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

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1	Pregnancy termination for fetal abnormality: Ambivalence at the heart of women's
2	experience
3	
4	Abstract
5	The aim of this article is to demonstrate the centrality of ambivalence in women's experience of
6	pregnancy termination for fetal abnormality (TFA). Data were collected from two qualitative
7	studies conducted in England and France with women who had undergone TFA (n = 44). The
8	findings point to eight manifestations of ambivalence throughout the process of TFA: hope and
9	despair, a choice but no choice, standing still and rushing, bonding and detaching, trauma and
10	peace, disclosure and secrecy, bridging past and future, and individual and societal experience.
11	Women's ambivalence illustrates their internal struggle to reconcile the act of termination with
12	their desire to become mothers. It also reflects societal tensions regarding abortion and
13	disability. We argue that the absence of normative responses, social desirability bias and the
14	potentially confusing coexistence of the fields of prenatal diagnosis and social integration of
15	people with disability account for the ambivalence women feel as they go though TFA. As
16	women's ambivalence may impact upon the way they adjust to TFA, it is important to remain
17	cognisant of the complexity of TFA to support women appropriately.
18	Keywords: termination of pregnancy, fetal abnormality, qualitative, ambivalence,
19 20	Introduction
21	The present article is based on a series of studies which aimed to investigate women's
22	experience of pregnancy termination for fetal abnormality (TFA). Our research endeavour
23	started with the completion of a doctoral thesis in psychology conducted in England, and was
24	later complemented by research carried out as part of a large programme on prenatal diagnosis
25	in France which involved a multidisciplinary team of researchers. Our aim in this article is to

26 illustrate the ambivalence expressed by women who undergo TFA, as well as the processes that 27 underpin it. Our focus on ambivalence is based upon the fact that it is one of the most prevalent 28 phenomena observed in our studies, and that it may represent a significant challenge to 29 women's adjustment to TFA and/or their help-seeking behaviour. 30 Termination of pregnancy for fetal abnormality in context 31 In Europe, termination of pregnancy for fetal abnormality (TFA) concerns on average 4.6 per 32 33 1.000 births. TFA is three times more common than stillbirths and infant deaths combined 34 (Boyle et al., 2018). The prevalence of TFA varies widely between countries, which reflects 35 differences in professional and legal frameworks as well as attitudes and beliefs towards TFA 36 (Zeitlin et al., 2013). In England<sup>1</sup>, TFA represents 2% of all terminations (3,158 in 2017; 37 Department of Health [DH], 2018). In France this percentage rises to 4% (7,084 in 2015; Agence 38 de la Biomédecine, 2016). 39 In England as in France, there is currently no time limit for pregnancy termination if 40 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 41 42 had initially fixed a term of 28 weeks of gestation for all terminations, including those for fetal 43 abnormalities. In 1992, the threshold was reduced to 24 weeks, but with no time limit in case of 44 fetal anomalies. This difference is reflected in practice with TFAs conducted at a later gestational 45 age in France compared to England<sup>2</sup>. However, the professional practices surrounding the

46 process of termination show a high level of similarity between the two countries. These include

<sup>&</sup>lt;sup>1</sup> 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. <sup>2</sup> 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).

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

49

#### 50 **TFA as a specific type of pregnancy loss**

51 TFA shares many characteristics with other pregnancy losses such as miscarriages and 52 stillbirths, but it also differs from them in very significant ways. In all cases, parents lose a child 53 before birth, at a time when they would normally rejoice. Evidence also suggests that parental 54 grief reactions following TFA are similar to those following other types of pregnancy losses 55 (Keefe-Cooperman, 2005). However, TFA differs from miscarriage and stillbirth in that parents 56 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. 57 58 Furthermore, the loss following TFA is generally not recognised by society in the same 59 way other bereavements are. In many cases, the baby<sup>3</sup> remains 'invisible' to the outside world 60 and many parents feel that their grief is disenfranchised (Doka, 1989). Parents may find it 61 difficult to disclose that they have chosen to end the pregnancy and publicly mourn their loss 62 (Leichtentritt, 2011; Maguire, Light, Kuppermann, Dalton, Steinauer, & Kerns, 2015), as they 63 have to contend with the incongruence (either experienced by themselves and/or by others) 64 between the decision to terminate the pregnancy and the feeling of loss. 65 TFA also bears a unique moral component. Being a form of abortion, TFA is intrinsically

66 linked to the polarised debate about abortion and the opposing views regarding the rights of the 67 women versus those of the fetus (Sharp & Earle, 2002). The dichotomy between these two 68 positions has been described as one between those who have rights and those who have 69 morality (Ludlow, 2008). The fact that the decision to terminate the pregnancy is based upon

<sup>&</sup>lt;sup>3</sup> 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

74 (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).

