3%	26.9%
21-60 minutes	4.9%	13.6%	11.4%
> 1 hour	2.9%	13.0%	10.4%
Don’t know / can’t say	5.8%	10.4%	9.3%
n (all women who saw their baby after the birth)	103	318	421

* $p \leq 0.05$; 1=Small effect size, 2=medium effect size, 3=large effect size (Phi/ Cràmer’s V)

**Amalgamation of 2 points on the Likert scale: “agree” (point 4) and “completely agree” (point 5)

There are a number of other characteristics of these events that were significantly ($p < 0.05$) associated with spending more than five minutes with the baby: i) the proportion that engaged in some further action, such as holding, rose from 42.0% to 82.0%; ii) the percentage with at least one memory object rose from 30.7% to 60.5%; iii) the percentage of women that responded that the body was not treated respectfully dropped from 27.8% to 11.2%; iv) and, the percentage that referred to the baby as ‘foetus’ dropped from 35.8% to 20.0%. The results also show that only half of professionals (51.1%) were judged to have participated in the process of seeing the baby, suggesting that they distance themselves, for whatever reason. These findings demonstrate that practices of seeing babies after the birth often take place within medicalised frames that place little emphasis on loss/grief.

It is unsurprising then that concepts of ‘time as constrained’ or ‘rushed’ are present in the narratives, notably how this is manifested through direct and indirect social mechanisms, which mean that health professionals, not parents, decide what is an appropriate amount of time to spend with the baby. In many cases, the process of viewing the body is dominated by the asymmetric decision-making described in Chapter 7, such as the imposition of protocols to cut short viewing events. However, here I want to focus on the influence of non-verbal communication and silence as a constraining force because it requires quite explicit access to broader cultural knowledge and discourses related to taboo and stigma. Celia, who had to insist on seeing her baby, recalls the effect of the doctors presence in the room on how she engaged with her baby (extract 11). Firstly, we can observe that the event is contextualised in two ways: within

an asymmetric relationship: “the doctors didn’t leave the room and I couldn’t think how to ask them to leave” (lines 1-2), and a style of care that lacked compassion and respect: “It didn’t help that they treated my baby unethically, without compassion” (line 8).

Celia recalls that the doctor’s presence made her feel self-conscious, that she didn’t have “the freedom” to do what she wanted with her baby, believing that “*they* would think it looked *morbid*” (lines 3-5, emphasis added) if she picked the baby up or “talked to him” (line 6). In the retelling of this interaction it is possible to consider Celia’s moral dilemma. How shame and embarrassment, or the potential for it, condition her actions as her moral self and identity become open to negotiation before the socially powerful gaze of the doctors. Yet, the dilemma or ability to position herself as moral is far more complex. In maintaining face to the doctors she enters a moral catch 22 by not fulfilling her maternal/parental obligations to her baby. These unresolved questions, born out of asymmetry, create long-term consequences for Celia. Hence, in the storytelling world we see that she positions the doctors themselves as having acted immorally.

Survey question: What was the thing that least helped you during the hospital stay? (something someone said or did)

<p>1 [...] 2 los medicos no salieron del cuarto 3 y no pude pensar en pedir que salieran, 4 y eso me hizo sentirme sin libertad 5 de hacer con mi bebe lo que sintiera. 6 Senti que verian morboso 7 que lo cargara o le hablara, 8 no se aun que pensar de lo que senti. 9 No me ayudo que trataran a mi bebe sin etica, 10 sin compasion. 11 [...]</p>	<p>[...] the doctors didn’t leave the room and I couldn’t think how to ask them to leave, and that made me feel that I didn’t have the freedom to do what I felt like with my baby. I felt that they would think it was morbid if I picked him up or talked to him I still don’t know what to think about what I felt. It didn’t help that they treated my baby unethically, without compassion. [...]</p>
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Celia, second trimester stillbirth, survey respondent

Extract 11. Case ID. B45

In contrast, Sonia (Case ID. B14) reported that her care was good at a humanistic level, but similarly recalled how the visible presence of the healthcare personnel outside the room lead herself and her partner to believe that they should not spend too much time with the baby, even though they never actually asked and no instructions were given. Therefore, non-verbal communication and silence are not neutral, but are simultaneously inference rich and ambiguous and lead to self-regulation. In this sense, they are deliberate, manipulative and goal oriented (Sobkowiak 1997). At a broader sociocultural level this also plays to tropes of the disproving health professional and the surveilling role of institutions in contemporary society (Foucault 1995:195). However, I would also argue that the medical gaze and silence directs Celia to the only available discourse or cultural values related to dead babies. Hence, the capacity for shame is rooted in notions of taboo and stigma revealed in the concern that interacting with the baby would be seen as unhealthy and unnatural (“morbid”, line 5).

To finish this section, we can examine Montse’ account of how her husband saw her daughter Nicole, who was stillborn in the third trimester (extract 12). While Montse chose not to see Nicole, her husband (Lorenzo) and in-laws saw her for a short time in a room adjoining the delivery suite (lines 6-9).

The following extract is taken from a section of the interview where Montse started talking about the decision to not see her daughter Nicole, but that her husband did. When I ask where he saw her, Montse gives more details about the event.

1	P	Ok, ehm.,	OK, ehm,
2		¿y., y dónde vi a Nicole tu. tu. marido?	and, and where did your husband see Nicole?
3	M	¿Dónde la vio?	Where did he see her?
4	P	Sí	Yes
5	M	[...]	[...]
6		y, entonces, luego, eh.,	and, so, later, eh.,
7		la pusieron en el cuarto de al lado,	they put her in the adjoining room
8		entonces, dejaron pasar a mi marido y a mis suegros,	so, they let my husband and in-laws go in
9		y allí la vieron.	and they saw her there.
10		Estaba desnuda y.	She was naked and.
11		tampoco la habían limpiado mucho,	they hadn't cleaned her either
12		y.. eso es lo que sé, eso	and.. well, that's what I know, that
13	P	¿En una cuna dijiste?	In a cot you said?
14	M	Sí,	Yes,
15		pero no estaba puesto como un bebé,	but she wasn't laid out like a baby,
16		estaba puesto como un cadáver.	she was laid out like a corpse.
17		O sea.,	I mean,
18		ni le habían limpiado,	they hadn't even cleaned her,
19		ni le habían puesto una ropita.	they hadn't even put some little clothes on her.
20		ni nada de nada.	Nothing, nothing at all.
21		[...]	[...]
22		[Lorenzo] me dijo que	[Lorenzo] said that
23		era muy, muy guapa.	she was really, really gorgeous.
24		Pues,	Well,
25		que era una monada,	that she was a real cutie,
26		que era igual que mi hermana,	that she was just like my sister,
27		y que era,	and that she was,
28		pues que parecía un bebé ya pues de seis meses,	well that she was like a baby, well a six month old
29		que era... preciosa	that she was... beautiful

Montse, third trimester stillbirth, interview participant

Extract 12, Case ID. A05, Transcript lines: 553-562

What Nicole learned from her husband was that Nicole was “naked and they hadn’t cleaned her either” (lines 10-11). Her use of “either” at the end of the sentence indicating that these were actions that the health professionals had failed or nor bothered to complete, which she clearly views as inappropriate. When I clarify that Nicole was in a cot (line 13), Montse’s response is designed to make sure that I don’t assume that this meant that she was treated like a “baby”, instead she emphasises that she was actually laid out like a “corpse” (lines 15-16). This repositioning from “baby” to “corpse” signifies a form of dehumanisation; something uncared for. In lines 17-20 she explains: “I mean, they hadn’t even cleaned her, they hadn’t even put some little clothes on her. Nothing, nothing at all.” The use of the evaluative indexical “even” before cleaned and dressed, followed by “nothing, nothing at all” indicates that the health professionals didn’t meet even a basic level of care of her baby and appeared to show no interest in providing it. It also presupposes that her presentation to the world in this this manner (“naked”) was undignified and disrespectful to her. Taking Montse’s narrative as a point of reference, we can understand why a significant proportion of women who saw their babies, around 1 in 5, did not ‘agree’ that the health professionals were ‘respectful in their physical treatment’ of the baby’s body (see table 17).

When we contrast what Montse knows of the viewing event to what Lorenzo tells her about Nicole, we see an obvious tension. In lines 22-29 Lorenzo describes Nicole using common adjectives for babies, such as “gorgeous”, “beautiful”, “cutie” and likened her appearance to Montse’s sister. He also specifies that she looked like a baby, and attempts to disavow what he

assumes to be Montse's fears (line 28). Nevertheless, what I wish to highlight is the paradoxical tension that can exist between social and biomedical frames. On the one hand, the physical qualities of Nicole's babyhood and similarity to Montse's sister re-affirm a cultural normativity and social position within the frame of the family history. On the other, the medical frame leads Montse to draw on a disconfirmation of normative expectations about the cultural treatment of corpses and babies, even as she feels unable to see her daughter. Hence, she positions the health professional's actions as immoral to her daughter. Similarly, we see that a characteristic of 'viewing' events is the provision of the possibility of seeing the baby but one which is defined within institutional values and which positions the baby as less than a person. The event is more a formality to be observed than the creation of a social space for grieving.

2.5. Caring for the dead

When we examine women's stories that position them within or close to normative cultural notions of motherhood and parenthood we see how different contexts of care can result in more positive mother-child relations and social positions. Like Lorenzo (Montse's husband in extract 12), when we examine how women talk about their babies after seeing them we find that they primarily use signifiers that draw on normative discourses, such as commenting on size and weight (Lorena, Gemma) and in most cases adjectives such as "gorgeous", "pretty" and "lovely" preceded by modifiers such as "very", "really", "super" (Lorena, Gloria and Nacho, Blanca and Albert, Gemma, Leticia). These categories permit a repositioning of dead babies from 'dead/anormal' to 'dead/normal', and, by consequence, allow a certain level of normativity in women's position as parents.

'Normalness' can also be a powerful argument in countering social stigma, but the use of normative physical qualities as a basis for validating grief runs into certain problems in cases such as Mar. As her daughter, "Butterfly", died of complications from chromosomal abnormalities that resulted in physical deformities she couldn't draw on the same arguments: "it's true that her body wasn't pretty to ... see." (Mar, A10). As such, while physical material qualities might provide normative discursive resources with which to talk about dead babies in the social milieu they do so by referring to the discourses of consumption and idealised babies that are also part of the initial problem within which part of the social taboo is located (see Chapter 2 for a discussion of the historical origins of stigma and ideal babies).

The following extract is taken from the renarration part of the interview, where I ask Leticia to go into more detail about the post mortem contact with her daughter Carla.

1	P	<¿Y cuándo la vistes,	And, when you saw her,
2		ehm, cómo fue de.., de verla?	how was it..., seeing her?
3	L	<¿De verla?	Seeing her?
4	P	<Sí, ¿qué. era directamente de nacer, o.. ?	Yes, what, was it straight after she was born or... ?
5	L	=Nada más nacer.	=As soon as she was born.
6	P	=la llevaron o?	=Did they take her away or...?
7	L	=Fue como un parto, cuando., normal,	=It was like when, a normal birth
8		directamente me la pusieron encima,	they put her on top of me straight away
9		[...]	[...]
10		y. entonces te la ponen	and. so they put her
11		y.. directamente ahí. ((señala su pecho)),	and.. directly there. ((signals her chest)),
12		pues nosotros nos pusimos a llorar,	well, we started crying,
13		y la empezábamos a abrazar,	and we started to hug her,
14		la dábamos muchos besos,	we gave her lots of kisses,
15		le pusieron un gorrito,	they put a little bonnet on her,
16		eh...,,,	eh...
17		Luego nos dejaron a solas,	Then they left us alone,

18		cuando ya. me habían..	when they had
19	P	<En el paritorio, ¿no?	<In the delivery room, right?
20	L	Sí,	Yes,
21		cuando ya me habían.. a mí, apañado,	when they had taken care of me
22		ya nos dejaron tranquilamente un rato a sol>	then they left us alone, for a while, alone
23		[...]	[...]
24		y.., y estuvimos ahí un poquito los tres.	and..., and we were there for a little while, the three of us.
25		Entonces nos dejaron ahí llorar..	So they left us to cry..
26		nuestro momento,	our moment [together]
27		eh., viendo cómo era de bonita,	eh., looking at how beautiful she was,
28		la naricita, los mofletes, toda rosadita.,	the nose, the cheeks, all rosy.,
29		la boquita,	the little mouth,
30		que es como la., es como la de su hermana.	that's like, that's like her sister's.
31		Luego ya entraron.,	Later they came in
32		y ya fue cuando..	and that was when...
33		Javier se quedó,	Javier [her husband] took her,
34		se la, me la quitaron para limpiarla,	she, they took her to clean her,
35		la cogieron Javier y.., y Amalia [matrona],	Javier and... and Amalia [midwife] took her,
36		para limpiarla,	to clean her,
37		para quitarla,	to take off,
38		que estaban las pinzas ahí, las tijeras estas,	she had the clamps there, the scissors things,
39		para ponerle unas cintitas.,	to put some tape on her..,
40	P	<Sí, sí	<Yes, yes
41	L	limpiarla un poquito,	to clean her a little.,
42		ya la pusieron otro gorrito.,	then they put a little bonnet on her.,
43		porque, creo que le habían puesto una gasa,	because I think they had put some gauze on her,
44		y.. bueno creo que es eso,	and.. well and I think that was it,
45		y la pesaron,	and they weighed her,

Leticia, third trimester stillbirth, interview participant

Extract 13. Case ID. A07. Transcription lines: 553-564

When we look more closely at stories of *post mortem* contact, such as Leticia's in extract 13, we get an insight into how engagement with the dead body relates to more fundamental questions of fulfilling social roles and responsibilities, even if this is not always easy or without some conflict. A first general observation of Leticia's story is that the health professionals and the medical frame occupy a far less prominent role when compared to other narratives. We can also consider that her daughter Carla is not taken away to be cleaned and made more presentable, but is placed on Leticia's chest "straightaway", like a "normal birth", (lines 7-11). This positioning of the birth as "normal" is important because it performs a mother-child role in bringing the child into the world in a way that fulfils social conventions *despite* the death; it was notable in the narratives that a number of mothers talked about having 'nice' or 'good' births in spite of the circumstances (see also Chapters 6 and 7).

After the birth, the midwife leaves Leticia and her husband alone with Carla, which permits an intimate moment between the mother-father-child triad: "and we were there for a while, *the three of us*" (lines 22-24, emphasis added). This gives space for Javier (Leticia's husband) to fulfil typical parenting roles in the care of a child. And, in contrast to other stories, Leticia portrays a certain freedom in their actions with the baby. In a post-stoic cultural frame, their behaviour is 'normative' in the sense of how you would imagine parents to behave after the birth of a child (hugging, holding and kissing) and also in the sense of how you would imagine parents to behave at the death of a child (crying, hugging, kissing). It is also notable that the midwife and Javier do the dressing, washing and weighing together (lines 33-42). This contrasts to other stories where health

professionals dominate such practices through kind paternalism or remain distant and control behaviour through silent observation. Compared to many other stories, one of the stand out features of Leticia's narrative was her sense of contentment with the process of the *post mortem* contact, although she deeply regretted not taking a photograph and, perhaps not spending a little longer with her daughter.

Nevertheless, it's important not to present an overly idyllic image of engagement with the dead and their material qualities. Descriptions related to death exist side-by-side with adjectives that describe babies in normative terminology, notably references to the colour of the baby's skin, which ranged from "a little purple" (Lorena, Leticia) to "purple" (Gloria, Blanca) and "very purple" (Gemma). Leticia, in fact, observed that the change in the colour of Carla's face from "pinkish" to "purple" signalled that it was time to say goodbye. Other women commented that the colour of the face and body were difficult to look at.

Additionally, engaging with dead babies, through acts such as seeing or holding, doesn't necessarily mean that their threat dissipates readily. In the following extract from Natalia we can observe how the potential for harm is evident in both the nurses actions and those of the mother and father. When the nurses bring the baby to the parents it is "wrapped up" with only her face visible (lines 9-10, 19), which as a practical action may be interpreted as a signal to not look at the body. At the outset of the story, the mother specifies that it is her husband who is worried about seeing the baby out of concern that it might cause her some harm (lines 1-7), even though this harm is unspecific, unknown ("somehow", line 6). Despite holding their girl and talking to her (lines 12-15), they don't uncover her and look at her body; something the mother expresses regret about later in the story. Interestingly, although the mother assumes responsibility for not uncovering the baby because she was "afraid" for her husband (lines 16-18), we can observe that neither did he. In reality, none of the actors did. In this sense, it is apparent that the dead body retains significant power during *post mortem* contact, particularly if health professionals don't help parents to overcome such fears, or unwittingly reinforce social taboos.

Survey question: Is there anything else in relation to seeing your baby that we haven't asked about that you'd like to tell us?

<p>1 Quise 2 desde el principio 3 ver a mi niña. 4 Mi marido no lo tenía claro, 5 temía que me haría daño 6 de alguna manera 7 verle. 8 [...] 9 Nos la traje en una cunita, 10 tapadita 11 y le pidió a la enfermera que nos dejara solos.</p> <p>12 La cogimos de la cunita, 13 mi marido me la puso en mis brazos, 14 y le miramos 15 y le hablamos. 16 Tuve miedo por él, 17 que fuera demasiado, 18 y no la destapé. 19 solo le vimos la carita guapa. 20 [...]</p>	<p>I wanted from the beginning to see my girl. My husband wasn't sure, he was worried it would do me harm somehow to see her. [...] We brought her to us in a little cot, covered up [said in the diminutive] and I asked the nurse if she could leave us alone. We pick her up from the little cot, my husband put her in my arms, and we looked at her and we spoke to her. I was afraid for him, that it would be too much, and I didn't uncover her. we only saw her little face. [...]</p>
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Natalia, second trimester stillbirth, survey respondent

Extract 14. Case ID. B02

A number of other narratives express similar ideas in relation to photographing babies. The survey found that only a very small percentage of parents had a photograph (see table 2), commonly expressed in the narratives as a source of great regret. In the following extract from Blanca and Albert's interview, they talk about how difficult it was to overcome their reluctance to take a photograph of their son Luis, who died 12 hours after the birth. While finding it difficult to express what she means, Blanca states: "taking a photo of a person who no longer exists, that went against all my ... , that, I mean, I mean, I would never think of taking a photo of a dead person" (lines 6-10). So, Blanca invokes wider cultural discourses about appropriate behaviour during engagement with the dead and that taking photographs is a serious contravention of such norms (lines 6, 8). Additionally, the silence or ellipsis in line 8 ("went against all my ") is highly important. This type of presuppositional silence, or failure to fully enunciate an idea, is noticeably present in the narratives when participants talk about death or dead babies, either in terms of cultural meaning or when referencing dead children. Although in this case we can take it to signify all her internalised cultural values, it is apparent that Blanca has trouble defining which cultural values or discourse adequately describe her experience. I would argue that the ellipsis represents values that are rarely enunciated socially and are a feature of the paradoxically categorical and ambiguous nature of taboo.

