

**The body and ontology:
Perinatal death and bereavement
in the technoscientific landscape
of hospital care**

***Cuerpo y ontología:
La muerte perinatal y su duelo
en el panorama tecno-científico del sistema sanitario***

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ABSTRACT

This study takes the body (of mother and child), the technoscientific hospital landscape and professional ritual as the locus of an endeavour to understand the embodied experience of perinatal death, in order to better comprehend how alternate understandings and ontologies of motherhood, personhood and bereavement emerge during care enactments. Grounded in a descriptive and ethnographic approach the research analyses data from the entries of 22 members of a pregnancy loss support forum and 10 narrative style interviews. The research traces embodied experience from pregnancy, through diagnosis to the

spatialised experience of the hospital, including the birth, postmortem contact and disposal of the corpse. Bounded by the sudden destruction of ontological security many of these women experience an existential crisis that results in a destructed stigmatised self. The research explores how overly medicalised obstetric care enacts understandings of perinatal death and bereavement that further problematizes postmortem relationships, creating toxic identities and embodied selves. Conversely, woman-centred midwifery that takes relational and social understandings as a basis for care can create the material conditions of possibility for a restoration of confidence in carnal self and a reconstruction of social bonds and order. Assembled through practice, discourse and policy, these bodies are individually, socially and politically enacted, but they are also multiple, mutable and enfolded assemblages of nature and culture. The research proposes that healthcare practice would benefit by considering natural stillbirths, just as contemporary obstetrics advocates natural childbirth.

KEYWORDS

Perinatal death, stillbirth, pregnancy loss, bereavement, hospital care, ontology, motherhood, personhood, hospital care, qualitative research.

RESUMEN

Este estudio considera el cuerpo (de la madre y del niño) y el entorno tecno-científico como lugar paradigmático para analizar la experiencia tras la muerte perinatal, con el fin de comprender como se desarrollan ontologías alternativas de la maternidad, la personalidad y del duelo. La investigación analiza las entradas de 22 miembros de un foro de apoyo a la muerte perinatal y 10 entrevistas narrativas. El artículo aborda la experiencia asociada al embarazo hasta la experiencia con el espacio físico del hospital, incluyendo el nacimiento, contacto posparto y la disposición del cuerpo. Delimitado por la destrucción repentina de seguridad ontológica estas mujeres experimentan una crisis existencial que se traduce en un yo deconstruido y estigmatizado. Exploramos la manera en que la atención obstétrica excesivamente biomédica promulga comprensiones de la muerte y el duelo perinatal que problematizan aún más las relaciones posmortem, creando así identidades encarnadas tóxicas, y por tanto exacerbando el duelo. Por el contrario, la atención centrada en la mujer y liderada por la comadrona puede crear las condiciones para una restauración de la confianza en uno mismo y la maternidad, y una reconstrucción de los lazos sociales. Estos cuerpos son situados en un espacio y condición individual a pesar de los múltiples

ensamblajes culturales y sociales que atestiguan su condición última. La investigación propone que la atención sanitaria debería considerar el stillbirth natural, de la misma manera que la obstetricia moderna aboga por el parto natural.

PALABRAS CLAVE

Muerte perinatal, pérdida gestacional, duelo, atención sanitaria, ontología, maternidad, personalidad, investigación cualitativa.

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Introduction

This study takes the pregnant body and the corpse (or remains) within the technoscientific landscape of healthcare as the locus of an endeavour to understand the embodied experience of death or loss during pregnancy or the neonatal period (referred to hereafter as perinatal death). Perinatal bereavement care and support is a relatively new phenomenon in Spain. Few health authorities have established care protocols and parent support and advocacy charities¹ have only been in existence for about 8 years, in comparison to those of the U.K. and the U.S.A. that set up in the 1970s. Recent quantitative research on care practices in Spain suggests that recommended bereavement support care, such as postmortem contact, options for disposition and keeping of linking objects, are often not in place and that care may be overly medicalized (Cassidy, pending). During exploratory qualitative interviews it was notable that in parents' descriptions of their interactions with health professionals that there was an absence of talk or any direct consideration of the emotional significance of the event (see also Pastor Montero, Sánchez Romero, Hueso Montoro *et al.*, 2007). Grounded in a descriptive and ethnographic approach,² the research investigates how care is practiced and enacted, rather than focusing on discourse and representation. By centring the analysis on a multidimensional spatialized and material world composed of the mother's body, the body of the dead child, and the technoscientific confines of the hospital, the primary objective of the research is to better comprehend how alternate understandings and ontologies of motherhood, personhood and bereavement emerge during care enactments.

Anthropological research shows how different cultures have negotiated very different understandings and practices around perinatal death and the personification of the unborn (Cecil, 1996a). These understandings and social rituals are variable over time too, acquiring new meaning in different epochs and cultures: catholic religious beliefs in the Middle Ages (Séguy, 2007); legal systems and socio-economics in 18th century Scotland (Jackson, 1986); and the introduction of perinatal death registers in England in the late 19th century (Armstrong, 1986). Latterly, consumer culture (Morgan, 1989), abortion rights (Morgan & Michaels, 1999) and the sequestration of death in a society focused on happiness (Ariès, 1974; De Miguel, 1995) all contribute to how perinatal death is socially understood and reg-

¹ Umamanita, Superando un Aborto and Petits amb llum.

