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Prenatal diagnosis: Women's interactions with practitioners when severe abnormalities are discovered at birth

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Abstract

Background: In an increasingly litigious medical environment, this study examined women's experiences of their interactions with practitioners when severe abnormalities are discovered at birth.

Methods: Eight in-depth interviews with women were conducted in France. Data were analysed using Interpretative Phenomenological Analysis.

Results: Four superordinate themes were identified: the importance of attunement to women's emotions and needs; the possibility of litigation but no direct accusation; reasons for not resorting to litigation; and reframing and positive transformations. Despite experiencing distress, women were reluctant to make a complaint against practitioners. Several factors may account for this, but practitioners' ability to relate to women with humanity was particularly significant.

Conclusion: Women understood the limits of technology and of the care practitioners can provide, but greatly valued practitioners' empathic and honest communications. Thus, adopting a transparent and open approach may foster trusting relationships with women/parents. In turn, this may lower the prospect of litigation being brought against practitioners when severe abnormalities are discovered at birth.

Introduction

Routine pregnancy care in France comprises three ultrasound examinations and several screening tests, of which combined screening for Down syndrome is possibly the most well-known. Down syndrome screening uptake in France is one of the highest in Europe (87%) compared to England (74%) and the Netherlands (< 30%; Crombag et al., 2014). However, not all anomalies can be detected prenatally and prenatal detection rates vary greatly according to the technology available and the operator's level of expertise (European Surveillance of Congenital Anomalies [EUROCAT]). For example, EUROCAT reports a prenatal detection rate for combined congenital anomalies of 61% for the Parisian registry compared to 43% in Brittany between 2013 and 2017 (EUROCAT, n.d). In France, 2.7% of live newborns are affected by congenital anomalies (Santé Publique, 2019), and a significant number of these diagnoses are made at birth.

Discovering a severe abnormality at birth may have negative long-term impacts on women. It may lead to a series of psychological and practical crises, challenge individuals' values about the world, and generate practical difficulties (Kandel & Merrick, 2007) such as requiring caring activities (feeding, dressing) and navigating complex healthcare pathways (Van Wyk & Leech, 2016). Evidence also suggests that women consider the transition to motherhood to be complete once they feel fully able to care for their child, which in the case of a child born with a severe impairment, might be protracted (Azad et al., 2013).

In the past 20 years, there have been significant advances in screening technologies, including the combined Down syndrome screening test (combining maternal serum values with fetal nuchal translucency ultrasound measurement), non-invasive prenatal testing (using fetal cells in maternal serum), and higher definition ultrasound equipment. These have led to higher detection rates of fetal abnormalities, particularly for Down, Edward and Patau syndromes (trisomies 21, 18 and 13). As screening technologies improved, societies have

also faced ‘wrongful birth’ and ‘wrongful life’ litigation (Giesen, 2012; Hassan et al., 2014).

Wrongful birth actions occur when a child is born with an impairment for which parents hold the medical team responsible (e.g. failure to identify the abnormality in utero) and seek compensation (Raposo, 2017). Wrongful life actions are brought on behalf of a child (usually affected by a severe impairment) for having to live a life of suffering when the birth could have been prevented (Giesen, 2012). At the core of these actions lies the notion that parents were denied the opportunity to terminate the pregnancy, and thus that their reproductive rights have been violated.

The 2001 Perruche lawsuit in France represents an important milestone in prenatal screening practices. The case concerned a child (Nicolas Perruche) born severely handicapped after his mother contracted rubella, undiagnosed, during pregnancy. The child’s representatives initially won a case for ‘wrongful’ life, but the judgement was later overturned by the French Supreme Court following uproar from professionals and the public. The impact of the Perruche case was to open a public debate on the right to ‘not be born’, the rights of disabled individuals and, more broadly, on the judicialization of medical practice (Costich, 2006; Mameri et al., 2015). The case also durably influenced prenatal screening practices in France and beyond, with practitioners becoming increasingly fearful of litigation, intensifying the use of ‘defensive medicine’, and a tendency to recommend and/or to increase the number of medical acts to protect the practitioner against potential litigation (Mameri et al., 2015; Moyse & Diederich, 2007). Yet, despite an increasingly litigious environment, the number of prenatal diagnosis related lawsuits remains small (Anumba, 2013; Mameri et al, 2015). In France, 10 cases were recorded in 2018 (Mutuelle d'Assurance des Professionnels de la Santé, 2019).