This extract is taken from a part of interview at the start where Blanca explains why they had a presentation card made with photographs of her twin boys on the cover. The photograph was taken on their own initiative without any suggestions from health professionals.

1	B	porque eso [sacando una fotografía] fue terrible,	because that [taking a photograph] was horrible
2	A	Ahmm ((sonido de afirmación))	Ahmm ((sound of agreement))
3	B	eso, es, estar despidiendo a tu hijo,	that, it's, you're saying goodbye to your son,
4		estar besándolo,	you're kissing him,
5		estar,	you're,
6		y sacándole una foto a una persona,	and taking a photo of a person
7		que ya no existe,	that no longer exists,
8		que va contra todos mis ...,	that went against all my ...,
9		que, es que, es que,	that, I mean, I mean,
10		a mi nunca se me ocurre sacar una foto a un muerto,	I would never think of taking a photo of a dead person,
11		pero es mi hijo,	but he's my son,
12		y, y, he tenido una, un rato para verlo	and, and I only had a short time to see him
13		y nunca quiero olvidarlo jamás.	and I never want to forget him, ever.

Blanca and Albert, neonatal death of twins following a premature birth in the second trimester, interview participant

Extract 15. Case ID. A03. Transcription lines: 286-293

The main point that Blanca's narrative tries to communicate is that she felt obliged to take the photograph: "but he's my son [...] and I never want to forget him" (lines 11, 13). Consequently, parental obligations to remember come into conflict with cultural conventions of death. Similarly, Silvia (Case ID. B39) told of how she had thought about taking a photograph, but didn't mention it to anyone because she thought "it would seem macabre and scandalous". To overcome or challenge such deeply rooted cultural values are not in the least easy, especially in the hours immediately after death, with so few competing discourses available. So one of the recurring ideas in the narratives is that perinatal death requires parents to navigate a series of moral dilemmas, where their face to society (as a certain type of person), comes into conflict with their face to their child (a certain type of parent). Yet, it was also clear during Blanca's interview, four months after the death of her twins, that the idea of having photographs of her boys was no longer a cultural issue for her, although it was for some members of her social milieu who didn't want to see them.

One of the most important results of the research is that, regardless of the difficulties of giving birth, spending time with a dead child and then saying good-bye, all in the space of a few hours, and often in conditions of poor care, 96.4% of women who saw their babies thought that it was a good decision (n=796). Of the 15 women who thought otherwise, eight specified that it was because of the conditions in which they saw the body, often after giving birth in a toilet or bedpan; which appears to be relatively frequent in second trimester births. On the other hand, 57.8% of women who didn't see their baby responded that they regretted the decision.

2.6. Conflict with the dead

Of the interview participants, Margarita and Beatriz were quite clear that they were happy with their decision to not see their babies. Indeed, they stressed that their decisions were autonomous and not related to the actions of the health professionals, even though I didn't ask them directly. I believe that the emphasis they placed on this relates to the new discourses of perinatal bereavement and that they possibly saw me as representing such a position. Hence, they felt it necessary to justify why they didn't see their babies. In this respect, even though they had no regrets, or moral conflict with their children, the transition from one culture of care to another creates oppositional discourses and new questions of morality in relation to the newly emerging community of bereaved parents. Whereas before the only possibility for moral failing related to the mother-child dyad because not seeing a baby was normative behaviour, now a new possibility has emerged where women may feel they are open to criticism for not seeing their baby. Indeed, a support group moderator has told me that it often comes up in group meetings and requires repair and justification.

Nevertheless, while I would argue that the process of care leading up to the decisions taken by Margarita and Beatriz were quite asymmetric, the main point is that neither appeared to have difficulties in their relationships with their dead children based on this decision. On the other hand, when we examine narratives where 'regret' about decisions and practices in the hospital are a central plot, we find that mother-child relationships have often become riddled with harmful discourses that complicate grief.

Extract 16 from Esther contains many of the elements that I have discussed in this and preceding chapters, such as a lack of compassion in care, decision-making undermined by asymmetry and state-of-mind (grief, exhaustion, the effects of anaesthetics), and *post mortem* contact with the characteristics of a viewing event. However, of interest here is the way that Esther positions herself in the story and how this relates to her present day regrets that she didn't hold, kiss and take photographs of her baby (lines 1-3). Each of these actions as I have already discussed, represent relatively normative parenting actions following a birth. Despite the numerous factors that can more properly account for lack of action and present day regrets, Esther places her own actions at the centre of the narrative. She characterises herself as being unable to overcome her fears ("I took a long time to decide", line 4), which results in her daughter suffering: "the poor little thing was alone for 2 hours in the next room waiting for me" (lines 15-16). Seen from Esther's point of view, her daughter is small and defenceless, and also rejected and abandoned by her mother, even if temporarily. In fact, Esther proposes that she only saw her daughter because of the pressuring from the doctor (lines 12-14). Thus, she portrays herself as a weak and selfish mother and this characterisation is independent of all the intrinsic and independent reasons that lead to this situation.

Survey question: Is there anything else in relation to seeing your baby that we haven't asked about that you'd like to tell us?

<p>1 De lo que más me arrepiento 2 es de no haberla cogido en brazos, besado, haberle hecho fotografías 3 No sabía como iba a reaccionar 4 y tarde mucho en decidirme a ver. 5 Primero fue mi marido a la habitación donde la habían puesto, 6 estaba en una cuna, 7 arropada por una toalla y con un gorrito. 8 El luego entró al paritorio 9 y me dijo que estaba como un bebe dormido 10 que me animara a verla 11 y yo seguía llorando sin parar.... 12 Ante la insistencia de la ginecóloga 13 de que se tenían que llevar el cadáver d mi niña a anatomía patológica 14 me decidí a verla. 15 La pobrecita estuvo 2 horas sola en la habitación contigua 16 esperando a que yo me decidiera. 17 Me la trajeron al paritorio 18 [...] 19 y la pude ver, 20 sólo fue rozar con mi dedo su carita, 21 la epidural me tenía totalmente dormido el cuerpo de caderas para abajo, 22 y mi marido me dijo que no la tocara, 23 me derrumbé 24 y me puse a llorar aún más</p>	<p>What I most regret is not having held her, kissed her and not having taken photographs I didn't know how I was going to react and I took a long time to decide to see [her]. First my husband went to the room where they had put her, she was in a cot, wrapped in a towel and with a little cap Then he came back to the delivery room and told me that she was like a sleeping baby that he would encourage me to see her and I kept crying non-stop.... At the insistence of the gynaecologist that they had to take the body of my little girl to the pathology department I decided to see her. The poor little thing was alone for 2 hours in the next room waiting for me to decide. They brought her to me in the delivery room [...] and I was able to see her, I just touched her little face with my finger, my body was totally asleep from the hips down from the epidural, and my husband told me not to touch her, I collapsed and I started crying even more</p>
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Esther, third trimester stillbirth, survey respondent

Extract 16. Case ID. B04

Blanca expressed a similar idea. She had to be persuaded by her partner to go and see her twin boys in the ICU even though at that stage they were still alive. In the interview, though, she referred to this reaction as “cowardly”, stating that she only went because she felt “obliged” and was too “ashamed” to do otherwise. Thereby, she also positions herself as experiencing a form of rejection of her boys. In the story, her shame or moral position exists in relation to the living others (hospital staff, her husband), and not her sons. The outcome being that she exists in opposition to the cultural norm of a good, brave mother, the yardstick to moral identity. Discourses like this, related to a lack of “bravery” and “cowardice”, are a common feature of the narratives, whereby women feel ashamed and therefore, discursively, not part of the member category ‘good mothers’.

At the time of the interview, Elisabeth was still troubled about not having the opportunity to apologise in person to her son Felipe for terminating the pregnancy. In the extract below, she talks about how the most difficult guilt that she feels (lines 1-3) relates to her failure to stand up to the health professionals and demand to know what had happened to Felipe’s body (lines 5-6). Hence, she fails in her role as a mother to protect her son. Despite the fact that Elisabeth also offers a contextualising justification (“I was so exhausted”, line 7), this doesn’t seem to do much to alleviate her sense of guilt.

This extract comes from a section of the interview where Elisabeth talks about various dimensions of the guilt that she felt for not seeing her son Felipe and not knowing what happened to his body.

<p>1 y, sobre todo, 2 ya pues luego, 3 me siento culpable</p>	<p>and, most of all, after everything, I feel guilty</p>
---	--

4	porque	because
5	no fui capaz de decir:	I wasn't capable of saying:
6	"bueno ¿y qué hacéis con él, dónde lo lleváis?"	"well, and what have you done with him, where did you take him?"
7	Es que estaba tan, tan guiñado	It's just that I was so, so exhausted

Elisabeth, second trimester termination, interview participant

Extract 17. Case ID. A09. Transcription lines: 794-796

Sara, very explicitly draws on ideal notions of mothers and their social roles. Some three years after the death of her baby, following a second trimester termination, her narrative presents many of the characteristics of disempowerment: domineering care and fear of meeting her dead son. Her decision to not see her baby is based on a closed-end question (line 5) in a context where her state-of-mind is conditioned by competing feelings of confusion, anger, sadness and also the effects of sedation (line 3). In communicating that she felt powerless (line 3), she also suggests that she wasn't really herself. Furthermore, her husband makes a categorical decision on her behalf, thinking that it will be for best (lines 6-7). Despite, the multiple contextualising factors that she identifies, which can explain why she "went along with it" (line 8), Sara still experiences such regret and sadness that she "feels like a very bad person for not wanting to see him" (line 10) and she still finds her actions unforgivable (line 13). She feels that she let her son down, failed in her moral obligations as his mother.

Survey question: Is there anything else in relation to not seeing your baby that we haven't asked about that you'd like to tell us?

1	En ese momento horrible,	In that horrible moment,
2	justo después de haber dado a luz	just after I had given birth
3	estaba muy aturdida, sedada, rabiosa, triste, impotente	I was really confused, sedated, angry, sad and powerless
4	y no tenía claro qué hacer	and I wasn't clear about what I wanted to do
5	cuando el ginecólogo me preguntó si quería verlo	when the gynaecologist asked me if I wanted to see him
6	y mi marido dijo que NO rotundo	and my husband said NO flat out
7	para no sufrir más	so as not to suffer more
8	y me dejé llevar.	and I went along with it
9	Y ahora vivo con el horrible pesar, tristeza y remordimientos	and now I live with a horrible regret, sadness and regret
10	y me siento muy mala persona por no haberlo querido ver en ese momento.	and I feel like a very bad person for not having wanted to see him.
11	Cuando pasó un poco de tiempo	When some time had gone by
12	me quería morir por no haberme despedido de mi niño..	I wanted to die for not having said goodbye to my boy..
13	es algo que no me perdonaré en la vida.	I'll never forgive myself for that.

Sara, second trimester termination, survey participant

Extract 18. Case ID. B09

Finally, Carlota, who also answered the survey three years after her baby died, said that despite the fact that the hospital provided no options for a private disposition (extract 19, lines 1-2), she felt like she "abandoned" her girl, which she repeats twice (lines 8-9). In cultural terms, "abandonment" is the worst possible action a mother can commit¹⁶, other than physical harm or homicide, which results in a severe tarnishing or relinquishment of 'mother' as a social position.

¹⁶ See the Cambridge online dictionary where the definition of the verb abandon is explicitly linked to women/mothers rather than men/fathers: <https://dictionary.cambridge.org/dictionary/english/abandon>

Survey question: Is there anything else in relation to not seeing your baby that we haven't asked about that you'd like to tell us?

<p>1 El ginecólogo nos dijo que 2 "se hacían cargo del cuerpo", 3 pero no sabemos qué se hizo exactamente... 4 a día de hoy, 5 pasado el trance, 6 de poder recuperarlo, 7 quizás haría sepultura... 8 mi sensación fue la de abandono, 9 abandoné a mi niña</p>	<p>The gynaecologist said that "they were taking charge of the body", but we don't know what they did exactly... now, now the haze has passed, if I could recover it [the body] maybe I would have a burial... My sensation was one of abandonment, I abandoned my girl</p>
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Carlota, third trimester stillbirth, survey participant

Extract 19. Case ID. B51

The narratives show that for a significant proportion of women regrets about *post mortem* contact and care of the body can have significant consequences for the quality of the relationship between women and their dead children and also their positions as mothers, which are fundamental to any recognition of their right to grieve, for them and also society.

3. Conclusions and discussion

The research finds that almost universally the women in this study considered their dead infants to have been children, sons and daughters, and that this positioning informs their own positions as mothers, with its associated rights, responsibilities and moral obligations. In counter position is the apparent reluctance of most health professionals to use dead babies' names, even within hospital cultures where humanistic care has been evaluated positively. When health professionals do affiliate and close distance through name use, it has an enormously positive impact on women's evaluations of their carers. On the other hand, the use of 'foetus' mostly has a contrary effect as it activates a medical frame, as has been recognised in the literature (Henley and Schott 2008; Sands 2016:51). However, even when the death is contextualised within a frame of loss/grief (see Chapter 6), the distinction between using 'a name' and the term 'baby' also marks another axis of difference within hospital cultures, signalling internal positions that identify more or less distance to the object. As such, apparently simple signifiers provide one of the key cues for how perinatal death is contextualised, social positions adopted and even the morality of health professionals and women established. They signal orientations around the categories human/not human, person/non person, mother/not mother, kind/unkind, moral/immoral, etc.

Nevertheless, the category son/daughter/child constituted (in whatever form) before death does not necessarily make a smooth and unaltered transition through death. It has to be negotiated and practiced. In contrast to the idealised expected baby, the category term 'dead' can make the intrauterine or even neonatal baby both fearful and threatening. Its 'imagined' material image thought to be capable of inflicting lasting psychological damage. In healthcare contexts where discourses of taboo and stigma are still dominant, these views appear to be shared by many health professionals, particularly for second trimester deaths. This links to the findings presented in Chapters 6 and 7 and shows how gestational age is highly influential in all aspects of care provision.

This helps us to access one of the primary mechanisms of taboo in the context of perinatal death. Dead and baby are culturally antonymous; one represents 'end' and the other 'beginning', at least in their normative meanings. But, when combined, the two categories become something

altogether more powerful and even nonsensical in western culture. In somewhat simplistic terms, they represent the very definition of bad death: sudden, unexpected, traumatic, uncontrolled, contravening normative expectations of lifecourse and the capacity of medicine and science to cure and/or explain (Bradbury 1996; Kellehear 2007:94; Seale and van der Geest 2004). In essence, a bad death lived as an embodied experience. Tied into this, the ‘image’ that dead babies occupy in contemporary western culture is quite horrifying, precisely because they are rarely seen in popular media and so require the construction of an illusory. In this respect, the research shows that dead babies are positioned sharply against the normative ideals of live newborns, either as justifications for not seeing babies or when health professionals (or family members) attempt to dissuade women from contact. Conversely, their likeness to live babies is used to persuade women to do otherwise.

The category ‘dead baby’ then is transgressive and powerful in the social imaginary. It has the capacity to interject in the mother-child relationship, creating moral conflicts between obligations to fulfil social roles and responsibilities and fear that motivates self-preservation or the possibility of shame. In the absence of alternative discourses, women’s own infants can become a threat to them; at least to some women (and their partners) and generally only temporarily. Importantly, this threat can also relate to preoccupations that past memories of the pregnancy will be affected. This is a very real concern as my own research on the role of materialities and objects has found that memories of the embodied aspects of pregnancy were highly important to meaning making and continuing bonds (Cassidy 2018c). In stories of care, such concerns function as orientations or justifications for not seeing babies after the birth and seems to be the primary reason that just more than half of the women in the study who didn’t see their baby felt that it was a good decision. Yet, on the other hand, less than 5% of those that did see their baby regretted the decision. This is more or less consistent with other research (Cacciatore and Flint 2012; Downe et al. 2013; Kingdon et al. 2015; Ryninks et al. 2014).

If *post mortem* contact such as seeing, holding, dressing and keeping vigil, have become normative ideals of positive care after a baby dies in western high-income countries (Health Service Executive 2016; PLIDA 2008a; RCOG 2010a; Sands 2016) then it is clear that practices in most Spanish hospitals are very different. Almost all parents see and spend time with their infants after second and third trimester stillbirth and termination of pregnancy in many Northern European and English-Speaking countries (Cacciatore, Rådestad, et al. 2008; Elklit and Björk Gudmundsdottir 2006; Hunt et al. 2009; Lee 2012; Rand, Keelner, and Massey 1998). In contrast, Spain appears to be similar to Italy and Latin American countries where these practices are present, but far from universal and appear to be tentatively employed (Boyle et al. 2017).

In both the quantitative data and narratives, conflict in relation to questions of possession, rights and responsibilities as they relate to control over the body of the baby is a highly important theme. As a practice, the imposition of institutional authority over the body relies on regulations and the situational dynamics of power (such as parents’ discursive incompetence, lack of information, respect for protocols), abusive use of technologies, separating women from support networks, taboos and fears of the baby, as well as women’s own respect for authority and expectations that the institution may hold rights to assume proprietorship over the body.

At the most extreme end of institutional configurations we find a severe form of paternalism where the body is treated almost exclusively as a material, its sociality and alternative cultural meanings and connections, beyond the biomedical, are rendered silent. Women are prohibited or successfully discouraged from seeing the body and the hospital takes charge of the disposition. This represents around three-in-ten cases overall, but around one-in-two in deaths under 26

weeks, which demonstrates how fetuses are positioned closer to babies/persons based on gestational age. Hence, maternal roles, rights, and responsibilities, even the idea that parts of women's bodies belonging to them, are annulled. Narratives of this form of care are almost identical to women's stories from the United States and Australia between the 1950s and 70s (O'Leary and Warland 2013; Rosenblatt and Burns 1986; Thompson 2008). It is clear then that this configuration of care is underscored by a continuation of practices and discourses rooted in paternalistic 20th century obstetrics and Catholic stigma related to the dead and unbaptised baby (see Chapter 1, section 2). A reading of Gálvez Toro's (2006) work with health professionals in Andalusia supports this conclusion.