² The author has been embedded, on a completely voluntary basis, as an independent researcher in the association Umamanita since 2012.

ulated (Nichols, 1989; Layne, 2003). From the accounts of older women's experiences, in the middle of the last century, it is apparent that this is also a story of patriarchy. Women's perspectives and their emotional wellbeing were almost completely marginalised from social and religious ritual and in healthcare, often with lifelong consequences (Cecil, 1996b; O'Leary & Warland, 2013).

At the heart of social tensions around perinatal death, in contemporary society, are cultural understandings of personhood in a society where religion, morality, medicine, feminism, biopolitics, parents and advocacy groups compete to define the unborn and/or dead fetus/child (Lim Tan, 2004; Williams, 2005; Keane, 2009; Martel, 2014). In essentialist terms, personhood is variably recognised on the basis of conception, as in some religious and anti-abortion stances, gestational age, as in stillbirth registers or at the moment of birth as in Spanish law (Article 30, 20/2011). On the other hand, relational and processual perspectives resist such dualism (Conklin & Morgan, 1996). From this perspective personhood is not an innate quality but culturally conferred (Kaufman & Morgan, 2005). So too motherhood and parenthood are constituted in social practice, such as healthcare, consumption and technoscience (George & Mitchell, 2000; Taylor, Layne & Wozniak, 2004). These views, largely emergent from anthropological research, are supported by research in psychiatry, which shows that maternal attachment may begin very early in the pregnancy or even beforehand and that grief experiences may be as strong for a miscarriage as a neonatal death (Peppers & Knapp, 1980). Although there is some disagreement about the existence of a positive relationship between gestational age and grief³ what is clear is that the advancement of the pregnancy is an unreliable predictor of attachment and the status of the unborn in the lives of the parents and their social network. So while for some women a miscarriage may be a relief, for others it might take years to overcome (Swanson, 1999).

Consequently, grief after perinatal death may be experienced at any gestational age. When it is experienced as grief it poses the same challenges of finding meaning, making sense of a changed reality and negotiating postmortem relationships (Uren & Wastell, 2002; Murphy & Thomas, 2013), much the same as in any bereavement (Klass, Silverman & Nickman, 1996; Neimeyer, 2000). As such, the boundaries between embodied maternal selves and the preborn are porous and entwined (Lupton, 2012), presenting great challenges to healthcare professionals. Layne (2003) proposes that a processual view of personhood, as varied and dynamic, permits the idea that for some parents an embryo might have person-

³ see Lasker & Toedter (1991) for an opposing viewpoint to Peppers & Knapp (1980).

hood and for others it might not. Within this understanding of perinatal death, psychosocial and relationship based care models take precedence over care that focuses exclusively on the physiological, meaning that the primary task of healthcare professionals is to build empathetic relationships with women and their families in order to establish how best they can adapt care to their individual needs (Cacciatore, 2010). In this respect, care after perinatal death must also be considered within the context of the natural childbirth movement, which seeks to reduce the proportion of unnecessarily medicalised births and promote rights to information and choice (Chalmers, 1992). Relationality, as such, provides a means of avoiding 'new' orthodoxy and permitting agency, while recognising individual, social and cultural influences (Layne, 2003). In this sense when the terms baby/child/son/daughter are used in the text they refer only to the status that these informants give the embryo/fetus and not to any generalised dogma that might exclude one person's lived experience in favour of another.

Accepting relational understandings of personhood, what about relationships with the dead? Firstly, contemporary sociological, anthropological and psychological understandings of grief and death recognise that the dead (and biologically alive but socially dead) maintain an active and dynamic presence in the lives of the bereaved (Mulkay, 1993; Klass *et al.*, 1996; Hockey & Draper, 2005). A concept supported by research in perinatal bereavement (Murphy & Thomas, 2013). So, while the identity of the living is firmly embedded in the body (Merleau-Ponty, 1962) so too is the dead body a powerful locus of identity and self. Through objects, places and spaces the absent are materialised (Hockey, Komaromy & Woodthorpe, 2010) or the immaterial made present (Bille, Hastrup & Sørensen, 2010), such that even the disembodied become paradoxically embodied. Social bonds in death are, as such, just as important and potent as in life, and bereavement clearly benefits when the relationship with the deceased is positive before and after death (Van Den Hoonaard, 1999).

My primary interest, therefore, is in the body (both alive and dead and entwined) as a site of experience and social enactment composed of various entangled materials and assemblages (Mol, 2002) that make up the cosmos of perinatal bereavement. By looking through these bodies and landscapes (Henare, Holbraad & Wastell, 2007; Tilley, 2008) the research seeks to consider the material, social and political manifestations of these bodies (of mother and unborn child in union and later separated) in the context of their histories and their multiplicity of forms. As these bodies move through time and space, the research sets out to better understand how complex, entwined and competing ontologies of perinatal death and bereavement are emergent in healthcare practice (Mol, 2002; Farquhar & Lock, 2007).

Method

Research design and fieldwork

This ethnographic research study was conducted through both participant observation and the analysis of data collected from two sources: a sample of entries from an online support forum (Superando un Aborto [SUA]) and narrative style interviews with parents. Employing data from two sources had one principal benefit. Firstly, the unmediated quality of naturally occurring data (Potter, 2004), such as the forum (parent to parent), reveals narratives and interactions that are more direct, emotional and explicitly personal in comparison to the interviews. On the other hand, the narrative interviews, understood as a joint production between informant and researcher, permitted more in-depth exploration of subject experiences, which reveals rich descriptive detail (Mishler, 1991).

