Pregnancy termination for fetal abnormality: ambivalence at the heart of women's experience

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Abstract

The aim of this article is to demonstrate the centrality of ambivalence in women's experience of pregnancy termination for fetal abnormality (TFA). Data were collected from two qualitative studies conducted in England and France with women who had undergone TFA (n = 44). The findings point to eight manifestations of ambivalence throughout the process of TFA: hope and despair, a choice but no choice, standing still and rushing, bonding and detaching, trauma and peace, disclosure and secrecy, bridging past and future, and individual and societal experience. Women's ambivalence illustrates their internal struggle to reconcile the act of termination with their desire to become mothers. It also reflects societal tensions regarding abortion and disability. We argue that the absence of normative responses, social desirability bias and the potentially confusing coexistence of the fields of prenatal diagnosis and social integration of people with disability account for the ambivalence women feel as they go though TFA. As women's ambivalence may impact upon the way they adjust to TFA, it is important to remain cognisant of the complexity of TFA to support women appropriately.

Keywords: termination of pregnancy, fetal abnormality, qualitative, ambivalence,

Introduction

The present article is based on a series of studies which aimed to investigate women's experience of pregnancy termination for fetal abnormality (TFA). Our research endeavour started with the completion of a doctoral thesis in psychology conducted in England, and was later complemented by research carried out as part of a large programme on prenatal diagnosis in France which involved a multidisciplinary team of researchers. Our aim in this article is to

illustrate the ambivalence expressed by women who undergo TFA, as well as the processes that underpin it. Our focus on ambivalence is based upon the fact that it is one of the most prevalent phenomena observed in our studies, and that it may represent a significant challenge to women's adjustment to TFA and/or their help-seeking behaviour.

Termination of pregnancy for fetal abnormality in context

In Europe, termination of pregnancy for fetal abnormality (TFA) concerns on average 4.6 per 1.000 births. TFA is three times more common than stillbirths and infant deaths combined (Boyle et al., 2018). The prevalence of TFA varies widely between countries, which reflects differences in professional and legal frameworks as well as attitudes and beliefs towards TFA (Zeitlin et al., 2013). In England[1], TFA represents 2% of all terminations (3,158 in 2017; Department of Health [DH], 2018). In France this percentage rises to 4% (7,084 in 2015; Agence de la Biomédecine, 2016).

In England as in France, there is currently no time limit for pregnancy termination if there is a serious risk that if the baby was born, he would be severely handicapped (Ground E of Abortion Act, 1967; Ministère de la santé, 1975). In contrast to the French law, the English law had initially fixed a term of 28 weeks of gestation for all terminations, including those for fetal abnormalities. In 1992, the threshold was reduced to 24 weeks, but with no time limit in case of fetal anomalies. This difference is reflected in practice with TFAs conducted at a later gestational age in France compared to England[2]. However, the professional practices surrounding the process of termination show a high level of similarity between the two countries. These include

[1] England and Wales form an entity separate from the rest of the UK in terms of health, whilst the Abortion Act covers England, Wales and Scotland. For simplicity purposes, we will refer to England throughout the article.

[2] In France, 36.9% of TFAs occur after 22 weeks of gestation, whereas in England only 7.8% of all TFAs are conducted after 24 weeks (Agence de la Biomédecine, 2016; Department of Health, 2018).

the protocols that frame TFA (e.g. methods of termination) as well as the practices surrounding bereavement care (e.g. use of photos, hand and foot prints).

TFA as a specific type of pregnancy loss

TFA shares many characteristics with other pregnancy losses such as miscarriages and stillbirths, but it also differs from them in very significant ways. In all cases, parents lose a child before birth, at a time when they would normally rejoice. Evidence also suggests that parental grief reactions following TFA are similar to those following other types of pregnancy losses (Keefe-Cooperman, 2005). However, TFA differs from miscarriage and stillbirth in that parents elect to terminate their pregnancy, and from abortion for non-medical reasons in that the pregnancy is, in most cases, wanted and the decision is based upon characteristics of the fetus.

Furthermore, the loss following TFA is generally not recognised by society in the same way other bereavements are. In many cases, the baby[3] remains 'invisible' to the outside world and many parents feel that their grief is disenfranchised (Doka, 1989). Parents may find it difficult to disclose that they have chosen to end the pregnancy and publicly mourn their loss (Leichtentritt, 2011; Maguire, Light, Kuppermann, Dalton, Steinauer, & Kerns, 2015), as they have to contend with the incongruence (either experienced by themselves and/or by others) between the decision to terminate the pregnancy and the feeling of loss.

TFA also bears a unique moral component. Being a form of abortion, TFA is intrinsically linked to the polarised debate about abortion and the opposing views regarding the rights of the women versus those of the fetus (Sharp & Earle, 2002). The dichotomy between these two positions has been described as one between those who have rights and those who have morality (Ludlow, 2008). The fact that the decision to terminate the pregnancy is based upon

[3] Throughout the article, the term baby has been used to render the perspective of the women who participated in our studies and used this terminology.

disability-related considerations adds to the moral dimension of TFA as it raises ethical questions such as 'whose right it is to make a decision' or 'what kind of life is worth living'. Although both advocates of women's rights and the rights of people living with a disability agree that the abortion law should not differentiate between reasons for terminating the pregnancy (medical versus non-medical) they are still at odds on whether TFA represents a basic human right exercised by the woman, or a eugenic practice (Sharp & Earle, 2002).

Finally, unlike other pregnancy losses, TFA is a relatively new phenomenon, which results from policies of mass screening developed in the 1970's and the legalisation of abortion (in 1967 in England and 1975 in France). Therefore, the experiential knowledge of how to deal with it is limited as women cannot turn to older generation for advice. This also means that there are, as yet, no normative responses to this type of loss or no social scripts on how to deal with it (McCoyd, 2009).

Psychosocial consequences of TFA

Several studies suggest that TFA has a significant impact upon women on three levels. First, at the individual or intra-personal level, TFA is generally experienced as a traumatic event, akin to an existential crisis (Sandelowsky & Barroso, 2005; Lafarge, Mitchell & Fox, 2014), which can have long-term, negative psychological consequences for women. These consequences have been well documented and include symptoms of depression, posttraumatic stress (Kersting et al., 2009; Korenromp et al., 2007) and complicated grief (Kersting et al., 2007; Nazaré, Fonseca, & Canavarro, 2013). Feelings of guilt relating to the decision are also prominent among women (Nazaré, Fonseca, & Canavarro, 2014). A systematic review of the qualitative evidence on women's experiences of TFA (Lafarge et al., 2014) indicates that many women feel unprepared for the severity and duration of the emotional pain following TFA. Many feel powerless over their situation and isolated in their experience, particularly when support is seldom available.