When the historical development of the regulatory framework that hospitals employ to justify legal proprietorship is examined, we find that legislation is also a key determinant. Provincial regulations and local hospital protocols have held that 180 days gestation marks a specific point of inflection when parents lose the legal right to a claim over the body (see AsturSalud n.d.). This requires that the institution organise the disposition of the body, most commonly as biological waste, and that autopsies could be practiced without consent. However, these ideas are based on Article 40 of the 1957 Civil Register Law, which sets 180 days gestation as the point at which foetal deaths have to be recorded in the Civil Register, for both statistical purposes and so that burial licences can be issued. There are two observations that can be made about these practices. The first relates to the data from the survey that suggests that there is significant inconsistency in the application of these concepts: a small proportion of women whose babies died under 26 were permitted private dispositions and a small proportion over 26 weeks were denied this possibility. We can also examine the robustness of the underlying legal argument. In February 2016, a mother whose baby had died at 22 weeks gestation, took a case to the Constitutional Court after she was denied the possibility of a private burial, first by the hospital and later by the Provincial High Court (Tribunal Constitucional 2016). The Tribunal ruled in favour of the mother for three reasons: firstly, the local courts had previously granted permission for the burial of a baby of similar gestational age due to religious beliefs; secondly, no law existed to prohibit the right to the issuing of a burial licence before 180 days, only an obligation to register the baby from 180 days onwards; thirdly, the local courts were judged to have shifted from positive discrimination based on religion to negative discrimination based on its absence (Elorza-Saravia 2016). In effect, the local regulations had no basis in the law and the court observed that no hospital protocol supersedes the basic fundamental rights of the person (Fernández 2017). The law now holds that any parent has the right to a private disposition of the baby's body, regardless of gestational age, though this is not obligatory. Nevertheless, the practical application of this law is dependent on many other factors, not least awareness, the development of practice guidelines, the dynamics of local interactions between health professionals and parents, and the economic cost of a private disposition. It would seem prudent therefore to consider the work that has been done in the United Kingdom to provide hospital based options for guaranteed ethical and respectful disposition of the body in first and second trimester losses that have no cost to parents (Davies 2009; McGuinness and Kuberska 2017; Royal College of Nursing 2018).

As opposed to absolute possession, 'viewing' of the body occupies a newer position where the criteria of proprietorship holds, but parents are given limited and controlled access to the body. Through various social mechanisms, health professionals 'manage' such interactions by interceding in the way that the body is presented (cleaning, covering up), by controlling time and exposure to the body, and through lack of privacy. This form of *post mortem* contact is also characterised by low levels of further interaction, such as holding. Rather than creating a social space for loss/grief, these practices are contained within medical frames and underscored by rationalism that focuses on demonstrating the material existence of the body and/or attempting to

fulfil recommendations for *post mortem* contact, but often in a way that can also amplify the threat of the baby. Within 'viewing' events health professionals also occupy two internal positions: one characterised by compassionate carers who engage with women and the other by coldness or distance and/or disrespectful treatment of the baby's body.

An important feature of this type of *post mortem* contact is an absence of explicit communication in conjunction with inference rich non-verbal gestures that modify behaviour and meaning - mostly with the goal of discouraging interaction with the baby. Non-verbal communication relies on a presupposition that health professionals' social role is to establish the bounds of healthy behaviour, but also to maintain the rules and procedures of the institution. It also encourages women, and their partners if present, to access the only discourses and social beliefs available, which are mostly founded in stigma and taboo. This can situate women in a moral dilemma between their positions in relation to their child and their social positions to the rest of society (in this case represented by health professional). Silence, observation and lack of information invoke the possibility of both shame and guilt due to interpretations that prolonged contact and physical interaction with the baby are dangerous and/or violates social norms and moral codes (Turner and Stets 2006). In the asymmetric relationship of hospital care, the perceived shame to society often holds sway, meaning that the shame for the transgression of the moral codes of motherhood are unattended to until after discharge, when the opportunity for repair has been lost. This form of *post mortem* contact is the most common in the study and is a long way from what the concept is designed to achieve. This highlights that 'seeing the baby' in and of itself is a relatively superficial barometer of care.

The process of institutionalising the parent and the body therefore relies on reducing and silencing their relationality, disconnecting them from each other and their social milieus, diminishing their capacities to affect and be affected in ways that are commensurate to social roles and positions. On this basis, through self regulatory effects (Foucault 1995:195), it can be extrapolated that *all* acts of discrete or manipulative silence and silencing (Huckin 2002; Jaworski 1997), be they informational or situational, position dead babies as threatening, shameful and taboo. And, this applies to both the parent-child relation and the person-society relation (parents to health professional in this case). The power of silence then operates through its capacity to be both unequivocal and unspecific, making it difficult to comprehend and resist. Thus, the way that the institution and their personnel treat the materiality of the corpse tells us much about how power is materialised and the cultural values surrounding death and how this impacts relationships between the living and the dead (Harper 2010; Hockey 1996; Langer 2010).

From this perspective, it is understandable that one of the main features of the stories is anger at the treatment of the body by the institution or regrets resulting from situations where the hospital operated a totalising possession of the body or when engagement with the body was constrained within viewing events. Regrets typically lie with not seeing the body, not spending enough time with the baby, not looking at the full body, not touching, holding or kissing, not taking photographs or not taking charge of the burial, which is similar to the findings of other studies (Cacciatore and Flint 2012; Downe et al. 2013; Gold et al. 2007; Ryninks et al. 2014). Through the use of narrative orientations, women communicate the incongruence between their social position as mothers and the lack of action that leads to such regret and shame (Stets 2006). They attempt to reconcile and explain their moral failings due to their state of mind, which resulted in actions that are not consistent with their real selves. Yet, such a self has come into being and cannot be easily dismissed or undone. Although women make evident the many other extenuating circumstances and possible justifications for lack of action, they rarely lay ultimate fault at the hospital, asymmetric care relationships, lack of knowledge, or indeed their partners or other family

members. Instead their narratives presuppose choice and the burden of responsibility (Bergmann 1998), and, in so doing, they draw on moral discourses related to good mothers and their social responsibilities to their children. They position themselves as being agentive yet self-interested, and adopt categories such as *cowardly*, *weak*, *bad* and being *women that have abandoned* their children. On top of this, most of these women feel some guilt or blame themselves for causing the death, which is consistent with other studies (Gold et al. 2017).

While the existence of such counterfactuals are said to be common after sudden, unexpected or traumatic deaths (Davis 2001), I would argue though that it is highly consistent with historical and contemporary discourses and social practices related to pregnancy and motherhood that constitute 'good' and 'bad' mothers (see Chapter 2, section 2). Much as 'unnatural' mothers were the foil to the moral mother of the early 20th century (Loredo Narciandi 2014; Nash 1993), the death of a baby opens up the possibility of a transition from good to bad, moral to immoral. Any moral failing in relation to the child can become integrated into their sense of self and who they are to the world. As such, failure to live up to this normative ideal places responsibility for the death and treatment of the body squarely on the shoulders of the individual. I believe this form of moralising founded in the burden of responsibility and sense of agency is critical because it isolates women from their milieu and the milieu from women, reducing their social capacities and possibilities of collective responses. Hence, it is a function of gendered discourses located in the cultural values of pregnancy and broader discourses that place women/mothers at the centre of the family, with very specific responsibilities (Alvarez-Uria and Varela 2009:29–31; Pedersen 2012). Within this idea, death may create an internal force that can act to pull loss and grief into the small, private world of the home or self, just as external forces attempt to do the same (Murphy and Thomas 2013). The dead baby and the bereaved mother become conjoined in a suffocating stigma but also in a conflict that is extremely difficult to resolve, as past actions cannot be undone.

As I have commented in the analysis, one of the principal social mechanisms that *post mortem* contact with babies permits is the use of the category 'normal', a disconfirmation of monstrosity and fears that the image of the baby will be damaging. These ideas draw on concepts of babies as established through the biometrics of maternal-foetal medicine and paediatrics, as well as consumerism and even religious imagery of the cherub (Layne 1992). Normalness is important because it positions the baby in the frame of personhood, even if in a superficial sense. Being able to share this information or photographs with the social milieu is an evidentiary basis for establishing that something of value has been lost and that a proper kin relationship existed. To see is to believe (Sandelowski 1994), and a right to grieve can be established (Fowlkes 1990). However, babies that cannot be described as 'pretty', because are very discoloured, small, wrinkly or that have physical deformities, problematise this strategy and disclose how society and bereaved parents themselves organise grief around deterministic criteria, which may even sustain taboo by reinforcing simplistic dichotomies of normal/anormal. Accordingly, normalisation always involves the negative positioning of another: alive/dead, pretty/not pretty, or, as in the past, baptised/unbaptised.

The most significant aspects of hospital rituals for babies who have died relates to a number of factors. Firstly, and I think most importantly, is an avoidance of the destructive potential of the institution, which I have hitherto described. Secondly, I don't think the data supports the idea that death and grieving is a linear transition from one state to another (Van Gennep 1960; Hertz 1960), which releases women and the unborn dead from the liminality of pregnancy (Layne 2003:59–64; Peelen 2011:37–38, 86). The principles of interactionism would suggest that to a degree everything is liminal in the sense that everything is open to negotiation and is unstable. Although I wish to allow myself some wriggle room for the following statement, women do not appear to have

experienced pregnancy/motherhood as wholly ambiguous, what they do experience is a challenge to the ideas of motherhood/personhood when the baby dies. I propose that they enter liminality as an effect of the ambiguous nature of taboo and stigma, which is to argue that liminality and taboo is actively done through social encounters, as opposed to being a space between categories. It is the interplay of absoluteness and inscrutability that make it highly effective.

To my eye, the central issue relates to a conflict between contraction and expansion. Grief and death exert a centrifugal force on social actors in the milieu if permitted or encouraged, which is evident in requirements for support and the reciprocal relations that can be formed between bereaved women and health professionals, as well as others, and also in ritual practices. This is congruent with a social and relational view of bereavement and the way that relations are maintained between the living and dead in new forms, which must be learned and cultivated, as well as revised and rewritten (Klass et al. 1996; Neimeyer 2000; Walter 1996). If this relationship doesn't take place in a social space, then it can only exist in the private, suffocating world of the individual and in conflict to social roles, positions and the cultural values of motherhood. It is in this sense, through either positive or negative *post mortem* relationships that the identities or social positions of the bereaved change in function of the nature of these dynamic and interactive relationships (Howarth 2000; Klass 1993, 2001). In terms of grief this is highly important because the quality of the relationship with the dead is often key to the narrative of grief and its social trajectory; when the relationship is positive, grief tends to be less problematic (Van den Hoonaard 1999; Klass 2006).

**Section 4.
General
discussion**

Chapter 9. Doing good/bad mothers

This research study set out to investigate women's experiences in hospitals after a baby has died during pregnancy or shortly afterwards, with an overall objective of trying to understand the impact of care on grief. To do this, the study employed an ethnographic methodology that combines quantitative analysis of survey data with linguistic analysis of stories of care. These methods are supported by statistics and documentation from secondary sources and participant observations. As the first, and to date, only study to generate national level data, the findings provide a much-needed barometer on clinical and bereavement practices in Spanish hospitals. The evidence generated by the narrative analysis builds on this data by taking an in-depth look at the way social meaning is produced through interaction between women, health professionals and other socio-materialities, including the body of the baby and technologies, amongst others. The research was interested in establishing links between the practice of care and the way that particular forms of grief relate to alternative configurations of loss, death, babies, and mothers. At a broader level, the research was also concerned with accounts of care that tell us about power and control, and discourses and social practices related to healthcare, pregnancy, motherhood, death, taboo and gender.

This document is also a story, my approximation to the social location of the study participants. The final result of a process in which, ultimately, I have had to decide what to say and what not to say, what data and ideas to include and what to leave out. Defined by theories, the study design and methodologies, available resources and my own knowledge, experience and values, it represents only one of various possible versions. At a fundamental level the research exposes the highly unequal social relations that surround this form of loss and grief. I hope that this piece of work goes some way to redressing the balance and providing actionable information that can contribute to improving the organisation and delivery of care, be that through knowledge transfer, training or activism. The rest of this chapter provides a summary of the main findings and conclusions and attempts to draw them together into broader ideas, points for discussion and possible future lines of inquiry.

Vulnerability and situational inequality

If giving birth to a live baby places women in a vulnerable position, often characterised by fear and imbalance in power, when a baby dies that vulnerability can multiply exponentially and the inequality it creates can underscore and condition all other actions in the hospital. Such vulnerabilities can be thought of in four ways. Firstly, those related directly to the event of the death, which include the effects of shock and embodied emotional experience of loss and grieving. Many women also experience a crisis of the self related to feelings of guilt about having caused the

death or fatalism about the immediate future. Secondly, the social irregularity of carrying a dead baby may cause women to feel deep concern for their own security and fear about giving birth, especially first time mothers. Thirdly, the stress associated with one or all of these, plus the mental and physical effects of a long, painful, pharmacological induction or a caesarean section, often with sedation or anaesthetics, can lead to high levels of exhaustion. While each of these factors relates to state-of-mind and embodied experience, the final factor connects to broader cultural knowledge of perinatal death, or rather lack of. This places women at a severe discursive disadvantage when interacting with health professionals because they have little prior knowledge or experience of appropriate care. This is magnified because the only available knowledge is the ambiguous discourse of taboo and stigma, which places women in a morally weak position. Apart from the obvious, why is this so totalising?

It is useful to consider this question through the prism of sociological theory grounded in phenomenology. In order to act, a social agent has to be able to make sense of the world, and to do this, they must be intersubjectively and reflexively engaged. As the body is our vantage point on the world, when it becomes unfamiliar to us, through illness or in this case intrauterine death, it can cause a retreat and inhibit capacity for communication at a fundamental level; one cannot draw on past experience to interpret embodied feelings or to know how to act (Csordas 1994; Leder 1990:91; Merleau-Ponty 2002:84). Building on this idea of embodiment, we can consider meaning as shared and created during social interaction. This implies that for understanding to occur between people, each participant must be able to make sense of what is happening by placing the situation in context against shared understandings, presuppositions or assumptions about the world (Garfinkel 1967; Mead 1934). In the context of perinatal loss, where women and their social milieu have very little prior understanding, this inhibits the basic coordination and cooperation required for communication, at least in the immediate term. From a more structural outlook, Bourdieu (1991:61) proposes that this situation is equivalent to a mismatch between embodied dispositions and the field of operation, meaning that the social actor has no practical knowledge and feel for how to act and behave. The world has become unrecognisable.

This results in a discursive inequality that diminishes women's basic capacity to communicate at a point in time when it is crucial to establish their rights and entitlements (Gumperz and Cook-Gumperz 1982). In the midst of confusion and a world that doesn't make sense, it would also hold that women continue to follow other social conventions in order to maintain some semblance of order, such as responding affirmatively and accepting the health professionals' lead, as has been suggested by other authors (Lovell 1983; Lundqvist et al. 2002). As we have seen throughout chapters 6 to 8, the outcome of many interactions between women and health professionals results in shame, embarrassment, anger, moral disgust and indignation, all signs of a breakdown in the interactive and moral order (Goffman 1983). Hence, before we can even consider the asymmetry of doctor-patient relations, and the problematic of gendered based inequality in obstetrics, the research establishes that women in the context of pregnancy loss should be considered a highly vulnerable group. Correspondingly, this places significant ethical responsibility on health institutions. Exploring this vulnerability in more detail, through future research, may also provide insights into the factors that contribute to posttraumatic stress following perinatal death.

Perinatal bereavement care in Spain: one foot in the past, one in the present

At an overall level, the research finds that across all the measures studied, care following perinatal loss/death is substantially less developed than most other high-income countries. Based on current data, Spain appears to have more in common with Italy and Central and South American countries than those in Northern Europe (Boyle et al. 2017; Ravaldi et al. 2018). The data suggests that there are very few or no hospitals providing excellent best practice care (Sands 2016). About 40-50% of hospitals provide good care, another 30-40% provide medium level care and around 20-30% provide highly deficient care. The most significant problems with care are power imbalance and highly asymmetric decision-making and the way that practices related to bereavement are absent or highly controlled. Lack of empathy and compassion during care is a less severe issue, but still highly significant. Regardless, when we take into account the extreme levels of vulnerability, anything less than very good care isn't really good enough. At a basic level, this means that for a significant proportion of women, care makes a negative contribution to grief and health, in some cases very severely (as discussed further on in the chapter).

On a positive note, the data also shows an upward trend, indicating that we are witnessing a significant cultural change in how perinatal bereavement care is practiced in Spanish hospitals, even if the starting base was very low. From a historical perspective, this picture makes sense. Following the transition to democracy, the national healthcare law didn't come into effect until the 1980s (Gobierno de España 1986) and was principally focused on structural reforms related to healthcare access, coverage and decentralisation to the autonomous regions (García-Armesto et al. 2010:43). The humanisation of healthcare, with its concern for holism and patient autonomy, is a relatively new concept, at a general level (Consejería de Sanidad Madrid 2016) and within reproductive health and obstetrics (Goberna 2013; Ministerio de Sanidad 2010, 2011). If we consider bereavement care within this historical context, it is easier to understand why Spain and countries such as Italy have perinatal mortality rates (a proxy for technical care) that are similar to other high-income countries but lag so far behind on bereavement care. This situation helps to explain that the lack of development in this form of care is not isolated, not just a peculiarity of perinatal death and its taboos, but corresponds to general trends in healthcare and the historical and contemporary pervasiveness of paternalism, doctor-centred care and gendered inequality in obstetrics. This is to say, general reforms in obstetric care should significantly improve bereavement care.

The disruptive and powerful baby

Central to any study of grief following the death of a baby is to understand how the personhood of the dead baby is actively established, negotiated, and/or denied in social interaction (Kaufman and Morgan 2005; Morgan 1997). The study shows how the positioning of dead babies during care is highly influenced by the determinism of biomedicine, the socio-relationality of pregnancy and motherhood, as well as the social mechanisms of taboo. Health professionals and institutions position babies as closer to 'persons' or 'non-persons' based on birth (alive/dead), viability, and gestational age, varying the support that they provide accordingly and framing appropriate treatment of the body. Conversely, the women in the study attempt to establish their babies as children, sons and daughters, invoking social positions and categories that embody rights and moral obligations, but often this only appears to take place in the storytelling world.

Both socio-relationality and biomedicine also exist in tension with the taboo and stigma associated with dead babies. In the case of some women *and* health professionals, the potency of taboo relates to the way that dead babies are contrasted to idealised babies and viewed as having the potential to cause harm through exposure. When health professionals position themselves in the paternalistic role of protecting women they reinforce stigma through confirmation of women's fears, or introduce taboo to the encounter. Engaging with dead babies can also invoke the possibility of shame by contravening moral codes, which health professionals can reinforce through the mechanisms of silence and observation that are consistent with biomedical frames and care that only attends to the body (see Chapter 8, conclusions). However, the potential for shame that women feel is highly ambiguous and unspecific, yet powerful and categorical in its effect. It is also interesting to observe that when parents interact with their children after the death they tend to overcome such concerns relatively quickly, even if engagement with death is not necessarily easy (see Chapter 8, conclusions). On the other hand, beyond the potential for a negative psychological impact from the image of the baby, health professionals don't appear to offer any specific reasons for protecting women, no basis in evidence. In this respect, there is an inverse symmetry between the determinism and absoluteness of biomedicine and the ambiguity of stigma; one appears to sustain the other. It could be said that stigma and silence is indeed a function of biomedicine and its restrictive economy, the other side of a particular elaboration: that which cannot be said (Foucault 1978:17). This is consistent with the historical basis of how the taboos of perinatal death shifted from those based in religion to the sphere of paediatrics and obstetrics throughout the 20th century. It is coherent with historical gendered discourses of women (Kanter 2002; Lutz 1996) and how infants and babies are enclosed within the cultural tropes assigned to women and mothers: closer to nature than culture, unruly and disorderly, requiring education and taming (Gordo López and Burman 2004; Loredó Narciandi 2014).