Extraction of data from the online support forum SUA

With agreement from the forum moderators about the protection of members' identities, a random sample of all the entries of 22 members was extracted from a sample frame of 450 members who had made between 5 and 30 entries.⁴ The final sample included intrauterine losses and deaths from all trimesters, approximately half of which were before 20 weeks gestation, as well as one neonatal death and two participants who had had a pregnancy termination for medical reasons. Seven forum members had had multiple pregnancy losses. Two members identified themselves as Latin American residents in Spain. It was not possible to determine social class or education level.

Interviews

The research employed a purposive sample to contact participants with as wide a range of socio-demographic characteristics and types of perinatal death as possible. In total ten interviews were conducted. The first three participants were couples who were contacted through the association Umamanita, two interviews were conducted after meeting the women at an annual commemor-

⁴ Of the 2,011 registered members in February 2013, 846 had made at least one entry.

ative event and the other five interviewees were contacted after participating in an online survey on healthcare experiences. Of the ten interviews, six had lost their child during the previous six months; the other four had lost their child between one year and six years previously. All the deaths occurred between twenty weeks gestation and 72 hours postpartum. Nine were singleton pregnancies and one was of twins. One death was a termination of pregnancy for medical reasons and two cases were neonatal deaths. One informant chose to homebirth after a death due to incompatibility with life at 26 weeks, which provides a counterpoint to the hospital births. The rest were spontaneous intrauterine deaths. Three women had living children before the death and two had had children since. One father was a Northern European and two mothers were Latin American residents in Spain. The participants were predominantly from middle and educated classes.

The author carried out all the interviews, which lasted between two and four hours. Two interviews took place in the researcher's home and the remainder in participants' homes. The interviews were conducted as narrative open-ended conversations (Mishler, 1991).

Transcription & Analysis

Interviews were conducted in Spanish and transcribed verbatim. The analysis was undertaken at the same time as the fieldwork and followed the principles of comprehension, synthesis, theorizing and recontextualizing of Morse and Field (1995). Through repeated readings a series of codes and sub-codes were generated until sufficient points of consensus could be identified in the data (Lincoln & Guba, 2000). The author has translated the interview extracts presented in the text. All names used in the text are pseudonyms.

Data quality

The research design strives to integrate strategies that promote reliability and validity through methodological coherence and transparency (Morse, Barrett & Mayan, 2002). Key to this approach is triangulation (Denzin & Lincoln, 2000), reflexivity and informant validation (Mays & Pope, 2000). The data is triangulated through the ethnographic approach, two sources of data (naturally occurring and interview) and the fact that this study is part of a wider research project that includes quantitative methods.

Limitations

The study has two principal limitations related to the sampling. Firstly, the difficulty of recruiting participants in general and in particular those of lower economic means and education levels, signifies that there is an over reliance on participants from middle to higher social classes. Furthermore, all of the women and men who participated in the study had some contact with support associations, although heavy users and moderators were excluded from the sample extracted from the forum and none of the participants in the personal interviews were actively involved in support associations at the time of the fieldwork.

Analysis and findings

The analysis, structured in four sections, roughly follows the temporal movement of the mother's embodied experience before and during the hospital stay. Firstly, the analysis focuses on experiences of pregnancy prior to diagnosis and shortly afterwards, then on embodied experiences within the spatialized confines of the hospital and finally on the birth, postmortem contact and the disposition of the corpse.

Technoscientific pregnancy and perinatal death

For most of these women second and third trimester perinatal death comes as a complete shock. For others repeated first trimester losses are a similarly devastating experience. Rosa, whose baby boy died after going on life support following an emergency labour at 39 weeks, describes her sense of shock at the unexpected turn of events, having already given birth twice:

I just cried and cried and I, I couldn't, I couldn't find the words, I was in shock, up till then it was "everything's great, everything's great", I was imagining the perfect birth, having had two children already, "everything's going to be just wonderful"

[Rosa, personal interview]

Laura, whose twin boys died shortly after a premature birth at 20 weeks, following an infection, describes her experience:

you just aren't prepared, you're in the bliss of preparing to receive your sons, and you're not prepared, not thinking, nor anything

[Laura, personal interview]

Despite cultural perceptions to the contrary, advocate associations have been trying to draw attention to the fact that many thousands of Spanish women still experience second and third trimester pregnancy loss or undergo medical terminations (Prats, *El Pais*, 2013). Underlying these assumptions is how 20th century medical advances have pushed pregnancy loss to the margins of social consciousness due to a hugely reduced infant and maternal mortality rate and a hegemonic belief that pregnancy is controllable and predictable through scientific knowledge and self-determination (Georges & Mitchell, 2000). Cultural expectations of linear progress and sequential life courses (Layne, 2003; Hockey & Draper, 2005) also play a role in the prevailing ontological security that women feel, which obscures the unpredictable 'nature' of pregnancy (Earle & Letherby, 2007). How this embodied corporeal confidence intersects with healthcare and discourse is evident in the following extracts. Firstly, Monica, whose baby boy was diagnosed as having died intra utero, following a check-up at 32 weeks:

because you always think that if something is going to happen, it's during the first three months, not to tell anyone, to take good care of yourself, to not overdo it physically, the usual things, but then after three months, then, for me it was no problem