Little is known of women’s experiences of their interactions with practitioners when severe abnormalities are discovered at birth. This insight would, however, be valuable to

practitioners caring for women during and after pregnancy. This article aims to address this gap.

Methods

Study background

This article reports qualitative data gathered as part of a project investigating women's experiences of prenatal screening and diagnosis in France. The project comprised an online questionnaire followed by in-depth interviews. Women who completed the online questionnaire were asked whether they wished to be re-contacted to further explore their experiences. Altogether, 1527 women completed the questionnaire with 564 (36.9%) agreeing to a follow-up interview. Using purposive sampling, 99 women were invited for an interview and 67 (67.6%) interviewed. Of those, eight had had a baby with a severe abnormality discovered at birth or with an abnormality more severe than anticipated, which is the article's focus. Data were collected between May 2015 and May 2017.

Participants

All women (n = 8) who had reported that their baby had been born with a severe abnormality discovered at birth (or with one more severe than anticipated) and who had agreed to be re-contacted, were interviewed. A further eight women would have been eligible for interview but either did not agree to be recontacted (n=2) or left incomplete contact details (n=6). Women were aged between 29 and 41; all were married or in a relationship and all were educated at university level. Most abnormalities had been discovered at birth. In one case, the woman had received a diagnosis of clubfoot in utero, but additional abnormalities were identified at birth. Four babies were diagnosed with genetic/chromosomal anomalies and four with structural anomalies. Two babies did not survive beyond five weeks, two were severely

handicapped and four experienced various levels of impairment. All women except one had undergone Down syndrome screening and all had attended routine ultrasound examinations.

Procedure

Six interviews were conducted over the phone and two face-to-face. As participants had completed the online questionnaire, researchers were familiar with their circumstances. Women were told that the aim of the study was to further explore their experience. Interviews followed an open topic guide, including questions such as “how did you feel about the abnormality being discovered at birth?” or “what was your relationship with practitioners (providing antenatal and/or postnatal care) like? Interviews were conducted in French by researchers experienced in gathering sensitive data. Interviews lasted between 35 minutes and 1 hour 45 minutes. All were digitally recorded and transcribed verbatim. Quotations used in this paper were translated into English.

Ethics

The project was registered to the National Commission on Informatics and Liberty (Anonymised). As women were participating in the research in a private capacity, no other permissions were required. Women interviewed had already consented to participating in the research when completing the online survey. To protect participants’ identity, names have been changed and identifiable information removed. References to women’s babies and professionals involved in their care have been made using masculine descriptors.

Analysis

Interpretative phenomenological analysis (IPA [Smith et al., 2009]) was used to analyse the data. Through its ideographic focus, IPA is appropriate to examine the experiences of a small purposively homogeneous sample. Its phenomenological and hermeneutic underpinnings also enable researchers to access and interpret participants’ inner world and the meaning they

attribute to their experiences (Smith et al., 2009). In accordance with Smith and colleagues' guidelines, the analysis was conducted case by case, separately by members of the team. The authors then devised a coding framework which was used to code all interviews.

Findings

Four superordinate themes were identified as best conveying women's experiences of their interactions with practitioners when severe abnormalities are discovered at birth.

The importance of attunement to women's emotions and needs

Women reported mixed experiences of the care they received. When describing positive interactions, women underlined practitioners' ability to attune to their emotions and respond to them in an empathic manner as critical to their experiences: "*Everyone, from the doctors to the midwives, to the assistants, really everyone was very, very good to us (...) These people are devoted body and soul*" (Julie). "*They [the midwives] were adorable. We have only come across people who were full of good-will and very kind*" (Lise).

However, women also reported a lack of empathy from some professionals. For example, Sarah evoked the blunt manner in which her baby's Down syndrome diagnosis was disclosed to her:

The midwife was sewing me up while the consultant was looking at my baby. I still had my feet in the stirrups! She put the baby on me and, then, there is the gentleman who comes: "well then, we suspect a trisomy 21."

Similarly, Anna recalled a consultant consistently referring to her baby using the wrong gender, dismissing her concerns about the baby's lack of movement in utero and accusing her of being "over-protective."