Dead babies are not passively involved in care process though, they participate in their own collaborative production. As we have seen they retain significant power and agentive capacity as materials and as the embodiment of culture and social relationships (Hallam et al. 1999; Harper 2010). For parents, negative and destructive power is located in the way that the taboo and stigma embodied in the baby (and the self) can cause a conflict between moral obligations to the child and protection of the self, or because they think they will contravene moral codes by interacting with the body. Socio-relational power resides in the obligations that the dead embody and the how they demand appropriate treatment and disposition. When stigma is overcome, this power can draw the social network back together or heal and provide solace to the bereaved.

Hence, the foetus/baby in care following perinatal loss can be simultaneously a patient, a person, a human, non-human, and an agent (Casper 1994a, [b] 1994) depending on the social frame that is applied. This ontological multiplicity (Mol 2002) is not necessarily problematic until the alternative frames come into conflict and asymmetric power means that one dominates at the cost of the other.

Power and gendered inequality in care

At an overall level, it is important to recognise that while the discourses of 'emotion', 'psychological support' and 'psycho-emotional' care are explicitly integrated into participant's narratives, autonomy and self-determination are mostly present in the background. When telling stories, the study participants locate their own knowledge and power in their capacity to evaluate the behaviour of health professionals. Whereas women are often highly grateful to compassionate carers, eulogising their efforts, even when care has been substandard at a technical level,

unempathetic carers are classed as cold, inhumane and immoral because they fail to recognise the significance of the loss/ death; their actions are lived as an insult to the child and the self.

Here, the power of health professionals is located in their authority to contextualise the social encounter (Blommaert 2005:71), to define it and frame it, determining what is permissible to say and what not. It is this power, working in tandem with vulnerability, that creates the extreme reactions (positive or negative) of women to their carers. The research shows how health professionals who refuse to engage with loss/ grief sustain their position by focusing care on the body and drawing on gendered discourses that configures women as overly emotional. Loss becomes a medical event rather than the death of a person, child, son or daughter.

Asymmetric decision-making, on the other hand, is a feature of care that is sustained by other power imbalances in the care encounter: women's situational vulnerability, lack of communicative competence, pressuring and coercion, but also the naturalisation of paternalism amongst patients. At a broader level, the data suggests that this problem is not exclusive to care following the death of a baby, but is a general feature of obstetric care. This is congruent with historical and contemporary studies in reproductive health and obstetrics that shows how inequality is sustained through discourses that position women as weak, irrational and incapable of making their own decisions (see Chapter 1, section 3). Hence, power to contextualise and decision-making authority overlap in the way that they define the birthing event: *a (bereaved) mother giving birth to a child or a health professional delivering a baby (regardless of whether it is alive or dead)*. When the health professional abuses authority to interject between the mother-child relationship they cancel, at least temporarily, women's roles and rights as autonomous individuals and mothers.

Does this mean that women are just highly malleable in this context? Yes and no, I think. Certainly, the context of vulnerability increases dependence on health professionals. This is supported by the results on decision influences in *post mortem* contact, where health professionals' actions were found to be highly decisive, for the majority of women. However, it also has to be taken into account that a characteristic of care in Spanish hospitals is to have a very short transition between diagnosis and the commencement of labour or the birth. The qualitative research shows how fast paced care undermines autonomy because it permits vulnerability to dominate women's actions. Unfortunately, the survey didn't collect data on the duration of the time from diagnosis to induction or birth, but it would be interesting to see if future research can examine how pace of care and perceptions of time affect women's influence over decisions.

It is also necessary to acknowledge that the data exposes some tensions between the concepts of emotional support and decision-making. I suspect that it is highly relevant that the quantitative analysis found that 'feeling listened to' was the single most significant variable in the study, predicting overall evaluations of care, including emotional support and decision-making. This chimes for a number of reasons not least because it relates to frequent feminist critiques that women's voice is silenced and absent from the organisation of care, or other social practices (Ehrenreich and English 2005). At a local level the concept of 'being listened to' is much more active than receiving support, it has connotations of directing action by expressing needs and opinions, and relates to equitable communication. Women in the study were also highly perceptive of organisational dynamics, yet most were unable to influence them. So, when women talk about 'emotional support', 'psychological support', or 'psycho-emotional care' mostly they appear to mean a demand for intersubjectivity, to be listened to and heard, and for emotional expression not to be disqualified. It has made me wonder if the foreground/background position of empathy/emotion and autonomy is somewhat simplistic. Might it be a reflection of women's embodied dispositions and the availability of emotional capital (Reay 2004), as well as the

influence of the pervasive discourses of psychology, which disproportionately diagnose women with mental health problems (Kaplan 1983; Stoppard 1999; Tebeau 2014). In this respect, does 'emotional care' adequately describe what health professionals seek to do? And, does it adequately describe what women want?

This is a concern because the concept of 'emotional support/care' is becoming highly integrated into the new bereavement care practices in Spanish hospitals (Furtado-Eraso, Escalada-Hernández, and Marín-Fernández 2020). I am somewhat preoccupied about this because I think it leads towards a psychologisation (Gordo López and de Vos 2011) of bereavement care that gives too much emphasis to emotion while ignoring the technical and organisational aspects of care. This may perpetuate longstanding discourses that position women as emotional and fragile, undermining perceptions about their capacity to participate in tasks related to technical and organisational components of care. Furthermore, demanding that health professionals provide 'emotional' support may also be laden with cultural values and meanings that allude to concepts that encourage some social and professional groups (older, male, doctors) to feel alienated or incapable of providing appropriate care. Consider this: despite the fact that perinatal bereavement care has been mainstream in many countries for more than 40 years, only 8% of the 415 delegates that attended the international conference on perinatal mortality and bereavement care in Madrid in October 2019 were male. This represents a clear gender based organisation of the field where, beyond the technical, this form of loss is viewed as women's issues, much like other forms of reproductive health. For these reasons, the concept of 'emotional support' appears to represent a very ambiguous view of 'emotion' and a narrow view of 'support'. Work on unpacking the taken-for-granted meanings of the concepts of 'emotional care/support' with women, their partners and health professionals might prove very useful for designing care programmes and training.

Perhaps, 'social support' is a more appropriate concept as it spans emotional, informational and instrumental components (Lin 1986), which are understood to be located within networks of social relations and wider structures (House 1987; Shinn, Lehmann, and Wong 1984). It also places an important emphasis on mutuality between carers and patients, which could be very important to redressing compassion fatigue, trauma and burnout (Adler 2002; Bakker et al. 2000), which is common in obstetrics and paediatrics, and more so in the context of death (Beck and Gable 2012; Mizuno et al. 2013; Weintraub et al. 2016). It also forces a shift in focus to wider structural problems in institutions, such as a lack of investment in care systems, poor support networks for personnel, divisive cultural values and institutionalised inequality.

A word on technologies of care

Technologies traverse stories of care, as naturally present as patients, health professionals and babies. At times they are metaphorically extant as signs of neglect and emotional abandonment, sometimes implicated in increased anxiety, often pacifying and controlling the birthing body. Sometimes they are employed as mechanisms of coercion and silencing, and occasionally they are wielded violently. It is also clear that many technological practices are carried out for reasons rooted in cultural and political values other than technological objectivism (Atkinson 1995:54); a characteristic of obstetric culture that places little value on women's autonomy (Sadler et al. 2016). But technologies are always a coming together of material and social (cultural, political) capacities. Enacted through practice, they afford different ways of being (Barad 2007:132; Leonardi 2012). So it is logical that technologies are also implicated in providing security and reducing anxiety, especially when plans for their use are established beforehand and consensually agreed. However, this face of technology is much less apparent in the research. This indicates that overuse of

technologies and their destructive power is an outcome of their capacities being underdetermined in the sense that their dependence on the social (cultural values, traditions) is under emphasised, hidden and retained within the control of the doctor (Mol 2002:171). In territorialising these technological capacities, expressed in asymmetric decision-making, women's capacity for action is reduced to a predetermined frame, through which unequal relations of power and gender are sustained (Fox Keller 1985:75).

Hence, this is not an argument against technologies, but rather a call to consider the prominence that technologies acquire, their capacities as socio-materials and the effects they have, not just in an operative, biological sense but in how they shape the social world. Apart from the impact of how power is distributed through access to technology, there are some simple practical ways to consider how they can over determine the social following a perinatal death. For example, an unnecessary caesarean section reduces a woman's capacity to participate in rituals or it may mean she has to miss the funeral of her child. Caesareans are also implicated in short and long-term physical morbidity and risks in future pregnancies, as well as increased interval until the next pregnancy (see Chapter 7, conclusions for references). The practice of a dilation and evacuation in a pregnancy termination, without discussing how this affects the possibility of *post mortem* contact by compromising the integrity of the body, is also to ignore the social implications of the technology. Administering sedatives during labour or at other times can reduce a woman's capacity to make decisions, but it can also cause memory loss, which is to defeat one of the main objectives of bereavement care and related rituals. In different ways each of these practices conditions the possibilities of the social, but this is not to say that under specific conditions, grounded in evidence and symmetric social relations, that they are inappropriate.

Obstetric violence and human rights following the death of a baby

One of the hardest parts of working on this project was listening to and reading so many instances of abuse, humiliation, and violation of consent, as well as the mistreatment of babies' bodies. In reality, it was much harder than hearing stories related to deep feelings of loss and sadness, which I was better prepared for. I felt both highly indignant and ashamed that it was possible for this happen. The concept of obstetric violence is one that is often hard for health professionals to countenance; it makes them defensive and feel attacked. Undoubtedly, the term itself is quite shocking when you hear it first, it appears to be a direct contradiction of the Hippocratic oath. But institutional violence is nothing new, it exists in the legal system, in mental healthcare care, in child services, and in medicine in general. There is also a long history of abusive practices in reproductive healthcare and obstetrics in Spain (UN Committee on the Elimination of Discrimination against Women 2020), ranging from the stolen babies scandal to the sexualisation to female subjects in teaching manuals (Fajula Colom 2013; Vera González 2020). And Spain is not unique in this respect.

Obstetric violence is a broad concept that is about much more than verbal abuse or mistreatment. It also includes physical and sexual abuse of women's bodies, dehumanisation, unnecessary medicalisation and pathologisation of childbirth, as well as the non-consensual practice of surgical procedures or administration of medication. Fundamentally, it is a structural problem rooted in cultural values that perpetuate gendered inequality, and recognises that health professionals are often victims of work conditions and education (Castro 2014; Goberna-Tricas 2019; Sadler et al. 2016). The research identifies very clear examples of all these forms of violence. But obstetric violence is not a problem affecting a small minority of women who have lost a baby. It is actually a much wider problem, a conclusion that is consistent with research on Spanish obstetrics more

generally (Iglesias et al. 2019; Ministerio de Sanidad 2012; Observatorio de la Violencia Obstetrica 2016). However, I cannot quantify the pervasiveness of the issue based on the design used in this study, other than concluding that it is not a minor problem and that it requires further research. Any future studies will have to consider the question of how to address practices that are not subjectively experienced as violent, but violate academic, national and international definitions of patient, human, reproductive and sexual rights. It is apparent that, for many health professionals and women in the study, lack of consent, for one, is normalised within care practices, such that it is self-reproducing. The research also shows that lack of consent has to be achieved through the application of power, consciously or unconsciously, and may not be recognised as such by health professionals, who have been educated to approach encounters with patients in this manner (Castro 2014). Exploring these dynamics more fully may prove fruitful.

Finally, why does this happen in cases where women are so very vulnerable and often grieving? There are a number of ways to look at this. On the one hand, feminist theory proposes that female bodies in childbirth stand in opposition to cultural values of femininity, meaning that they require control and domination (Cohen Shabot 2016). If live babies represent the 'product' or success of medicalised obstetric care (Davis-Floyd 1993; Martin 2001:57), then the female body giving birth to a dead baby is doubly disruptive, as it represents a system failure (Layne 2003:148). On the other hand, if the death of the baby is framed uniquely within biomedicine and not considered as the loss of a person, then it is just another birth, like any other. But, if the mother's reactions to the death/loss are considered hysterical or if the health professional believes that her expressions of pain are exaggerated, when in fact it is known that labour pain is experienced more intensely when a baby has died (Gold et al. 2007; Rådestad et al. 1998), it may be that certain cultural values and beliefs act to justify violence. Additionally, vulnerability also means greater asymmetry and a reduction in the possibility of resisting abusive behaviour.

Generally, this is an area that requires further investigation and definition in the context of pregnancy loss. Apart from the ideas already mentioned, future research could focus more deeply on the circumstances of labour and birth, identifying more systematically the forms of violence that women experience and how these are interactively achieved. It may be useful to combine such analysis with other methodologies to explore links to trauma, mental health problems, and problematic grieving. To do this, I think it is fundamental to broaden the definition of obstetric violence in the case of the death of a baby to explicitly incorporate concepts of violence against the dead or dying baby before birth, during birth and after birth.

Grief, bad death, gender inequality and taboo

So, finally, how does all this relate to grief and understandings of death? Generally speaking, the findings indicate that for many women the processes of care following the death of a baby during pregnancy or shortly afterwards resulted in what might classically be called unrecognised (Fowlkes 1990) or disenfranchised grief (Doka 1989). What the research gives insight to is how unrecognised grief is actively achieved. Principally, the research results explore how, when the double-edged sword of gender inequality (expressed through obstetric biomedicine) and taboo related to perinatal death come together, the processes of care affect a significant proportion of women. To different degrees, the institution undertakes a process of role and identity dispossession of the properties and evidentiary resources associated with person, woman, (bereaved) mother and baby/child (Goffman 1961:14–43). In remaking mothers and babies within the predetermined ideal of biomedicine, each is reconfigured as an un-social patient or foetus. The self-determined, disciplined and responsible woman of pregnancy (Georges and Mitchell 2000;

Kukla 2010) becomes incapable and weak. Hence, the event of the death *and* the shift from subject to object within childbirth practices relocates women/mothers into social positions that are incompatible with their conceptualisations of themselves and out of sync with canonical narratives (Goffman 1961:14–43).

In the way that gender impacts pregnancy and care during childbirth, this also demonstrates how gender is a factor that manifestly shapes grief as much as it is made real during care. In this respect, perinatal grief is not just about mothers before their dead children, but also about mothers *and* their babies before society, as well as women *and* their bodies before the world. I believe this focus on gender is fundamental to understanding the moral dimensions of perinatal grief and why the burden that women face is so high. Yet gender is largely ignored in the literature. In fact, in efforts for fathers not to be excluded from grief, which is a very valid concern, there is pressure to conceptually unify the relationship dyad and downplay gender-based differences. The two do not have to be mutually exclusive.

In this respect, it is of little surprise that stories of care following the death of a baby are mostly stories of biomedical care, redolent of professionalised, sequestered and technologically dominated deaths, such as those of the elderly (Illich 1976:179; de Miguel 1995; Rubinstein 1995). The search for meaning (Neimeyer 2000) can become dominated by the search for why the institution behaved in such a way. Hence, perinatal death in hospitals has many characteristics of bad death: high levels of vulnerability, lack of self-determination, medical and technological invasiveness, lack of dignity for self or the dead, inability to fulfil cultural expectations, and subsequent unresolved issues with the dead (Bradbury 1996; Counts and Counts 2004; Johnson et al. 2000; Seale and van der Geest 2004).

New forms of bereavement care stand in opposition to sequestration, but only partially. As we saw with some of the study participants, new practices encourage bereaved parents to engage actively with death through touching, holding, dressing and washing of the body. In contemporary western society, this is not typical. Hence, it might be said that it has features of medieval (in relation to non-ecclesiastical aspects of death ritual), romantic 19th century death, and postmodern 'natural' death (Gilchrist 2005; Walter 2005). It represents a hybrid, confined to the institution and, in a sense, dislocated from the community and home, but intense in its practice. Almost all of the women in the study who engaged in some form of *post mortem* ritual with the baby were positive about it, while a small majority of those that didn't see their baby had regrets. Future lines of research could examine bereavement practices from the perspective of the hybrid, comparing institutionally framed ritual versus home based practice.

Of great significance in this study is the form that *post mortem* contact and ritual takes in relation to content. By examining the characteristics of bereavement ritual, the research could identify that the predominant practice of engaging with babies after the birth is contrary to the ideas expressed in the literature. In the way that this is controlled and managed, bereavement practices in hospitals are best described as 'viewing' events, reminiscent of body identification, rather than the expansive and liberating space that rituals are proposed to create (Turner 1967:94). Such events are often associated with regrets, moral failings and reproduction of stigma, even though the intention is to achieve the opposite. This means that the shame for the transgression of the moral codes of motherhood are unattended to until after discharge, when the opportunity for repair has been lost. This indicates that the challenges for hospitals is to examine how they can alter their practices and modes of interaction in order to de-medicalise these encounters and create social spaces within maternity wards that are conducive to the practice of loss/grief.

How does this affect grief beyond the hospital apart from its impact on the mother-child relation, which I have addressed in the conclusions to Chapter 8? In order for continuing bonds to be effective they must be social (Klass 2006), otherwise the mother/baby to the world is intersubjectively impossible. When an authority and expert figure such as a doctor appears to place no emphasis on loss/grief, then it is logical that the milieu will have little conflict in accessing discourses that frame the event in stigma or taboo, or as insignificant. If *post mortem* contact has been absent or highly constricted and furtive, women and their partners will not have valuable material and discursive resources at their disposal to challenge stigma and negotiate social support. Death and grief are already culturally framed as private affairs, located in the individual (de Miguel 1995; Walter 1996), the danger then is a highly individualised grief, compressed into a tight social space. A form of forced embodied retreat, or mortification, as Goffman (1961:14–43) termed it, where society and the milieu become the ‘institution’.