82

#### 83 **Psychosocial consequences of TFA**

84 Several studies suggest that TFA has a significant impact upon women on three levels. First, at 85 the individual or intra-personal level, TFA is generally experienced as a traumatic event, akin to 86 an existential crisis (Sandelowsky & Barroso, 2005; Lafarge, Mitchell & Fox, 2014), which can 87 have long-term, negative psychological consequences for women. These consequences have 88 been well documented and include symptoms of depression, posttraumatic stress (Kersting et 89 al., 2009; Korenromp et al., 2007) and complicated grief (Kersting et al., 2007; Nazaré, Fonseca, 90 & Canavarro, 2013). Feelings of guilt relating to the decision are also prominent among women 91 (Nazaré, Fonseca, & Canavarro, 2014). A systematic review of the qualitative evidence on 92 women's experiences of TFA (Lafarge et al., 2014) indicates that many women feel unprepared 93 for the severity and duration of the emotional pain following TFA. Many feel powerless over 94 their situation and isolated in their experience, particularly when support is seldom available.

95 The review also indicates that some women question their identity, between that of a bereaved 96 mother versus that of a woman who has lost a pregnancy, with at its core the concept of 97 personhood attributed (or not) to the fetus (Parsons, 2010). Some women also question their 98 body for producing an imperfect pregnancy.

99 The impact of TFA upon women can also be felt at an inter-personal level, as women 100 reassess their relationships with others. Research suggests that women's partners also 101 experience difficulties following TFA, and that they tend to grieve differently for the loss of the 102 baby after TFA, with women experiencing more intense grief than their partners (Nazaré et al., 103 2013, 2014). Although in some cases, the TFA experience brings partners closer together, at 104 least initially, these differences can contribute to increasing women's feelings of isolation 105 (Nazaré et al., 2013, 2014). TFA also impacts upon women's relationships with their friends, 106 family and colleagues, which is usually contingent on the level of support women feel they 107 receive. A perception of limited support or lack of understanding can significantly alienate 108 women.

109 Finally, TFA also has an impact upon women's perception and engagement with the 110 world. Some women have described the experience of TFA as a loss of innocence (Rillstone & 111 Hutchinson, 2001). In line with Janoff-Bullman's shattered assumptions theory (1992), women's 112 visions of the world are irremediably altered by their TFA experience (Lafarge et al., 2014; 113 McCoyd, 2007). Women engage in a process of rebuilding their world views whilst 114 accommodating their TFA experience. The fact that TFA is linked to the abortion and eugenics 115 debate can also make the experience stigma-bearing (Hanschmidt, Treml, Klingner, Stepan, & 116 Kersting, 2018; Maguire et al., 2015), which adds another level of complexity and further 117 alienates women.

118

119 Ambivalence at the heart of the TFA experience

120	In England and France, the experience of TFA follows a sequential series of events or
121	experiences which include the diagnosis, the decision-making process, the procedure, the
122	immediate aftermath and the long-term adjustment. Each point brings its own set of challenges
123	including: waiting for the diagnosis, reaching a decision about the pregnancy, making decisions
124	about the procedure, whether to see the baby or not, what to do with the baby's remains, what
125	to disclose to others, how to grieve for the pregnancy and/or the baby, how to deal with a new
126	pregnancy and how to adjust long-term (Hunt, France, Ziebland, Field, & Wyke, 2009; Rapp,
127	2000). Each point is characterised by conflicting feelings and emotions, or even uncertainty
128	about how to feel about the experience. It is this ambivalence and the tensions it generates
129	which is the focus of this article. The aim of this article is, therefore, to demonstrate the
130	relevance of ambivalence to the experience of TFA. Data from two qualitative studies conducted
131	with women who had undergone TFA, one in England, the other in France, have been used to
100	
132	convey and illustrate the ambivalence that characterises the TFA experience.
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148 reported in detail elsewhere (Anonymised for peer review), therefore only the key 149 methodological points are mentioned in this paper. Women were recruited from a UK-based 150 organisation that provides support to parents when an anomaly in their babies is identified in-151 utero. A message advertising the study was posted on the online forum of the support 152 organisation and disseminated through the email network. To be eligible to the study women 153 had to be over 18 years old and had undergone TFA. No time limit was put on when the 154 termination had occurred. Altogether, twenty seven women took part in the study between 155 2010 and 2011. The topic guide included 12 open-ended questions exploring what the 156 termination meant for women, what coping strategies they used at the time of the termination 157 and afterwards, how their experience was influenced by time, and what their plans and hopes 158 for the future were.