The review also indicates that some women question their identity, between that of a bereaved mother versus that of a woman who has lost a pregnancy, with at its core the concept of personhood attributed (or not) to the fetus (Parsons, 2010). Some women also question their body for producing an imperfect pregnancy.

The impact of TFA upon women can also be felt at an inter-personal level, as women reassess their relationships with others. Research suggests that women's partners also experience difficulties following TFA, and that they tend to grieve differently for the loss of the baby after TFA, with women experiencing more intense grief than their partners (Nazaré et al., 2013, 2014). Although in some cases, the TFA experience brings partners closer together, at least initially, these differences can contribute to increasing women's feelings of isolation (Nazaré et al., 2013, 2014). TFA also impacts upon women's relationships with their friends, family and colleagues, which is usually contingent on the level of support women feel they receive. A perception of limited support or lack of understanding can significantly alienate women.

Finally, TFA also has an impact upon women's perception and engagement with the world. Some women have described the experience of TFA as a loss of innocence (Rillstone & Hutchinson, 2001). In line with Janoff-Bullman's shattered assumptions theory (1992), women's visions of the world are irremediably altered by their TFA experience (Lafarge et al., 2014; McCoyd, 2007). Women engage in a process of rebuilding their world views whilst accommodating their TFA experience. The fact that TFA is linked to the abortion and eugenics debate can also make the experience stigma-bearing (Hanschmidt, Treml, Klingner, Stepan, & Kersting, 2018; Maguire et al., 2015), which adds another level of complexity and further alienates women.

Ambivalence at the heart of the TFA experience

In England and France, the experience of TFA follows a sequential series of events or experiences which include the diagnosis, the decision-making process, the procedure, the immediate aftermath and the long-term adjustment. Each point brings its own set of challenges including: waiting for the diagnosis, reaching a decision about the pregnancy, making decisions about the procedure, whether to see the baby or not, what to do with the baby's remains, what to disclose to others, how to grieve for the pregnancy and/or the baby, how to deal with a new pregnancy and how to adjust long-term (Hunt, France, Ziebland, Field, & Wyke, 2009; Rapp, 2000). Each point is characterised by conflicting feelings and emotions, or even uncertainty about how to feel about the experience. It is this ambivalence and the tensions it generates which is the focus of this article. The aim of this article is, therefore, to demonstrate the relevance of ambivalence to the experience of TFA. Data from two qualitative studies conducted with women who had undergone TFA, one in England, the other in France, have been used to convey and illustrate the ambivalence that characterises the TFA experience.

Research methodology

This article is based on two datasets gathered as part of the first author's doctoral thesis conducted in England and, of a wider research programme on the practice and experience of prenatal diagnosis in France. The larger project was led by the third author and involved all three authors alongside a multidisciplinary team of French academics. The article's stance, the theories and the majority of the literature cited in this article are rooted in the discipline of psychology. However, where relevant, we have also borrowed concepts and literature from sociology and the feminist paradigm.

Study 1

The first study was carried out in England and consisted of an online qualitative questionnaire conducted amongst women who had undertaken TFA. The study methodology has been

reported in detail elsewhere (Anonymised for peer review), therefore only the key methodological points are mentioned in this paper. Women were recruited from a UK-based organisation that provides support to parents when an anomaly in their babies is identified in-utero. A message advertising the study was posted on the online forum of the support organisation and disseminated through the email network. To be eligible to the study women had to be over 18 years old and had undergone TFA. No time limit was put on when the termination had occurred. Altogether, twenty seven women took part in the study between 2010 and 2011. The topic guide included 12 open-ended questions exploring what the termination meant for women, what coping strategies they used at the time of the termination and afterwards, how their experience was influenced by time, and what their plans and hopes for the future were.

Study 2

The second study was a qualitative study conducted in France as part of a larger research programme about women's experience of prenatal diagnosis (Funding details anonymised for peer review). The project used a mixed methods approach and comprised an online quantitative questionnaire to which over 1,500 women responded, followed up by in-depth interviews with women who had agreed to be re-contacted. Using purposive sampling, 107 women were invited for an interview to explore their experience further. Of those, 69 were interviewed. It is as part of this qualitative phase that 17 women were interviewed about their experience of TFA. Data were collected between May 2015 and May 2017 through face-to-face and telephone interviews. Participants were invited to provide a narrative of their experience, and questions were used to elicit feedback on: the way the diagnosis and prognosis were presented; the information provided (e.g. about the condition and how it may translate after birth); the interactions with practitioners; the role of the entourage and the media; and the process that

led to the decision to terminate the pregnancy. Interviews were recorded and transcribed verbatim.

The studies used different methods of data collection. The data collected through online narratives (Study 1) generated reflective accounts and provided insights into the meaning women attributed to their experience. Nevertheless, the data did not offer the same level of detail as the data collected through in-depth interviews (Study 2). By contrast, although interviewing participants enabled the researchers to collect more granular data (through probing), the topic guide was broader and less focused on the meaning of women's experience. However, both studies generated rich data and both achieved data saturation.

Data analysis

For the purpose of this article, data were analysed using thematic analysis (Braun & Clarke, 2006). Thematic analysis (TA) was selected as a method of analysis because of its flexibility. TA can be used inductively (bottom up) and deductively (top down) as well as across data sets. As the aim of the present analysis was to explore the manifestation of ambivalence, conflicts and uncertainty during the TFA experience across both datasets, TA was deemed the most appropriate method. The analytical process closely followed the guidelines recommended by Braun and Clarke (2006). Both sets of transcripts were read several times, initial codes and themes were generated, themes were defined and labelled (and later relabelled when deemed necessary) and quotations were selected to illustrate the themes. The results of the analysis were also considered within the literature on TFA and abortion more generally. Where relevant, evidence from the literature was incorporated to support the article's narrative. To protect the participants' identity, names have been changed to pseudonyms and any identifiable information has been removed. All references to babies have been made using the masculine

198 pronoun. The analysis identified that most themes were present in both datasets, therefore,
199 quotes from both studies have been used to illustrate these.
200 Given the similarity of the professional practices surrounding TFA between the two
201 countries, our approach in this article is not comparative. Our aim is to illustrate the
202 manifestations of ambivalence observed in both datasets, rather than seeking to link these
203 manifestations to the modes of regulation and organisation of care in each country.
204
205 **Results and discussion**

