**Women’s experience of care when undergoing termination of pregnancy for fetal anomaly in England**

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**Abstract**

**Objective:** This study investigated women’s experience of care when undergoing TOPFA with a view to assisting healthcare professionals in providing optimum care to women.

**Background:** Technological developments in antenatal screening and testing mean more women are given a prenatal diagnosis of fetal anomaly and confront the possibility of terminating the pregnancy. TOPFA is a psychologically significant life event, but there islimited evidence on how women perceive their termination care.

**Methods:** A cross-sectional online survey was used to elicit qualitative data as part of a study examining women’s experience of the TOPFA procedure, in particular, the choice of method. Women were asked to comment on what they had found helpful and unhelpful in their termination care.Participants were recruited from a national support organisation. 361 women offered qualitative comments, which were analysed using thematic analysis.

**Results:** Women’s experience of termination care varied. Five themes were identified as underpinning what women considered ‘good care’: being cared for in a timeframe and environment that feels right, receiving the right level of care, the role of healthcare professionals and support organisations, acknowledging women’s particular circumstances and enabling women to make choices. Regarding the last theme, women particularly valued being offered a choice of termination method.

**Conclusions:** The findings suggest that many women undergoing TOPFA perceived their care as lacking in some way. Recommendations on improving practice are made and areas of further research are suggested, which may deepen knowledge on how best to care for these women.

**Keywords – 5 or 6:** Termination of pregnancy for fetal abnormality, perception of care, thematic analysis, women’s preferences, prenatal diagnosis, antenatal screening

**Introduction**

All pregnant women in England are offered antenatal screening tests for genetic and structural fetal anomalies, overseen by the United Kingdom National Screening Committee (UKNSC, 2013). National programmes currently include tests for sickle cell and thalassaemia, Down’s syndrome and a mid-pregnancy ultrasound scan to screen for various anomalies. In the past decade there has been an increase in screening provision in the first trimester of pregnancy, with the aim of offering earlier reassurance to most and enabling women opting to end the pregnancy to do so at an earlier stage (Nicolaides, 2011). At the time of writing, non-invasive prenatal testing (NIPT) for Down’s syndrome is widely available in the UK private sector from ten weeks’ gestation. NIPT is more accurate than standard Down’s syndrome screening tests as it has a detection rate above 99% (Nicolaides, Syngelaki, Ashoor, Birdir, & Touzet, 2012). An evaluation study funded by the National Institute for Health Research is currently underway to validate test performance in a ‘medium risk’ population and examine how NIPT might best be implemented into the National Health Service (Chitty, Hill, White, Wright & Morris, 2012).

While detection rates for fetal anomaly continue to improve, there are still few in-utero treatments available for major anomalies. Therefore after a prenatal diagnosis, women have the option of continuing or terminating the pregnancy. The majority of women in England choose the latter option when Down’s syndrome or major structural anomalies are indicated (Boyd et al., 2008; Morris & Springett, 2014). Termination for fetal anomaly (TOPFA) is legally sanctioned, under ‘Ground E’ of the abortion law covering England, Scotland and Wales (Abortion Act 1967, as amended in Human Fertilisation and Embryology Act, 1990). The ground states that the anomaly diagnosed must represent ‘substantial risk’ that the child if born would be ‘seriously handicapped’. Neither phrase is further defined and there is no gestational limit applied.

Research into the psychosocial sequelae of TOPFA suggests that it is a traumatic life event with potentially significant and lasting emotional impact (Korenromp, Page-Christiaens, van den Bout, Mulder, & Visser, 2009; Rillstone & Hutchinson, 2001; Statham, Solomou & Green, 2001; Lafarge, Mitchell & Fox, 2013a; McCoyd, 2007). Negative psychological consequences include posttraumatic stress, complicated grief and depression (Davies, Gledhill, McFadyen Whitlow & Economides, 2005; Kersting et al., 2005; Korenromp et al., 2005). Evidence also indicates that healthcare professionals’ behaviour, most notably their ability to provide empathetic care, impact women’s experience of TOPFA (Asplin, Wessel, Marions & Georgsson Öhman, 2013; Koponen, Laaksonen & Vehkakoski, 2013; McCoyd, 2009; Statham, 2002).

There is also evidence that it is helpful for women to have a choice of termination method in the circumstances of TOPFA, i.e. the opportunity to decide whether a surgical procedure under general anaesthetic or a medical induction of labour best suits their individual coping style (Kerns et al., 2012). It should be noted that both methods have a similar risk profile (Bryant, Grimes, Garrett & Stuart, 2011; Kelly, Suddes, Howel, Hewison & Robson, 2010). Evidence also suggests that there is a relationship between satisfaction with some aspects of care (e.g. reaching a diagnosis and sensitivity towards the baby) and psychological adjustment following TOPFA (Statham et al., 2001). As TOPFA is psychologically painful for women, one may assume that co-ordinated, high quality care based on individual needs and delivered in an empathetic way would, in theory, promote psychological adjustment.

