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Women's Experiences of Coping With Pregnancy Termination for Fetal Abnormality

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Abstract

Pregnancy termination for fetal abnormality (TFA) can have significant psychological consequences. Most research focus on measuring the psychological outcome of TFA, and little is known about the coping strategies involved. In this article, we report women's coping strategies used during and after the procedure. Our account is based on experiences of 27 women, which we analyzed using interpretative phenomenological analysis. Coping comprised four structures, consistent across time points: support, acceptance, avoidance, and meaning attribution. Women mostly used "adaptive" coping strategies but reported inadequacies in aftercare, which challenged their resources. The implications of this study focus on the provision of a sensitive, nondirective care rooted in the acknowledgment of the unique nature of TFA. Enabling women to reciprocate to emotional support, promoting adaptive coping strategies, highlighting the potential value of spending time with the baby, and providing long-term support (including during subsequent pregnancies) might promote psychological adjustment to TFA.

Keywords

Abortion; bereavement / grief; coping and adaptation; interpretative phenomenological analysis (IPA); lived experience; perinatal health; pregnancy; psychology; research, qualitative

Progresses in antenatal screening and delayed maternal age have resulted in the increased detection of fetal abnormalities and terminations for fetal abnormality (TFA; Korenromp et al., 2007). For example, in England and Wales in 2010, TFA represented 1% of all terminations (Department of Health, 2011). Despite being small, this number is likely to rise as more couples delay starting a family, thus increasing the risk of fetal abnormalities occurring (Royal College of Obstetricians and Gynaecologists, 2009). TFA is at the center of many ethical and clinical debates. First, it is closely associated with the abortion debate and the question of the impact of abortion on women's mental health. Evidence on the subject is inconsistent with some reviews indicating a negative impact of abortion (Coleman, 2011), whereas others suggest otherwise (Major et al., 2009; National Collaborating Centre for Mental Health, 2011). TFA is also linked to the eugenics debate, as demonstrated by arguments about how late in the pregnancy and for which medical conditions could TFA be performed (House of Commons, 2007a,b; the Heartbeat bill, nd). Ethical questioning also occurs at an individual level; first, for the women who might be challenged by the morality of their decision (McCoyd, 2007). It also extends to the health professionals who might object to these procedures (Marshall & Raynor, 2002; Strickland, 2011). These debates have legal, political, and clinical implications, which affect the care provided to women and their psychosocial well-being.

Much research has centered on the decision making following antenatal screening, particularly when a diagnosis of fetal abnormality is made. Evidence suggests that this is a complex process (McCoyd, 2008; Sandelowski & Barroso, 2005). Many researchers have attempted to understand the psychological impact of TFA on women's mental health, and the literature suggests that TFA can have long lasting psychological consequences for those involved. Occurrences of complicated grief, depression, and posttraumatic stress following TFA have been well documented (Davies, Gledhill, McFadyen, Whitlow, & Economides, 2005; Green

& Statham, 2007; Kersting et al., 2005; Korenromp et al., 2007). Complications are particularly manifest among mothers, but accounts of psychological distress have also been reported among fathers (Robson, 2002). Grief reactions following TFA have been shown to resemble those experienced in other types of perinatal loss (Keefe-Cooperman, 2004; Salvesen, Oyen, Schmidt, Malt, & Eik-Nes, 1997). Still, ending a pregnancy for fetal abnormality bears an additional moral component in that the parents choose to terminate a pregnancy. Research indicates that several years post-TFA, women continue to display symptoms of grief (Green & Statham, 2007). Thus, like other types of bereavement, the process of coping with TFA is ongoing.

To date, little is known about the coping processes involved in dealing with TFA, which we aim to address in this article. Coping is a relevant field of investigation within the context of TFA. Research indicates that people who face similar stressful events adjust in different ways, and coping processes influence psychological outcomes (Carver & Connor-Smith, 2010). Many research studies have emphasized the role of coping in adjusting to stressful situations among various populations (Cartwright, Endean, & Porter, 2009; Schnider, Elhai, & Gray, 2007). Lazarus and Folkman (1984) defined coping as psychological processes that occur when facing stressful situations, comprising appraisal of the threat (perception and evaluation) and coping *per se* (resources involved in managing the problem). Coping consists of appraising the threat to reduce its magnitude and its subsequent impact on the individual (Carver & Connor-Smith, 2010).