206 **Participant's profile**

207 The profiles of participants of both studies are displayed in Table 1 and Table 2.
208 In both studies, women participants tended to be well-educated, with 17 out of 27 and 12 out of
209 17 educated at degree level and beyond in the English and French study respectively. On
210 average, pregnancies were terminated at an earlier gestational age in the English study
211 compared to the French one: 19 weeks of gestation (range 12-30) versus 26 weeks (range 12-
212 36). Reasons for terminating the pregnancies varied. In the French sample, most of the
213 pregnancies were terminated because of genetic/chromosomal anomalies (13 out of 17), with
214 the other pregnancies terminated because of structural abnormalities. In the British sample,
215 reasons for terminating the pregnancy were more even; seven pregnancies were terminated for
216 genetic/chromosomal anomalies, seven for structural anomalies and four for other reasons (e.g.
217 hormone imbalance, mixed reasons).
218
219 **Analysis**

220 The data analysis identified eight significant points at which women experience ambivalence,
221 from the moment a severe abnormality is suspected to sometimes long after the termination.
222 These manifestations of ambivalence, tension and conflicts can be depicted as: hope and

despair, a choice but no choice, standing still and rushing, bonding and detaching, trauma and peace, disclosure and secrecy, bridging past and future, and individual and societal experience.

Hope and despair

Across both datasets, the discovery of a severe anomaly represents the first tension and source of ambivalence in women's experience of TFA. Women usually start their pregnancy hopeful that everything will be fine and in the belief that taking good care of themselves will guarantee a positive pregnancy outcome (McCoyd, 2007). They have started to plan their future and formed an image of their baby in their mind. The suspicion or the discovery of an anomaly, therefore, comes as a shock. It shakes women's sense of security and destroys their hopes and plans for the future: "*We had hopes for our future as a family and saw ourselves as parents from when I was pregnant"* (Lucy, UK).

From that point, women embark on a journey of uncertainty, over which they feel they have no control:

> *"There is this feeling of having put your finger in a sort of thing that will sweep you away and which, in any cases, is called a tragedy. So I, I try to believe in it a little and have a little bit of hope, but deep down I don't"* (Lara, FR).

This state of shock is usually compounded by the fact that many women are unaware that ultrasounds examinations are an integral part of the screening process: "*The second trimester ultrasound, I had no idea that it was a screening test*" (Florence, FR). This also includes the third (and usually last) ultrasound in France conducted at around 33 weeks of gestation. At this point, women tend to feel 'safe' in their pregnancy and allow themselves to look forward to the future: "*At the last ultrasound, honestly you don't ask yourself any more questions. The last ultrasound, for me, is just to control [that all is well], and the pleasure to see your baby*" (Clara, FR).

Until a diagnosis is given, women harbour concurrent feelings of hope and despair. They are still hopeful for a positive outcome but worried about the potential decisions to come. This is Laura's case (UK) who, when hearing about of her baby's anomalies, starts planning for logistic and material adjustments whilst still hopeful the outcome may be manageable. However, as further tests demonstrate the gravity of the situation, her hope gradually turns into despair:

> *"She said that our baby had [major structural anomalies]. (…) First I thought we could work around this. (...) I had thoughts about having a stair lift in the future, ramps, teaching the child how to use these. (…) I thought that [other child] would be a loving sibling and really helpful but then had to question how he would deal with having a sibling who needed so much, and the affect this may have on him. (…) The decision was agonising.*"

In some cases, the coexistence of hope and despair resemble a roller coaster, a term that has been used to characterise women's experience in the TFA literature (Bryar, 1997):

> "*The day of the CVS, the measure of the nuchal translucency had decreased a little bit. So the nurse said to me 'there is some positive [news].' So, hope came bouncing back. The Saturday, two days later, someone called to tell me that it was Down's syndrome. A catastrophe"* (Marie, FR).

In many cases, the first suspicion that all may not be well signals the end of innocence (Rillstone & Hutchinson, 2001) with women facing an uncertain future and difficult decisions to make, not least, about the management of the pregnancy. As the pregnancy's outcome no longer matches their initial expectations, women are left wondering which other areas of their life they may harbour a false sense of security for.

The discovery of the anomaly represents the starting point in the TFA journey, and is characterised by uncertainty and the coexistence of mixed emotions. For women, it is often a brutal reminder that reproduction is not a process with a guaranteed positive outcome.

A choice but no choice

Ambivalence is also manifest in the decision to terminate the pregnancy as it involves conflicting feelings between doing the right thing, whilst wishing one never had to make that decision: "*I ended the life of my baby and I wanted him so much*" (Gemma, UK). The decision-making process following the discovery of a fetal anomaly has been described in the literature as "a Sophie's choice", a "travesty of choosing", "chosen loss and lost choices" (Sandelowski & Barroso, 2005). In both studies, women also describe the decision-making process as a no-choice since it offers no positive outcome: "*You are damned whatever you do*" (Wendy, UK). For many, the decision is about choosing the least awful scenario, or between "terrible and horrible" (Rillstone & Hutchinson, 2001).

To reach a decision, women have to balance a number of considerations that are often in contradiction with each other, such as their desire to have a healthy baby with their desire to spare their child a life of suffering: "*I had too much information that told me that it could be very hard, very painful for him and that his life could be just one of suffering. I could not take that risk for him. It was too much" (Marie, FR).* Women also have to balance their own projections of what a life with a disabled child may be like with what they know of their own coping processes and resources, and those around them: "*I was concerned that I may become depressed*. *I do not follow a faith, and feel that I would not have that strong faith to offer our baby to help him come through tough times"* (Laura, UK).

For many, the decision-making process is a struggle between heart and mind: "*It was hard to separate heart and head when making the decision*" Zoe (UK). In some cases, the option to terminate directly conflicts with what they had previously expected they would do in that situation: "*I had always thought that termination, in whatever circumstances, was completely wrong. Now I had to face the fact that I'd had one*" (Justine, UK). The decision to terminate can also conflict with personal beliefs "*I also have conflicts with my Christian faith and this is probably a cause of my current conflict*" (Gemma, UK). It can also divide partners. For example, Marie (FR) and her partner disagreed on which decision to make. Whilst her partner considered terminating the pregnancy as "*a selfish act driven by a desire not create problems for oneself"* Marie believed the opposite: "*If I had been really selfish, I would have kept him. (…) I had too much information telling me that it could be very hard. (…) I couldn't take that risk for him*."