160 A lack of empathy could cause professionals to read women's emotions inaccurately. This is
161 the case of Sarah who after being told that her baby had Down syndrome was visited by two
162 hospital psychologists. She recalled being taken aback by the psychologists' gloomy
163 demeanour, which seemed to frame her baby's birth as a negative experience:

164 *They came, they had very long faces... we were wondering what was going on. We*
165 *had more or less digested the news. For us it was OK, we were right in our heads. We*
166 *had accepted it.*

167 Conversely, Camille felt that some professionals had failed to grasp the severity of her baby's
168 condition and the depth of her sorrow. Recalling an interaction during which she was told her
169 baby had severe genetic anomalies, she said:

170 *[He said] "He's had a good life up to now." And I got angry, because my baby, who*
171 *was 6 months old, regurgitated every day, had epileptic fits every day. I said: "No, he*
172 *doesn't have a good life."*

173 A lack of empathy could also result in practitioners failing to adequately respond to women's
174 needs, in particular with regards to information. Noemi recalled some practitioners
175 withholding information from her, which she interpreted as a sign of contempt: *"I cruelly*
176 *lacked information (...) I had zero information. Ultimately, what was I? A number that*
177 *gave birth, that had a problem afterwards?"* In that instance, Noemi experienced
178 practitioners' attitudes as dehumanising and disempowering. Similarly, Anna found herself
179 'kept in the dark' and yearning for information. She expressed anger at the fact that
180 information had not been forthcoming:

181 *What makes me angry is that all the things that were useful, that help move thing*
182 *forward, I found them myself, through looking on the Internet or into [Town and*
183 *hospital]. It's not normal really that we were not given the right advice. It's not*
184 *normal.*

185

186 ***The possibility of litigation but no direct accusation***

187 Women expressed anger and sadness that the anomalies had not been identified prenatally:

188 “A part of me resents him [the gynecologist]... well resents him, yes and no, but I mean he

189 could have been less “lax” I don’t know. With him it was always ‘all is good, all is good’”

190 (Sarah). Some women questioned the quality of their pregnancy care. This is the case of

191 Ariane who recalled that her gynecologist had not scanned her baby’s umbilical cord despite

192 the fact that this examination had been carried out for her first child: “I was not going to tell

193 him what he had to do, but I remember that he had not checked it.”

194

195 Women were aware that the discovery of a severe abnormality at birth leaves practitioners

196 vulnerable to litigation. Commenting on the fact that her baby’s Down syndrome had not

197 been detected in utero, Catherine reported:

198 *My gynaecologist said to me: “On ultrasounds, we could not see anything because the*

199 *nuchal translucency was good and he doesn’t have heart problems, he was growing*

200 *properly” (...) I think there are doctors who are a little freaked out and who say to*

201 *themselves: my god, we did not see the first trisomy, we are going to be taken to court.*

202 Similarly, Julie recalled professionals initially attempting to minimise her baby’s

203 malformations, only to inquire later if other practitioners had told her whether the

204 abnormality could have been detected in utero: “They were worried enough to transfer me

205 (...) but they asked later – did they [at the other hospital] tell you that it would have been

206 possible to detect it?”

207

208 Yet, none of the women filed a complaint against the medical team (antenatal or postnatal),

209 and only one, Noemi, considered it. Instead, women expressed loyalty towards professionals

210 who had cared for them during pregnancy. Ariane repeated several times “*having confidence*”
211 in her gynaecologist, and not resenting him. Most women remained under the care of the
212 same practitioner, including Noemi who said that she “*still trusted her gynaecologist.*”
213

214 ***Reasons for not resorting to litigation***

215 Instead of accusing professionals of malpractice and/or filing a complaint, women offered
216 their own explanations as to why the abnormality had been missed. Some women held the
217 rarity of the condition responsible for the failure in detecting it: “*it [the condition] is*
218 *sonographers’ worst nightmare... very difficult to detect in utero*” (Lise). Others underlined
219 human limitations: “*We ought to be realistic. These things happen*” (Julie), and heavy
220 workload: “*If I put myself in his shoes, he sees so many people, with problems, without*
221 *problems*” (Sarah). Lise described practitioners as fallible and drew parallels with her own
222 shortcomings: “*He’s not a god, he’s not a robot (...) I sometime mess up in my job.*”
223 Technology and professional expertise were also questioned: “*the scans in [other hospital], it*
224 *looks like they are much more detailed there... So maybe we need to revise doctors’ training*
225 *(...) and the ultrasound machines.*” (Ariane)
226

227 Women also reported various reasons as to why they did not consider/resort to litigation. For
228 some participants, the fact that professionals displayed genuine concerns and/or regret
229 following the discovery of the abnormality was enough to exonerate them. Ariane described
230 at length how her gynaecologist appeared affected by her predicament and how she took
231 comfort from it:

232 *The gynaecologist called me almost every fortnight to find out how I was doing. We*
233 *could see very well that he was feeling guilty (...) It is someone who is serious and this*
234 *has led him to question his entire work.*

235 For Noemi, the failure to detect the anomaly in utero was offset by the fact that it had been
236 identified, albeit postnatally, which saved her baby's life: "*It could have been detected, but*
237 *no, we didn't [file a complaint] (...) the fact that the paediatricians saw it, it saved my baby.*
238 *Had they not seen it, probably [baby] would no longer be here.*"

239

240 Finally, some women alluded to the fact that making a complaint would negatively reflect
241 upon them. Catherine stated that "[*complaining*] *is not their style*" describing parents who do
242 so as "*bitter*" and "*vindictive*," while Anna refused to be drawn into what she considered to
243 be simplistic and opportunistic arguments: "*my goal is not to fight to say: 'you are bad guys,*
244 *I want money.*" In these cases, a complaint was viewed as diverting resources away from the
245 real goal of improving their baby's situation and as an opportunistic endeavour.

246

247 ***Reframing and positive transformations***

248 The reasons put forward by women to account for the failures to detect the abnormalities
249 prenatally may also constitute a way to reframe their situation. Some women depicted being
250 unaware of the abnormality as a 'blessing in disguise,' which had enabled them to experience
251 a stress-free pregnancy:

252 *I prefer to have had it this way, because to have known before, I think I would not*
253 *have had a good experience of my pregnancy; whereas I had a perfect pregnancy, a*
254 *perfect delivery.* (Noemi)

255 Being unaware of the baby's condition also meant that women did not have to make difficult
256 decisions about the management of the pregnancy, a thought that filled Julie with dread: "*It*
257 *was not diagnosed. If it had been, I don't want to think about what I would have done.*" For
258 Catherine, these questions would have conflicted with her religious faith: "*You can have the*
259 *strongest convictions, the day you are told during your pregnancy that your child has a*

260 *disability, the question of abortion inevitably arises. Honestly, this question... is a horrible*
261 *question.”* For Camille, the thought of having to ponder whether to continue or terminate the
262 pregnancy would have invalidated her child’s life; thus, she was relieved to have been spared
263 this dilemma: *“I didn’t want to have to choose (...) to think that we can ... that I can*
264 *terminate the pregnancy, it was as ifas if, on the other hand, I was regretting my child*
265 *being here.”*

266 Some women sought to derive meaning from their experience. Ariane’s baby only lived for a
267 few days but she was grateful for the opportunity to meet him. In this context, Ariane might
268 have been reluctant to taint her experience with negative thoughts about practitioners and a
269 potential complaint: *“We got some positive out of it – we have known him alive. I gave birth*
270 *to a child who was alive and we had him for some days, alive and in our arms.”* For others,
271 the experience triggered profound changes. Lise expressed the need to help others so that her
272 experience had not been in vain:

273 *I wanted for a long time to do something other with my life than the commute-work-*
274 *sleep routine, do something a little more useful to the community (...) I need to feel*
275 *useful, to tell myself that if this experience can be useful to other parents, to help them*
276 *through a difficult time, all is not completely lost.*

277 Camille also reported that her experience had enabled her to acquire a more mature vision of
278 life:

279 *The experience that we had has really helped me to develop. It remains difficult. I am*
280 *not going to say that disability is great and that we’re in Teletubby land! Far from it.*
281 *But it brings other things. It made me grow and look at life differently.*

282

283 Women also pointed to positive transformations among practitioners. For example, Anna’s
284 situation led professionals to reflect upon their practice, which she considered to be positive:

He promised me – whether he does or not I don't know - that for the next patients, he would systematically ask for an MRI, so no other moms have to go through what I have. He told me that he would tell his colleagues, in their multidisciplinary meetings, to be more attentive and to prescribe an MRI in this case.

Discussion

This study investigated women's experiences of their interactions with practitioners when severe abnormalities are discovered at birth. In line with the literature, women in this study valued practitioners' empathy, particularly during the communication of the diagnosis and their ability to read women's emotions accurately (Goff et al., 2013; Skotko et al., 2009). There was also evidence of incongruence between women and professionals when practitioners failed to acknowledge the birth as a joyful, albeit challenging experience. Women also valued transparent information. These findings support research suggesting that poor interactions with practitioners and a lack of transparency in complex obstetrics situations can have negative consequences upon women's wellbeing (Fisher & Lafarge, 2015; Graungaard & Skov, 2007; McCoyd 2009).