There are many ways of categorizing coping processes from approach/avoidance coping (Roth & Cohen, 1986), problem/emotional focused coping (Lazarus & Folkman, 1984), through to the multidimensional approach to coping that includes processes, such as behavioral disengagement, religion, and acceptance (Carver, 1997). More recently, researchers have identified five core categories of coping: problem solving, support seeking, distraction,

avoidance, and positive restructuring (Skinner, Edge, Altman, & Sherwood, 2003). Additional categories have also emerged such as accommodative, meaning-focused, and proactive coping (Carver & Connor-Smith, 2010). Given the influence of coping on psychological adaptation, it is important to understand the coping strategies women use when they undergo TFA, during the termination procedure itself and afterwards. In this article, we report a qualitative study of 27 women who underwent TFA. To our knowledge, this is the first time that an investigation focused exclusively on coping strategies employed both during and after the procedure.

Methods

We conducted a cross-sectional retrospective study to explore women's coping strategies during and after TFA. The qualitative interview schedule consisted of open-ended questions about the process of coping with the termination, with specific attention paid to coping strategies. We left the questions open and provided few prompts to ensure that the feedback collected was, as much as possible, participant-led (Biggerstaff & Thompson, 2008). Topics such as what the termination meant for the participants and how they felt about the future were also investigated. We collected the following information about the terminated pregnancy: number of pregnancies, existence of other children at the time of TFA, gestational age, reproductive history post-TFA, method of abnormality detection (routine scan or directed search), abnormality prognosis (incompatible or compatible with life), method of termination (medical, surgical, or induced labor), and how participants felt about their decision to end the pregnancy. Demographic data were also gathered.

Participants were members of a support group based in the United Kingdom, which provides support to parents when an abnormality is detected in their unborn baby. We recruited the participants through the group's e-mail network and forum. We provided them with information about the study (e.g., aims, confidentiality, and right to withdraw) and the

opportunity to ask questions before we formally obtained their informed consent. To be eligible, women had to be at least 18 years old and, initially, they had to have undergone TFA at least six months prior to participating in the survey. We later broadened the latter criterion to include any women who had undergone TFA irrespective of when the procedure took place, in light of comments from potential participants who were willing but unable to take part because of the six months exclusion criterion. Altogether, 27 women participated in this study. We decided to stop collecting data after 27 accounts, given that saturation of themes was reached at 25. Participants were mainly White, and two-thirds had completed higher education. Their ages ranged between 24 and 44 years. Pregnancies were terminated between 12- and 30-weeks of gestation. For 13 participants, this was their first pregnancy, whereas two had undergone three TFAs.

The data collection took place online between April 2011 and February 2012. Participants had the flexibility to leave and re-enter the survey, enabling them to complete it in their own time and pace. Collecting data electronically presented a number of advantages, not least enhancing confidentiality with no intervention from the researcher in the data collection. We also believe that answering questions online might have enabled women to open up more easily than in a face-to-face environment and to think carefully about their answers, thus providing valuable insight. At the end of the survey, women had the opportunity to comment on the study and leave their contact details if they wished to receive a summary of the findings. We conducted a pilot study with three participants, which resulted in no changes being made. However, one respondent suggested that a preview of the questions would be helpful to start the reflection process prior to filling the survey, which we subsequently implemented.