As women struggle to reconcile those conflicting considerations, some opt to frame their decision as an "*act of love*" (Ingrid, FR) towards the baby: "*I don't want him to suffer, I don't want him to be in pain*" (Inès, FR). Yet, they also know that this is a decision that, in some cases, denies life and opportunities: "*Yes he would have been in a very bad state, but he was viable and it's like I did not give him any chance*" (Céline, FR). Thus, some women compare their act to compassionate euthanasia, which illustrates the tension they experience:

> "*There comes a point, I suppose (not that I have ever had this experience), where there is no hope of recovery, no hope of anything approaching a normal life, no hope of progress. Then it is probably the kindest thing to turn off the machine. That's what I did for my baby, in a way – I turned off the life support that was the pregnancy*" (Sally, UK).

Ambivalence regarding the decision can remain after the termination: "*Up until this point [the post-mortem results] we were never sure of the extent of the abnormalities and we tortured*

ourselves with the "what ifs" (Beatrice, UK). Some women still question their decision long after the termination:

> "*It was the right decision for us at the time, but the wrong decision for our child. That hurts so much and I wish it didn't (…) I try not to have regrets, but I do. I know I could have had a baby, even with disability*" (Gemma, UK).

Even when they believe that they have made the right decision, women can find it hard to accept their decision: "*I have played God and unlawfully killed my baby but it was for the correct reasons. It just does not ever seems right*" (Ellie, UK), and remain uncertain about the future: "*I feel like we are in limbo, as in an addition to losing a child, we had plans to move and I was considering giving up work*" (Yvonne, UK).

The ambivalence expressed by women about the decision to terminate the pregnancy, even when the decision appears to be the most appropriate for them, illustrates women's difficulty in exercising their right to terminate the pregnancy within a social context that personifies the fetus increasingly early (through ultrasound examinations), and where popular discourses around the fetus' right to life are widespread (Purcell, Hilton, & McDaid, 2014). Women's ambivalence is compounded by the fact that most diagnoses only offer an insight into what the impairment will actually translate into (Whitmarsh, David, Skinner, & Bailey, 2007).

Standing still versus rushing

Women's relation to time during the process of TFA represents the third source of ambivalence, with time appearing either static or hurried, and/or women wishing to speed up or slow down the process. Women generally describe their experience of getting the diagnosis as their world coming to a halt:

> "*The moment I was told my baby had trisomy 21, my world stopped. Everything stopped, there were no birds, nothing in the sky and the trees did not even seem to be moving …. I*

remember looking at the world and thinking how dare the world carry on as if nothing has happened" (Ulrika, UK).

This sense of 'time being suspended' or being 'out of time' is particularly manifest when the diagnosis is protracted and women's experience is paced by the sequence of investigations that have to be carried out to reach a diagnosis; a process Beatrice (UK) describes as "*a waiting game.*" Laura echoes this sentiment:

"*These five weeks, I am in this kind of spatio-temporal tunnel. I do not see at all, I'm not... I am not aware of anything. I do not know what day it is, if it's the weekend, not the weekend"* (Lara, FR).

The duality of time standing still versus rushing can, in some cases, be experienced concurrently: *"There is a side that takes a long time and there is the other side: the teams of doctors, one must acts quickly*" (Lara, FR). Anne (FR) also describes this temporal process between the discovery that "*something was not right*" at 22 weeks of gestation and the termination at 32 weeks. Of her 10 weeks wait to get a diagnosis she says: "*it is urgent to wait: At the same time, one does not have much time to lose and at the same time, one must not go too fast either*."

Women's perceptions of time are often shaped by practical constraints such as the time needed to conduct further tests to confirm the diagnosis, or the necessity to proceed rapidly if the woman is to have a surgical termination (usually carried out in the first trimester of pregnancy in both England and France):

"*She [the midwife] told me: 'In 2 days it's the aspiration, we're going to take the tablets now.' Until then, I was saying 'I have to turn the page quickly, it has to be quick.' In fact, I completely froze. It was too fast (…) when they saw that I was completely stuck, they told me: 'it is not an obligation, you have a choice.' But they had planned everything. They*

already had the tablets on the desk. Because I was at the limit. I was 14 weeks' pregnant so at the limit for a curettage by aspiration" (Marie, FR).

Women's perceptions of time in the context of TFA often generates tensions, with some women wanting to accelerate the process. This is the case of Ingrid (FR), who wanted to put an end to her baby's suffering and avoid getting her hopes up: *"The desire to speed up the termination process was also linked to the idea that one had to put an end to the baby's suffering: one had to stop her suffering and not give me any hope."* By contrast, this suspended temporality can be welcome and seen as necessary to reach a decision or start coming to terms with the situation: *"The delay [10 day delay] meant that my husband and I had time to come to terms with what was happening. I didn't feel it was rushed and I felt better equipped to cope"* Beatrice (UK).

The perception of being rushed can be experienced as painful and bring regrets: "*It would have been better to give me more time to digest, say goodbye to my baby, etc. But it really is down to the individual. Me, I had this guilt (…) I could have accompanied him a little bit more*" (Maud, FR). In some cases, women actively slow down the process of termination. When Marie's (FR) baby is diagnosed with Down's syndrome at 14 weeks of gestation, she rejects the surgical option in favour of a medical termination, which enables her to give birth:

"*At first, I was not sure, I wanted it to be quick but once I knew [the diagnosis], I didn't want it to be quick in fact. I don't know why. In fact, it became concrete and until then I was hoping, so I was telling myself: any way, it is not possible. When it became concrete I told myself: I want... first I wanted to respect his body. We all have our quirks I think, but I didn't want him to be reduced to a thousand pieces. It was my priority to keep him whole. (…) I didn't want to rush things. I did not want to get rid of him.*"

Women's ambivalence with time is also present after the termination with some women rushing to get back to their activities, but regretting it later on: "*Going back to work too soon was a major 'no–no'. I went back after 4 weeks – I should have taken twice as much time off work*" (Beatrice, UK).

The tensions women experience between standing still and rushing reflect the difficulty in processing the termination cognitively and emotionally. It is also rooted in social practices that form the backdrop of women's experience such as the term at which a baby can be registered and thus be conferred a social identity, and/or in medical practices which are used at different times during pregnancy (e.g. surgical versus medical termination).