159

160 **Study 2** 

161 The second study was a qualitative study conducted in France as part of a larger research 162 programme about women's experience of prenatal diagnosis (Funding details anonymised for 163 peer review). The project used a mixed methods approach and comprised an online quantitative 164 questionnaire to which over 1,500 women responded, followed up by in-depth interviews with 165 women who had agreed to be re-contacted. Using purposive sampling, 107 women were invited 166 for an interview to explore their experience further. Of those, 69 were interviewed. It is as part 167 of this qualitative phase that 17 women were interviewed about their experience of TFA. Data 168 were collected between May 2015 and May 2017 through face-to-face and telephone 169 interviews. Participants were invited to provide a narrative of their experience, and questions 170 were used to elicit feedback on: the way the diagnosis and prognosis were presented; the 171 information provided (e.g. about the condition and how it may translate after birth); the 172 interactions with practitioners; the role of the entourage and the media; and the process that

173 led to the decision to terminate the pregnancy. Interviews were recorded and transcribed174 verbatim.

175

176 The studies used different methods of data collection. The data collected through online 177 narratives (Study 1) generated reflective accounts and provided insights into the meaning 178 women attributed to their experience. Nevertheless, the data did not offer the same level of 179 detail as the data collected through in-depth interviews (Study 2). By contrast, although 180 interviewing participants enabled the researchers to collect more granular data (through 181 probing), the topic guide was broader and less focused on the meaning of women's experience. 182 However, both studies generated rich data and both achieved data saturation. 183 184 Data analysis 185 For the purpose of this article, data were analysed using thematic analysis (Braun & Clarke, 186 2006). Thematic analysis (TA) was selected as a method of analysis because of its flexibility. TA 187 can be used inductively (bottom up) and deductively (top down) as well as across data sets. As 188 the aim of the present analysis was to explore the manifestation of ambivalence, conflicts and 189 uncertainty during the TFA experience across both datasets, TA was deemed the most 190 appropriate method. The analytical process closely followed the guidelines recommended by 191 Braun and Clarke (2006). Both sets of transcripts were read several times, initial codes and 192 themes were generated, themes were defined and labelled (and later relabelled when deemed 193 necessary) and guotations were selected to illustrate the themes. The results of the analysis 194 were also considered within the literature on TFA and abortion more generally. Where relevant, 195 evidence from the literature was incorporated to support the article's narrative. To protect the 196 participants' identity, names have been changed to pseudonyms and any identifiable 197 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

223	despair, a choice but no choice, standing still and rushing, bonding and detaching, trauma and					
224	peace, disclosure and secrecy, bridging past and future, and individual and societal experience.					
225 226	Hope and despair					
220						
227	Across both datasets, the discovery of a severe anomaly represents the first tension and source					
228	of ambivalence in women's experience of TFA. Women usually start their pregnancy hopeful					
229	that everything will be fine and in the belief that taking good care of themselves will guarantee					
230	a positive pregnancy outcome (McCoyd, 2007). They have started to plan their future and					
231	formed an image of their baby in their mind. The suspicion or the discovery of an anomaly,					
232	therefore, comes as a shock. It shakes women's sense of security and destroys their hopes and					
233	plans for the future: "We had hopes for our future as a family and saw ourselves as parents from					
234	when I was pregnant" (Lucy, UK).					
235	From that point, women embark on a journey of uncertainty, over which they feel they have no					
236	control:					
236 237	control: "There is this feeling of having put your finger in a sort of thing that will sweep you away					
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237 238 239 240	"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).					
237 238 239 240 241	"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					
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249 250 Until a diagnosis is given, women harbour concurrent feelings of hope and despair. They are still 251 hopeful for a positive outcome but worried about the potential decisions to come. This is 252 Laura's case (UK) who, when hearing about of her baby's anomalies, starts planning for logistic 253 and material adjustments whilst still hopeful the outcome may be manageable. However, as 254 further tests demonstrate the gravity of the situation, her hope gradually turns into despair: 255 "She said that our baby had [major structural anomalies]. (...) First I thought we could 256 work around this. (...) I had thoughts about having a stair lift in the future, ramps, 257 teaching the child how to use these. (...) I thought that [other child] would be a loving 258 sibling and really helpful but then had to question how he would deal with having a 259 sibling who needed so much, and the affect this may have on him. (...) The decision was 260 agonising." 261 262 In some cases, the coexistence of hope and despair resemble a roller coaster, a term that has 263 been used to characterise women's experience in the TFA literature (Bryar, 1997): 264 "The day of the CVS, the measure of the nuchal translucency had decreased a little bit. So 265 the nurse said to me 'there is some positive [news].' So, hope came bouncing back. The 266 Saturday, two days later, someone called to tell me that it was Down's syndrome. A 267 catastrophe" (Marie, FR). 268 269 In many cases, the first suspicion that all may not be well signals the end of innocence (Rillstone 270 & 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.