Guidance issued in 2010 by the Royal College of Obstetricians and Gynaecologists (RCOG) states that TOPFA management should include provision of choice of termination method, non-judgemental and supportive care from staff and well-organised follow-up care (RCOG, 2010). This updated previous guidance which had also emphasised continuity of care and advocated that termination care be delivered by ‘expert sympathetic staff’ (RCOG, 1996). There is, however, limited evidence on how well these directives are being implemented in practice. This is particularly relevant because the low incidence of TOPFA (2,732 in England and Wales in 2013 representing 1.5% of all abortions) means that most healthcare professionals will not have extensive experience of caring for women undergoing TOPFA. The number of women undergoing TOPFA continues to rise steadily, mainly due to developments in screening technologies leading to increased detection of major anomalies (Department of Health, 2012, 2013, 2014; Lewis, Hill, Silcock, Daley & Chitty, 2014; Korenromp et al., 2007a). Yet the number of TOPFA cases most healthcare professionals manage will remain relatively small so understanding women’s experience of care is essential in order to improve care provision.

This paper reports the qualitative element of a study undertaken by Antenatal Results and Choices (ARC) into women’s experience of care when undergoing TOPFA, which focused particularly on the choice of method of termination. ARC is a UK-based charity that has a remit to offer non-directive support and information to parents through antenatal testing and its consequences. ARC has contact with between 500 and 700 women annually who have undergone TOPFA. In recent years the ARC helpline team noted a rise in the number of women contacting the helpline expressing concern that they had not been offered the option of a surgical termination of pregnancy by their NHS hospital, particularly if the diagnosis of fetal anomaly was made after 13 weeks gestation. In order to investigate this apparent lack of adherence to clinical guidance, ARC was awarded a voluntary sector grant from the Department of Health for England. This enabled ARC to convene an expert advisory group to guide the research into women’s experience of TOPFA with a view to recommending improvements in care pathways. A self-administered online survey was developed with help from the advisory group to investigate whether women in England were given a choice of termination method and to enable respondents to comment on their experience of care. The results of the quantitative part of the survey pertaining to the procedure and the choice of method are reported elsewhere (Anonymised). This paper adds to the limited literature regarding women’s perceptions of care and, by doing so, provides an opportunity for healthcare professionals to develop their knowledge in this challenging area.

**Methods**

***Design***

A cross-sectional, retrospective, online survey was used to assess women’s experiences of the procedure of TOPFA and, in particular, of the choice of termination method, and to enable respondents to comment on their experience of care.

***Participants***

Participants were recruited from ARC’s membership of women who have had TOPFA. ARC membership mainly comprises parents who have had a TOPFA and opted to join the organisation’s mailing list. ARC members have the opportunity to share their stories in the ARC newsletter, the password-protected online forum and during facilitated face-to-face parents meetings. Information about the study, including the link to the survey, was emailed to 600 ARC members. The study was also promoted on the ARC website and in a post on their online forum. No limitation was put on the time elapsed since TOPFA or any obstetric characteristics (e.g. gestational age at TOPFA).

***Data collection***

The survey was developed with help from the expert advisory group, which comprised professionals from fetal medicine, obstetrics, antenatal screening, maternity and abortion care, and NHS commissioning. It consisted of closed questions about women’s experiences of the TOPFA procedure (e.g. the information received, provided by whom) and the choice of method (e.g. ‘what method of termination was offered to you’). For the qualitative element, participants were invited to respond to two open-ended questions about what they had found helpful and unhelpful in their care when undergoing TOPFA: ‘Thinking about how your termination procedure was managed, what did you find helpful?’, ‘And what did you find unhelpful?’ Information about the terminated pregnancy (e.g. gestational age, type of anomaly) was also collected. The entire survey was piloted internally at ARC and a pilot interview was conducted with one participant. These resulted in no changes being made. The survey was hosted on a secure website (SurveyMonkey) using the Enhanced security option. This option maximises participants’ anonymity by creating a secure connection between an individual and a web server through the encryption of the information exchanged (www.surveymonkey.com). Data collection took place between January and March 2012.

***Ethics***

A one-page summary describing the project was emailed to the National Research Ethics Service (NRES) queries line to ascertain whether ethical approval was required. The NRES advised that ethical approval was not required for this project. Every effort was made to conduct the survey in accordance with the ethical standards specific to online research (British Psychological Society’s guidelines, 2013; Knussen & McFadyen, 2010). Potential participants received information about the aim of the survey and its sponsors. Participants were informed that that their data would be kept confidential. They could withdraw from the survey at any time. Given the sensitivity of the subject matter, participants’ potential for distress was acknowledged. They were advised to contact ARC’s helpline should they need to speak to someone about the study. They also had access to ARC’s UK network of support volunteers. The ARC staff team is in regular contact with its membership, therefore they are in a unique position to understand women’s expectations and issues, and are accustomed to dealing with parents’ intense emotional reactions. Thus the expert advisory group was confident that any distress would be managed in the most appropriate and sensitive way. To safeguard participants’ anonymity, only the research team (the papers’ authors) had access to the data. Data were downloaded in password-protected computers and IP addresses removed from the dataset.