Bonding versus detaching

The fourth source of tension or ambivalence is women's relation to their baby. From the moment an anomaly is suspected, women are conflicted between the states of continuing "*giving life while thinking about taking it*" (Leichtentritt, 2011). As they wait for the diagnosis, women find themselves in a state of limbo, unsure about the way they ought to relate to the baby. Lara (FR) describes her difficulty in establishing for herself how to care for her baby as the investigations are ongoing:

> "*And this baby? And this baby who is alive? This live baby in my tummy? And you don't know what's going to happen… perhaps the worst, probably… but may be also some good? And even if the worse happens, we're in the middle of investigations that are going to last for a while, so I can't completely… the only thing I was able to do to take care, so to speak, of this child, well of this baby was to remain lying down, rest and try to eat well*."

As they wait for a diagnosis, women are torn between attachment and detachment towards their baby and "fighting love for their baby" (Bryar, 1997):

"*I think that all night I tried to say to myself: that's it, I don't love him anymore, I have to stop loving him, I have to stop loving him. And then I think he never moved more than that night. And then I said to myself: no, it's not possible, I still have 1%, 1% chance that he has nothing"* (Claire, FR).

Once the decision to terminate is made, women generally have to wait a few days for the procedure to take place. This period brings its own set of tensions as women continue to carry life whilst anticipating death:

"*It was a weird sensation. Being happy, being sad, trying to feel all the little joys. I hummed, I listened to music, as if he was going to live, as if I was going to welcome him. It was weird. At the same time, I was crying and explaining to him. I was explaining to him what was going to happen"* (Claire, FR).

From the state of pregnancy during which they form a unit with the baby, women have to separate and learn to 'become one again.' During pregnancy, many women engage in unspoken dialogues with their baby, who in most cases, they can feel moving. Some describe a symbiotic relationship in which emotions are shared: "*All I thought about, in my head was, not to be afraid, not to be afraid. Not to be afraid, not to make him sense my fear*" (Claire, FR). In parallel, women also watch for any signs that the baby may be communicating with them as illustrated by Claire's quotation above.

For terminations after 21 weeks of gestation a feticide is usually recommended, which generally consists of an injection in the fetal heart, amniotic fluid or umbilical cord to stop the baby's heart. Whilst the feticide is usually carried out on the day of the delivery in France, it is conducted two days before in England. Thus, in England, after the feticide, women are sent home for 48 hours. This period presents some challenges to women who find themselves

suspended between two realities, as they continue to carry their dead baby whilst the outside world remains oblivious to their predicament:

> "*I just took the tablets and was sent on my way to carry my dead son around in my tummy for two days until I had my termination"* (Megan, UK).

> "*I was given a tablet to soften my cervix. The midwife spoke to us to prepare us for leaving the hospital saying life will be going on as normal all around you*" (Rose, UK).

This duality between life and death is particularly salient when women carry twins and undergo a feticide on one of the babies. Pregnant with twins, one of which is affected by Down's syndrome, Alexandra (FR) undergoes a feticide on one of the twins at 32 weeks of gestation, two days before having a caesarean. In her case, feticide and childbirth are events combining both life and death:

> *"I kept life and death in my belly for two days... two long days during which I suffered terribly morally. The weight of a dead baby in a tummy, this is a very strong feeling... It's downright horrible. It is a dead baby, who does not hold himself anymore, who collapses completely [in the stomach]. (…) Then I had an emergency caesarean section two days later... It was the most traumatic period, to keep the dead baby in my tummy for two days."*

Ambivalence also characterises women's experience immediately after the procedure, for example in the decision whether to see the baby or not, which can be experienced as soothing, yet also distressing:

> "*Seeing the baby was helpful in some ways as I was able to hold him and say goodbye. (…) But the reality is that he had died two days before and also had been very unwell, and also at a very early stage of development when he wouldn't normally have been born, so*

he did look strange and that frightened me, I was scared to look at him and that made me feel guilty as if I didn't really love him as much as I should" (Wendy, UK).

The ambivalence as to whether to see the baby may be linked to professional practices which traditionally considered viewing the baby as facilitating the grieving process and actively promoted it (Sloan, Kirsh, & Mowbray, 2008). Although it is now acknowledged that viewing the baby or not has to be women's choice, the practice may still be engrained in some practitioners and some women may perceive it as being expected of them.

Ambivalence is also present sometimes long after the termination as women are torn between their desire to resume a normal life and move on from their experience, and their wish to remember the baby: "*There are days when we say to ourselves: we have to move on and then there are days when we say to ourselves: we have no right to move on"* (Claire, FR). Ultimately women have to reconcile the duality of roles between the mother who brings life and the mother who denies it, with the latter labelled as counter-natural. This is Bonnie's (UK) opinion: "*Mothers are not supposed to kill their own children";* a viewed echoed by Isabelle (FR)*: "It completely goes against nature. Normally we are supposed to bring life, not death. And we brought death. He did not die naturally, we brought him death."*

Women find themselves suspended between two realities: one that empowers them through exercising their right to terminate the pregnancy, and the other that condemns them for it. The ambivalence women feel about bonding or not with the baby may also reflect the debates surrounding the concept of personhood of the fetus, and whether it is possible, or even desirable, for women to reconcile their right to abort and their wish to bond with the baby (Ludlow, 2008).

Trauma and peace

The birth of the baby represents another source of ambivalence for some women who consider it as a traumatic yet also peaceful experience. Women describe the feticide as the most traumatic part of their experience: *The pain of that needle going through my tummy and knowing I was stopping my baby's heartbeat was so bad*" (Ellie, UK). The anticipation of the birth can also fill women with fear, fear of the unknown and/or seeing the baby:

> "*I was scared like when I was a kid, scared of the unknown. Then, like I said, I never gave birth, so one doesn't know what childbirth is. One is scared, and one's like: 'I'm going to suffer'; and then one thinks: 'We're going to see the baby, he's going to be dead, how's it going to be*?" (Inès, FR).