We used interpretative phenomenological analysis (IPA) to analyze the data. IPA is particularly suited to this type of analysis because it uncovers people's individual experience and the meaning they attribute to it. Thus, it is deeply rooted in individual narratives and represents a

bottom-up rather than a top-down analytical approach. In analyzing the data using IPA, the researcher also seeks to provide an interpretation of these narratives (Larkin & Thompson, 2012). IPA is most commonly used to analyze data collected through semi-structured interviews; however, other types of data have also been successfully used in conjunction with IPA. These include diaries, personal accounts, letters, questionnaires with open-ended questions aiming to capture additional comments, internet forum posts (Mulveen & Hepworth, 2006; Smith, Flowers, & Larkin, 2009), and focus groups (Palmer, Larkin, de Visser, & Fadden, 2010). A key requirement of IPA is that the data should be rich and "participants should have been granted an opportunity to tell their stories, to speak freely and reflectively, and to develop their ideas and express their concerns at some length" (Smith, Flowers, & Larkin, 2009, p.56). Our data fulfilled these criteria.

Conducting IPA analysis consists of identifying commonalities and differences about the meaning of a given experience. We formatted and line-numbered the data and changed names to protect participants' identities. The first author read and re-read the texts and made some notes about the concepts emerging, the text itself, its emotional content, the language used, and so forth. From these observations emerged a number of themes, which were classified into categories or superordinate themes. Themes were compared across individual accounts, and a framework of superordinate themes and subthemes was created, which most accurately epitomized women's experiences. In accordance with IPA requirements, the aim of our analysis was to create a "whole" that would go beyond the sum of its parts to provide an interpretation for the meaning of the experience (Smith, Flowers, & Larkin, 2009). Throughout the analysis process, peer-debriefing was used to enhance transparency and trustworthiness. Randomly selected sections of text were also co-coded by the third author to enhance rigor.

Ethical approval was obtained from the University of West London's Psychology Department. Given the sensitive nature of the subject, several ethical considerations had to be addressed. First, we had to consider the potential for distress to be experienced by participants as a result of participating in the study. Accordingly, participants were advised to contact the support group helpline or network of volunteers should they feel the need to speak to someone after completing the survey. However, evidence has suggested that participation in group discussions is beneficial to women who have experienced TFA (Statham, Solomou, & Green, 2001). Similarly, self-disclosure of thoughts and feelings has been shown to enhance psychological adjustment (Pennebaker, 2004), and many participants commented that participating in our study constituted an opportunity to share their story and help other women in the future. None of the respondents reported experiencing distress as a result of participating in our study. Thus, the benefits of their participation might have outweighed any potential negatives.

The second ethical consideration related to the first author's membership to the support group's network of volunteers. This had potential implications in terms of confidentiality and duality of roles. To safeguard confidentiality, the data were password-protected and participants' names were changed. With regard to a potential conflict of interest, we genuinely felt that being a group volunteer benefited the study in many ways. Still, in an effort to promote high ethical standards, the first author's details were removed from the list of volunteers sent to women contacting the helpline as a result of participating in the study.

Results

We set out to investigate coping strategies at two different points of the TFA process, during the procedure and afterwards, to identify differences and commonalities in coping. These periods are different in nature. Whereas the procedure represents a short-term medical intervention, the

aftermath represents the beginning of a long-term process of grieving. Thus, we wondered whether different coping strategies could be used at each point. In our study, we identified more commonalities than differences and uncovered the role of key coping strategies that are support, acceptance, avoidance, and meaning attribution throughout the experience of TFA.

Coping With the Procedure

Five coping strategies emerged as most relevant to women when dealing with the termination procedure. These included receiving/giving support, acknowledging the baby, problem solving, dissociating oneself from the procedure, and attributing meaning to the birth experience.

Receiving/giving support. Support was one of the main coping strategies used during the procedure. Women unanimously identified their partners as their main source of support. Nevertheless, support from health professionals was also considered essential to women's experience of the procedure. It involved listening to and addressing women's fears about the procedure, as well as providing physical and emotional comfort. Ellie described, "The consultant also held my hand tight . . . this warmth from the staff I will always remember." The provision of professional support led to better coping, but the absence of it resulted in negative experiences. Justine was left on her own for most of the procedure, including the baby's delivery:

> It was so undignified and to see that little body on my own with no support was terrible. I called for the midwife who laughed and made a joke about how quick I had been then she left the room, allowing me then to deliver the after birth myself, again alone.