[Monica, personal interview]

you don't smoke, you don't drink, you take such good care of yourself

[Celia, personal interview]

I was 15 weeks gone and as I'd passed 12 weeks, well, I just didn't think anything could happen... later you realise that it can happen in any week

[Almudena, forum member]

When so much responsibility for a healthy birth is placed on the mother, and female identity is socially manifest and so strongly related to motherhood, it is understandable that some of these women recur to a self-criticism and call into question their own normality and sense of identity

(see also Gerber-Epstein, Leichtentritt & Benyamini, 2008; Murphy, 2012; Kelley & Trinidad, 2013), particularly when the loss occurs during a first pregnancy:

I wanted to meet women who had experienced the same as me because I saw myself as a something weird [...] incapable of the most basic thing, to be a woman, man is born, grows up, reproduces and dies, I couldn't do something basic, you know?

[Maria, personal interview]

what I mean is, this goes against nature, I don't know, and it's also something that in the physical part and all, I don't know, I don't see myself as the same person now as six months ago or a year ago, I feel, I'm a different person, I don't know

[Rosa, personal interview]

Eva, whose daughter died at 39 weeks, some four years previously, expressed throughout the interview how much the loss affected her sense of self and identity as a woman. Consequently, during the hospital stay she isolated herself from support:

because, well when you have a baby in your room, ok, then they should come and see you, but when you've just lost her, why would they come? [...] and later, well, for sure everyone on the ward knows that I'm the one that lost her baby

[Eva, personal interview]

Women's sense of control over their pregnancies and their faith in medical advice contrasts with the lack of medical knowledge when death occurs:

they said that she was dead, that they couldn't do anything and that.. they said at one stage at the start that it could have been a small displacement of the placenta, but that in reality they didn't know anything, anything at all

[Arantxa, personal interview]

This juxtaposition of the 'all-knowing' scientific and technological model with this 'lack of knowing' can be understood in Barthesian terms as a destruction of myth, whereby a naturalized

and taken for granted cultural meaning “reflects an unchanging and universal order of things” (Parker, 2004: 310). We might also say that one ontology of pregnancy, as controllable and predictable, has, over the past century, come to ignore the subjectivity of nature, and objectified the body as bendable to our will and “devoid of intentionality and intersubjectivity” (Csordas, 1994: 4). However, in the time immediately after the diagnosis, an ontology that recognises the unruliness of nature cannot be so easily assimilated. Many bereaved women only recognise a personal bodily failure and encounter an existential crisis of ontological security. Paradoxically, therefore, some women may recur to a singular understanding of themselves as ‘unnatural’; freaks, bracketed to the “normals” (Goffman, 1963), at least in the time immediate to diagnosis. At a minimum they are also confused and disoriented, which, as we shall see, underscores their interactions with health professionals during the hospital stay, which may reinforce stigma or counteract it.

Technoscientific landscapes of care

Bearing in mind the findings of the previous section, the analysis turns to interactions between the mother and health professionals in the spatialized socio-material world of the hospital, to analyse how enactments create alternate ontologies of healthcare, personhood and parenthood. Belén, who was cared for in a hospital renowned for promoting less medicalised and respected childbirth, recounts her interactions with staff on the maternity ward, after her daughter was diagnosed as having died intra utero at 32 weeks:

we had so much emotional support, from the nurse, midwife, gynaecologist, and the woman who cleaned the room too, I even cried with the woman who cleaned the room, she started crying and, well, it's so important, to me at least I think they helped us start a healthy grief, very healthy

[Belen, personal interview]

When Belén was asked to expand on the way that the health professionals interacted with her, it is notable how she focuses on what they did and how they did it rather than on the specifics of talk. The practice of care in its physical embodiment of body language, touch and tone of voice creates the possibility of understandings of perinatal death as socially significant and emotionally understood:

when they were putting in the epidural I had a nurse holding me by the hand, you know?
[...] holding me by the hand, or when the midwife came, it was how they talked, the ges-
tures they made and their body language

[Belen, personal interview]

Conversely, and in support of other research (Pastor Montero, Vacas Jaén & Rodríguez Tirado, 2007; Pastor Montero *et al.*, 2011), care with a physiological focus, is notable in the narratives for a one-dimensional physical interaction that avoids emotional expression or direct talk about the loss/death, and evokes a silence that like matter is solid and impenetrable:

just doctors and nurses coming in and going out of the room, examining me physically
without saying anything.

[Patricia, forum member]

In the following extract, María Carmen describes, in matter of fact language, the treatment of a second trimester loss as routine and systematized, notable for its focus on physiology, paper-work and her juxtaposition in a hallway with happy pregnant women:

I had a small amount of spotting and when I went to the gynaecologist, she told me that my baby's heart wasn't beating. They gave me a curettage, it's horrible... the paperwork, that they treat you like something routine, that they put you in the hallway with all the women who will give birth happily... etc.

[María Carmen, forum member]

In the next section I explore enactments around birth in more detail but here it is worth examining a narrative from the forum about a mother's experience during a failed attempt to accelerate (physiologically) the delivery of her stillborn daughter at 22 weeks gestation. Beatriz, a forum member, who initially found the idea of giving birth difficult, narrates that she decided to "enjoy the last few moments of the pregnancy and the feeling of having her inside me". The

birth, a potentially positive and important experience (Rådestad & Christoffersen, 2008) becomes subsumed in unnecessary⁵ technological attempts to speed up the delivery.

they didn't help me much, they put a balloon in me, yes you've read correctly, inside me, to help me dilate, [...] they inflated it too much, so as soon as I opened my legs it flew out, after that they didn't put it back in, they told me that I'd have to have my dead daughter inside me for two or three days, can you imagine!