Yet, Inès also describes the birth as a gentle moment: "*Childbirth for me was a moment of gentleness.*" This view is echoed by Laura (UK) who describes giving birth as an unexpected peaceful moment: "*It was like meeting our lovely baby, almost a wonderful moment in a surreal setting. Almost proud parents but knowing that our baby was at peace now. It was very peaceful and special time.*"

The birth also contrasts with the rest of the TFA experience as women focus on bodily functions and sensations. It is a time where the body seems to temporarily take over the mind: "*During labour I just focussed on what I needed to do*" (Valentine, UK). To some women feeling the 'baby going through' is an opportunity to bond with their baby: "*I needed to be with him throughout and feel him"* (Theresa, UK). Others marvel at what their body has achieved: "*The delivery itself was not as traumatic as I thought it was going to be as I was amazed by body's capabilities*" (Beatrice, UK). Beatrice adds that the birth was a moment of "*euphoria as I felt that I had weathered the storm and survived*", signalling the transition to the post-termination phase.

Women's ambivalence about the birth exemplifies the coexistence of excitement at meeting the baby and fear of what the encounter might bring physically and emotionally. It may also reflect

society's pervasive depiction of the birth as a joyful, yet risky phenomenon, which is manifest in the highly medicalised clinical practices surrounding birth (Scamell, 2014).

Disclosure and secrecy

Whether to disclose what has happened to them and to whom, represents another source of ambivalence for women. Without disclosure, women cannot fully process their experience. They may also be unable to access adequate support. Yet many women are unsure about the appropriate level of disclosure, as they try to balance the need to be true to their experience with the risk of being judged. This explains why some women feel uncomfortable when their experience is labelled a miscarriage, a label they feel does not represent their experience: "*I found people often referred to me having a 'miscarriage' which was so incorrect*" (Olivia, UK). However, at the same time, women are aware that the term termination may bring condemnation from others: *"I was careful not to tell everyone… I felt insecure about what judgments people would make about what we'd done" (*Bonnie, UK); a view echoed by Olivia (UK): *"It's also a matter of having to cope with facing people. Termination is a taboo subject, and unless you have found yourself in this situation, people are quite un-aware."*

Another challenge women encounter in disclosing their experience is avoiding upsetting or putting people off: "*I love to talk about him and so that I can, I try to make it a pleasant subject so that people don't mind me talking about him*" (Gemma, UK). Regardless of whether they choose to disclose their full story or not, most women feel that their loss is not recognised by others and that their grief is disenfranchised, a concept discussed in the TFA literature (Bryar, 1997; Leichtentritt, 2011; McCoyd, 2007). This societal inability to acknowledge women's grief following TFA leads women to feel isolated in their grief. It also means that they (and at times their partners) become the sole guardians of their baby's memory: "*We're the only ones to have*

seen him, no one has any memory of this child and it is important, this memory. So it is difficult to carry a grief like that" (Claire, FR).

Some women start feeling at odds with their environment, particularly when their partner, friends and family expect them to resume a normal life: *"I feel extremely angry that people expect me to carry on as normal. I feel that no respect is being paid to my baby by this expectation"* (Wendy, UK). This furthers women's sense of isolation and generates tensions within relationships that were once thought to be secure:

> "*The support from my partner was very good during the termination and for about 6 weeks afterwards. However, from that point our coping mechanisms have been very different and have put a massive strain on our relationship. He cannot understand why I still need to go for counselling, can't understand why I have struggled with the arrivals of other babies and pregnancy announcements. This adds to my loneliness as I now cannot voice my sadness"* (Christine, UK).

Women's ambivalence at whether to disclose their story or not is grounded in the belief that should they choose to disclose it, they risk being misunderstood and/or judged for it. These experiences are testament to the stigma surrounding TFA, and more generally abortion, which is still pervasive (McGuinness, 2015). This stigma is reflected in highly emotive and moralising public discourses about abortion that focus on the risk posed by abortion on women's wellbeing and provide a reductionist view about why women terminate their pregnancy (Purcell et al., 2014).

Bridging past and future

The TFA experience also generates tensions for women on how to reconcile past and present experiences with expectations for the future. In some cases, these tensions are present from the beginning of the pregnancy, even before any suspicion of abnormality is raised. Lara (FR) did

not fully invest in her pregnancy because she had had two miscarriages previously. Thus, for her, the baby was "*neither in the present nor in the future, in fact, he was nowhere*."

As the first suspicions that all may not be well with the pregnancy emerge, women start projecting themselves in a future without a baby who, in many cases, already carries their hopes and expectations and whose presence, physical or psychological, is already acutely felt:

> *"Talking about the future without him whilst, first, we do not want to be without him and he is still there. I didn't yet feel him moving at the time, but hey, there are signs that attest of his presence. It's clear. And we have seen him, even if not that much. We've seen on the ultrasound, it's not a creation of the mind"* (Marie, FR).

The aftermath of the termination represents another point of tension as women are conflicted between their desire to get better, resume a normal life and 'move on', and their desire not to forget their baby. Ellie (UK) is committed to keep her baby's memory alive, but she also believes that she owes it to her baby to carry on living:

> *"[Baby] will be in our lives every day, and I will light his candle and think about him each evening. Our lives need to continue, I cannot dwell on the past...it would probably send me insane. I chose to make the decision to end baby's life to stop him from suffering*."

Bridging past and future is a delicate operation as some women fear being disloyal to their baby's memory by moving on: *[Moving on]…"Although I know I probably have, I don't like to think I have because I don't want to move on from my son. I like to think that the future will always have him in it in some way*" (Anna, UK). In some cases, women express an intense fear of forgetting their baby: "*I have a desperate fear of forgetting him, what he looks like, smells like, how it felt to hold him*" (Zoe, UK).

One way to reconcile these conflicting drives is for women to integrate their TFA experience and the feelings it generates, within a new all-encompassing narrative:

> *I want to acknowledge the experiences, my emotions and feelings and have time to feel sad and remember my baby, but I do not want it to take over my life in a negative way – to become absorbed in grief*" (Laura, UK).

The process of creating a new narrative may constitute an important coping strategy for women. It may also reflect professional practices surrounding perinatal bereavement care in which women are routinely encouraged to create memories (e.g. photos, hand prints) in order to promote acceptance (Lafarge, Mitchell and Fox, 2013).

A new pregnancy presents another opportunity to bridge past and future. However, it is often an additional source of ambivalence for women as they feel hope and excitement concurrently with anxiety, guilt for 'replacing' the baby and sometimes disengagement towards the new pregnancy. This phenomenon has been referred to as 're-emergence of anguish' (McCarthy et al., 2015; Rillstone & Hutchinson, 2001) in the literature, and is illustrated by Ellie's quotation: "*Falling pregnant again was a very happy but difficult time for us both. We felt guilty to replace [baby] but happy and also nervous.*" Similarly, when Anna (FR) becomes pregnant again after two TFAs, she oscillates between investing and not investing the pregnancy. She opts for disengagement, possibly because she feels this will help her emotionally: "*All these feelings, these questions about I invest, I don't, we tell others or we don't. For me, not investing was clear, except for health professionals, no one knew, it stayed between my husband and me*."