***Analysis***

The data were analysed using thematic analysis. Thematic analysis is an inductive method of data analysis widely used in reproductive health research (Hadjigeorgiou & Coxon, 2013; Malik & Coulson, 2008). It is suited to explore topics on which there is limited evidence or where there is no specific theoretical underpinning to the data collection and analysis (Braun & Clark, 2006). In addition, given its non-ideographic focus, thematic analysis is appropriate for analysis of relatively large sample sizes, as is the case in this study; the aim being to identify patterns across data items, rather than examine the unique features of individual experiences (Braun & Clark, 2006).

The analytical process closely followed the guidelines provided by Braun and Clarke (2006): data familiarisation, generation of initial codes, identification of themes, revision and refinement of themes, definition and naming of themes, and report writing. Both authors read the transcripts several times. Author B carried out the initial coding and identified the sub-themes and themes. Author A also independently coded a subsample of the data. Coding across the whole data set was reviewed by both authors. The level of agreement between them was high. Where disagreements occurred, these were resolved through discussion. Participants’ quotations representative of the majority of accounts are presented to illustrate the themes. Disconfirming cases have also been included.

**Findings**

***Participant characteristics***

Altogether, 430 participants started the survey with 379 (88.1%) completing it in full and providing comments to at least one open-ended question about the experience of care. A further 18 participants completed the survey but chose not to comment on the open-ended questions. Thirty three participants completed less than half of the questions and thus, were removed from the dataset. Of the 379 respondents who completed the survey in full, 361 and 356 answered the ‘helpful’ and ‘unhelpful’ questions respectively, with 344 answering both. This gave a response rate of 83.9.0% and 82.8% and 80% respectively. Participants’ characteristics are displayed in Table 1. Information on the 33 participants who completed less than half of the survey questions is too incomplete to enable comparison.

A large proportion of participants lived in London and the South East. Time elapsed since TOPFAs varied between 1 and 43 years, with most taking place after 2007. The mean gestational age at TOPFA was 18 weeks (range 8-35 weeks). The great majority of TOPFAs were undertaken within the NHS. Participants who did not provide qualitative comments (N = 18) had had their termination more recently (72% from 2010) and were more likely to have had their antenatal care in the Yorkshire area.

Women’s experience of care when undergoing TOPFA could be articulated around four themes: being cared for in a timeframe and environment that feels right, receiving the right level of care, the role of healthcare professionals and support organisations, and acknowledging women’s particular circumstances and enabling choices. Each theme was a critical component of good care, with the last two themes underpinning the successful delivery of each aspect of care as described in themes one to three.

***Being cared for in a timeframe and environment that feels right***

As evidence points to the experience of TOPFA being challenging physically and emotionally, being cared for in a timely manner and in an environment that feels right was paramount to women.

*Being cared for in a timely manner*

Time was an important element in women’s experience of TOPFA. The issue of time encompassed balancing the need to gather information and reach a decision that felt right against the emotional cost of waiting, while also having to consider the clinical and legal frameworks for TOPFA. In this study, women’s needs and experiences with regards to time were contrasted. Some participants were satisfied with the time taken to deal with their situation, while others expressed frustration at being rushed or delayed.

Positive comments generally focused on the speed of diagnosis and the relatively short wait for the procedure. Thus, ‘seeing a consultant quickly’ (P23), being ‘pushed to the front of the queue for basic procedures like bloods’(P9) and ‘speed of going to hospital’(P79), contributed to mitigating women’s distress. Other participants emphasised their satisfaction at having time to reach a decision: ‘going at my own speed and not [being] rushed into a decision’ (P154). Once the decision was made, women valued prompt referral to the hospital: ‘[it was helpful that] the process was started quickly after the decision was made*.’* (P342)

Time could also be an issue and some women reported feeling rushed into deciding whether to continue or terminate the pregnancy. Gestational age, in particular, seemed to impact on care, with some women reporting increasing pressures around 13-14 weeks’ gestation, after which surgical terminations are harder to access in the NHS: ‘Due to the short time window for surgery, the decision felt pressurised’ (P352, 13 weeks’ gestation). Pressure was also noted around the 24 week legal limit for most abortions:

The policy at the hospital I was at was that it [the termination] couldn’t be carried out after 24 weeks. There was a possibility that the results from the amniocentesis would be back very close to this time. When I asked if I could go past the 24 weeks so I would have more time to think about the decision I was told that it was their policy not to go past this date. (P377)

Other participants described long delays between the diagnosis and the procedure. One participant mentioned a 6-week delay due to ‘waiting for test results and appointments to see geneticist’ (P8, 20 weeks’ gestation). Waiting for the procedure could be distressing, with one participant comparing it to ‘being on death row’ (P298): ‘The wait for the procedure. It was awful to feel my baby moving inside me knowing that I was going to take their life before it had begun’ (P37). Finally, for some participants undergoing a medical termination, the 48 hour delay between taking the first set of medication or having the feticide (in utero injection to cause fetal demise) and induction of labour could feel ‘like an eternity’ (P307).