274

275	The discovery of the anomaly represents the starting point in the TFA journey, and is
276	characterised by uncertainty and the coexistence of mixed emotions. For women, it is often a
277	brutal reminder that reproduction is not a process with a guaranteed positive outcome.
278 279	A choice but no choice
280	Ambivalence is also manifest in the decision to terminate the pregnancy as it involves conflicting
281	feelings between doing the right thing, whilst wishing one never had to make that decision: "I
282	ended the life of my baby and I wanted him so much" (Gemma, UK). The decision-making
283	process following the discovery of a fetal anomaly has been described in the literature as "a
284	Sophie's choice", a "travesty of choosing", "chosen loss and lost choices" (Sandelowski &
285	Barroso, 2005). In both studies, women also describe the decision-making process as a no-
286	choice since it offers no positive outcome: "You are damned whatever you do" (Wendy, UK).
287	For many, the decision is about choosing the least awful scenario, or between "terrible and
288	horrible" (Rillstone & Hutchinson, 2001).
289 290	To reach a decision, women have to balance a number of considerations that are often in
290	
291	contradiction with each other, such as their desire to have a healthy baby with their desire to
292	spare their child a life of suffering: "I had too much information that told me that it could be very
293	hard, very painful for him and that his life could be just one of suffering. I could not take that risk
294	for him. It was too much" (Marie, FR). Women also have to balance their own projections of
295	what a life with a disabled child may be like with what they know of their own coping processes
296	and resources, and those around them: "I was concerned that I may become depressed. I do not
297	follow a faith, and feel that I would not have that strong faith to offer our baby to help him come
298 299	through tough times" (Laura, UK).

300	For many, the decision-making process is a struggle between heart and mind: "It was hard to
301	separate heart and head when making the decision" Zoe (UK). In some cases, the option to
302	terminate directly conflicts with what they had previously expected they would do in that
303	situation: "I had always thought that termination, in whatever circumstances, was completely
304	wrong. Now I had to face the fact that I'd had one" (Justine, UK). The decision to terminate can
305	also conflict with personal beliefs "I also have conflicts with my Christian faith and this is
306	probably a cause of my current conflict" (Gemma, UK). It can also divide partners. For example,
307	Marie (FR) and her partner disagreed on which decision to make. Whilst her partner considered
308	terminating the pregnancy as "a selfish act driven by a desire not create problems for oneself"
309	Marie believed the opposite: "If I had been really selfish, I would have kept him. () I had too
310	much information telling me that it could be very hard. () I couldn't take that risk for him."
311 312	As women struggle to reconcile those conflicting considerations, some opt to frame their
313	decision as an "act of love" (Ingrid, FR) towards the baby: "I don't want him to suffer, I don't
314	want him to be in pain" (Inès, FR). Yet, they also know that this is a decision that, in some cases,
315	denies life and opportunities: "Yes he would have been in a very bad state, but he was viable
316	and it's like I did not give him any chance" (Céline, FR). Thus, some women compare their act to
317	compassionate euthanasia, which illustrates the tension they experience:
318	"There comes a point, I suppose (not that I have ever had this experience), where there is
319	no hope of recovery, no hope of anything approaching a normal life, no hope of progress.
320	Then it is probably the kindest thing to turn off the machine. That's what I did for my
321	baby, in a way – I turned off the life support that was the pregnancy" (Sally, UK).
322 323	Ambivalence regarding the decision can remain after the termination: "Up until this point [the
324	post-mortem results] we were never sure of the extent of the abnormalities and we tortured

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

- 327 "It was the right decision for us at the time, but the wrong decision for our child. That 328 hurts so much and I wish it didn't (...) I try not to have regrets, but I do. I know I could 329 have had a baby, even with disability" (Gemma, UK). 330 331 Even when they believe that they have made the right decision, women can find it hard to 332 accept their decision: "I have played God and unlawfully killed my baby but it was for the correct 333 reasons. It just does not ever seems right" (Ellie, UK), and remain uncertain about the future: "I 334 feel like we are in limbo, as in an addition to losing a child, we had plans to move and I was 335 considering giving up work" (Yvonne, UK). 336 337 The ambivalence expressed by women about the decision to terminate the pregnancy, even 338 when the decision appears to be the most appropriate for them, illustrates women's difficulty in 339 exercising their right to terminate the pregnancy within a social context that personifies the 340 fetus increasingly early (through ultrasound examinations), and where popular discourses 341 around the fetus' right to life are widespread (Purcell, Hilton, & McDaid, 2014). Women's 342 ambivalence is compounded by the fact that most diagnoses only offer an insight into what the 343 impairment will actually translate into (Whitmarsh, David, Skinner, & Bailey, 2007). 344 345 Standing still versus rushing 346 Women's relation to time during the process of TFA represents the third source of ambivalence, 347 with time appearing either static or hurried, and/or women wishing to speed up or slow down 348 the process. Women generally describe their experience of getting the diagnosis as their world 349 coming to a halt: 350 "The moment I was told my baby had trisomy 21, my world stopped. Everything stopped,
- 351 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).

354

353

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:

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

361 weekend" (Lara, FR).