Support was also derived from the presence, actual or virtual, of other family members. Ellie mentioned her mother waiting in the corridor; Wendy had her mother and Rose, her mother-in-law, in the delivery room. Christine carried a picture of her three year old son in the

delivery room, which provided focus and strength. Religious support was important to some participants. Given the perceived moral dimension of TFA, some women such as Laura expressed the fear of being judged: "We went to the Hospital Chapel and met with a Chaplain. She was absolutely lovely. I was initially worried that she may judge us, but she didn't. She was sympathetic and very understanding, which helped."

For some women, supporting their partner through the procedure and focusing on their partner's fear and pain helped alleviate their own. For others, supporting their baby through the procedure was essential. This was particularly the case when the termination involved a feticide, a procedure to induce the baby's death through intra-cardiac or intra-amniotic injections. Recalling the moment the feticide was performed, Rose described how she tried to shield her baby from the stress of the procedure:

> I tried to just breathe through it using deep calm breaths so as not to move too much. I didn't want to cause the baby any distress and I wanted him to die peacefully. It was very important that I obeyed the doctor's instruction to make it as quick and straightforward for them.

Acknowledging the baby. Acknowledging the baby was seen as a way to accept, and thus, cope with the loss. This took many forms. Most participants spent time with their baby after delivery, which most found comforting. It provided women with the opportunity to acknowledge and bond with their baby. Women were also able to check any resemblance with family members, thus recognizing the baby as their own, and see their child's anomaly for themselves. Seeing her baby helped Laura come to terms with her decision: "He did not have any legs and this made it easier to know that he definitely did have abnormalities that were apparent and that we had made the right decision." For many women, spending time with their baby was the first

step in accepting what had happened. For a few, however, it proved upsetting, confronting them with the reality of the baby's death. Others felt disturbed at how "weird" their baby looked. A handful of participants opted against seeing their baby, mostly because they feared being scarred for life.

Acknowledgement also involved conferring an identity on the baby. This included naming the baby, taking photos, and showing them to others. The importance of a clear identity for the baby is illustrated by Penny's story. Penny was distraught to learn that the gender given to her baby at the autopsy differed from the birth report. It left her confused about which baby she had lost:

> We were devastated to realize that we'd had the funeral in the wrong name, the wrong name was on the coffin and we'd told our friends and family the wrong name which left us having to deal with some very difficult questions. This left us absolutely furious, even to the extent that it felt like the initial grieving process had been taken away from us or even at times that we'd lost two babies.

Underlying this anger was the feeling of having betrayed and denied the baby a proper goodbye, another important factor in coping with the loss. Women described leaving the hospital without their baby as heart-breaking and the process of saying goodbye as surreal. Parting with the baby typically involved three actions: arranging the funeral (which most participants hoped would bring some sense of closure), having the baby blessed, and/or placing soft toys or photos of themselves in the coffin with the baby. Anna recalled, "I held the toy throughout the labor and then left it with him. It was cremated with him. This helped and still brings me comfort to know he had a 'friend' to look after him on his journey."

Problem solving. In some instances, the procedure was thought of as a practical problem to be solved. This implied preparing for the procedure and focusing on the task ahead. Preparation for the procedure consisted of seeking factual information about the baby's conditions and the termination. This information was often sourced from the Internet and, in some cases, from support group leaflets. Women also relied on experiential knowledge. Isobel had already undergone two TFAs, and thus, felt prepared for the third procedure: "We knew the drill as it were." Others had contact with a group volunteer before the termination, and therefore were aware of what to expect during the procedure. Some of the women who had not been through labor before sought information about the birth process from friends and relatives. Information seeking sometimes engendered a sense of empowerment as exemplified by Laura: "I am the type of person who likes to have prior knowledge about things as it helps me deal with them when they happen; it prepares me." Concentrating on the task of delivering the baby was another way of focusing the mind, and thus coping with the procedure. For Yvonne, "[T]aking one thing at a time, or think[ing] of it in four hour blocks" helped her through the termination.