*Being cared for in the right environment*

Being in an environment that felt congruent with their experience also greatly influenced women’s experiences. Most women had vivid memories of the procedure and thus, the way they felt about the setting for the termination, particularly the ward they were in (gynaecological or labour), was important. The issue of environment related to the physicality but also the meaning women ascribed to the place where they underwent the procedure. There was, however, no consensus about which environment was seen as most suitable. Women simply valued being admitted on the ward they felt most appropriate to them. A gynaecological ward was generally favoured by women in the earlier stages of pregnancy or those fearful of being in close vicinity of mothers and newborns. Other participants, however, felt that a labour ward was more compatible with their experience: ‘Being in the delivery unit. I felt I was recognised as a pregnant mum. Rather than being in a gynae ward.’ (P165, 17 weeks’ gestation).

Being admitted to the ‘wrong’ ward could cause distress. Some women on the labour ward found it difficult to hear other babies being born and ‘leave the hospital without [their] baby’ (P234). Similarly, being admitted to a gynaecological ward felt inappropriate for some women who saw it as a failure to acknowledge that their pregnancy was wanted. This was particularly true of women who had their termination in the independent sector, although some did not report these concerns.

Participants also commented on the level of privacy they were given. Most had individual rooms and greatly valued this.Being able to ‘wait separately from other people’ (P108), ‘having privacy to spend a few precious hours with [their] baby’ (P234) was appreciated, as was the possibility for their partner to stay with them. Conversely, unmet needs could cause distress: ‘Halfway through my labour, my partner and my mother were told to leave – I had to threaten to discharge myself for them to relent and allow my partner to stay*.’* (P168)

***Receiving the appropriate level of care***

Alongside being cared for within a timeframe and environment that felt right, women valued receiving what they considered to be the right level of care. This included being cared for by experienced confident staff, receiving appropriate clinical care, continuity of care and aftercare.

*Being cared for by experienced staff*

Women valued being cared for by experienced members of staff, ‘specialist midwives’ (P203) or ‘having the most experienced consultant in carrying out selective feticide’ (P167). Having access to staff with expertise seemed to provide reassurance to women: ‘I felt I was being treated by experts’ (165). Less positive comments related to hospitals being short-staffed, which could result in long waits and being cared for by junior or inexperienced members of staff: ‘Normal midwives seemed not to know what to do. One told me that she had never delivered a still born baby. This was the last thing I needed to hear.’ (P333).

*Receiving the right level of clinical care*

Having access to analgesia, particularly morphine, was important to women undergoing medical terminations: ‘I was able to have anything to help with the labour and this was very reassuring’ (P198). Among women who had a medical termination, negative experiences often related to the degree of pain experienced, either because the wrong type of analgesia had been provided or because it was insufficient. The fact that the pain could have been lessened or avoided altogether furthered women’s suffering: ‘I found being in pain throughout labour unnecessary, and it turned out to be because I was on half-dose of morphine which wasn’t enough’ (P158). Some women, however, were less positive about analgesia, describing unpleasant side-effects such as ‘drop in blood pressure’ (P14). Other negative experiences of clinical care included babies being placed in bedpan or kidney trays after delivery, which some women found upsetting:

It was a very busy maternity ward and the midwives did not spend much time with me. I ultimately gave birth to my baby on the toilet into a bedpan in the absence of any midwives with my husband with me, which was horrific experience for both of us. (P345)

*The importance of continuity of care and aftercare*

Continuity of care, particularly ‘by the same midwife’ (P57) was important to women. In some instances healthcare professionals seemed not to have read women’s medical notes, and thus were ill-informed about their circumstances and more likely to make comments that women found upsetting ‘One nurse didn’t realise I was a different case and she came into the room all smiles asking why I looked so sad and where was my chubby baby for her to cuddle’ (P231). Poor continuity of care or miscommunication between staff led to some women being referred to antenatal care or contacted by children’s services after their termination.

Aftercare was another important element in women’s experience. However, most participants reported not receiving any, which one equated to ‘feeling abandoned’ (P234). Many women had to take matters in their own hands: ‘I also had to cancel all my other antenatal appointments as my midwife had failed to close the loops’ (P 294). Some had to arrange their follow-up appointment themselves: ‘I was supposed to have a follow-up consultant appointment, I was never told this and eventually when I found this out I had to contact the hospital for it.’ (P291). In some cases, community healthcare professionals failed to visit women after the procedure:

We were told we would have a visit by a midwife, she rang 2 days later but never turned up for a week. By which time I was in a terrible pain and we found out that I had an infection!! (P45)

When aftercare was available, women found it beneficial: ‘The care was v [very] good. [The] bereavement midwife [was] excellent and I saw her lots after.’ (P102)

***The role of healthcare professionals and support organisations***

Women’s experience of TOPFA was greatly influenced by their interactions with healthcare professionals, whom they consider as having two main roles: informing them and supporting them in an empathetic way. They also spoke positively of being signposted to information and support from external support organisations.