362

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."* 

369

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):

# 374 "She [the midwife] told me: 'In 2 days it's the aspiration, we're going to take the tablets 375 now.' Until then, I was saying 'I have to turn the page quickly, it has to be quick.' In fact, I 376 completely froze. It was too fast (...) when they saw that I was completely stuck, they told 377 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).

380

379

381 Women's perceptions of time in the context of TFA often generates tensions, with some women 382 wanting to accelerate the process. This is the case of Ingrid (FR), who wanted to put an end to her 383 baby's suffering and avoid getting her hopes up: "The desire to speed up the termination process 384 was also linked to the idea that one had to put an end to the baby's suffering: one had to stop her 385 suffering and not give me any hope." By contrast, this suspended temporality can be welcome 386 and seen as necessary to reach a decision or start coming to terms with the situation: "The delay 387 [10 day delay] meant that my husband and I had time to come to terms with what was happening. 388 I didn't feel it was rushed and I felt better equipped to cope" Beatrice (UK).

389

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."

402

403 Women's ambivalence with time is also present after the termination with some women rushing 404 to get back to their activities, but regretting it later on: "Going back to work too soon was a major 405 'no-no'. I went back after 4 weeks – I should have taken twice as much time off work" (Beatrice, 406 UK). 407 408 The tensions women experience between standing still and rushing reflect the difficulty in 409 processing the termination cognitively and emotionally. It is also rooted in social practices that 410 form the backdrop of women's experience such as the term at which a baby can be registered 411 and thus be conferred a social identity, and/or in medical practices which are used at different 412 times during pregnancy (e.g. surgical versus medical termination). 413 414 Bonding versus detaching 415 The fourth source of tension or ambivalence is women's relation to their baby. From the 416 moment an anomaly is suspected, women are conflicted between the states of continuing 417 "giving life while thinking about taking it" (Leichtentritt, 2011). As they wait for the diagnosis, 418 women find themselves in a state of limbo, unsure about the way they ought to relate to the 419 baby. Lara (FR) describes her difficulty in establishing for herself how to care for her baby as the 420 investigations are ongoing: 421 "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 423 good? And even if the worse happens, we're in the middle of investigations that are

- 424 going to last for a while, so I can't completely... the only thing I was able to do to take
- 425 care, so to speak, of this child, well of this baby was to remain lying down, rest and try to 426 eat well."
- 427

422

428 As they wait for a diagnosis, women are torn between attachment and detachment towards 429 their baby and "fighting love for their baby" (Bryar, 1997):

430	"I think that all night I tried to say to myself: that's it, I don't love him anymore, I have to
431	stop loving him, I have to stop loving him. And then I think he never moved more than
432	that night. And then I said to myself: no, it's not possible, I still have 1%, 1% chance that
433	he has nothing" (Claire, FR).
434 435	Once the decision to terminate is made, women generally have to wait a few days for the
436	procedure to take place. This period brings its own set of tensions as women continue to carry
437	life whilst anticipating death:
438	"It was a weird sensation. Being happy, being sad, trying to feel all the little joys. I
439	hummed, I listened to music, as if he was going to live, as if I was going to welcome him.
440	It was weird. At the same time, I was crying and explaining to him. I was explaining to
441	him what was going to happen" (Claire, FR).
442	
443	From the state of pregnancy during which they form a unit with the baby, women have to
444	separate and learn to 'become one again.' During pregnancy, many women engage in unspoken
445	dialogues with their baby, who in most cases, they can feel moving. Some describe a symbiotic
446	relationship in which emotions are shared: "All I thought about, in my head was, not to be
447	afraid, not to be afraid. Not to be afraid, not to make him sense my fear" (Claire, FR). In parallel,
448	women also watch for any signs that the baby may be communicating with them as illustrated
449	by Claire's quotation above.
450 451	For terminations after 21 weeks of gestation a feticide is usually recommended, which generally
452	consists of an injection in the fetal heart, amniotic fluid or umbilical cord to stop the baby's
453	heart. Whilst the feticide is usually carried out on the day of the delivery in France, it is
454	conducted two days before in England. Thus, in England, after the feticide, women are sent
455	home for 48 hours. This period presents some challenges to women who find themselves

456 suspended between two realities, as they continue to carry their dead baby whilst the outside457 world remains oblivious to their predicament:

458 "I just took the tablets and was sent on my way to carry my dead son around in my 459 tummy for two days until I had my termination" (Megan, UK). 460 "I was given a tablet to soften my cervix. The midwife spoke to us to prepare us for 461 leaving the hospital saying life will be going on as normal all around you" (Rose, UK). 462 463 This duality between life and death is particularly salient when women carry twins and undergo 464 a feticide on one of the babies. Pregnant with twins, one of which is affected by Down's 465 syndrome, Alexandra (FR) undergoes a feticide on one of the twins at 32 weeks of gestation, 466 two days before having a caesarean. In her case, feticide and childbirth are events combining 467 both life and death: 468 "I kept life and death in my belly for two days... two long days during which I suffered 469 terribly morally. The weight of a dead baby in a tummy, this is a very strong feeling... It's 470 downright horrible. It is a dead baby, who does not hold himself anymore, who collapses 471 completely [in the stomach]. (...) Then I had an emergency caesarean section two days 472 later... It was the most traumatic period, to keep the dead baby in my tummy for two 473 days." 474 475 Ambivalence also characterises women's experience immediately after the procedure, for 476 example in the decision whether to see the baby or not, which can be experienced as soothing, 477 yet also distressing: 478 "Seeing the baby was helpful in some ways as I was able to hold him and say goodbye. 479 (...) But the reality is that he had died two days before and also had been very unwell, and 480 also at a very early stage of development when he wouldn't normally have been born, so

481 *he did look strange and that frightened me, I was scared to look at him and that made*482 *me feel guilty as if I didn't really love him as much as I should"* (Wendy, UK).
483
484 The ambivalence as to whether to see the baby may be linked to professional practices which
485 traditionally considered viewing the baby as facilitating the grieving process and actively
486 promoted it (Sloan, Kirsh, & Mowbray, 2008). Although it is now acknowledged that viewing the
487 baby or not has to be women's choice, the practice may still be engrained in some practitioners

488 and some women may perceive it as being expected of them.

489

490 Ambivalence is also present sometimes long after the termination as women are torn between

491 their desire to resume a normal life and move on from their experience, and their wish to

492 remember the baby: "There are days when we say to ourselves: we have to move on and then

493 *there are days when we say to ourselves: we have no right to move on"* (Claire, FR). Ultimately

494 women have to reconcile the duality of roles between the mother who brings life and the

495 mother who denies it, with the latter labelled as counter-natural. This is Bonnie's (UK) opinion:

496 "Mothers are not supposed to kill their own children"; a viewed echoed by Isabelle (FR): "It

497 completely goes against nature. Normally we are supposed to bring life, not death. And we

498 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).

506

499

507 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).

517

518 Yet, Inès also describes the birth as a gentle moment: "Childbirth for me was a moment of

519 gentleness." This view is echoed by Laura (UK) who describes giving birth as an unexpected

520 peaceful moment: "It was like meeting our lovely baby, almost a wonderful moment in a surreal

521 setting. Almost proud parents but knowing that our baby was at peace now. It was very peaceful

522 and special time."

523

524 The birth also contrasts with the rest of the TFA experience as women focus on bodily functions 525 and sensations. It is a time where the body seems to temporarily take over the mind: "During 526 labour I just focussed on what I needed to do" (Valentine, UK). To some women feeling the 'baby 527 going through' is an opportunity to bond with their baby: "I needed to be with him throughout 528 and feel him" (Theresa, UK). Others marvel at what their body has achieved: "The delivery itself 529 was not as traumatic as I thought it was going to be as I was amazed by body's capabilities" 530 (Beatrice, UK). Beatrice adds that the birth was a moment of "euphoria as I felt that I had 531 weathered the storm and survived", signalling the transition to the post-termination phase. 532 533 Women's ambivalence about the birth exemplifies the coexistence of excitement at meeting the 534 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).

537

#### 538 Disclosure and secrecy

539 Whether to disclose what has happened to them and to whom, represents another source of 540 ambivalence for women. Without disclosure, women cannot fully process their experience. They 541 may also be unable to access adequate support. Yet many women are unsure about the 542 appropriate level of disclosure, as they try to balance the need to be true to their experience 543 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 544 545 found people often referred to me having a 'miscarriage' which was so incorrect" (Olivia, UK). 546 However, at the same time, women are aware that the term termination may bring 547 condemnation from others: "I was careful not to tell everyone... I felt insecure about what 548 judgments people would make about what we'd done" (Bonnie, UK); a view echoed by Olivia 549 (UK): "It's also a matter of having to cope with facing people. Termination is a taboo subject, and 550 unless you have found yourself in this situation, people are quite un-aware." 551 552 Another challenge women encounter in disclosing their experience is avoiding upsetting or 553 putting people off: "I love to talk about him and so that I can, I try to make it a pleasant subject 554 so that people don't mind me talking about him" (Gemma, UK). Regardless of whether they 555 choose to disclose their full story or not, most women feel that their loss is not recognised by 556 others and that their grief is disenfranchised, a concept discussed in the TFA literature (Bryar, 557 1997; Leichtentritt, 2011; McCoyd, 2007). This societal inability to acknowledge women's grief 558 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).