Dissociating oneself from the procedure. Most women described TFA, and, in particular, the procedure to end the pregnancy, as the most difficult experience they ever had to go through. Thus, many tried to distance themselves from what they considered an ordeal. This involved self-distraction, such as watching television, reading magazines and newspaper, or going for walks. Attempts to block the pain were also common, with some participants reporting having an "out of body experience" or going into "autopilot." The use of analgesia during labor was also widespread because it was seen as a way to disconnect with the procedure and avoid unnecessary suffering. Keira used analgesia despite being physically comfortable: "Directly afterwards I was offered some pethidine for the pain, and although I wasn't in pain I accepted it.

It numbed my brain and helped me sleep when I got home." Underpinning the use of analgesia laid expectations and meaning attributed to the birth experience itself.

Attributing meaning to the birth experience. Among women who gave birth to their baby, the birth experience was an influential factor in the way they coped with the whole procedure. The birth often conveyed specific expectations and meanings. In some cases, attributing meaning to the birth constituted a resource women could draw on to help them cope with their baby's delivery. Whereas some women tried to shield themselves from the physical pain of labor as much as possible, others considered the pain to be constitutive of the birth process and embody a particular meaning. Beatrice believed the pain to be "cathartic." Anna regarded the use of analgesia as a failure on her part and wanted to experience the pain to punish herself for the decision she had made: "Initially I wanted to feel all the pain of my labor to make myself suffer, but then I couldn't cope so the midwife gave me diamorphine." For Theresa, giving birth without analgesia was her way to normalize the birth and bond with her child. She had used very little pain relief for the birth of her previous children and wanted to do the same for this baby:

> I also wanted to approach my daughter's labor as similarly as possible to the labors of my previous children. I felt like I owed it to her. That at least I could bond with her to that extent, give her the same labor as I'd given my other two children . . . For me it was very important. There maybe wasn't a baby to "protect" as such, but there was still a baby to bond and connect with for as long as possible. I needed to be with her throughout and feel her.

Finally, some women mentioned their wish to give birth with dignity, which implied the provision of sensitive care. Although this was in most cases provided, there were instances where

it was not, which could have far-reaching consequences on women's psychological adjustment to TFA.

Post Termination Coping

Women mostly relied on four coping strategies to deal with the aftermath of the termination: remembering the baby, receiving/providing emotional support, avoidance, and looking to the future.

Remembering the baby. Remembering the baby was a key element in post-TFA coping. This involved talking about the baby to partners, friends, and family, as well as sharing stories with other group members, which most found soothing. Having a remembrance service also enabled women to acknowledge the baby and provided some closure. A few women chose to read poems at the service, others played meaningful music; however, for some, the service was a painful experience, emphasizing the unnatural order of the loss in which a parent loses a child. Holding a service was a way to give the baby social recognition. This was particularly important given that many women felt that their loss was not fully sanctioned by society. Many, like Justine, reported feeling isolated and misunderstood in their grief: "Nobody can understand the torture unless they have experienced it themselves as I don't think it can be likened to anything else."

The use of rituals and token acts was widespread. Visiting a place of remembrance was common and most women kept a memory box. In some cases, the memory box was provided by the hospital, but more often it was sourced by the parents. Rose recalled her partner building the box over a period of time, almost mirroring his mourning process: "My partner built a little box to put little mementos into. It took him many months to complete it as I think it was his time to think about the son he had lost." The memory box usually contained copies of the scans of the baby, photos of the baby, letters of condolence, poems, baby's hand and foot prints, toys, clothes,

and other symbolic objects. Women reported initially looking at the box on a daily basis, but this need tended to lessen in time. Gemma recalled the location of the box being a source of conflict with her partner, a possible reflection of grieving differences between them:

> More recently he has been happier to talk about it; though he would prefer that her memory box was tucked away (it is on top of the unit in the living room and not obvious). But for a long time, he got cross.

Some women carried a photo album in their bag. Others displayed the baby's photos next to their other children's. Other token acts included getting a tattoo, or planting a tree, a permanent and ever-growing feature in the women's lives.