Research validity

The methodology for this research study is based on an understanding that all knowledge is culturally bound and that there is no way to arrive at an objective understanding of the world or object of inquiry. This is equally applicable to both the quantitative and qualitative methods, meaning that although I have used quantitative techniques I don’t pretend to a positivist or post-positivist view of knowledge production. Validity in this sense does not refer to objectivity (Lincoln et al. 2018). Regardless, there are a number of principles that can be aspired to ensure that the methodological and interpretative work is both sound and achieves its goals. I have identified three broad areas for considering validity: ethics and responsibility, catalysing social change, and methodology.

The ethics and responsibility of conducting social research relates to a variety of axiological concerns, each of which tie the researcher up in a moral relationship to specific participants in a study and the broader community of stakeholders. These include: representativeness and polivocality, reflexivity and positionality, standpoints and judgements, responsibilities to the stories of participants and reciprocity (Biglia and Bonet i Martí 2017; Kohler Riessman 2015; Lincoln et al. 2018; Schwandt 1996). On the issue of polivocality and stakeholder representativeness, perhaps the most glaring gap in the research is the lack of primary data related to the views of health professionals. This is justified on the basis of the research demand, available resources and gaps in the literature. The primary objective of the study was to focus on the experiences of bereaved women because almost no primary data existed when the study was commissioned, while a number of studies had addressed the experiences of health professionals (Gálvez-Toro et al. 2002; Pastor-Montero et al. 2011). Nevertheless, at a secondary level in the project, health professionals, mostly midwives and psychologists, have been widely involved in the study design and methodological development. There has also been wide engagement with health professionals through the participant/observation. Steps to ensure ethical and responsible engagement in the field and reflection on standpoint have also been specified throughout the study. The ethical considerations of engaging with study participants on a sensitive subject such as the death of a child have been covered in the chapters on methodology, which identify specific strategies to minimise any potential for harm.

In terms of social change, it is important to ask what impact the research has on the world. Is it relevant and effective? Does it meet its goals? Does it enhance moral critique, raise awareness, or catalyse political action (van Dijk 1993; Lincoln et al. 2018; Mays and Pope 2000; Schwandt 1996)? At the most basic level, this relates to the acceptance or approval of the work from within the

community where the demand initiated. The publication of the results, and the distribution of the data are synonymous with a certain level of relevance and effectiveness. To date, this includes seven abstracts presented at congresses and ten presentations, a research article in a high impact journal, two literature reviews/practice guides and the publication of a full report of 8 chapters of statistical evidence from the survey research, as well as editorial work on other publications. Much of this work has been widely distributed within the community of lay associations and healthcare practitioners that are working to improve care processes, and has been cited in other publications. To date, the research has also received significant coverage in national and regional media. The research has also been used in training sessions and for the development of care standards and hospital guidelines. Similarly key findings from this study will published, in Spanish and English.

Finally, methodological validity refers principally to ideas of rigour in the implementation of accepted standards in the practice of conducting quantitative and qualitative research. The project strives to be as transparent as possible, providing details on methodological processes and documentation (Valles 2005), which are available in the appendices and signalled in each chapter. Steps were taken to ensure validity within each method and also between methods, most notably in the triangulation of the approaches and integration of methods that is described in detail in each chapter and specifically in Chapter 3, section 6. Here, there are a few relevant issues. As I discuss in more detail in the sample sections of both the qualitative and quantitative methodologies, there are weaknesses and strengths in the sampling. The most obvious strong points relate to the coverage in terms of type of death and the fact that the survey sample has a strong geographic reach and appears to be an accurate representation of clinical practice, based on comparisons to national data. On the other hand, there are important biases in the samples in relation to the representation of women with formal educations lower than third level and a lack of foreign nationals resident in Spain. Future studies should attempt to address this issue because these populations may be at greater risk of mortality, silencing mechanisms and abuse of power. Finally, as a principle of critical and feminist ethnography, the study attempts to locate the research results theoretically, socio-culturally and locally in as much contextual detail as possible in order to aid interpretation (Sprague 2005). For this purpose the presentation of the research results places interview and story extracts at the centre of the analysis, permitting readers to come to their own opinion on the soundness of my own conclusions and interpretations.

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Appendices

Appendix 1. List of participant observations

Training courses attended

- Workshop for providing care in cases of perinatal death. Organised by Umamanita, 15th January 2012.
- Conference on perinatal death and grief for health professionals. Barcelona, 25-26th February, 2017
- International Stillbirth Alliance annual conference on perinatal mortality and bereavement care, Cork, Ireland, 22-24th September 2017.
- Pathology Information Workshop for Advocacy and Support Groups, Cork, Ireland, 21st September 2017.
- IMPROVE Workshop on care following perinatal death, Cork, Ireland, 21st September 2017.
- International Conference on Stillbirth, SIDS and Baby Survival. Glasgow, UK, 7th-9th June 2018.
- Workshop on perinatal death classification systems. Glasgow, UK, 6th June 2018.
- Advocacy Workshop. Glasgow, UK, 6th June, 2018
- International Stillbirth Alliance, Annual Conference on Perinatal Mortality and Bereavement Care, Madrid, Spain. October 5-6th, 2019
- Workshop for support group moderators. Madrid, Spain, 4th October 2019.
- Workshop on lactation for health professionals. Hospital Materno-Insular, Las Palmas, Gran Canaria, 9th February, 2020

Training provided to health professionals

- Workshop on providing care in cases of perinatal death. Hospital El Vendrell, Tarragona, 27th March 2014.
- Workshop on providing care in cases of perinatal death. SERGAS, Madrid, 8th October 2014.
- Workshop on providing care in cases of perinatal death. SERGAS, Madrid, 15th October 2015.
- Workshop on providing care in cases of perinatal death. Hospital Infanta Cristina, Madrid, 4th November 2015.
- Workshop on providing care in cases of perinatal death. Hospital El Clínico San Carlos, Madrid, 5th November 2015.
- Workshop for providing care in cases of perinatal death. Hospital Infanta Cristina, Madrid, 30th May 2016.
- Conference on perinatal death and grief for health professionals. Barcelona, 25-26th February, 2017.
- Seminar on perinatal grief. Instituto Europeo de Salud Mental Perinatal. Madrid, 21st March 2018.

Congresses and conferences organised

- Umamanita conference on perinatal death and grief for health professionals. Barcelona, 25-26th February, 2017
- International Stillbirth Alliance, Annual Conference on Perinatal Mortality and Bereavement Care, Madrid, Spain. October 5-6th, 2019

International Research Programme

- International Stillbirth Alliance international survey on parent's experiences of care. Spanish representative responsible for instrument review and translation, promotion of fieldwork and co-author on relevant publications. 2016.

Parent Commemorative events

- El día del recuerdo. Madrid, October, 2012-2018.

Appendix 2. Sample of an interview transcription

Transcripción de entrevista //// Final

Código: 008
 Entrevistados: XXXXX (X), madre de XXXXX
 Entrevistador: Paul Cassidy (P)
 Fecha: Viernes, 1, Noviembre, 2013
 Hora: De 17.00 a 19.30
 Lugar: Casa, Entrevistada

Símbolos:

. silencio / pausa medido - duración corto
 .. silencio / pausa medido - duración medio
 ... silencio / pausa medido - duración largo
 Palabra seguida por ... arrastra el sonido de la última letra
 () duda del transcriptor
 < interrupción o introyección
 > Palabra no terminada
 = hablando a la vez
 (()) observación

Sonidos:

ahum Sonido de afirmación / consentimiento para continuar / acuerdo
 eh. Sonido de enlazar cláusulas
 ehm. Sonido de duda / pensar
 sst Sonido de enojarse
 pff. Sonido de exasperación / mucha emoción

Palabras : 26,368

Line	S	Text
		EXAMPLE OF INFORMED CONSENT
1	P	Vale, está acabando, y voy a poner otro por si acaso que se estrop> y pierdo todo,..
2		Vale, ya está.. mm.. también.. las formalidades que hay. éste es un Informe de
3		Consentimiento para la grabación.
4	X	Vale
5	P	Esto lo que significa es lo que he dicho, lo que he dicho en el email. básicamente para, en
6		este tipo de Investigación,. ehm. igual queremos usar algunas citas a modo de
7		ilustración de. explicar. eh. resultados, etc., ¿no?
8	X	<Sí
9	P	Entonces hace falta usar, hace falta usar citas, ¿no? Eh. eh. específicas. Pero van todos
10		a modo anónimo, al menos que.. eh. la madre quiere que vaya su nombre, o el nombre de
11		su hijo. o
12	X	<Ah, yo en eso no tengo ningún problema, o sea que...
13	P	<Vale, entonces, pero lo que haré es ehm antes de publicar nada, eh, yo te pasare un. una un
14		borrador del Informe
		EXAMPLE OF AN INTERVIEW START
63	P	Eh.., como dije, es como una conversación. Ehm., lo que me gustaría hacer es que me.. que
64		básicamente que me cuentes, ehm, tu historia

- 65 X ¿Cómo fue?
 66 P Cómo fue, a modo que tu quieras, con el detalle que tú quieras. Ehm. entonces no te
 67 preocupes que sea demasiado detalle
 68 X <Ahum
 69 P o demasiado poco. Ni tiene que ser cronológico, es lo que. lo que a ti es, eh, es importante.
 70 Luego, después de que me que me cuentes tú.. la historia, igual podemos volver, te puedo
 71 X <Vale
 72 P preguntar. cosas más específicas o lo que sea, ¿no? entonces no, no te preocupes por.. no
 73 olvidar.. algo en la historia, o lo que sea, porque lo podemos repasar>, repasar, ¿no?
 74 X Vale
 75 P Eh.,
 76 X <Había
 77 P <¿Tienes alguna pregunta antes de empezar o?

EXAMPLE OF THE START OF A MAIN NARRATION AFTER THE PARTICIPANT PROVIDES SOME BACKGROUND INFORMATION ABOUT HER RELATIONSHIP WITH HER PARTNER

- 182 X <Así que, así que nada, y.., ehm, no sé qué más decirte, si ya.. si quieres te, te cuento la.
 183 Pues nada, era.. el día 6 de marzo, era cuando iba a nacer, [Baby's name], que me habían
 184 programado a mí el parto., y.. cuando llegamos allí, pues con toda la ilusión del mundo..
 185 bueno, con unos nervios tremendos porque iba a nacer nuestra chuiquitina, que ya se había
 186 retrasado.., se había retrasado... muchísimo el parto, eh., la semana 41 más tres era cuando.
 187 nació, o sea que ya. se había ido, y.., y.., y nada, llegamos allí, nos estuvieron preparando en
 188 la habitación, "pues tienes que hacer esto y tal, vamos a bajar a la sala de dilatación, y
 189 cuando llegamos a la sala de dilatación, eh., pues te empiezan a poner los monitores, para
 190 controlar.. el latido y todo", y ahí fue cuando. una de las enfermera o una matrona, estaba
 191 intentando localizar el corazón de [Baby's name]
 192 P <((P. tose))
 193 X y.., y no lo localizaba. Entonces me dice, "¿por dónde suelen ponerte las matronas cuando
 194 vienes a. aquí a monitores?" Pues digo, "por aquí, por la derecha", y lo intenta poner, y
 195 nada, no.., no.., no lo conseguía, y dice, "pues esto está estropeado". Se fue, vino con otro
 196 aparatito para ponerlo, y bueno pues ni [husband's name] ni yo. teníamos la, en mente.. o sea, no..,
 197 no.., dentro de todas las cosas que pudiesen pasar..
 198 P <Eso
 199 X <no era.. no estaba dentro.. el que pudiera haberse.. ido, y.. pues bueno, pues ha
 200 estropeado. Pero claro, la matrona cuando ya dijo, "ay, voy a ir por la máquina de, de
 201 ecografías porque este... tranquila, eh, no pasa nada, eh". A mí ya el "tranquila, no pasa
 202 nada" me... a mí ya me... me dio un toque de que algo pasaba, algo pasaba, que no iba bien.
 203 Y.. bueno, yo realmente nunca había.., no notaba que fuera mal el embarazo, porque
 204 [Baby's name] era una niñita muy tranquilita, o sea, no... no es como [other baby's name], que se movía un
 205 montón, y daba un montón de patadas. Te daba así. toquitos, jugaba con ella cuando yo le
 206 hacía en la barriga, ella me contestaba, y podíamos tirarnos así un ratito, o sea que, pero en
 207 plan de estar en movimiento como otros bebés., era muy tranquila. Entonces.. a mí nada me
 208 hacía pensar que., que la estuviera pasando algo. Que. hubiese fallecido. Entonces., ya vino

Appendix 3. Open-ended survey questions (Spanish version)

Post mortem interaction with the baby

[Q48. Si un profesional le dijo que no podría ver el bebé] *¿Qué razón te dieron para decirte que no podrías ver a tu bebé/s?*

Ejemplo de respuesta: no me dieron razones para decirme no me pusieron cara de sorpresa x querer verla y me preguntaron 3 o 4 veces si estaba segura

[Q49. Al final de la sección sobre contacto *post mortem* - si no vio al bebé] *¿Hay algo más, que nosotros no hemos preguntado, relacionado con el hecho de no ver a tu bebé/s que te gustaría contarnos?*

Example response: Filtrado

[Q54. Al final de la sección sobre contacto *post mortem* - si no vio al bebé] *¿Hay algo más, que nosotros no hemos preguntado, relacionado con el hecho de ver a tu bebé/s, que te gustaría contarnos?*

Example response: Quien me preparó y asesoró muy bien para ver a mi bebé fue la matrona del ambulatorio, no las del hospital. En el hospital en el momento del parto había tantos profesionales a mi alrededor y cada uno con una opinión diferente que gracias a que fui preparada no me confundieron sus mensajes y actuaciones.

Investigation of the cause of death

[Q74. Si se realizó una autopsia] *¿Hay algo relacionado con la autopsia, biopsia u otra prueba médica que no hemos preguntado que le gustaría contar?*

Example response: tambien me hicieron pruebas de coagulacion en sangre y sobre estas ultimas pruebas solicite el resultado por correo electronico visto el trato tan frio y desconectado de la medico y el ginecologo que me atendieron en la primera visita posterior a la perdida en que me dieron los resultados de la autopsia.

Disposition of the body

[Q77. Si la disposición fue organizado por el hospital] *Nos has indicado que elegiste cremar en el hospital sin poder recuperar las cenizas, indícanos abajo por qué elegiste esta opción:*

Example response: la beneficencia del hospital se hizo cargo de enterrarlo en un nicho comun

Overall comments on the experience in the hospital

[Q80. A todas las participantes] *Pensando en la estancia hospitalaria, ¿qué fue lo que más te ayudó (de lo que alguien hizo o dijo)?*

Example response: En el momento del parto: la medico anestesista q me VIO q no queria epidural ni anestias pues el dolor q sentia mayormente no era físico (era del alma) y paró al equipo q me estaba presionando para q me colocara en tal postura y ME DEJO PARIR tranquila ofreciendome un poquito de sedante q ni lo note y me sentó muy bien (creo q fue propofol)

[Q81. A todas las participantes] *Pensando en la estancia hospitalaria, ¿qué fue lo que menos te ayudó (de lo que alguien hizo o dijo)?*

Example response: la falta de coordinación de los profesionales, me encontré q no me dejaban llevar el móvil para sacar fotos, lo llevamos a escondidas, no me ofrecieron sacar fotos ni

Appendix 3. Open-ended survey questions sample (Spanish version)

recuerdos. las caras raras de miedo, pena lástima q vi en casi todo el equipo q me atendió en la sala de partos, q querían esconder al bebé de echo se lo llevaron y me la trajeron limpia y cuidada pero no me lo explicaron. que el ginecologo me preguntara "por qué" lloraba ¿¿?? me enfadé mucho. Y la medico q me dio los resultados estuviera dura a la defensiva y que me dijera q igual había tenido una placenta de mala "calidad", le pregunté q me quería decir con eso y no me explicó, se molestaba ante mis preguntas, me dolió mucho. parecía q no podía llorar o mostrarme debil y lo sufrí mucho porque me sentía muy frágil.

Appendix 4. Framework for the analysis of local speech events

<p>Orientations Contexts and backgrounds to complicating actions, when, where, who of the narrative, plus state of mind or other factors that contextualise the narrative or capacity for action</p>	
When (time, deictic words)	<ul style="list-style-type: none"> • Literal time • Prepositions: then, now, before, after, since, for, until
Where (place, locations)	<ul style="list-style-type: none"> • Naming of locations • Adjectives to describe locations as context to action (not evaluative)
Who (characters, actors)	<ul style="list-style-type: none"> • Story characters (non-interactive): self (mother), baby (son/daughter/child/boy/girl), partner, family, healthcare professionals (doctors, nurses, midwives, administrators, porters, funeral representatives, 'no-one')
What (non-human social actors)	<ul style="list-style-type: none"> • Fittings and furnishings: • Objects and medical devices: • Chemical objects: induction medication, sedatives, anesthetics, etc.
State of mind orientations	<ul style="list-style-type: none"> • State of mind: descriptions of mental or physical condition as a context/backdrop to complicating actions, which may function as a justification for an action, express lack of power or capacity to act or acting in a way that is not commensurate to self-identity
<p>Complicating events, actions and encounters The main purpose of the narrative or sub-plot, what the narrator wants to tell the listener about, e.g. an encounter with a healthcare professional</p>	
Identification of events/ encounters	<ul style="list-style-type: none"> • Care in general • Care events: diagnosis, labour, seeing the baby, etc. • Inter-event interaction: adjacency pairs - greetings, questions/answers, offers (denial, acceptance), requests (denial and permission), silence
Content/ topic of the encounter	<ul style="list-style-type: none"> • Strictly medicine, lifeworld inclusion? • Rekeying or reframing during encounter • De-emphasizing • Interruption, cutting off • Silence
Affiliative and disaffiliative actions	<ul style="list-style-type: none"> • Affiliative actions (agreement, acceptance) and disaffiliative actions (disagreements, rejections): detail in the disaffiliative actions, occurring in the storied world or the storytelling world? • Social categories used during interaction • Possessive pronoun: 'my', 'mine' • Attempts to affiliate/ disaffiliate social actors to social categories: doctor may attempt to re-categorise the baby
Sounds, language styles, genres, terminology	<ul style="list-style-type: none"> • Affiliation or distancing to group membership • Exclusion from categories, group or communication: e.g. doctors using technical language
Verbs	<ul style="list-style-type: none"> • Meta pragmatic descriptors - verbs actors used (reported) • Descriptions of way actors spoke, verbs (shout, whine), adjectives (speak softly, references to volume) • Epistemic modalisation to suggest equivocation (non-commitment) or subjectivity: 'I think', 'I guess' • Verbs that denote lack of agency: 'they left me', 'they put me', 'they allowed me', 'they took me' • Imperative verbs: indicates being ordered or domineered. Can also suggest open strategic action oriented to success or predetermined outcome (power). • Modal verbs: indicates discussion and communicative action oriented toward consensus and recognising subjectives in interaction. Use to identify direct/indirect requests, offers, refusals
Silence	<p>5 types of textual silence</p> <ul style="list-style-type: none"> • Speech act silences: explicit communication of information, approval or disapproval. Intentional, understanding relies on presupposition and shared expectations or same frame of reference • Presuppositional silence - not stating taken-for-granted information/beliefs: 1) logical presupposition, 2) textual silence based on pragmatic presupposition, e.g.