[Beatriz, forum member]

The health professionals recur to what they know, delivery, even though under normal circumstances there is no health benefit to an accelerated delivery of a stillbirth (Royal College of Obstetricians and Gynaecologists, 2010). The dominance of the enactment by the professionals obscures other possibilities, of going slower, of expectant management and of woman-centred socially focused care. Instead, in this instance, the actions of the professionals create an understanding that is toxic, inconvenient and that frames the death as unnatural.

The understandings that are emergent in these enactments and practices around the body show how meaning and self are developed in practice and through the materiality of the body. Where ontologies clash and emerge as incompatible, the primary focus of care is on the body and pathology: examinations, measurements, procedures, protocols and on paper-work too. Csordas (1994) maintains that objectification can result in the individuation of the psychological self and the instantiation of dualism in the conceptualization of the human being. So the emergent ontologies in the hospital can encourage the mother toward silence, a lack of confidence in her carnal self and an amplification of the sense of failure that greets the diagnosis, defining death as illness, biological and of the individual as opposed to the embodied and social.

Research suggests that in light of poor training health professionals will continue to do what their obstetric training demands, often recognising that they are at a loss as to how to communicate with the mother on any other level than the physical (Pastor-Montero *et al.*, 2011). While the health professional may feel that they are doing all they can, or all they are trained to, the chasm of emotional distance, paradoxical to physical nearness acts to define grief and loss as emotionally insignificant, an illness, enacting one kind of understanding and closing off pathways to alternatives.

⁵ Having consulted with an obstetrician it appears that the use of a dilating balloon is not a normal or necessary procedure for induction of a normal stillbirth.

In the next two sections we look at the birth, the moment of physical separation of the mother and child, and how practices define the possibilities of postmortem contact and the way that the body of the child is treated as a matter-person composite or just matter.

Birth and postmortem contact

Postpartum contact has been a recommended aspect of perinatal bereavement care since the 1970s when it became associated with positive outcomes (Kirkley-Best & Kellner, 1982; Kowalski, 1983). However, such social action and ritual after perinatal death is particularly difficult. As we have seen in the previous sections, the principal actor is not only in shock but most importantly they are faced with a changed reality and perception of self so completely unexpected that they are disoriented and have trouble comprehending what is happening. In support of other research (Rådestad, Surkan, Steineck *et al.*, 2009; Ryninks, Roberts-Collins, McKenzie-McHarg & Horsch, 2014) most, but not all of the interviewed women, testify that the news that they were carrying their dead child and that they would have to give birth is quite terrifying. Similarly, the idea of postmortem contact evokes great fear. As Peelen (2012) observes there is amongst some of these women a self-protective emotional detachment after diagnosis.

For this reason the spatialized environment and performative actions of the health professionals play a critical role in opening and closing pathways to alternative, complementary and/or competing understandings of perinatal death. If we first take the case of Celia, who was cared for by a midwife who had received bereavement support training, we see a small example of the role that the midwife plays in supporting a reconstruction of the bond between mother and daughter, as information is shared and new histories enacted.

and later when she was born, really it was so beautiful. It was... she is, is beautiful, Miriam is beautiful ((voice trembles)), such a pretty face, [...]. As soon as I relaxed a little, slept a little, they lowered the lighting and then it happened, and, she was born with her hand first, Charo (midwife) told us, and it was just like she always was in the ultrasounds

[Celia, personal interview]

Belen tells how the stillbirth of her daughter at 32 weeks is comparable to the previous live birth of her son. Also notable is how the midwife is incorporated into the circle of family:

... Miguel's birth was fantastic, just lovely, a wonderful experience and I think that Susana's birth as well, in a different way, logically, but it was for me ((too emotional to speak)), well, surrounded by her father, her mother, a midwife and almost no one else, she wasn't born in a surgery, full of stressed out people, she was born in a peaceful place and had the best birth she could have.

[Belen, personal interview]

Notable too, in Estela's interview, was the social support and integration of her midwives into the family before and during the birth of her daughter at home. In these cases the protagonists of the action are the mother and her child as the health professionals play a supporting, through social and participatory, role. In these cases woman-centred midwifery and a spatialised landscape of care oriented toward natural and respected birth opens up the possibility of a shared ontology and understanding of what it means when a child dies during pregnancy. The mother can take control of her embodied experience as both physical and social, defining through enactment her status as mother who brings her child into the world. As Estela states, referring to the birth:

it's the only moment that you can perform the role of mother

[Estela, personal interview]

In contrast, the following quote shows how the material conditions of possibility of postmortem contact are made especially difficult by the performative and spatialized context of a delivery room oriented toward biomedicine. The midwife, who had also received training, had encouraged María to see and hold her 39-week-old daughter Angela throughout the induction. After the delivery, while doctors continue their work, she tries to reassure María that holding her child will be a positive experience. In the end she only saw her daughter briefly and expressed many regrets about not having held her:

maybe if there weren't so many people around [...] the gynaecologist was looking to see if my uterus was alright, you know?, it was then, you know? She was there, right between my legs, examining me, and the midwife was in my face with, with Angela. Then there were, the people all around, doing their thing, that they have to do, it would have been better if it had been more private...