*Informing women*

Information was an important factor in women’s experience of care. It was central to the decision to terminate the pregnancy and the experience as a whole. Given that this paper concentrates on the experience of care when undergoing TOPFA, this section focuses on the information provided to women before and at the time of the procedure and not on information related to the fetal anomaly. Information about the procedure was generally given by healthcare professionals. Women valued this information because it enabled them to prepare for the physical side of what was to come: ‘The information given to me by the midwife and nurse was very good, [they told] me all what I should expect to happen’ (P317). Being given explanations about the procedure as ‘they went along’ (P147) was also critical, particularly because a medical procedure could be lengthy. Women also welcomed the opportunity to ask questions: ‘Also I was given a lot of time to ask questions before the termination with the genetic counsellor, midwife and doctors (P194).

By contrast, a lack of information could cause anguish. Many participants undergoing medical terminations had not expected the procedure to last for as long as it did: ‘Nobody told me how long I might be in the labour ward for (I was told 6 – 12 hours and I was there for 3 days which I later found out was quite common)’ (P333). This was particularly pertinent to those who had not given birth before and among whom ‘a fear of the unknown’ (P165) was reported. In addition, some women felt uninformed about ‘how [they] might feel psychologically afterwards’ (P92), possible medical complications or lactation: ‘with the additional trauma that brought in not having to feed a baby’ (P234). Lack of information about what would happen to the baby’s remains could also cause distress: ‘After I was discharged I was supposed to be told when the baby would be cremated or if I wanted a funeral and I never was.’ (P291). Some participants were also angered by inconsistent and ‘conflicting information’ (P38). Finally, timing of information provision could be experienced by some women as inappropriate, particularly when relating to the post-mortem:

The doctor brought in the post-mortem consent when I was in the middle of labour and expected me to listen and make decisions about what I wanted to find out after the birth (...) the time she chose to do it didn’t really work for me. (P334)

*Providing empathetic care*

Possibly the most influential element in women’s experience was healthcare professionals’ ability to care for them in an empathetic way. Again, women’s accounts on this varied. Women were forthcoming in commending professionals who dealt with them with empathy, describing the care received as, for example, attentive, caring, compassionate, considerate, friendly, humane, kind, sensitive, understanding, warm: ‘All the staff were wonderful from the moment we were given the news that our 12 week scan had shown a problem – caring, supportive, kind, professional – it helped enormously’ (P23). Empathetic care meant different things to women. Some found healthcare professionals’ closeness, e.g. ‘having someone with [them] throughout labour’ (P184) comforting. Others found solace in healthcare professionals appearing to validate their decision: ‘Medical staff were very supportive and caring and reassured me that I made the right decision, which helped.’ (P284). Generally, however, it was healthcare professionals’ kindness women were most grateful for. Kindness could be displayed towards the woman, her partner but also her baby: ‘The care and attention the midwife on duty showed to our son i.e. talking to him as she washed and dressed him’ (P172). Other participants were grateful for staff’s discretion: ‘Nursing staff were caring and understanding, but not fussing, [they] gave us plenty of space - respectful in fact’ (P256).

Care was, however, not always provided in an empathetic way. Some women described the care they received as appalling, blunt, cold, dismissive, impersonal, judgmental, uncaring or unfriendly. A lack of understanding about women’s circumstances was often mentioned as a source of distress. Healthcare professionals could appear dismissive of the physical and emotional pain women endured.

*The role of support organisations*

Alongside healthcare professionals, women also saw support organisations such as ARC or the Stillbirth and Neonatal Death Charity (SANDS) as pivotal in providing them with information and emotional support. Many women considered it to be healthcare professionals’ duty to signpost them to these organisations, and this did not happen consistently. Among women signposted to support organisations, many stated that they would have liked to have been referred to them earlier in the process: ‘The midwife was very kind though we didn’t find out about ARC until after our daughter was born.’ (P158)

Women generally rated the information they received from support organisations very highly and for some, it was their only source of information: ‘The ARC booklet I was given at the initial diagnosis straight after the scan, without it I would have been completely unaware of what to expect from the birth’ (P310). Women also sourced emotional support from these organisations, which one participant described as ‘a lifeline’ (P106). These were particularly helpful in alleviating women’s sense of isolation: ‘The leaflets given to me helped knowing that it wasn’t just me.’ (P280). No negative outcomes of accessing support organisations were mentioned.

***Acknowledging women’s particular circumstances***

Underpinning women’s experience of care was their desire for their particular circumstances to be acknowledged. This involved healthcare professionals acknowledging the unique nature of TOPFA and the psychological challenges that may be associated with it.

*Acknowledging the unique nature of TOPFA*

Participants were keen for healthcare professionals to recognise that their pregnancy was very much wanted: ‘There was a real awareness that this was a desperately wanted pregnancy’ (P259). Women also wanted the uniqueness of their situation to be acknowledged in the context of terminations for non-medical reasons:

I fully support women's choice to have terminations, but at the time, it was hard to be in the same room as many young girls, when I did not want to be there at all. I did not have a choice as the diagnosis meant my baby would die anyway. (P87)

This was particularly important to those who had their termination in the independent sector, where most terminations for non-medical reasons are carried out. Some women reported being offered contraceptives after the procedure, which they found upsetting.