Receiving/providing emotional support. Support after the termination was essential to the way women coped. This support took many forms. Support from health professionals was particularly important but in many cases, this support was limited post termination. Often, it was the interaction women had with health professionals during the procedure, which had a lasting influence on the way they coped with the event. Instances where clinical care went beyond the traditional doctor-patient relationship were received with much gratitude and had a soothing effect long after the termination. As Bonnie recalled,

> I think of his words. He very kindly and reassuringly said that he would make the same decision in our position—something that he confessed he shouldn't say but something we found so helpful since he was the person who had the skill to "fix the problem."

Support from health professionals post termination extended to other forms of care and communication. Rose's district nurse had not read the paperwork prior to visiting her. Rose was particularly upset when the nurse came to obtain a blood sample from the baby: "I had to tell her

the baby had died. She hadn't read the notes properly! I was furious and very distressed." The language used to refer to the baby, particularly in postmortem reports, also influenced women's experience, as illustrated by Olivia:

> All of her paperwork stated she was a "nonviable fetus." I felt she deserved to be recognized . . . because to us, she very much existed. P.S. - something that really doesn't help, is paperwork saying "non-viable fetus." Very upsetting to read.

Professional support was also dispensed in the form of counseling, which was mainly used by women more advanced in the recovery process. Even though the majority found counseling helpful, some felt that they had started the process too early and felt vulnerable as a result. The timing of the intervention might therefore be an important factor.

Emotional support was also sourced from friends and relatives, but its quality varied greatly. Support was key in helping women cope with their loss, but most women indicated that it faded over time. A lack of support, particularly in the early stage, engendered much suffering as exemplified by Penny:

> I was horrified to spend a weekend with some of [my] closest friends, the week of the funeral and not once did they ask about the funeral or how we were . . . remember feeling like a leper after that weekend and that people avoided talking to me.

In rare instances, women chose to withdraw from their social network, particularly when friends went on to have successful pregnancies.

Support groups were another source of emotional support, which is unsurprising given that the sample was drawn from a support group. Support groups form a distinctive category in that they involve a reciprocal support relationship based on a common experience. Most women

considered the group e-mail network/forum to be one of the most helpful elements in the coping process. Being able to reciprocate, getting support as well as offering support, was of great benefit to the women. Gemma recalled,

> [It] has been the most amazing thing though as everyone really understands more than anyone else ever could. I still read the posts every day and have done some fund-raising for them. I would never, ever have done so well without their support.

Reasons for using the group e-mail network/forum varied, but the underlying drive was to derive a sense of solidarity. For some women, like Christine, the forum became the only opportunity to share their story: "I feel completely alone in my grief as no one seems to understand just how profound it is. This includes my partner." However, other women reported having ambivalent feelings about using the forum. Ulrika saw the forum as a lifeline during dark days, but actively avoided it on good days to prevent being "brought back to the darkness." Bonnie also had mixed feelings about the e-mail network because some of the comments led her to believe that her way of grieving was inadequate:

> Sometimes I found reading other people's accounts on the forum unhelpful as I felt guilty for not feeling as emotional or terrible as they did, but in time I was able to feel that this was positive, that I was coping and mentally strong.

Going to parents' meetings was another coping resource, and it provided women with a "sense check" regarding where they were in the healing process. A few participants also used a support group specialized in stillbirth and neonatal deaths. Some found it helpful, but others reported feeling uncomfortable given that this particular group only dealt with naturally occurring or accidental deaths rather than terminations.

Avoidance. Avoidance constituted another coping strategy, although a less commonly used one. Avoidance usually involved self-distraction, such as going away after the termination or on the baby's due date, decorating, or moving house. Keeping busy was seen as an antidote to feeling the pain as illustrated by Holly:

> When it was most painful I kept myself busy so that I [made] an effort to put it to the back of my mind and made sure I was tired each evening so that I could get some sleep at night.