[María, personal interview]

Here the socially oriented actions of woman-centred midwifery compete with the physiologically oriented actions of the doctor. Potential action, such as placing the baby beside the bed and giving the parents some time alone in a peaceful environment are not possible in this configuration of care. Rather, the mother finds herself between two embodied experiences, one as object the other as subject, required to express agency under the constraining forces of circumstance and a medicalised birth.

In the next example the mother was asked shortly before the birth if she wanted to see her son, but declined. Arantxa stated that she was happy that she didn't, preferring to remember him through the positive memories of the pregnancy (Monica expressed a similar sentiment). However, this view is informed by her husband's recollection of seeing the child. Her narrative reveals how the family was relegated to a role of passive observation, whereby the material conditions of postmortem contact cast the baby/body in a biomedical light, displayed for objective examination, rather than social ritual:

They let my husband and my in-laws see her, she was naked and they hadn't cleaned her much, and that's all I know, [...] she wasn't presented like a baby, she was laid out like a corpse, I mean, they hadn't even cleaned her, nor dressed her in any way.

[Arantxa, personal interview]

In Lucia's case there was no discussion of the possibility of contact nor any preparation for the birth, which took place after the mother was administered medication to terminate the pregnancy⁶ and she quickly went into labour in her room. Lucia's narrative describes how the actions of the doctor create absolute authoritative and material blockages to any possibility of autonomous decision making. Death here is enacted as toxic and polluting and delivery proceeds straight to disposal:

...he put a green cloth over my legs and he said, I was pushing and all, and he said, "now don't look, ok!", I mean, I had my boy, and he said, "now, don't look, ok!", I was like this, looking to one side, he must have taken him to the bathroom, my husband and my mother-

⁶ In this case the mother had lost all the amniotic fluid almost a week previously and was bed bound in the hope that the pregnancy would recover. When her condition didn't improve a decision was taken to terminate the pregnancy through medication and induction. Although the mother recognises that there was little alternative and consented, she feels that she had little participation in the decision-making process.

in-law outside, I imagine that he put him in a container, I don't know, I wasn't able to ask at the time, "now, don't look, ok!"

[Lucia, personal interview]

The guilt and frustration at lost opportunities that Lucia expressed throughout her interview, some three years later, is similar to the Beatriz's feelings of guilt about not having received her child, who died at 22 weeks, into the world in a loving respectful way:

I saw how they wrapped her in a sheet and until this day, at the time I rejected her and I'll never forgive myself, she left without being able to ask her forgiveness for not protecting her, without telling her I loved her like crazy.

[Beatriz, forum member]

Peelen (2012) has proposed that postmortem contact helps the mother to overcome a temporary detachment and to release the baby from the liminal status of pregnancy, avoiding the polluting effect of ambiguous categorization. However, taking an ontological approach, that seeks to avoid reliance on any clear categorizations between life and death (Howarth, 2000) or birth and personhood, it might be considered that in the light of the death event that there are a series of competing ontologies enacted in social practice that direct understandings of both motherhood and personhood. From this viewpoint, when death occurs, the healthy socialized intrauterine baby shifts from an unambiguous relationally developed status to an ambivalent and confused status, becoming temporarily interwoven and inseparable from the death event. The overlapping and inseparable identities of both mother and child acquire a toxic status that represents a destruction of self and motherhood (guilt, shame etc.) and a physical threat and fear of carrying a dead being, *in addition* to the status of son/daughter. From this point social practice and ritual can direct both the mother and the baby back toward unambiguous identities and a restoration and reconstruction of social bonds or towards a reinforcement of toxicity, stigma and a destruction of the moral order (Davies, 2002).

In this sense the assemblage of materials and bodies that make up these enactments are multiple, creating multiple forms and identity. They can direct the birth and embodied experience toward alternate understandings, between what is a good birth from a biomedical perspective and what is a good birth in the context of perinatal death, grief and potential loss of motherhood.

Disposition of the corpse

Prior to the 1970s, in many western countries, it was common for stillborn babies to be buried in common plots, in unconsecrated ground or under church walls, amongst other methods (Lovell, 1997; Garattini, 2007; Peelen, 2009). Now, in the United Kingdom, for example, parents have the right to the respectful disposal of an embryo or fetus lost at any gestational age (Royal College of Obstetricians & Gynaecologists, 2005; 2010), but in Spain many ambiguities about disposal practices persist, particularly for early losses.

For many of the women in this study, who had had losses before 26 weeks, the proprieties of disposition and the right to possession and a dignified burial or cremation are an important and often distressful theme. This finding supports the results of a recent quantitative study that found that the practice of fetal disposal is somewhat haphazard and varies from one case, or hospital, to the next; between 16 and 26 weeks gestation health professionals rarely broach the subject of disposition and in almost all cases parents were not given any options on the disposal method, other than hospital incineration (Cassidy, pending).