	<p>omission of agent; 3) context sensitive because it is obvious, 4) manipulative or non-manipulative?</p> <ul style="list-style-type: none"> • Discreet silences (specific silence about sensitive or taboo subjects): 1) confidentiality, 2) tactfulness or embarrassment; 3) taboo • Genre based silence: e.g. obituaries omit negative comments about the dead; objectivism in research omits researchers positionality because it undermines machinistic infallible qualities • Manipulative silences (intentional concealment): Depend on not being noticed. Information that could have been said is intentional left out. Can be difficult to identify. 1) Contextuality - what could have been said but wasn't. How context model is controlled. If context is dictated by one party it requires a "compliant interpreter" to accept the semiotic cues and context. If there is resistance or attempts to reframe, such as rejecting crying requests for help <p>Markedness theory:</p> <ul style="list-style-type: none"> • Silence is limited in that it lacks metalinguistic function • Not as common as speech (more unusual, which says something in itself): • Less specific, requires use of contextual clues (has few built in assumptions, not semantically determinate) and recoding requires greater cognitive effort • It is ambiguous: leads to complications and complicated reflection: can imply many things (inference rich). Completely counter to the idea of one meaning-one form
<p>Evaluations What the narrator wants the listener to think about the event, person, thing, place or more globally. Evaluations occur through the narrative.</p>	
<p>Rhetorical devices</p> <p>Emotion</p> <p>Pronouns/ articles</p> <p>Adverbs and associated adjectives</p> <p>Nominalisation/ passive voice</p> <p>Silencing</p>	<ul style="list-style-type: none"> • Reported speech: de-emphasising, rekeying/ reframing • Sarcasm/ non-humorous irony: soften or enhance criticism • Non-verbal irony: air quote • Imitating gestures: e.g. arrogance • Dominance gestures: cut-offs, interruptions • Approval: Joy, contentment, happiness, gratefulness • Disapproval: Anger, frustration, sadness • Impersonal articles to create distance: he/ she, him/ her, 'that' + 'category term' • Evaluative adjectives related to social categories or actions: it was..., he/ she was.. • Use of intensifiers: 'very', 'really', extremely, use of capitalisation in written texts • Evaluative indexicals: 'only' (e.g. only allowed, only did, 'even', 'every', 'all', 'none', 'no one', 'always') • Absence of social actor in action, faceless actor (e.g. institution) • Exclusion of agents may relate to intentional (hiding) or unintentional (obvious) omissions. May be used in strategic sense to refer to a hidden superior authority. • Silencing strategies: topic constraint, deflecting, minimising, reformulating
<p>Resolutions Outcomes</p>	
<p>Feelings</p> <p>Alternatives/ preference organisation</p> <p>Consequences</p> <p>Repair</p>	<ul style="list-style-type: none"> • In the storied world vs. storytelling world: difference, closure, open-ended? • Alternative (imagined) outcomes, contrasted to actual outcomes. Challenges to outcomes • Impact of dispreferred actions/ outcomes • Repair and solutions to disaffiliative and dispreferred actions

Appendix 5. Questionnaire (original Spanish version)

ENCUESTA A MADRES SOBRE SUS EXPERIENCIAS EN EL SISTEMA SANITARIO ESPAÑOL DESPUÉS DE LA MUERTE PERINATAL

SOBRE LA ENCUESTA:

- El objetivo de este estudio es mejorar nuestra comprensión de las experiencias de madres y padres en el hospital durante y después de una muerte gestacional ocurrida a partir de la semana 16.
- El cuestionario ha sido desarrollado por Umamanita, una asociación sin ánimo de lucro, que apoya a las madres y padres después de una muerte perinatal.

¿PARA QUIÉN ES EL CUESTIONARIO?

- Aunque entendemos que no importan las semanas de gestación por razones relacionadas con los procesos hospitalarios, este cuestionario está destinado solamente a madres que han sufrido una pérdida desde la semana 16 del embarazo en adelante e incluye las ocurridas durante el parto. Si tu bebé nació vivo/a, este cuestionario no es aplicable. Contempla los casos de muertes espontáneas, terminación terapéutica del embarazo por problemas del feto o amenaza para la salud materna y reducción selectiva en embarazos múltiples.
- Aunque el cuestionario está dirigido sólo a las madres, no se excluye la posibilidad de que tu pareja pueda ayudarte a completarlo ya que entendemos que muchas veces, en el hospital, la pareja por encargarse de ciertos trámites, ha podido estar expuesta a otras experiencias o puede tener recuerdos más nítidos de ciertos momentos.
- Si has tenido más de una pérdida, por favor contesta en base a tus experiencias de la última pérdida.
- Para pérdidas múltiples, ocurridas en el mismo embarazo, tan sólo se debe contestar un cuestionario, no varios.

INFORMACIÓN IMPORTANTE ANTES DE RELLENAR EL CUESTIONARIO:

- Somos conscientes de que la encuesta trata asuntos emocionalmente difíciles y por ello te agradecemos mucho tu participación. Nuestro compromiso es utilizar los resultados de la encuesta como base para promover mejoras en los cuidados.
- Es importante recordar que no hay respuestas correctas ni erróneas, sólo existe tu opinión personal, por ello es muy importante para la fiabilidad de la encuesta que te centres sólo en tus propias experiencias.
- Si hay una pregunta que no entiendes o crees que no puedes contestarla bien, no te preocupes, déjala en blanco y pasa a la siguiente.
- El cuestionario debería llevar unos 45 minutos, lo óptimo es rellenarlo en una sola vez pero si tienes que parar y volver no hay problema, simplemente deja el cuestionario abierto en el explorador/ordenador.
- El cuestionario es anónimo, recuerda que todas tus respuestas y datos serán tratados con fines estadísticos y nunca de forma individual, así que te garantizamos absoluta confidencialidad de acuerdo con la Ley de Protección de Datos de Carácter Personal 15/99.
- Si tienes alguna duda acerca del cuestionario y te gustaría aclararla puedes contactar con Paul Cassidy por e-mail: paulcassidy@umamanita.es.

Antes de empezar queremos hacerte una serie de preguntas que nos ayudarán a clasificar tus respuestas.

1 ¿En qué provincia vives ahora?

2 ¿En qué provincia vivías cuando tuviste la pérdida?

3A ¿El hospital donde estabas ingresada era privado o público?

- Hospital público..... 1 → P3C
 Hospital privado..... 2 → P3C
 Primero privado y luego público..... 3

Si fue trasladada de un hospital privado a uno público

3B ¿En qué momento te trasladaron al hospital público?

- Después del diagnóstico..... 1
 Después del parto..... 2
 Otro, especificar por favor..... 3

3C ¿Cuál es el nombre del hospital donde estuviste ingresada? Si estuviste en más de un hospital elige el hospital donde pasaste más tiempo (noches ingresadas).

4 ¿Cuántos años tienes?

5 ¿Cuál es tu nacionalidad?

6 ¿Cuál de las siguientes opciones describe mejor tu nivel de estudios?

- No sé leer o escribir (cuestionario cumplido con asistencia)..... 1
 Fui menos de 5 años a la escuela..... 2
 Fui a la escuela 5 años o más pero sin completar EGB, ESO o Bachillerato elemental..... 3
 Bachiller elemental, EGB o ESO completa (Graduado escolar)..... 4
 Bachiller superior, BUP, Bachiller LOGSE, COU, PREU..... 5
 FPI, FP grado medio, Oficialía industrial o equivalente..... 6
 FP II, FP superior, Maestría industrial o equivalente.... 7
 Diplomatura, Arquitectura o Ingeniería técnica; 3 cursos aprobados de Arquitectura, Ingeniería o equivalente..... 8
 Licenciatura o equivalente..... 9
 Máster o Doctorado..... 10

7 ¿Cuál de las siguientes opciones describe mejor tu ocupación?

- Profesional, técnico..... 1
 Directivo de la administración pública y de empresas.. 2
 Personal administrativo..... 3
 Comerciante y vendedor..... 4
 Personal de servicios..... 5
 Agricultor, ganadero, arboricultor, pescador y cazador..... 6
 Trabajador de la producción, conductores de equipos de transportes y peones (no agrarios)..... 7
 Profesional de las fuerzas armadas..... 8
 Estudiante..... 9
 Persona dedicada a las labores de su hogar..... 10
 Jubilado, retirado, pensionista y rentista..... 11
 Persona que no puede ser clasificada..... 12

8 ¿Cuál es tu estado civil actual?

- Casada / pareja de hecho / cohabitando con pareja ... 1
 Soltera..... 2
 Viuda..... 3
 Separada..... 4
 Divorciada..... 5
 Divorciada y nuevamente casada / pareja de hecho / cohabitando con pareja..... 6

9 ¿Cuál era tu estado civil cuando tuviste la pérdida?

- Casada / pareja de hecho / cohabitando con pareja ... 1
 Soltera..... 2
 Viuda..... 3
 Separada..... 4
 Divorciada..... 5

10 ¿Qué tipo de embarazo tuviste?

- Singular..... 1
 Gemelar / mellizos..... 2
 Trillizos..... 3
 Cuatrillizos o más..... 4

11 ¿Cuál de las siguientes opciones describe mejor el tipo de pérdida que tuviste?

- Pérdida espontánea/muerte súbita intrauterina..... 1
 Terminación terapéutica del embarazo por problemas del bebé..... 2
 Terminación terapéutica del embarazo por amenaza para la salud materna..... 3
 Reducción selectiva en embarazos múltiples..... 4
 Neonatal..... 5
 Muerte durante el parto..... 6
 Otro, especificar por favor..... 7

12 ¿Por favor, nos podrías indicar en qué momento del embarazo murió tu bebé/s?

- Entre la semana 16 y 19..... 1
 Entre la semana 20 y 21..... 2
 Entre la semana 22 y 25..... 3
 Entre la semana 26 y la 29..... 4
 Entre la semana 30 y la 33..... 5
 Entre la semana 34 y la 36..... 6
 Entre la semana 37 y la 41..... 7
 Entre la semana 42 y el parto (no durante el parto).... 8
 Durante el parto..... 9

13 ¿Cuántos bebés perdiste?

Chicos Chicas

14A ¿En qué mes y año perdiste a tu bebé/s?

Mes Año

14B ¿Cuánto hace que sufriste la pérdida?

- Durante las últimas 6 semanas 1
- Durante los últimos 3 meses (90 días) 2
- Entre 4 meses y 6 meses 3
- Entre 7 meses y 12 meses 4
- Hace más de 12 meses 5

15 ¿Hubo tratamiento de fertilización en la concepción?

- Sí 1
- No 2

16 ¿Habías tenido previamente alguna de las siguientes pérdidas?

Marca todas las opciones que sean necesarias

- No 1
- Aborto/s espontáneo/s (hasta la semana 12) 2
- Aborto/s espontáneo/s (semana 13 hasta 19) 3
- Muerte/s intrauterina/s espontánea/s (semana 20 hasta el parto) 4
- Reducción selectiva en embarazos múltiples 5
- Interrupción voluntaria del embarazo por problemas del bebé 6
- Interrupción voluntaria del embarazo por amenaza de la salud materna 7
- Muerte/s neonatal/es (desde nacimiento hasta 28 días) 8
- Muerte de un hijo mayor de 28 días 9
- Otro, especificar por favor 10

Si la pérdida fue hace más de 3 meses...

17 Estás contestando el cuestionario sobre tu última pérdida entre la semana 16 y el parto. Desde esta última pérdida hasta ahora, ¿has tenido una pérdida más temprana?

- No 0
- Sí, he tenido una pérdida temprana 1
- Sí, he tenido más de una pérdida temprana 2

18 ¿Tenías hijo/as nacidos/as con vida antes de esta pérdida?

- Sí 1
- No 2

Si la pérdida fue hace más de 6 semanas...

19 ¿Estás embarazada en este momento o has tenido hijos nacidos con vida después de esta última pérdida?

Marca todas las opciones que sean necesarias

- Estoy embarazada en este momento 1
- Sí, he tenido hijos nacidos con vida 2
- No 3

20 ¿Conocías el sexo del bebé/s antes de que te comunicasen que el bebé/s había muerto o antes de su nacimiento?

- Sí 1
- No 2 → P22

21 Si conocías el sexo antes de que te comunicaran que el bebé/s había muerto, ¿ya le habías puesto nombre?

- Sí 1
- No 2

22 ¿Hubo alguna de las siguientes complicaciones durante el embarazo?

Marca todas las opciones que sean necesarias

- No tuve ninguna complicación durante el embarazo .. 1
- Diabetes gestacional: exceso de los niveles de azúcar en la sangre durante el embarazo 2
- Diabetes mellitus tipo I: Diabetes mellitus insulino-dependiente 3
- Hiperémesis gravídica (Hyperemesis gravidarum, HG): Náuseas y vómitos intensos y persistentes durante el embarazo, más extremos que las "náuseas matutinas" 4
- Hipertensión (relacionada con el embarazo): Hipertensión que comienza después de 20 semanas de embarazo y desaparece después del parto 5
- Anemia: Nivel de glóbulos rojos sanos más bajo de lo normal 6
- Desprendimiento placentario: La placenta se separa de la pared uterina antes del parto, lo que puede significar que el bebé no reciba suficiente oxígeno 7
- Placenta previa: La placenta cubre toda la apertura del cuello uterino dentro del útero o parte de ella 8
- Retraso del crecimiento intrauterino 9
- Poco líquido amniótico (oligohidramnios) 10
- Corioamnionitis (infección de las membranas placentarias y del líquido amniótico) 11
- Problemas de tiroides de la madre 12
- Obesidad o sobrepeso importante de la madre 13
- Amenaza de parto prematuro 14
- Rotura prematura de membranas 15
- Cuello uterino incompetente 16
- Amenaza de aborto (hasta 20 semanas) 17
- Sangrado vaginal 18
- Colestasis gravídica 19
- Exceso de líquido amniótico 20
- Otro, especificar por favor 21

23 ¿Dónde estabas cuando te comunicaron la muerte de tu bebé/s o qué el pronóstico no era bueno?

- En una sala de urgencias/UCI 1
- En la consulta / despacho del médico 2
- En una habitación para familias 3
- Reanimación 4
- Neonatología/ UCIN 5
- UCI 6
- Paritorio 7
- Ecografía-monitores 8
- Centro Salud 9
- Habitación 10
- Quirófano 11
- Sala de dilatación 12
- Por teléfono 13
- Casa 14
- Otro, especificar por favor 15

24 ¿Quién te comunicó las malas noticias?

- Un médico 1
- Una matrona o enfermera 2
- Mi pareja u otro familiar 3 → P26
- Otro, especificar por favor 4

Si un médico o enfermera comunicó las malas noticias

25 ¿Estabas acompañada cuando te comunicaron la muerte de tu bebé/s o que el pronóstico no era bueno?

- Sí, por mi pareja 1
- Sí, por un miembro de la familia o amigo . 2
- No, estaba sola 3 → P27

Si, estaba acompañada

26 ¿Te ofrecieron un sitio privado donde estar con tu pareja o familia para asimilar la noticia?

- Sí 1
- No 2

27 Ahora nos gustaría que pensaras en la interacción con los profesionales en el momento que te comunicaron que el bebé/s estaba muerto o que el diagnóstico no era bueno.

Marca el número que mejor indique el grado de acuerdo o desacuerdo actualmente con cada una de ellas. Si no estás segura, usa la categoría "Ni estoy de acuerdo/ni en desacuerdo". Por favor, trata de usar esta categoría cuando verdaderamente no tengas una opinión clara.

- 1 = Estoy totalmente de acuerdo
- 2 = Estoy de acuerdo
- 3 = Ni estoy de acuerdo/ni en desacuerdo
- 4 = No estoy de acuerdo
- 5 = Estoy totalmente en desacuerdo

- Cuando me presenté en el hospital / centro salud me trataron con prioridad 1 2 3 4 5
- Intuí por la reacción del profesional sanitario que el pronóstico no era bueno 1 2 3 4 5
- Observando el monitor intuí que el pronóstico no era bueno 1 2 3 4 5
- El/la medico tardó mucho tiempo en verme 1 2 3 4 5

- Recibí una explicación clara del diagnóstico, en un lenguaje fácil de entender 1 2 3 4 5
- Tuve la oportunidad de hacer más preguntas sobre el diagnóstico 1 2 3 4 5
- La persona que me comunicó las malas noticias era una persona empática y comprensiva 1 2 3 4 5
- Me sentí acompañada por los profesionales en el tiempo después de recibir las malas noticias 1 2 3 4 5

28 ¿Cuál de las siguientes opciones describe mejor tu alojamiento?

- Habitación privada / no compartida 1
- Habitación compartida con otra madre embarazada o en posparto 2 → P30
- Habitación compartida con una paciente que no era de maternidad 3
- Sala común 4
- Urgencias 5
- Sala dilatación-paritorio 6
- Primero compartida-después individual 7
- Habitación compartida, con otra madre con pérdida 8
- No hubo ingreso 9
- Otro, especificar por favor 10

29 ¿Desde la habitación donde estabas alojada podías escuchar los llantos de los bebés en la unidad de maternidad?

Marca todas las opciones que sean necesarias

- No 1
- Algo 2
- Sí 3

30 ¿Qué tipo de parto tuviste?

- Parto eutócico o espontáneo (parto vaginal que se inicia de forma espontánea, es decir, sin medicación y termina también de forma espontánea, es decir, no es necesario realizar maniobras quirúrgicas para facilitar la expulsión del bebé) 1
- Parto distócico (parto vaginal en el que se necesitan maniobras o intervenciones quirúrgicas para la finalización del parto, es decir, instrumental para facilitar la expulsión del bebé, lo normal es ventosa, espátulas o fórceps) 2
- Parto inducido-estimulado (parto vaginal en el que es necesario inducir las contracciones del trabajo de parto mediante medicación: prostaglandinas y/u oxitocina) 3
- Parto inducido-estimulado y distócico (parto vaginal en el que se inducen las contracciones del trabajo de parto mediante prostaglandinas y/u oxitocina y finaliza el parto necesitando realizar maniobras quirúrgicas para facilitar la expulsión del bebé) 4
- Cesárea programada 5
- Cesárea de urgencia 6
- Cesárea por fallo de inducción 7
- Otro, especificar por favor 8

31 ¿Estuvo alguien contigo durante el parto?