Similarly, some women were eager to return to work soon after the termination. Although women reported that this initially helped, they also recognized that this strategy might have pushed emotions aside and hampered the grieving process. Keira recalled, "Keeping busy and going back to work might have helped initially, but I think they stored up the emotions for later." For some participants like Megan, concentrating on other children helped alleviate the pain, by channeling their energy and deriving meaning: "I kept myself busy with my other kids. I went into overdrive I think; almost like I had to prove my worth as a mum." Avoidance also meant actively trying to block the pain, which only a few participants mentioned. This implied avoiding thinking about the baby and trying to rationalize the loss by framing it in a practical rather than an emotional way. This strategy was used by women like Natalie for whom this was not the first TFA: "I have never allowed myself to think as if I was having a baby. I've always thought it too good to be true so I have just not imagined a baby at the end. I think this has really helped." A handful of participants also recalled drinking heavily initially in an attempt to block the pain. Avoidance also extended to avoiding pregnant women or women with young babies, which a few participants admitted to.

Looking to the future. Most women reported that looking to the future helped them cope with their loss. One of the first steps in this process was to regain a sense of normality. This was achieved by getting back into a routine, going back to work, and trying to function as normally as possible. As Beatrice recalled, "I went back to work four weeks after the termination. I thought getting back into a routine would help the grieving process." Looking to the future was also linked to getting closure. All women reported the process of healing as uneven, similar to a roller coaster, and lengthy. This process was usually punctuated by important milestones such as the funeral, postmortem results, due date, and the first birthday. Ellie described, "As closure was provided through the funeral, postmortem, due date passing, the first birthday, now it is time to move on with our lives."

The baby's funeral was usually the first milestone in the process, and generally provided some closure with the physical side of the loss: the loss of the "actual" baby. The postmortem constituted a second milestone for those who requested it. Participants found the postmortem results helpful in reaching some closure on the decision they had made, as illustrated by Frances: "The postmortem report also helped as it confirmed the diagnosis and put closure to that irrational fear that we might have made the wrong decision." The baby's due date was perhaps the most important milestone. It was often an anxious time because it directly confronted women with the reality of the loss, as described by Ulrika: "I will be mourning the loss of Oscar all over again." Many reported being unable to "let go" before the due date, and it appeared to provide some closure on the pregnancy, the "virtual" baby, and the hopes the pregnancy had brought. The baby's first birthday was the fourth significant milestone. It signaled the beginning of a new type of mourning process, which up to that point consisted of getting from one milestone to the other, each milestone bringing closure to some aspects of the loss. After the first birthday, the

focus moved from grieving for the lost pregnancy, dream, and baby to a long-term grieving for the child. For Gemma, birthdays were important and a way to honor her daughter's memory: "I celebrate Louise's birthdays with cake, lantern, a card, and I often receive cards from lovely people who remember." Focusing on another pregnancy was another widely used coping strategy. It involved closing on the TFA and projecting oneself in the future. This focus was, in some instances, all-consuming and often bittersweet. A new pregnancy was usually a source of worry and failure to get pregnant often led to feelings of despair, as illustrated by Keira:

> The only time when I felt like I was unable to cope again was when it came to be nearly a year and half after the termination and I was still not pregnant. I felt that only having another baby would heal the wound which I still have, and a seeming inability to conceive again was almost like a punishment.

Women who became pregnant were eager to stress that their new baby was not a replacement for the baby they had lost.

Finally, looking for positives in their experiences also contributed to women's coping. Although women described the decision to end their pregnancy as the hardest they ever made, most were at peace with their decision. Some drew comfort from the fact that their baby's condition was detected early enough to enable them to make a decision. For some, terminating the pregnancy was the only parental decision they could make, as Laura recalled:

> I understood that as a mother, there are times when you have to make decisions for your children, on their behalf if it relates to safety, etc. Although this decision was a bit extreme, I felt that as a mother, I was making a decision to take away my child's pain and it was for reasons out of love.