The potential for toxicity and spoiled identity when birth and disposition become conjoined and inseparable is already evident in some of the extracts in the previous section (see the quotes from Beatriz, Arantxa and Lucia). Here, Beatriz goes on to describe how her rejection of the option to see her child, leads her to imagine a disposal that is undignified for a person. She experiences considerable anguish and regret at not having ensured a proper burial, which now means she has less opportunity for further ritual and contact:

... at least they gave you your son's body and you could give him a dignified and loving burial. I lost my first daughter at 22 weeks, the last thing I remember is that they took her away wrapped in a sheet, IT HURTS when I think that she is thrown in some rubbish dump, that I can't go and see her and keep her company

[Beatriz, forum member]

Three years after the loss of her son at 21 weeks, Lucia, still bitter at the very paternalistic care she received in a large public hospital, finds it hard to understand that her son has seemingly disappeared without any trace or knowledge of what happened to him.

I haven't been able to get any closure [...] how is it possible that a person just disappeared?

[Lucia, personal interview]

This not knowing was a source of much distress, as she expressed during the interview that she could only imagine a dishonourable impersonal disposal of matter, which now contaminates her relationship with her son. She questions how someone providing healthcare could have the right to take possession of something that was hers, without any information or consent:

because he's mine, he's mine, he's mine, I mean ((voice trembles)) he's mine, he's my son, you haven't taken, you've helped me resolve a health problem, but he's mine and you never asked me anything, not even "do you want to see him?, do you want to hold him?"

[Lucia, personal interview]

In the next extract Sara, who had a first trimester loss, describes a confrontation with a nurse who tries to rectify a procedural error, whereby the mother had been given her baby's remains by the gynaecologist. Despite threats to call security a standoff ensued and the mother eventually held onto the remains. Here the remains are a site of different ontological enactments, as both the mother and the nurse struggle to apply their own understandings of social order:

the gynaecologist gave me a small container with my baby's little body, which I held on to with all my might [...] a nurse, Maria Jesús (I'll never forget her name) asked me what I had in my hand. The porter told her. She told me that I had to give it to her and I said no, that it was mine, that I needed to bury it to close a cycle in my life and live my grief and she told me that fetal remains (it almost broke my heart to hear her speak like that) couldn't be taken out of the hospital [...] and that I had to give it to her.

[Sara, forum member]

In the final extract, María Carmen, whose baby died at 14 weeks, was able to recover some remains from the private clinic where she had been treated. Away from the bounds of hospital practice and procedure, the agency that the mother expresses is potent, as she describes an embodied, social and physical practice of carrying out an informal ritual, on her own terms:

In the end I went to get my little daughter from the clinic and I know that was the best, I feel so happy to have had her at home for a night [...] we dispersed the ashes of the letters in the river and found a tree where we could bury her, that was the hardest moment, I had to leave her there, but the good thing was I did it with my own hands, I had her with me, I kissed her, I smelled her once again. I gave her some flowers and I said goodbye.

[María Carmen, forum member]

These narratives show that the corpse, as Oestigaard (2004) points out, is ambivalent and potent, as it straddles both nature and culture, is both matter and of the soul, human and non-human, requiring a successful disposal to avoid problematic transitions between life and death (Oestigaard, 2004). However, it is apparent that a successful disposition for the technocratic hospital may be an unsuccessful and problematic disposition for parents, which provokes a destruction of identity and social bonds that may problematize postmortem relationships. Similarly, it has to be recognised that for some parents the technocratic efficient hospital disposition may be an appropriate resolution. In this sense the corpse is also multiple.

Problems arise from strict procedural practices that draw clear lines between one woman's experiences and another's on the basis of biometrics and not processual understandings of relationships. However, as mentioned earlier, disposal practice is not uniform or consistent. At least part of the problem appears to lie in the regulatory and legal framework around personhood, birth registration and disposal. Personhood is not legally recognised unless the fetus is born alive (Article 30, 20/2011), yet article 45 of the law states that all fetal deaths after 180 days (26 weeks) must be recorded in the births register for statistical purposes (Article 45, Law of 8 June 1957). Furthermore, in each region different mortuary regulations govern local disposal practices. As Puras-Gil, Teijeira-Alvarez and Balana-Asurmendi (2009) point out, the laws and regulations related to disposal and pathology practices of fetuses, under 26 weeks gestation, use variable and imprecise terminology, contributing to confusion and variation in practice. Regardless, any reduction of diverse narratives and embodied experiences to singular, hierarchical and simple understandings potentiates the possibility of problems in post-mortem relationships and diminishes the possibility of autonomous and social enactment. That said, as the U.K. laws demonstrate it is possible to fully involve parents and give them options in disposal decisions, while also fulfilling public sanitation needs.

Summary and discussion

This study set out to develop a better understanding of how care enactments can influence the process of bereavement after perinatal death by examining the pregnant woman and the corpse as sites of social and cultural practice. The findings should be interpreted within the context of the limitations of the sampling and cannot be taken as a universal reflection of care practices or parents views on pregnancy loss and perinatal death, but of the cohort of women who participated as informants.

A fundamental basis of grief, are the attempts by the bereaved to re-establish order amidst the disorder and chaos of loss and death; "relearning the world" as Attig (2011) puts it. Contemporary theory increasingly recognises that adverse social dynamics can negatively impact grief (Klass, 2006), understood as a process of reconstruction and managing post-mortem relationships. In this sense the fact that perinatal bereavement may be an unusually traumatic experience (Turton, Hughes, Evans & Fainman, 2001; Engelhard, Van den Hout & Arntz, 2001) and that women are prone to heightened feelings of vulnerability and loss of control (Ujda & Bendiksen, 2000; Wojnar, Swanson & Adolfsson, 2011), social dynamics are particularly relevant. While the study looks only at experiences during the hospital stay and not at other individual, social or institutional influences on the process of grief, it is important to consider the role that hospital care plays in why some of the women in this study appeared to have continued difficulty establishing a form of order and stability after perinatal death, and others seem to struggle.