Other women were keen for their experience to be differentiated from a miscarriage: ‘[Unhelpful] Being handed a leaflet about dealing with a miscarriage almost immediately afterwards when I was clearly dealing with an awful decision which was NOT a miscarriage’ (P134).

Many women were sensitive to the terms used by healthcare professionals to refer to their baby or their experience. Referring to the baby as ‘product of conception’ (P333) was experienced as particularly hurtful as it seemed to invalidate the baby: ‘I was made to feel like my baby wasn’t a baby’ (P133). This was, however, contrasted by one participant who was keen to distance herself from the concept of baby: ‘The midwife was a natural birth midwife and kept referring to the foetus as a baby which I found upsetting’ (P44).

*Acknowledging the psychological challenges associated with TOPFA*

Women mentioned a number of psychological challenges associated with undergoing TOPFA, the most prominent one being a fear of being judged. Some women reported being worried they would be judged for their decision to terminate and thus, were grateful when healthcare professionals cared for them in what they perceived to be a non-judgemental way: ‘At every point I was well cared for, able to be open and never once felt judged’ (P129). The value placed on non-judgmental attitudes extended to other professionals such as faith leaders, with some participants finding comfort in being supported by a ‘hospital chaplain’ (P26).

Attitudes seen as judgemental were, however, also recounted: ‘I found the treatment of the midwife unhelpful as she was very offhand and I felt she didn’t approve of my decision to end the pregnancy’ (P312). In some cases, healthcare professionals not only appeared to be judgemental towards women’s decision but also the way women behaved during the termination : ‘One rude and pushy midwife who wanted me to hold the dead baby/fetus which I was too distressed to do – saying that ALL MOTHERS DO – I felt she made me feel unworthy for my decision’ (P143).

Finally, a few women reported experiencing feelings of guilt: ‘I had to wait a while for a hospital bed, it was about a week which made me anxious and feel progressively guilty.’ (P47) Feelings of guilt could also relate to not being prepared for what would happen to the baby after the termination: ‘On [the] day they talked about whether we wanted a funeral, to put anything in with the baby, e.g. cuddly toy, [I] felt inadequate and even more guilty as [I] hadn't thought of any of that!’(P79). These accounts, however, represent a minority.

***Enabling women to make choices***

Acknowledging women’s particular circumstances, and in particular the unique nature of TOPFA, also involved enabling women to make choices about their care should they wish to do so.

*The importance of choice*

In this study, most women greatly valued being given choices, including whether to have the termination or not, the method of termination, the types and levels of analgesia, whether to spend time with the baby or not, what to do with the baby’s remains. For many women, these choices appear to give them a level of control over a situation most felt they had no control over: ‘I did not have a choice as the diagnosis meant my baby would die anyway, be it at full term, immediately after birth, or somewhere along the pregnancy’ (P87), or again: ‘My termination was extremely late and we had no choice’ (P91). Some women clearly stated that they were grateful for having ‘had the choice to terminate’ (P136) in the first place. The choice over the ‘antenatal ward or the gynaecological ward’ (P335), the type of analgesia and whether/how ‘to spend time with the baby after birth’ (P234) could be seen by some women as a way to empower themselves. Women who had limited choices reported more negative experiences.

While choice was mainly reported as positive, some women also described being somewhat overwhelmed by the choices they had to make: ‘On the day, I found the choices of medication method e.g. self-administered pain relief at regular intervals via cannula or injection, a bit confusing’ (P244) or ‘[it was unhelpful] not realising how many choices we'd have to make in terms of post mortem and funeral arrangements’ (P270). However, this feeling was often more related to the lack of preparation and anticipation than the choice itself.

*Choice of method of termination*

A choice over the method of termination was greatly valued, but, in this study, only 50 women out of 361 (14%) were offered a choice of method. Among those who had the choice, the majority (N = 30, 60%) chose to have a surgical termination: ‘The consultant really listened and went out of her way to give me the procedure I wanted’ (P327, surgical termination, year of termination 2009). Being able to make that choice was particularly important to participants fearful of giving birth to a dead baby and /or who had never given birth before.

The lack of choice over the termination method could be a major issue with some women unable to access surgical termination despite it being their preferred method:

I was absolutely against delivering my baby as I felt I wasn’t strong enough to go through labour, but I wasn’t offered any alternative. (…) I was so concerned and afraid, it was almost a factor in me not going ahead with the termination. (P65, 2011)

In some cases, surgical terminations were actively ‘undermined as an option’ (P179, 14 weeks’ gestation, 2011): ‘I never considered there was an alternative to an induced labour as I was told that if I had a surgical removal it could possibly mean I could not have future pregnancies’ (P206, 13 weeks’ gestation, 2008). Other women were unaware until they responded to the survey that they ‘could have had a choice of method’ (P23, 2012).