Women's ambivalence regarding a new pregnancy illustrates their difficulties in projecting themselves in the future whilst still being firmly anchored in the past. With a new pregnancy, the termination becomes a liminal event, during which women transition from the state of

bereaved mother to that of expectant mother (Reiheld, 2015), resulting in belonging to neither temporality.

Individual and societal experience

The last point of tension relevant to the TFA experience is between women's view of TFA as a deeply personal and intimate experience and the fact that women's experience is largely driven by societal structures and attitudes. Whilst this tension may not be directly felt by women, it is nonetheless an important reality that fosters ambivalence. Bonnie expresses a widespread view that TFA "*is something that will always be with us and feels very personal – something only we can understand."* As a result of TFA*, w*omen's beliefs about the world, their sense of self, and their relationship to their environment is permanently altered. Yet, this intimate experience is largely shaped by local laws and policies governing termination of pregnancy, local professional practices, as well as societal attitudes and beliefs about TFA and, more generally, disability (Lafarge et al., 2014). These factors contribute in shaping women's expectations for the pregnancy, underpin their decision to terminate and influence the way they grieve for their loss.

First, local abortion laws define the timeframe and conditions for which a pregnancy can be terminated. They determine the modalities for accessing termination services, including the scale of the service provision, the setting (e.g. public hospital vs private provider) and the financial cost (e.g. whether the state covers it or not). Women's experience is also directly influenced by local professional practices. For example, speeding up the process of termination is sometimes necessary to enable women to have a surgical termination. In France and England, surgical terminations are rarely conducted beyond the first trimester of pregnancy. However, there is evidence that this method of termination is safe to use in the second trimester of pregnancy and that the low incidence of surgical termination after 15 weeks of gestation, at least in England, is due to a lack of health professionals skilled to perform such procedures

(Lyus, Robson, Parsons, Fisher, & Cameron, 2013). Ingrid (FR), mentioned earlier, was keen to accelerate the process. By contrast, Marie (FR) wanted to wait 15 weeks so she could give birth to her baby.

Professional practices also include bereavement care surrounding TFA, another important factor in women's experience. In both England and France, women are given the opportunity to create memories following the termination, which is considered to be helpful for processing the loss. Clara (FR) illustrates this when describing the care she had received after the birth of her baby:

> *They offered [to take a picture of the baby] straight away. They put a small cap on him, to hide his slightly deformed head. They brought him back to us. They told us we could keep him for as long as we wanted. After, for a week (…) we could come back as much as we wanted to the maternity to see him (…) For me, the women who do best are those who have an environment that recognises and makes the child exist."*

Notably, although professional practices seem to encourage acceptance of TFA and aim to somehow normalise women's grieving process, wider collective attitudes and beliefs about TFA result in women feeling disenfranchised and stigmatised about their experience. In turn, the way women chose to silence their story or part of their story means that TFA continues to be a taboo subject and prevents women from accessing appropriate support.

Finally, women's experience of TFA is also shaped by the way societies regard disability. Céline (FR) mentions that a key reason for terminating her pregnancy is the marginal place assigned to individuals living with disabilities in France. She further links her decision to eugenic practices:

> "*I felt that if we had let our baby come alive, we would have tipped into another world. Perhaps my husband or I would have had to stop working to take care of him. We would have had to fight to get material or financial aid. Disability is really on the margins of society. And I admit that this idea disturbs me in the decision we made because, if we*

push it a little further, it is eugenics when we end pregnancies for medical reasons. It's complicated. On that too, I think that if everybody who faces the question of disability during pregnancy makes the same decision as us, then we will never deal medically with the issue, we will never be able to give them a chance, to make progress. There's a lot of ambivalence around the handicap in my head."

Similarly, Laura (GB) decided to terminate her pregnancy having reached the conclusion that, as a family, they would not be able to cope financially and logistically, alluding to the lack of social and economic support for people living with a disability in England:

"My mother asked me whether I would be able to find childcare for the baby if I returned to work and if I couldn't, then could I afford to live without my financial income? I looked into Disabled Living Allowance on the internet and it was not straight forward whether we would be entitled to it."

TFA is a deeply personal and intimate experience for women. However, it is also a socially constructed phenomenon as women's experiences are shaped by local laws and policies, professional practices and societal attitudes and beliefs. Thus, women's ambivalence may reflect societies' own uncertainty and conflict about abortion and disability, which in turn may be re-enacted by the women. Health professionals caring for women who undergo TFA are not immune to these tensions. It is likely that their own ethical and moral position would influence the way they care for women undergoing TFA (Garel, Gosme-Seguret, Kaminski, & Cuttini, 2002), thus directly impacting upon women's experiences.

Conclusions

Our findings demonstrate the relevance of ambivalence to women's experience of TFA, as women face uncertainty as well as conflicting thoughts and emotions. Our findings also indicate that the TFA experience has to be considered in relation to the social context in which it takes

718 place. Women's ambivalence about TFA may be fuelled by the fact that TFA is a relatively
719 recent phenomenon and thus, there are, as yet, no normative responses TFA (McCoyd, 2009).
720 Women are unlikely to have encountered this situation amongst their friends, and they cannot
721 turn to older generation for understanding and advice. This points to a deficit in experiential
722 knowledge, which may lead to women feeling pressured to feel or act in ways they think they
723 ought to and/or are socially acceptable. This phenomenon, coined as 'feeling rules' by
724 Hochschild (1983), has been evidenced in the context of TFA (McCoyd, 2009).
725 Women's ambivalence may also stem from the gradual transformation of prenatal
726 diagnosis practices over the past four decades, in which the concept of responsibility has moved
727 from the public health sphere to that, more private, of the person and informed choice. This
728 evolution has gradually placed women at the centre of the decision-making process (Löwy,
729 2017). Yet, if women have become more empowered to make decision about their pregnancy,
730 they are also expected to make these decisions in the absence of social scripts (McCoyd, 2009).
731 Finally, the ambivalence experienced by women who undergo TFA may also illustrate the
732 tension generated by the coexistence of prenatal diagnosis, which could be regarded as aiming
733 to prevent disability, and the drive for social integration of people with disability (Ville, 2011).
734 Women may find it difficult to reconcile their decision to terminate their pregnancy on the
735 ground of abnormality when societies promote social participation of disabled individuals and
736 the adoption of anti-discriminatory legislation. This is complicated by the fact that some
737 diagnoses do not offer certainty about the level of impairment the baby may experience and
738 women have to rely on probabilistic calculation to make their decision (Ville & Mirlesse, 2015).
739 Women's ambivalence about their TFA experience may have important implications on
740 the way they adjust to it. Research suggests that women find it hard to share their story (Hunt
741 et al., 2009), many experience guilt (Nazaré et al., 2014), and some develop symptoms of