- Sí, mi pareja 1 → P33
- Sí, un familiar o amigo 2 → P33
- No, estaba sola 3

32 Nos has indicado que no estuviste acompañada durante el parto, ¿Por qué?

- Lo elegí así 1
- No había nadie para estar conmigo 2
- Mi pareja no quiso entrar 3
- A mi pareja no le dejaron entrar 4
- Otro, especificar por favor 5

33 ¿Hubo alguna complicación durante el parto, aparte de la pérdida?

- Sí 1
- No 2

34 ¿Cuántas noches estuviste ingresada en el hospital, contando desde el ingreso hasta el alta?

- Menos de 1 día / no pasé la noche 1
- 1-2 noches 2
- 3-4 noches 3
- 5-7 noches 4
- 8 noches-2 semanas 5
- Más de 2 semanas 6

35 ¿Te dieron sedantes o tranquilizantes en algún momento? (fármacos para sedarte o tranquilizarte NO fármacos para el dolor, analgésico, anestésicos como la epidural o pastillas para dormir)
 Marca todas las opciones que sean necesarias

- No 1 → P43
- Después de la comunicación de las malas noticias o durante la parte inicial del trabajo de parto 2
- Durante el parto (justo antes o durante el expulsivo) 3
- Después del parto 4

Si te administraron sedantes antes del parto

36 Nos has indicado que te dieron sedantes, después de la comunicación de las malas noticias o durante la parte inicial del trabajo de parto, ¿cuál de las siguientes opciones describe mejor la razón por la que te dieron sedantes en aquel momento?

- Pedí que me dieran algo para relajarme 1
- Me dijeron que sería mejor que me tomara algo para relajarme 2
- Me dieron sedantes sin consultar conmigo 3

37 ¿Te explicaron los efectos de los sedantes antes de administrártelos?

- Sí, me lo explicaron muy bien 1
- Sí, pero no del todo 2
- No 3

Si te administraron sedantes durante el parto

38 Nos has indicado que te dieron sedantes, durante el parto (justo antes o durante el expulsivo), ¿cuál de las siguientes opciones describe mejor la razón por la que te dieron sedantes en aquel momento?

- Pedí que me dieran algo para relajarme 1
- Me dijeron que sería mejor que me tomara algo para relajarme 2
- Me dieron sedantes sin consultar conmigo 3

39 ¿Te explicaron los efectos de los sedantes antes de administrártelos?

- Sí, me lo explicaron muy bien 1
- Sí, pero no del todo 2
- No 3

Si te administraron sedantes después del parto

40 Nos has indicado que te dieron sedantes, después del parto, ¿cuál de las siguientes opciones describe mejor la razón por la que te dieron sedantes en aquel momento?

- Pedí que me dieran algo para relajarme 1
- Me dijeron que sería mejor que me tomara algo para relajarme 2
- Me dieron sedantes sin consultar conmigo 3

41 ¿Te explicaron los efectos de los sedantes antes de administrártelos?

- Sí, me lo explicaron muy bien 1
- Sí, pero no del todo 2
- No 3

42 ¿Sientes que los sedantes afectaron tus recuerdos del tiempo en el hospital?

- Sí, mucho (creo que no recuerdo cosas importantes) 1
- Sí, un poco (pero creo que recuerdo la mayoría de las cosas importantes) 2
- No creo que los sedantes me afectaron los recuerdos 3

43 ¿Después del parto, tú o tu pareja (si corresponde) viste/vio al bebé/s?

- No 1
- Sí, pero yo no, sólo mi pareja 2
- Sí, sólo yo 3 → P44 t P50
- Sí, yo y mi pareja 4 → P44 t P50

44 ¿Otro familiar o amigo de la familia vio el bebé/s?
 Marca todas las opciones que sean necesarias

- No, nadie 1
- Sí, un abuelo/a u otro familiar 2
- Sí, un/a amigo/a 3

Si no viste a tu bebé...

45 Nos has indicado que no viste a tu bebé. Por favor, marca el número que mejor indique el grado de acuerdo o desacuerdo actualmente con cada una de las siguientes frases. Si no estás segura, usa la categoría "Ni estoy de acuerdo/ni en desacuerdo". Por favor, trata de usar esta categoría cuando verdaderamente no tengas una opinión clara.

- 1 = Estoy totalmente de acuerdo
- 2 = Estoy de acuerdo
- 3 = Ni estoy de acuerdo/ni en desacuerdo
- 4 = No estoy de acuerdo
- 5 = Estoy totalmente en desacuerdo

Recibí bastante información acerca de la decisión de ver o no ver al bebé/s 1 2 3 4 5
 Me aconsejaron que sería mejor que no viera al bebé/s..... 1 2 3 4 5
 Aunque decidí no ver a mi bebé me sentí presionada a verle 1 2 3 4 5
 Mi pareja y yo tuvimos opiniones diferentes acerca de ver al bebé/s..... 1 2 3 4 5
 Me arrepiento de no haber visto a mi bebé/s 1 2 3 4 5

46 ¿En algún momento algún profesional te dijo que no podrías ver a tu bebé/s?

No 1
 Sí..... 2 → P49

Si le dijeron que no podría verle

47 Por favor, indican quién te/os decía que no podrías ver a tu bebé/s.

Marca todas las opciones que sean necesarias

Un/a médico..... 1
 Un/a matrona/ o enfermera/o..... 2
 Otro, especificar por favor..... 3

48 ¿Qué razón te dieron para decirte que no podrías ver a tu bebé/s?

Puedes contárnoslo en el espacio de abajo

Si no viste a tu bebé...

49 ¿Hay algo más, que nosotros no hemos preguntado, relacionado con el hecho de no ver a tu bebé/s que te gustaría contarnos?

Puedes contárnoslo en el espacio de abajo

Si viste a tu bebé...

50 Nos has indicado que tuviste ocasión de ver a tu bebé/s, ¿dónde le viste?

Marca todas las opciones que sean necesarias

En la habitación donde nos alojaron..... 1
 En una sala de urgencias/UCI..... 2
 En la sala de consultas / despacho del medico..... 3
 En la sala de partos..... 4
 En una sala contigua a la sala de partos..... 5
 En una habitación para familias..... 6
 Neonatología..... 7
 Quirófano/sala contigua..... 8
 Reanimación..... 9
 Otro, especificar, por favor..... 10

Si viste a tu bebé...

51 ¿Indica si tú o tu pareja hicisteis algo de lo siguiente cuando visteis a tu bebé/s?

Marca todas las opciones que sean necesarias

	Yo	Yo y mi pareja	Mi pareja	No
Tocarle/s.....	1	2	3	4
Sostenerle/s.....	1	2	3	4
Vestirle/s o arroparle/s.....	1	2	3	4
Lavarle/s.....	1	2	3	4
Velarle/s durante un tiempo...	1	2	3	4
Tomar fotografías.....	1	2	3	4

Si viste a tu bebé...

52 ¿En total, durante cuánto tiempo aproximadamente, estuviste con tu bebé?

1-2 minutos..... 1
 3-5 minutos..... 2
 6-20 minutos..... 3
 21-60 minutos..... 4
 1 hora a 2 horas..... 5
 Más de 2 horas..... 6
 No sé, no puedo decirlo..... 7

Si viste a tu bebé...

53 Nos has indicado que viste a tu bebé. Por favor, marca el número que mejor indique el grado de acuerdo o desacuerdo actualmente con cada una de las siguientes frases. Si no estás segura, usa la categoría "Ni estoy de acuerdo/ni en desacuerdo". Por favor, trata de usar esta categoría cuando verdaderamente no tengas una opinión clara.

- 1 = Estoy totalmente de acuerdo
- 2 = Estoy de acuerdo
- 3 = Ni estoy de acuerdo/ni en desacuerdo
- 4 = No estoy de acuerdo
- 5 = Estoy totalmente en desacuerdo

Recibí bastante información acerca de la decisión de ver o no ver al bebé/s 1 2 3 4 5
 Me aconsejaron que sería mejor que no viera al bebé/s..... 1 2 3 4 5
 Me sentí presionada a ver a mi bebé/s..... 1 2 3 4 5
 Me presentaron al bebé/s de una manera respetuosa y afectuosa..... 1 2 3 4 5
 El sitio donde vi a mi bebé/s fue un lugar privado..... 1 2 3 4 5
 Sentí que podría pasar todo el tiempo que quería con mi bebé..... 1 2 3 4 5

Los profesionales fueron respetuosos en el trato físico de mi bebé/s 1 2 3 4 5
 Los profesionales participaron en el proceso de ver / sostener/ velar al bebé/s... 1 2 3 4 5
 Mi pareja y yo tuvimos opiniones diferentes acerca de ver al bebé/s..... 1 2 3 4 5
 Fue una buena decisión ver a mi bebé/s..... 1 2 3 4 5

Si viste a tu bebé...

54 ¿Hay algo más, que nosotros no hemos preguntado, relacionado con el hecho de ver a tu bebé/s, que te gustaría contarnos?

Puedes contárnoslo en el espacio de abajo

55 Cuando las enfermeras y/o matronas te hablaron del bebé, ¿cómo se referían a él/ella?

Marca todas las opciones que sean necesarias

Por su nombre 1
 El / la bebé 2
 El feto 3
 Él / ella o se 4
 No sé / no recuerdo 5

56 Cuando los/las médicos/as te hablaron del bebé, ¿cómo se referían a él/ella?

Marca todas las opciones que sean necesarias

Por su nombre 1
 El / la bebé 2
 El feto 3
 Él / ella o se 4
 No sé / no recuerdo 5

57 ¿Cuáles de los siguientes recuerdos guardaste del hospital?

Marca todas las opciones que sean necesarias

Ninguno..... 1
 Fotografía(s) 2
 Impresión de las huellas de las manos / pies 3
 Mechón de pelo 4
 Pulsera de identificación 5
 Ecografía..... 6
 Manta / ropa..... 7
 Pinza del cordón umbilical 8
 Informes médicos/historial/autopsia 9
 Otro, especificar por favor..... 10

58 ¿Tienes algún recuerdo físico u objeto del hospital o del embarazo que sea especialmente importante para ti y tu relación con tu bebé?

Puedes contárnoslo en el espacio de abajo

59 ¿Te preguntaron por creencias religiosas o espirituales importantes?

Sí..... 1
 No 2
 No sé..... 3

60 ¿Te ofrecieron la posibilidad de hablar con un/una psicólogo/a formado/a en duelo gestacional / neonatal, durante la estancia hospitalaria?

Sí..... 1
 No 2 → P62

Si le ofrecieron la posibilidad de apoyo psicológico

61 ¿Aceptaste la oferta de hablar con el/la psicólogo/a o psiquiatra?

Sí..... 1
 No 2

62 Ahora nos gustaría que pensaras en las relaciones con los médicos, matronas y enfermeras. Por favor, marca el número que mejor indique el grado de acuerdo o desacuerdo actualmente con cada una de las siguientes frases. Si no estás segura, usa la categoría “Ni estoy de acuerdo/ni en desacuerdo”. Por favor, trata de usar esta categoría cuando verdaderamente no tengas una opinión clara.

1 = Estoy totalmente de acuerdo
 2 = Estoy de acuerdo
 3 = Ni estoy de acuerdo/ni en desacuerdo
 4 = No estoy de acuerdo
 5 = Estoy totalmente en desacuerdo

Sentí que los profesionales me escuchaban 1 2 3 4 5
 Sentí que podía expresarme emocionalmente delante de los profesionales..... 1 2 3 4 5
 Los profesionales fueron siempre respetuosos hacia mí y hacia mi familia 1 2 3 4 5
 Me / Nos dieron bastante información para ayudarnos con las decisiones que tuvimos que tomar.....
 Los profesionales fueron sensibles en el uso del lenguaje 1 2 3 4 5
 Aunque perdí mi bebé fui tratada como una madre 1 2 3 4 5
 Me sentí emocionalmente apoyada por los/as médicos (ej. ginecólogos, obstetras) ... 1 2 3 4 5
 Me sentí emocionalmente apoyada por los/as enfermeras y matronas..... 1 2 3 4 5
 Sentí que podría hacerles preguntas si quería 1 2 3 4 5
 Me / Nos ayudaron bastante para guardar recuerdos físicos del bebé/s, como una fotografía, la pulsera de identificación, etc..... 1 2 3 4 5
 Algunos de los profesionales me trataron bien y otros mal..... 1 2 3 4 5
 Las enfermeras/matronas parecían saber cómo tratar con casos de pérdida..... 1 2 3 4 5
 Los médicos no parecían saber cómo tratar con casos de pérdida 1 2 3 4 5

63 ¿Cuáles de los siguientes estudios patológicos o pruebas médicas te ofrecieron (luego te preguntaremos sobre cuales se realizaron)?

Marca todas las opciones que sean necesarias

- Ninguno..... 1
- Autopsia general/ necropsia 2
- Autopsia de la placenta..... 3
- Biopsia 4
- Estudio fenotípico (estudio genético)..... 6
- Otro, especificar por favor..... 7

64 Por favor, indícanos quién te/os explicó las posibilidades de realizar estudios patológicos o pruebas médicas.

Marca todas las opciones que sean necesarias

- Nadie..... 1
- Un/a médico 2
- Un/a patólogo..... 3
- Un/a matrona o enfermera/o..... 4
- Otro, especificar por favor..... 5

65 Por favor, indícanos en qué momento te/os hablaron de la posibilidad de realizar estudios patológicos o pruebas médicas.

Marca todas las opciones que sean necesarias

- Antes del parto..... 1
- Durante el parto 2
- Después del parto..... 3

66 Te hemos preguntado qué estudios patológicos o pruebas médicas te ofrecieron, ahora nos gustaría saber cuáles se realizaron.

Marca todas las opciones que sean necesarias

- Autopsia general/ necropsia 1
- Autopsia de la placenta..... 2 → P68
- Biopsia 3 → P68
- Estudio fenotípico (estudio genético)..... 4 → P75
- No, ninguna prueba, ni patológica ni médica.. 5 → P75

Si se realizó una autopsia...

67 ¿Tu o tu pareja firmasteis un consentimiento oficial para la autopsia?

- Sí..... 1
- No 2
- No sé / no recuerdo 3

Si se realizó una autopsia o biopsia...

68 ¿Cuánto tiempo tardaron en llegar los resultados de la autopsia o biopsia?

Si hubo autopsia y biopsia, contesta sobre la autopsia

- Menos de 1 mes 1
- 1-3 meses 2
- 3-6 meses 3
- Más de 6 meses..... 4
- Aún no han llegado 5 → P75

69 ¿Cómo te llegaron los resultados?

- Si ya has recibido los resultados de la autopsia o biopsia.
- Por correo ordinario 1
 - Con cita en el hospital/durante una revisión 2
 - Por correo electrónico..... 3
 - Reclamando/visita de reclamación 3
 - Otro, especificar por favor..... 4
 - 5

70 Por favor, indícanos quién te/os explicó los resultados de la autopsia o biopsia.

Marca todas las opciones que sean necesarias

- Nadie..... 1
- Un/a médico 2
- Un/a patólogo..... 3
- Un/a matrona o enfermera/o..... 4
- Otro, especificar por favor..... 6

71 Con respecto a la explicación de los resultados de la autopsia o biopsia, indica tu grado de acuerdo con la siguiente frase:

- 1 = Estoy totalmente de acuerdo
- 2 = Estoy de acuerdo
- 3 = Ni estoy de acuerdo/ni en desacuerdo
- 4 = No estoy de acuerdo
- 5 = Estoy totalmente en desacuerdo

Me explicaron de una manera clara y entendible los resultados de la autopsia o biopsia..... 1 2 3 4 5

72 ¿Proporcionó la autopsia o biopsia una causa de muerte?

- Sí 1
- Sí, pero no definitiva 2
- No 3

Si no fuera una obligación legal / Si se realizó una autopsia (no biopsia)...

73 ¿Cuál de las siguientes opciones describe mejor tus sentimientos actuales sobre la decisión de autorizar la autopsia?

- Fue una buena decisión..... 1
- Estoy indecisa, no sé si fue una buena decisión 2
- Ojalá no lo hubiera hecho 3

Si se realizó una autopsia o biopsia...

74 ¿Hay algo relacionado con la autopsia, biopsia u otra prueba médica que no hemos preguntado que le gustaría contar?

Puedes contárnoslo en el espacio de abajo

75 ¿Quién te/os explicó el procedimiento y opciones para la disposición del cuerpo?

Marca todas las opciones que sean necesarias

- Nadie..... 1
- Un/a médico..... 2
- Un/a matrona/ o enfermera/o..... 3
- Alguien de la funeraria..... 4
- Trabajador o asistenta social..... 5
- Celador..... 6
- Administrativo..... 7
- Se encargo pareja/un familiar..... 8
- Otro, especificar por favor..... 9

76 ¿Cuál de las siguientes opciones describe mejor el procedimiento del funeral o la disposición de su cuerpo/s?

- Donamos su cuerpo/s a la investigación 1 → P78
- Entierro particular..... 2 → P78
- Cremación particular mediante funeraria, recuperamos las cenizas..... 3 → P78
- Cremación en el hospital, no recuperamos las cenizas..... 4
- No nos devolvieron el cuerpo/s al ser una pérdida temprana..... 5 → P78
- Nos dijeron que si hubo autopsia no podemos recuperar el cuerpo/s..... 6 → P78
- Entierro (fosa común) mediante el hospital..... 7
- Cremación particular sin recuperar las cenizas..... 8
- No sé/ no había opciones..... 9
- Otro, especificar por favor..... 10 → P78

77 Nos has indicado que elegiste cremar en el hospital sin poder recuperar las cenizas, indícanos abajo por qué elegiste esta opción:

- Falta de información/mala comunicación..... 1
- Decisión rápida/apresurada/en estado de shock..... 2
- Parecía mejor opción/fue mejor opción..... 3
- No había otra opción/dijeron que era lo habitual..... 4
- Era el protocolo..... 5
- Madre no participó en la decisión..... 6
- Pensaba que íban a devolver las cenizas..... 7

78 Pensando en los procedimientos de cuidados en el hospital, marca el número que mejor indique el grado de acuerdo o desacuerdo actualmente con cada una de las siguientes frases. Si no estás segura, usa la categoría "Ni estoy de acuerdo/ni en desacuerdo". Por favor, trata de usar esta categoría cuando verdaderamente no tengas una opinión clara.