As a context to hospital care we saw how the event of perinatal death may be traumatic and disorienting, unearthing as it does a critical disjunction between what these women thought they knew and a changed reality that they must try to comprehend. Underscoring this is the way that the pregnant natural body is culturally appropriated and divested of subjectivity and intentionality until nature in the form of unexpected death destabilises and exposes the naturalized actors (Law, 2009) that make up modern technoscientific pregnancy. As such, the flip side of biomedically oriented care is that when it cannot prevent death there is a vacuum of experience and knowledge that may precipitate an evaporation of the ontological security that it has helped to create. The relative rarity of the event and its status as taboo mean that in the time immediately after diagnosis, when they have little opportunity to seek out new meaning and understanding, many of these women recur to a stigmatised destructured sense of self (Goffman, 1963), bounded by guilt and shame and feeling unworthy of the status of mother (Layne, 2003). For this reason the enactments of

healthcare professionals play a critical role in the social understandings of the significance of the event that develop in the short time that these women spend in the hospital (see also Lovell, 1983).

On the one hand, woman-centred care can support these mothers towards emotional and social understandings of pregnancy loss that recognises the individual significance of the death or loss within relational constructions of personhood. In contrast to their initial feelings, all of the women who had respectful post-mortem contact viewed it as a positive empowering ritual. However, when postmortem contact is absent, or when it is overly dominated by a medicalised ontology, there is a greater possibility that the relationship between the mother (or father) and their child will suffer. Klass (1997) points out that bereaved parents' negative perceptions of themselves as parents can have a deleterious impact on post-mortem relationships with their children. In a similar way these parents view any failures to receive and dispose of their baby honourably and in a dignified manner as an enactment of poor parenting that has a destructive impact on their sense of self and the process of bereavement. Taking a relational approach, healthcare professionals can support parents in enactments that create the material conditions of possibility to continue the process of socialization and parenting that have begun during pregnancy, redirecting embodiment towards a restoration of confidence in carnal self and a reconstruction of social bonds (Walter, 1996; Klass, 2006), albeit in an unexpected and unplanned manner.

On the other hand, biomedical care, oriented toward physiological attention, can, as Lunquvist, Nilstun and Dykes (2002) have also found, have a disempowering effect through reduced participation in decision-making and emotional silence. In this sense the continuation of medical work and professional ritual (Illich, 1976) creates authoritative blockages to alternate understandings that take into account the individual and wider social significance of the death or loss. So, although the dead body of the baby has been described as matter out of place in the delivery room of modern obstetrics (Bleyen, 2010), it may also be that the dead baby as a site of practice brings into even sharper focus the conflicting ontologies between women's needs and authoritative and paternalistic obstetric practices. This is not to suggest that healthcare professionals act with malice. Research shows that healthcare professionals often remain silent as a means of self-protection from the distress of death (Santisteban-Etxeburu & Mier-Zárraga, 2005) and in perinatal death it is recognised that they often feel emotionally overwhelmed and powerless (Fenwick, Jennings, Downie *et al.*, 2007). It may be that in the absence of proper training they recur to their own secure ontology of physiological care, as would be suggested by the research of Pastor-Montero *et al.* (2011). From this point of view we can consider the idea of a natural stillbirth (Warland,

Davis *et al.*, 2011) just as much as we can a natural childbirth, which encompasses emotional support, immediate postpartum contact, reduction of medicalization and technological intervention and of course a right to information and choice about all aspects of care (Chalmers, 1992).

The practice of disposition emerges as an important consideration for restoration not only of motherhood/parenthood and the ability to protect their child, even in death, but of how practice enacts personhood. The proprietaries of possession and disposition of the corpse, particularly in early losses, highlights how the corpse too is not a unified entity but can mean multiple things, often simultaneously (Harper, 2010). For the hospital an efficient disposition of biological waste may be a dishonourable, traumatic and distressful resolution for parents, while for others it may not. The corpse, therefore, while both present and particularly when absent, expresses a potent agency as it plays an important role in defining relationships and identity not just between the living and the dead but also amongst the living (Kaufman & Morgan, 2005). As Morgan (2002) points out assemblages of scientific, sanitation and other social practices that denoted embryos and fetuses as medical waste, at the beginning of the 19th century are no longer wholly pertinent, even if they are still practiced, as new assemblages have created new complexities and new meanings that need to be addressed. Legal and regulatory ambiguity complicates practice and patently needs revision and the development of a framework that is acceptable to parents, healthcare, sanitation and legislatures.

The statuses of parent and child that are developed (individually and socially) during pregnancy are not easily discarded, once they have become a fundamental part of one's sense of self and the social order. Just as when the pregnancy is going well, in death praxis enacts multiple competing and/or complementary ontologies and understandings of the embodied meaning and sense of self, and one's place in the wider world. Thus in pregnancy and in pregnancy loss both the mother and the baby are constituted individually, spatially, materially, socially and politically (Farquhar & Lock, 2007), but are also transmutable and multiple (Mol, 2002). The challenge for health professionals and society is to consider all the versions of these entangled objects as they are enacted in practice and to avoid simple reductionism and singular ontologies.

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