depression and posttraumatic stress or complicated grief (Kersting et al., 2007, 2009; Korenromp et al., 2007) as a result. It is likely that the stigma surrounding TFA (Hanschmidt et al., 2018) hinders women's help-seeking behaviour as some women may feel undeserving of receiving care (Lotto, Armstrong, & Smith, 2016). In this context, it is also important for health professionals to be aware of their own position on the issue of termination and of the biases that they may hold as it would influence the way they care for women. This is particularly important given that women's relationship with health professionals and their experience of care has been shown to contribute to women's adjustment to TFA (Fisher & Lafarge, 2015; Lotto et al., 2016).

The aim of this article was to demonstrate the centrality of ambivalence in women's experience of TFA. However, we do not imply that women's experience of TFA is solely one of ambivalence, nor that women necessarily experience ambivalence at all the stages described in this article. The experience of TFA is idiosyncratic (Lafarge et al. 2014). As such, our findings need to be considered as a contribution to the understanding of this complex phenomenon. Interestingly, there were more commonalities than differences between the two studies. It is likely due to the fact that the laws and practices surrounding TFA in France and England are quite similar. The ambivalence surrounding the experience of TFA, whether at the individual or societal level, as well as its uniqueness in relation to other pregnancy losses, makes TFA an ill-defined phenomenon that is still misunderstood and stigma-bearing. This raises important questions about the support provided to women.

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Name	Age	Level of education	Gestational age	*Abnormality*	Pregnancy	Year of TFA
Anna	34	Postgraduate	21 weeks	Spina bifida	1st	2009
Bonnie	36	Postgraduate	22 weeks	Multiple cardiac abnormalities	2nd	2010
Christine	41	Postgraduate	13 weeks	Down's syndrome (Trisomy 21)	2nd	2010
Donna	31	1st degree	20 weeks	Spina bifida	2nd	2009
Ellie	25	1st degree	24 weeks	Brain abnormalities	1st	2009
Frances	31	Postgraduate	23 weeks	Stomach abnormalities	1st	2010
Gemma	44	A levels	17 weeks	Down's syndrome (Trisomy 21)	1st	2008
Holly	36	1st degree	17 weeks	Turner's syndrome	1st	2009
Isobel	35	A levels	12 weeks	Multiple abnormalities	4th	2010
Justine	34	Postgraduate	14 weeks	Structural abnormalities	4th	2009
Kerry	32	Postgraduate	14 weeks	Edwards' syndrome (Trisomy 18)	1st	2009
Lorna	40	1st degree	15 weeks	Structural abnormalities	2nd	2010
Megan	31	GCSE's	18 weeks	Spina bifida	4th	2010
Natalie	33	A levels	13 weeks	Growth deficiency	3rd	2010
Olivia	31	GCSE's	21 weeks	Cardiac abnormality	2nd	2009
Penny	31	1st degree	21 weeks	Lungs abnormalities	1st	2010
Rose	38	Postgraduate	23 weeks	Brain abnormalities	1st	2009
Sally	37	1st degree	24 weeks	Edwards' syndrome (Trisomy 18)	1st	2004
Theresa	N/D	N/D	18 weeks	Mosaic trisomy	4th	2010
Ulrika	36	A levels	16 weeks	Down's syndrome (Trisomy 21)	4th	2011
Valentine	38	A levels	30 weeks	Brain abnormalities	1st	2011
Wendy	38	1st degree	23 weeks	Multiple abnormalities	1st	2011
Xara	34	Postgraduate	20 weeks	Cardiac abnormality	1st	2011
Yvonne	35	1st degree	21 weeks	Spina bifida	2nd	2011
Zoe	33	GCSE's	26 weeks	Brain abnormalities	3rd	2011
Alison	24	GCSE's	14 weeks	Structural abnormalities	2nd	2011
Beatrice	28	1st degree	13 weeks	Multiple abnormalities	1st	2011

Table 1 – Sample profile from the British study

Name	Age	Level of education	Gestational age	Abnormality	Pregnancy	Year of TFA
Alexandra	43	1st degree	34 weeks	Down's syndrome (Trisomy 21)	2nd	2012
Fanny	33	Postgraduate	36 weeks	Multiple abnormalities	1st	2012
Céline	30	Postgraduate	30 weeks	Brain abnormalities	1st	2013
Véronique	32	Postgraduate	17 weeks	Down's syndrome (Trisomy 21)	2nd	2014
Ingrid	34	1st degree	26 weeks	Structural anomalies	2nd	2015
Lea	30	1st degree	27 weeks	Genetic deletion	2nd	2014
Anna	35	Postgraduate	12 weeks	Cystic fibrosis	4th	
Marie	36	Postgraduate	16 weeks	Down's syndrome (Trisomy 21)	1st	2015
Patricia	32	1st degree	30 weeks	Cystic fibrosis	1st	2014
Lara	37	Postgraduate	18 weeks	Down's syndrome (Trisomy 21)	3rd	2015
Maud	36	Postgraduate	15 weeks	Turner syndrome & cardiac abnormalities	1st	2010
Florence	38	Postgraduate	28 weeks	Patau's syndrome (Trisomy 13)	1st	2016
Brigitte	38	Postgraduate	22 weeks	Patau's syndrome (Trisomy 13)	2nd	2014
Isabelle	37	Postgraduate	27 weeks	Edwards' syndrome (Trisomy 18)	1st	2014
Claire	34	GCSE	29 weeks	Patau's syndrome (Trisomy 13)	4th	2015
Inès	38	Postgraduate	35 weeks	Brain abnormalities	1st	2014
Clara	29	Postgraduate	35 weeks	Genetic abnormalities	1st	2016

A level + 1 or 2 years of university study has been recoded as 1st degree ; A level + 3 or 4 years of university study has been recoded as Postgraduate ; A level + 5 years of university study has been recoded as Postgraduate

Table 2 – Sample profile from the French study