- 1 = Estoy totalmente de acuerdo
- 2 = Estoy de acuerdo
- 3 = Ni estoy de acuerdo/ni en desacuerdo
- 4 = No estoy de acuerdo
- 5 = Estoy totalmente en desacuerdo

Me explicaron de una manera clara y entendible el proceso del parto en casos de pérdida..... 1 2 3 4 5
 Me/nos presentaron los informes oficiales relacionados con la muerte en un momento adecuado (certificados de defunción, autopsia, nacimiento, boletín estadístico,

- etc.)..... 1 2 3 4 5
- La habitación donde estaba alojada era un lugar tranquilo..... 1 2 3 4 5
- Todo el personal de la planta estuvo al tanto de mi situación..... 1 2 3 4 5
- En general me/nos informaron bien sobre todos los pasos y trámites durante la estancia hospitalaria..... 1 2 3 4 5
- Los/as médicos me parecieron competentes en su trabajo..... 1 2 3 4 5
- Los/as enfermeras/matronas me parecieron competentes en su trabajo..... 1 2 3 4 5
- Los/as médicos, matronas y enfermeras parecían trabajar bien en equipo..... 1 2 3 4 5
- Había un/una profesional que me/nos guió durante el proceso..... 1 2 3 4 5
- Sentí que tuve control sobre las decisiones relacionadas con los aspectos médicos (ej. el parto, sedantes)..... 1 2 3 4 5
- Sentí que tuve control sobre las decisiones relacionadas con los aspectos de ritual (ej. cómo ver/ sostener)..... 1 2 3 4 5

79 Por favor, usando la escala, indica la cantidad de información (verbal o escrita) que recibiste durante la estancia hospitalaria, respecto a los siguientes temas:

- 1 = Nada
- 2 = Poca
- 3 = Bastante
- 4 = Mucha

- Información sobre la posibilidad de guardar recuerdos físicos del bebé/s, como una fotografía, la pulsera de identificación, etc..... 1 2 3 4
- Información sobre el proceso de duelo y su desarrollo normal..... 1 2 3 4
- Información sobre dónde podría encontrar información sobre el duelo perinatal/gestacional (ej. páginas web, libros)..... 1 2 3 4
- Información sobre auto-cuidados en el puerperio y para después del alta (ej. con la lactancia)..... 1 2 3 4
- Información acerca de la disposición del cuerpo (ej. el manejo del funeral / cremación, etc.)..... 1 2 3 4
- Información acerca de la autopsia y otras pruebas médicas..... 1 2 3 4

80 Pensando en la estancia hospitalaria, ¿qué fue lo que más te ayudó (de lo que alguien hizo o dijo)?

81 Pensando en la estancia hospitalaria, ¿qué fue lo que menos te ayudó (de lo que alguien hizo o dijo)?

82 Cada una de estas afirmaciones representan los pensamientos y sentimientos de algunas personas que han tenido una pérdida similar a la tuya. En estas afirmaciones no hay respuestas correctas ni incorrectas. Marca el número que mejor indique el grado de acuerdo o desacuerdo actualmente con cada una de ellas. Si no estás segura, usa la categoría "Ni estoy de acuerdo/ni en desacuerdo". Por favor, trata de usar esta categoría cuando verdaderamente no tengas una opinión clara.

- 1 = Estoy totalmente de acuerdo
- 2 = Estoy de acuerdo
- 3 = Ni estoy de acuerdo/ni en desacuerdo
- 4 = No estoy de acuerdo
- 5 = Estoy totalmente en desacuerdo

	1	2	3	4	5
Me siento deprimida.....					
Se me hace difícil llevarme bien con ciertas personas.....	1	2	3	4	5
Siento un vacío interior.....	1	2	3	4	5
No puedo seguir el ritmo de mis actividades cotidianas.....	1	2	3	4	5
Siento la necesidad de hablar de mi bebé.....	1	2	3	4	5
Estoy en duelo por mi bebé.....	1	2	3	4	5
Estoy asustada.....	1	2	3	4	5
He pensado en suicidarme desde que perdí a mi bebé.....	1	2	3	4	5
Tomo pastillas para los nervios.....	1	2	3	4	5
Echo mucho de menos a mi bebé.....	1	2	3	4	5
Siento que me he adaptado bien a la pérdida.....	1	2	3	4	5
Es doloroso recordar la pérdida de mi bebé.....	1	2	3	4	5
Me altero cuando pienso en mi bebé.....	1	2	3	4	5
Lloro cuando pienso en mi bebé.....	1	2	3	4	5
Me siento culpable cuando pienso en mi bebé.....	1	2	3	4	5
Me siento físicamente enferma cuando pienso en mi bebé.....	1	2	3	4	5
Me siento desprotegida en un entorno hostil desde que mi bebé murió.....	1	2	3	4	5
Trato de reírme pero ya nada me hace gracia.....	1	2	3	4	5
El tiempo pasa muy lentamente desde que murió mi bebé.....	1	2	3	4	5
Lo mejor de mí murió con mi bebé.....	1	2	3	4	5
He decepcionado a personas desde que murió mi bebé.....	1	2	3	4	5
Siento que no valgo nada desde que mi bebé murió.....	1	2	3	4	5
Me culpo por la muerte de mi bebé.....	1	2	3	4	5
Me enfado más de lo que debiera con mis amigos y familiares.....	1	2	3	4	5
Algunas veces siento que necesito ayuda profesional para rehacer mi vida.....	1	2	3	4	5
Me siento como muerta en vida desde que murió mi bebé.....	1	2	3	4	5
Me siento muy sola desde que mi bebé murió.....	1	2	3	4	5
Me siento apartada y aislada incluso cuando estoy con mis amigos.....	1	2	3	4	5
Siento que es mejor no querer a nadie.....	1	2	3	4	5
Se me hace difícil tomar decisiones desde que murió mi bebé.....	1	2	3	4	5
Me preocupa cómo será mi futuro.....	1	2	3	4	5
Siento que mi dolor por la pérdida de mi bebé es invisible ante la sociedad.....	1	2	3	4	5
Me siento feliz por el simple hecho de estar viva.....	1	2	3	4	5

Si las semanas de gestación son 22 o más

83 ¿Antes del alta te dieron el Boletín Estadístico de Parto?

El Boletín Estadístico de Parto es un documento del Registro Civil con muchas casillas que tiene los datos sobre los padres y del parto, como el sexo, las semanas de gestación. Es un documento que el ginecólogo debería darte relleno y firmado.

No.....	1
Sí, completamente relleno.....	2
Sí, parcialmente relleno.....	3
Sí, pero no estaba relleno.....	4
No sé / no recuerdo.....	5

Si recibieron el BEP

84 ¿Has llevado (u otra persona) el Boletín Estadístico de Parto al Registro Civil de tu ciudad o municipio?

Sí, lo llevé/llevamos.....	1
Sí, se encargó la funeraria.....	2
Todavía no, estoy en ello.....	3
No, no me acordé/no nos acordamos llevarlo.....	4
No, no sabía/sabíamos que había que llevar un boletín estadístico de parto para una pérdida perinatal.....	5
No sé / no recuerdo.....	6

85 Después de que te dieran el alta, ¿cuál de las siguientes opciones describe mejor la forma en que te hicieron el seguimiento?

Marca todas las opciones que sean necesarias

No tuve ningún seguimiento después del alta/ aún no porque es pronto.....	1
Fui a una revisión en el mismo hospital.....	2
La matrona del centro salud me visitó en casa.....	3
Fui a una cita con la matrona en el centro salud.....	4
Fui a una cita con el/la médico en el centro salud.....	5
Me siguieron desde Salud Mental.....	6
Fui al ginecólogo a las 6 semanas.....	7
Fui al ginecólogo a las 1-3 semanas.....	8
Revisión con ginecólogo privado.....	9
Seguimiento de especialidades/diagnósticos.....	10
Urgencias por complicaciones/restos.....	11
Revisión periódica/ continua.....	12
Otro, especificar por favor.....	13

86 Pensando en cómo te sientes actualmente, ¿cuál de las siguientes opciones describe mejor cómo estás sobrellevando la muerte de tu bebé/s?

Muy mal (todos los días me parecen malos).....	1
Mal pero no del todo (más días malos que buenos).....	2
Ni mal ni bien (los días malos y buenos me parecen iguales).....	3
Bastante bien (más días buenos que malos).....	4
Muy bien (la mayoría de los días son buenos con alguno malo a vez en cuando).....	5
No lo sé.....	6

87 ¿Has recibido apoyo psicológico / terapia, respecto a la pérdida, en alguna de las siguientes fases o momentos?

Marca todas las opciones que sean necesarias

- No 1
- Después del alta 2
- Durante un embarazo posterior 3
- Ambos, después del alta y durante un embarazo posterior 4

88 ¿Dónde acudiste para tal apoyo psicológico / terapia?

Marca todas las opciones que sean necesarias

- Psicólogos/psiquiatras de salud mental (público) 1
- Enfermera de la unidad de salud mental (público) 2
- Un psicólogo/psiquiatra privado general 3
- Un psicólogo/psiquiatra privado especialista en duelo 4
- Un psicólogo/psiquiatra privado especialista en duelo gestacional / neonatal 5
- Asociación de apoyo al duelo general 6
- Asociación/grupo de apoyo padres 7
- Terapia alternativa/natural 8
- Psicólogos/psiquiatras de salud mental (público) especialista 9
- Otro, especificar por favor 10

Si sigue casada/pareja de hecho

89 ¿Tu pareja ha recibido apoyo psicológico / terapia, respecto a la pérdida, en alguna de las siguientes fases o momentos?

Marca todas las opciones que sean necesarias

- No 1
- Después del alta 1
- Durante un embarazo posterior 2
- Ambos después del alta y durante un embarazo posterior 4

90 ¿Dónde acudió para tal apoyo psicológico/ terapia?

Marca todas las opciones que sean necesarias

- Psicólogos/psiquiatras de salud mental (público) 1
- Enfermera de la unidad de salud mental (público) 2
- Un psicólogo/psiquiatra privado general 2
- Un psicólogo/psiquiatra privado especialista en duelo 3
- Un psicólogo/psiquiatra privado especialista en duelo gestacional / neonatal 4
- Asociación de apoyo al duelo general 6
- Asociación/grupo de apoyo padres 7
- Terapia alternativa/natural 8
- Psicólogos/psiquiatras de salud mental (público) especialista 9
- Otro, especificar por favor 10

Filtrar, excluir embarazos de múltiples

91 ¿Si hubieras tenido la posibilidad de donar tu leche a un banco de leche lo hubieras hecho?

- Sí, definitivamente 1
- Sí, probablemente 2
- No sé, no estoy segura 3
- No, definitivamente 4

92 Por favor, indícanos si crees que hubo alguna negligencia médica en tu caso.

- No 1
- Sí, fue denunciado 2
- Sí, no fue denunciado 3
- No sé, no estoy segura 4

93 ¿Has buscado información sobre la muerte perinatal en internet en algún momento?

Marca todas las opciones que sean necesarias

- No, nunca 1
- Sí, durante la estancia hospitalaria 2
- Sí, después del alta 3

94 ¿Has tenido contacto con algún grupo o asociación de apoyo o con otras madres/padres que han experimentado una muerte perinatal?

Marca todas las opciones que sean necesarias

- No 1
- Sí, he estado en contacto con una asociación o un grupo de apoyo por teléfono o e-mail 2
- Sí, he visitado o participado en un grupo de apoyo online 3
- Sí, he visitado o participado en un grupo de apoyo presencial 4
- Sí, he estado en contacto con otros madres/padres pero no en un grupo de apoyo formal 5
- Sí, he asistido a un evento de conmemoración 6

95 ¿Cómo valorarías el nivel de apoyo que recibiste de las siguientes personas?

- Nada de apoyo = 1
- Un poco de apoyo = 2
- Bastante apoyo = 3
- Mucho apoyo = 4
- No relevante/no les conozco = 5

- 1) Enfermeras/matronas 1 2 3 4 5
- 2) Médicos 1 2 3 4 5
- 3) Pareja 1 2 3 4 5
- 4) Familia cercana 1 2 3 4 5
- 5) Familia en general 1 2 3 4 5
- 6) Amigos cercanos 1 2 3 4 5
- 7) Amigos en general 1 2 3 4 5
- 8) Un psicólogo/psiquiatra 1 2 3 4 5
- 9) Otras madres/padres que han tenido una pérdida 1 2 3 4 5
- 10) Un grupo de apoyo online 1 2 3 4 5
- 11) Un grupo de apoyo presencial 1 2 3 4 5
- 12) Compañeros de trabajo 1 2 3 4 5
- 13) Un asociación de apoyo 1 2 3 4 5

96 Pensando en tus sentimientos generales sobre los cuidados en el hospital, marca el número que mejor indique el grado de acuerdo o desacuerdo actualmente con cada una de las siguientes frases. Si no estás segura, usa la categoría “Ni estoy de acuerdo/ni en desacuerdo”. Por favor, trata de usar esta categoría cuando verdaderamente no tengas una opinión clara.

- 1 = Estoy totalmente de acuerdo
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- 3 = Ni estoy de acuerdo/ni en desacuerdo
- 4 = No estoy de acuerdo
- 5 = Estoy totalmente en desacuerdo

A pesar de las circunstancias me siento satisfecha con los cuidados que recibí en el hospital..... 1 2 3 4 5
Recomendaría este hospital a otras madres / parejas 1 2 3 4 5

97 ¿Cómo te defines en materia religiosa?

- Católica..... 1
- Evangélica o protestante..... 2
- Judía..... 3
- Musulmana..... 4
- Mormón..... 5
- Ortodoxa..... 6
- Budista..... 7
- Testigo de Jehová..... 8
- No creyente / agnóstica..... 9
- Atea..... 10
- Estoy en un momento de dudar de mis creencias..... 11
- Otra..... 12

Si está en pareja (aparece por filtro)

98 ¿Cuál de las siguientes opciones describe mejor el nivel de estudios de tu pareja?

- Fue menos de 5 años a la escuela..... 1
- Fue a la escuela 5 años o más pero sin completar EGB, ESO o Bachillerato elemental..... 2
- Bachiller elemental, EGB o ESO completa (Graduado escolar)..... 3
- Bachiller superior, BUP, Bachiller LOGSE, COU, PREU..... 4
- FPI, FP grado medio, Oficialía industrial o equivalente..... 5
- FP II, FP superior, Maestría industrial o equivalente.... 6
- Diplomatura, Arquitectura o Ingeniería técnica; 3 cursos aprobados de Arquitectura, Ingeniería o equivalente..... 7
- Licenciatura o equivalente..... 8
- Master o doctorado..... 9

Si está en pareja (aparece por filtro)

99 ¿Cuál de las siguientes opciones describe mejor la ocupación de tu pareja?

- Profesional, técnico..... 1
- Directivo de la administración pública y de empresas.. 2
- Personal administrativo..... 3
- Comerciante y vendedor..... 4
- Personal de servicios..... 5
- Agricultor, ganadero, arboricultor, pescador y cazador..... 6
- Trabajador de la producción, conductores de equipos de transportes y peones (no agrarios)..... 7
- De transportes y peones (no agrarios)..... 8
- Profesional de las fuerzas armadas..... 9
- Estudiante..... 10
- Persona dedicada a las labores de su hogar..... 11
- Jubilado, retirado, pensionista y rentista..... 12
- Persona que no puede ser clasificada..... 13

100 ¿A qué clase social dirías que perteneces?

- Alta..... 1
- Media-alta..... 2
- Media..... 3
- Media-baja..... 4
- Baja..... 5

101 ¿Cuál de las siguientes opciones describe mejor donde vives?

- En una capital de provincia..... 1
- En los suburbios/periferia de una capital de provincia. 2
- En una ciudad pequeña o un pueblo grande..... 3
- En un pueblo..... 4
- En una aldea..... 5
- En una granja o una casa en el campo..... 6

102 Actualmente, entre todos los miembros del hogar y por todos los conceptos, ¿en qué franja estarían los ingresos netos de tu hogar al mes?

- Menos o igual a 300 €..... 1
- De 301 a 600 €..... 2
- De 601 a 900 €..... 3
- De 901 a 1.200 €..... 4
- De 1.201 a 1.800 €..... 5
- De 1.801 a 2.400 €..... 6
- De 2.401 a 3.000 €..... 7
- De 3.000 a 4.500 €..... 8
- De 4.501 a 6.000 €..... 9
- Más de 6.000 €..... 10

103 ¿Estarías interesada en ayudarnos con otras investigaciones que realicemos? También te pasaremos los resultados de la investigación en cuanto se publiquen.

- Sí, me gustaría participar..... 1
- Tal vez, pero me gustaría recibir más información antes de comprometerme..... 2
- No, gracias..... 3 → P105

104 *Nos has indicado que te gustaría participar en otras investigaciones o recibir más información, por favor deja tu nombre, teléfono y e-mail y estaremos en contacto. Recuerda que todos tus datos personales son estrictamente confidenciales y tu nombre nunca aparecerá relacionado a los resultados de la investigación.*

Nombre	
Teléfono	
E-mail	

Si contesta que no quiere participar en otras investigaciones

105 *¿Estarías interesada en recibir noticias sobre los resultados de esta encuesta?*

Sí.....	1	
No	3	→ P107

Si contesta que no quiere participar en otras investigaciones

106 *Nos has indicado que te gustaría recibir los resultados de la investigación, por favor deja tu nombre y e-mail, estaremos en contacto. Recuerda que todos tus datos personales son estrictamente confidenciales y tu nombre nunca aparecerá relacionado a los resultados de la investigación.*

Nombre	
E-mail	

107 *Si hay algo sobre la encuesta que te gustaría comentarnos que te parece importante o que hemos olvidado preguntar puedes contárnoslo en el espacio de abajo.*

Muchas gracias por tu ayuda, nos comprometemos a usar la información que nos has proporcionado para promover mejoras en los cuidados que reciben los padres después de una muerte perinatal.

AYÚDANOS CONTACTAR CON OTRAS MADRES

Es muy importante para esta investigación que contactemos con el mayor número de madres posible. Si conoces a otra madre o un familiar de otra madre que ha sufrido una pérdida gestacional entre la semana 16 y el parto, te agradeceríamos que copiases este enlace y que se lo enviases por correo electrónico o en el caso de no saber su correo electrónico que se lo comunicases por otro medio.

Enlace para mandar la encuesta a otras madres:

XXXX

INFORMACIÓN ACERCA DE LA ENCUESTA:

Si te gustaría recibir más información acerca del cuestionario puedes contactar con Paul Cassidy por e-mail: paulcassidy@umamanita.es

INFORMACIÓN SOBRE EL DUELO PERINATAL Y APOYO

Si te gustaría obtener más información acerca del duelo perinatal y apoyo te invitamos a visitar nuestra página web o página de Facebook:

<http://www.umamanita.es>
<https://www.facebook.com/uma.manita?fref=ts>

Para información acerca de apoyo grupal, pincha aquí:

[Grupo de apoyo a la pérdida](#)

También podemos recomendar las siguientes asociaciones que apoyan a madres y padres después de la pérdida perinatal y gestacional:

Petits am llum
<http://www.petitsamllum.org/>

Superando un aborto (SUA)
<http://superandounaborto.foroactivo.com/>