562

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:

568 *"The support from my partner was very good during the termination and for about 6* 

569 weeks afterwards. However, from that point our coping mechanisms have been very

570 different and have put a massive strain on our relationship. He cannot understand why I

571 still need to go for counselling, can't understand why I have struggled with the arrivals of

- 572 other babies and pregnancy announcements. This adds to my loneliness as I now cannot 573 voice my sadness" (Christine, UK).
- 574

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.,

581 2014).

582

#### 583 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 587 not fully invest in her pregnancy because she had had two miscarriages previously. Thus, for her, 588 the baby was "neither in the present nor in the future, in fact, he was nowhere." 589 590 As the first suspicions that all may not be well with the pregnancy emerge, women start 591 projecting themselves in a future without a baby who, in many cases, already carries their hopes 592 and expectations and whose presence, physical or psychological, is already acutely felt: 593 "Talking about the future without him whilst, first, we do not want to be without him and 594 he is still there. I didn't yet feel him moving at the time, but hey, there are signs that 595 attest of his presence. It's clear. And we have seen him, even if not that much. We've 596 seen on the ultrasound, it's not a creation of the mind" (Marie, FR). 597 598 The aftermath of the termination represents another point of tension as women are conflicted 599 between their desire to get better, resume a normal life and 'move on', and their desire not to 600 forget their baby. Ellie (UK) is committed to keep her baby's memory alive, but she also believes 601 that she owes it to her baby to carry on living: 602 "[Baby] will be in our lives every day, and I will light his candle and think about him each 603 evening. Our lives need to continue, I cannot dwell on the past...it would probably send 604 me insane. I chose to make the decision to end baby's life to stop him from suffering." 605 606 Bridging past and future is a delicate operation as some women fear being disloyal to their 607 baby's memory by moving on: [Moving on]..."Although I know I probably have, I don't like to 608 think I have because I don't want to move on from my son. I like to think that the future will 609 always have him in it in some way" (Anna, UK). In some cases, women express an intense fear of 610 forgetting their baby: "I have a desperate fear of forgetting him, what he looks like, smells like, 611 how it felt to hold him" (Zoe, UK). 612

- 613 One way to reconcile these conflicting drives is for women to integrate their TFA experience and 614 the feelings it generates, within a new all-encompassing narrative:
- 615 I want to acknowledge the experiences, my emotions and feelings and have time to feel
  616 sad and remember my baby, but I do not want it to take over my life in a negative way –
  617 to become absorbed in grief" (Laura, UK).
- 618

619 The process of creating a new narrative may constitute an important coping strategy for

620 women. It may also reflect professional practices surrounding perinatal bereavement care in

621 which women are routinely encouraged to create memories (e.g. photos, hand prints) in order

- 622 to promote acceptance (Lafarge, Mitchell and Fox, 2013).
- 623

624 A new pregnancy presents another opportunity to bridge past and future. However, it is often 625 an additional source of ambivalence for women as they feel hope and excitement concurrently 626 with anxiety, guilt for 'replacing' the baby and sometimes disengagement towards the new 627 pregnancy. This phenomenon has been referred to as 're-emergence of anguish' (McCarthy et 628 al., 2015; Rillstone & Hutchinson, 2001) in the literature, and is illustrated by Ellie's guotation: 629 "Falling pregnant again was a very happy but difficult time for us both. We felt quilty to replace 630 [baby] but happy and also nervous." Similarly, when Anna (FR) becomes pregnant again after 631 two TFAs, she oscillates between investing and not investing the pregnancy. She opts for 632 disengagement, possibly because she feels this will help her emotionally: "All these feelings, 633 these questions about I invest, I don't, we tell others or we don't. For me, not investing was clear, 634 except for health professionals, no one knew, it stayed between my husband and me." 635 636 Women's ambivalence regarding a new pregnancy illustrates their difficulties in projecting 637 themselves in the future whilst still being firmly anchored in the past. With a new pregnancy,

638 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 neithertemporality.

641

#### 642 Individual and societal experience

643 The last point of tension relevant to the TFA experience is between women's view of TFA as a 644 deeply personal and intimate experience and the fact that women's experience is largely driven 645 by societal structures and attitudes. Whilst this tension may not be directly felt by women, it is 646 nonetheless an important reality that fosters ambivalence. Bonnie expresses a widespread view 647 that TFA "is something that will always be with us and feels very personal – something only we 648 can understand." As a result of TFA, women's beliefs about the world, their sense of self, and 649 their relationship to their environment is permanently altered. Yet, this intimate experience is 650 largely shaped by local laws and policies governing termination of pregnancy, local professional 651 practices, as well as societal attitudes and beliefs about TFA and, more generally, disability 652 (Lafarge et al., 2014). These factors contribute in shaping women's expectations for the 653 pregnancy, underpin their decision to terminate and influence the way they grieve for their loss. 654 First, local abortion laws define the timeframe and conditions for which a pregnancy can be 655 656 terminated. They determine the modalities for accessing termination services, including the 657 scale of the service provision, the setting (e.g. public hospital vs private provider) and the 658 financial cost (e.g. whether the state covers it or not). Women's experience is also directly 659 influenced by local professional practices. For example, speeding up the process of termination 660 is sometimes necessary to enable women to have a surgical termination. In France and England, 661 surgical terminations are rarely conducted beyond the first trimester of pregnancy. However, 662 there is evidence that this method of termination is safe to use in the second trimester of 663 pregnancy and that the low incidence of surgical termination after 15 weeks of gestation, at 664 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.