The study also shows that women were cognisant of the fact that failures to detect abnormalities prenatally leave practitioners vulnerable to litigation. However, none of the women chose to make a complaint, and only one considered it. Instead, they offered their own explanations as to why the abnormalities had been missed, incriminating the care system, the condition itself, technology or human limitations. Yet in seven out of eight cases, the anomalies could potentially have been detected prenatally, giving women the opportunity to terminate their pregnancy.

The reluctance to file a complaint may be explained by the fact that women were grateful that the condition had been identified, enabling their baby to receive appropriate

care, and that they had been spared having to make difficult decisions during their pregnancy. It may also illustrate women's desire to retain the moral ground in a 'rhetoric of blame', epitomised by wrongful life and wrongful birth litigation, and underpinned by the concept of 'medical negligence'. Women may fear depicting their situation as intrinsically negative, as this would leave little hope for positive emotions, and would somehow invalidate their child's life. In choosing not to file a complaint, women may also assert their sense of agency over their situation, thus gaining/regaining a degree of control over their narratives. This may also enable them to distance themselves from the position of 'victim' and the concept of 'loss', which are central to the medical approach to disability (Watermeyer, 2009).

Indeed, women's attitudes towards litigation may reflect a more holistic approach to the disability experience (Priestley, 2001) and a move towards greater inclusion of people with disability in societies, initiated by the disability studies movement. Research suggests that parents tend to focus on their child's potentials rather than their lack of abilities (Graungaard & Skov, 2006). Recent studies have also highlighted the positive consequences of raising a child with a disability, with parents reporting emotions such as joy, hope and pride in their children, as well as positive transformations such as an increased sense of strength and stronger family cohesion (Beighton & Wills, 2017; McConnell et al., 2015).

Women's reluctance to file a complaint also needs to be considered alongside the feelings of loyalty and empathy they expressed towards professionals. These feelings appeared fuelled by the emotional connection between women and practitioners resulting from having shared a difficult experience. It is possible that women felt emotionally invested in their relationships with practitioners and unable to relinquish them. Together, these factors might account for the fact that despite an increasing trend toward litigation in obstetrics, the number of prenatal diagnosis-related litigation cases remains small (Mameri et al., 2015).

The findings also show that the experience of discovering a severe abnormality at birth can be transformative. Some women ascribed meaning to their situation and/or experienced positive growth as a result. Some reported that the experience had triggered a change of direction in their career and enabled them to acquire a different life perspective. These findings are consonant with research on challenging reproductive experiences (Lafarge et al., 2017), indicating that following a traumatic experience, some women develop new capabilities, a deepened sense of connection to others and a new sense of purpose. In this study, the transformative nature of the experience was also manifest amongst practitioners with some appearing eager to change their practice as a result.

Our study has limitations. With eight interviews, the sample size is small. However, it fulfils IPA's ideographic criterion (Smith et al., 2009), and reflects the low incidence of these obstetric situations. Participants were well-educated, therefore, the risk of bias cannot be excluded. For example, participants' ability to engage in complex reasoning may be reflected in their acceptance of human fallibility and of what can be achieved with technology. Given that the study was conducted in France, the findings may not be transferrable to all settings. However, the findings will be relevant to other Western countries because despite variations in pregnancy care and practice (EUROCAT, 2010) these countries also have well-established prenatal diagnosis care pathways and face wrongful birth litigation (Giesen, 2012). Importantly, our study contributes new insights into women's experiences of their interactions with practitioners when severe abnormalities are discovered at birth. It deepens our understanding as to why women might not file a complaint against the medical team, and highlights the significance of the quality of their interactions with practitioners in preventing them doing so.

The study findings have important implications. Practitioners need to be aware of the idiosyncratic nature of women's experiences and avoid framing the birth as a negative event.

Women understood the limits of technology and of the care practitioners can provide. They also clearly valued empathy from professionals, as well as transparent information and honest communications. Although practitioners may be hesitant to counsel women beyond their sphere of responsibility, a perceived reluctance to share information or be open about women's situation can undermine trust. Thus, adopting a transparent and open approach may foster trusting relationships with women. This is particularly relevant because, in this study, it was practitioners' ability to relate to women with humanity and their willingness to change that mattered to women; elements that may have significantly contributed to lessening the prospect of litigation.

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