**Discussion**

In this paper, we set out to examine women’s experience of care when undergoing TOPFA. The study’s findings show that the organisation of care and healthcare professionals’ support were paramount in women’s experience of TOPFA and that women valued individualised care that answered their particular needs. More precisely, for women, good care encompassed: being cared for in a timeframe and environment that feels right, receiving the right level of care, receiving information and empathetic support from healthcare professionals and support organisations, having their particular circumstances and the psychological challenges associated with it acknowledged and being able to make choices. These findings have several practical implications.

***Timing and environment***

Many women were satisfied that their care was managed in a timely fashion, but others described feeling pressured. Time pressures due to diagnoses made after the mid pregnancy anomaly scan (scheduled at around 20 weeks’ gestation) may be unavoidable if clinicians believe the fetal indication does not fulfil the criteria for Ground E of the abortion law. In this instance, the termination can only be sanctioned under an alternative ground before 24 gestational weeks. Some parents approaching this ‘deadline’ will have the additional stress of having to make their decision within a tight timeframe. It is therefore important to provide extra psychological support to parents in this circumstance as they may feel particularly vulnerable. Referral to staff trained in providing psychological support or support organisations may address this. Another reported time pressure concerned access to surgical termination. Few NHS hospitals have the in-house surgical expertise to provide surgical terminations after 13 weeks’ gestation (Lyus, Robson, Parsons, Fisher, & Cameron, 2013). In our study, some of the women given a diagnosis of fetal anomaly following first trimester screening with a preference for this procedure felt they had to make decisions quickly. Therefore, it may be helpful for healthcare professionals to inform women that surgical termination procedures after 13 weeks are available in the independent sector under NHS contract. Even though in some parts of the country women will have to travel some distance to an independent provider, some may be willing to do this.

With regards to environment, there was no consistency in women’s preference but women valued being able to decide on the ward that felt right for them. Therefore, it is important that, where possible, healthcare professionals accommodate women’s preferences.

***Competent confident staff***

Women were positive about being cared for by skilled ‘experienced’ staff that were responsive to their needs and could provide continuity of care, including aftercare. Discrepancies in care in this area may partly be due to sub-optimal staffing levels (Royal College of Midwives, 2013). While there may be no ‘quick fix’ to the strain on NHS resources, implementing a co-ordinated care pathway for women facing TOPFA and ensuring all staff involved receive adequate training could be beneficial. An example of this would be the training run by ARC that is accredited by the Royal College of Midwives which covers all aspects of providing individualised care for women and couples facing TOPFA including the practical and ethical issues facing staff.

***Providing empathetic care***

Healthcare professionals’ ability to provide empathetic care was also a key component of women’s experience, a finding previously noted in the literature (Asplin et al., 2013; Korenromp et al 2007b). Women spoke positively of empathy and kindness from healthcare professionals and conversely, were critical of behaviours they perceived as insensitive Women also spoke of the psychological challenges associated with TOPFA (e.g. fear of judgement), which made the provision of empathetic care all the more crucial. This finding is particularly relevant given the current impetus within the NHS, following the Francis report (2013), to develop a new model of care based on compassion and respect. Furthermore, as there is no evidence to suggest that there is a ‘typical’ response to TOPFA (Sloan, Kirsh, & Mowbray, 2008) healthcare professionals should take the lead from parents in how they wish to approach this experience, including whether they refer to a ‘fetus’ or ‘baby’ and how they might want to acknowledge the loss.

Providing empathetic care to parents in this context can be demanding on a personal level for healthcare professionals (Garel, Etienne, Blondel, & Dommergues, 2007; Hunt, France, Ziebland, Field, & Wyke, 2009; Menezes, Hodgson, Sahhar, & Metcalfe, 2013). The extreme level of distress experienced by parents facing TOPFA can mean some are unappreciative of their care, however well-managed. Access to support organisations such as ARC can complement the care provided by hospital staff by offering an independent space for parents to offload emotions. Staff are also likely to benefit from having formalized support for themselves in place. This could be addressed through supervision at work or support organisations. For example, ARC’s confidential helpline is also used by healthcare professionals.

***Providing information and enabling choice***

Women appreciated clear, accurate, and consistent information provided at appropriate times. They needed to know what would happen before, during and after the procedure to help them prepare for what was ahead and the options they had. The findings suggest that women are not always offered adequate information. Discrepancies between women’s information needs and the information provided has already been documented (Hunt et al., 2009). Providing information may be challenging for healthcare professionals as women facing TOPFA might find it hard to assimilate information (Hunt et al., 2009). Therefore, women may benefit from having a named professional, most likely a midwife or genetic counsellor, who they can contact with questions or concerns. They could also be signposted to support organisations for more detailed information (e.g. ARC’s parent ‘handbook’, 2012; Sands’ healthcare professionals’ guidelines on discussing post-mortem, 2013).