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669 Professional practices also include bereavement care surrounding TFA, another important factor 670 in women's experience. In both England and France, women are given the opportunity to create 671 memories following the termination, which is considered to be helpful for processing the loss. 672 Clara (FR) illustrates this when describing the care she had received after the birth of her baby: 673 They offered [to take a picture of the baby] straight away. They put a small cap on him, 674 to hide his slightly deformed head. They brought him back to us. They told us we could 675 keep him for as long as we wanted. After, for a week (...) we could come back as much as 676 we wanted to the maternity to see him (...) For me, the women who do best are those 677 who have an environment that recognises and makes the child exist." 678 679 Notably, although professional practices seem to encourage acceptance of TFA and aim to 680 somehow normalise women's grieving process, wider collective attitudes and beliefs about TFA 681 result in women feeling disenfranchised and stigmatised about their experience. In turn, the 682 way women chose to silence their story or part of their story means that TFA continues to be a 683 taboo subject and prevents women from accessing appropriate support. 684 685 Finally, women's experience of TFA is also shaped by the way societies regard disability. Céline 686 (FR) mentions that a key reason for terminating her pregnancy is the marginal place assigned to

688 *"I felt that if we had let our baby come alive, we would have tipped into another world.* 

individuals living with disabilities in France. She further links her decision to eugenic practices:

- 689 Perhaps my husband or I would have had to stop working to take care of him. We would
- 690 have had to fight to get material or financial aid. Disability is really on the margins of
- 691 society. And I admit that this idea disturbs me in the decision we made because, if we

692push it a little further, it is eugenics when we end pregnancies for medical reasons. It's693complicated. On that too, I think that if everybody who faces the question of disability694during pregnancy makes the same decision as us, then we will never deal medically with695the issue, we will never be able to give them a chance, to make progress. There's a lot of696ambivalence around the handicap in my head."

697

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:

701 "My mother asked me whether I would be able to find childcare for the baby if I returned
702 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

- 704 we would be entitled to it."
- 705

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,

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#### Conclusions

715 Our findings demonstrate the relevance of ambivalence to women's experience of TFA, as

2002), thus directly impacting upon women's experiences.

vomen 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

place. Women's ambivalence about TFA may be fuelled by the fact that TFA is a relatively recent phenomenon and thus, there are, as yet, no normative responses TFA (McCoyd, 2009). Women are unlikely to have encountered this situation amongst their friends, and they cannot turn to older generation for understanding and advice. This points to a deficit in experiential knowledge, which may lead to women feeling pressured to feel or act in ways they think they ought to and/or are socially acceptable. This phenomenon, coined as 'feeling rules' by 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

742 depression and posttraumatic stress or complicated grief (Kersting et al., 2007, 2009;

743 Korenromp et al., 2007) as a result. It is likely that the stigma surrounding TFA (Hanschmidt et 744 al., 2018) hinders women's help-seeking behaviour as some women may feel undeserving of 745 receiving care (Lotto, Armstrong, & Smith, 2016). In this context, it is also important for health 746 professionals to be aware of their own position on the issue of termination and of the biases 747 that they may hold as it would influence the way they care for women. This is particularly 748 important given that women's relationship with health professionals and their experience of 749 care has been shown to contribute to women's adjustment to TFA (Fisher & Lafarge, 2015; Lotto 750 et al., 2016).

751 The aim of this article was to demonstrate the centrality of ambivalence in women's 752 experience of TFA. However, we do not imply that women's experience of TFA is solely one of 753 ambivalence, nor that women necessarily experience ambivalence at all the stages described in 754 this article. The experience of TFA is idiosyncratic (Lafarge et al. 2014). As such, our findings 755 need to be considered as a contribution to the understanding of this complex phenomenon. 756 Interestingly, there were more commonalities than differences between the two studies. It is 757 likely due to the fact that the laws and practices surrounding TFA in France and England are 758 quite similar. The ambivalence surrounding the experience of TFA, whether at the individual or 759 societal level, as well as its uniqueness in relation to other pregnancy losses, makes TFA an ill-760 defined phenomenon that is still misunderstood and stigma-bearing. This raises important 761 questions about the support provided to women.

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

Table 1 – Sample profile from the British study

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

A level + 1 or 2 years of university study has been recoded as 1<sup>st</sup> 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