Women also valued being able to make choices and having a degree of control over their care. In relation to choice, being enabled to have the termination method that they wanted was important to women. This supports existing literature indicating that women prefer surgical method of termination after 13 weeks’ gestation and that it is important to offer them a choice of method (Kelly et al., 2010). Despite the existence of RCOG guidelines, improving care in this area is challenging. Unless a full post mortem is required, there is usually no clinical reason to restrict the choice of method (RCOG, 2010). The main obstacle is the dearth of doctors working in NHS hospitals trained in dilatation and evacuation procedures (Lyus et al., 2013), which is partly due to abortion provision shifting into the independent sector (DH, 2013). As independent providers are licenced to provide abortions until 24 weeks’ gestation, women should be made aware that these services exist and can most often be NHS funded. However, they may also need to be prepared for an abortion clinic setting where other women are ending unwanted pregnancies. This is particularly important given that many women in our study were keen to have the uniqueness of their experience acknowledged, which could involve differentiating themselves from women having terminations for non-medical reasons. As a result, staff working in the independent sector might also benefit from more insight into the needs of this client group.

***Strengths and limitations of the study***

This study adds to the limited literature about women’s experience of care when undergoing TOPFA. It involved a large group of women who had undergone TOPFA with a range of experiences, TOPFA for different indications, using different methods and over a range of gestations. However, the study has some limitations. The data was collected through retrospective self-reports, therefore, recall bias and posthoc rationalisation cannot be excluded. Given that there were no limit to the time elapsed since termination, it is possible that recall may have been difficult for those whose termination had occurred some time ago. The online methodology meant that there was no opportunity for probing. The sample came exclusively through ARC, which means all the participants had actively sought additional emotional support. Therefore the results may not be transferrable to women who do not approach support organisations. There was a geographical bias, which while it reflects ARC’s membership, may impact on the findings. Finally, as the survey focused on the choice of termination method, it is likely that participants were, to some extent, primed in discussing issues around choices. However, given that the study was initially undertaken in response to women’s accounts on this topic, we can assume that the choice of method is a legitimate issue for women. Further qualitative research, particularly with women who have not been in contact with support organisations, would increase our understanding of women’s experience and aid healthcare professionals in delivering individualised care.

**Conclusion**

This qualitative study highlights a number of elements women ranked highly in their experience of care when undergoing TOPFA. Some, such as timing and clinical environment, can sometimes be outside the control of healthcare professionals due to the law and pressures on ward space. However, having a named professional providing continuity of care for women through the process would mean any distress when expectations cannot be met could be acknowledged and extra support provided when necessary. Other aspects women deemed important such as clinical expertise, empathetic care, continuity and aftercare, information provision, acknowledgement of their particular circumstances and having choices are areas where healthcare professionals can have agency in addressing individual needs. To do so consistently will necessitate co-ordinated planning of care and appropriate staff training both within the NHS and independent sector. This study has also identified the need for further research, particularly with women who have not been in contact with support organisations, which would increase our understanding of women’s experience. Research evidence will help establish models of best practice to inform the implementation of auditable care pathways, protocols and staff training. As developments in prenatal testing lead to more women confronting the prospect of TOPFA, it is important that caregivers are able to meet their needs.

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**Table 1 – Participants’ characteristics**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Helpful question**  **(n= 361)** | **Unhelpful question**  **(n= 356)** | **Did not  comment**  **(n= 18)** |
| **Region of antenatal care** |  |  |  |
| North East | 2.8% (n= 10) | 3.1% (n= 11) |  |
| North West | 4.5% (n= 16) | 4.6% (n= 16) | 11.1% (n= 2) |
| Yorkshire and the Humber | 6.4% (n= 23) | 6.8% (n= 24) | 22.2% (n= 4)\* |
| West Midlands | 4.8% (n= 17) | 4.8% (n= 17) | 5.6% (n= 1) |
| East Midlands | 7.8% (n= 28) | 8.0% (n= 28) | 11.1% (n= 2) |
| East of England | 7.6% (n= 27) | 7.7% (n= 27) |  |
| London | 18.8% (n= 67) | 19.1% (n= 67) | 11.1% (n= 2) |
| South West | 10.4% (n= 37) | 10.8% (n= 38) | 11.1% (n= 2) |
| South East % | 27.4% (n= 98) | 26.8% (n= 94) | 27.8% (n= 5) |
| South Central | 9.5% (n= 34) | 8.3% (n= 29) |  |
|  |  |  |  |
| **Year of termination (average)** | 2007 | 2007 | 2010 |
| From 2007 | 75% (n= 270) | 73.5% (n= 260) | 100% (n= 18)\* |
| From 2010 | 46.7% (n = 168) | 45.5% (n = 161) | 72.2% (n = 13)\* |
|  |  |  |  |
| **Method of termination** |  |  |  |
| Medical | 81.8% (n= 287) | 81.2% (n= 280) | 88.9% (n= 16) |
| Surgical | 18.2% (n= 64) | 18.8% (n= 65) | 5.6% (n= 1) |
|  |  |  |  |
| **Gestational age (weeks)** | 18 | 18 | 19 |
|  |  |  |  |
| **Termination setting** |  |  |  |
| NHS | 80.9% (n= 292) | 80.8% (n= 287) | 88.9% (n= 16) |

\*Statistical differences significant at .05 level when compared to previous column