Looking for positives also involved putting the experience to good use. Some participants sponsored a child, some ran marathons to raise money for charities specialized in their baby's condition, while some found solace in helping other women. For some participants, the termination also instigated personal positive growth, with some reporting feeling stronger and more confident as a result. For Theresa, the termination triggered a sense of urgency to live life to the full, fulfill her potential, and follow her dreams:

> This feeling of doing things in her memory and of using her memory to instigate positive things has also been hugely important in terms of ways of coping . . . I've been filled with an urge to do things that I hadn't been confident to do otherwise beforehand. It has made me realize the fragility of life, and it has made me want to treasure each day more, risk things more in order to live the life I really want to live.

For others, the termination triggered a desire to address unresolved issues or explore new career paths, thus having a positive impact.

Discussion

To our knowledge, this study is the first to focus exclusively on women's coping strategies used throughout the process of TFA, both during and after the procedure. Thus, our study provides a valuable insight into the lived experiences of women who are coping with this traumatic life event. We hope that this insight will inform clinical practice and be valuable to women who undergo this procedure. In this article, we suggest that coping with the procedure of TFA involved five processes: seeking and providing support, acknowledging the baby, problem solving, dissociating oneself from the procedure, and attributing meaning to the birth experience.

Regarding post termination coping, we identified four processes: seeking and providing emotional support, remembering the baby, avoidance, and looking to the future.

Throughout the TFA process, four major structures of coping emerged: support, acceptance, avoidance, and meaning attribution. The consistency of these structures across time indicates the importance of dispositional characteristics. Problem solving was specific to coping with the procedure, whereas elements of looking to the future (e.g., returning to normality and focusing on a new pregnancy) only related to post termination coping. Our results are in line with some of the current literature on coping. For example, in their review of 100 coping assessments, Skinner and colleagues (2003) suggest that there are five core categories of coping: problem solving, support seeking, avoidance, distraction, and positive cognitive restructuring.

Support was the first essential coping structure present throughout the TFA process. The concept of support involved two separate activities: receiving and providing it. Receiving support was crucial to women. Research has shown that receiving social support contributes to general well-being (Lakey & Orehek, 2011). It is particularly important in the context of TFA because a lack of support has been associated with mood disturbances in women (Green & Statham, 2007). Similar to research studies about perinatal loss (Lasker & Toedter, 1991) and TFA (Statham et al., 2001), partner's support was critical to the women in our study. Many participants felt that their loss was not fully recognized by society and, in numerous cases, women only fully shared their experience with their partners.

Support from health professionals was also critical to women's coping. This included emotional support from health professionals, as documented elsewhere (Geerinck-Vercammen & Kanhai, 2003), and care provision both during and after the procedure. Most participants in our article found the care in hospital satisfactory, which contributed to alleviating their distress. However, the aftercare was often seen as deficient. Many women reported feeling unsupported

post termination, a finding in line with most TFA literature (Green & Statham, 2007; Statham et al., 2001).

Many women used various support groups as a source of comfort, which is unsurprising given that all participants were to some degree active on the forum or e-mail network of the group we recruited from. Nevertheless, the extensive use of support groups also underlined the importance of the reciprocal nature of support. The positive impact on mental well-being of being in a position to provide support has been reported in studies across various fields of psychology (Knoll, Kienle, Bauer, Pfuller, & Luszczynska, 2007; Warner, Schuz, Wurm, Ziegelman, & Tesch-Romer, 2010). Comments left by participants at the end of our survey corroborate this view. Thus, supporting others seemed to enable women to transcend their pain, put it to good use, and frame it in a positive way.

Acceptance was the second key coping structure common to both periods. It involved acknowledging and remembering the baby, which was attained in different ways and predominantly experienced as helpful. Trying not to think of the baby, blocking the pain, or busying oneself often resulted in short-term gain but long-term loss. Women engaged in rituals and token acts. Women who opted to see their baby after delivery found this comforting, but a minority found it disturbing.

Whether or not to spend time with the baby in the context of perinatal loss has generated clinical discussion. For example, until recently in the United Kingdom, parents were routinely encouraged to spend time with their baby on the assumption that doing so facilitated the grieving process (Bennett, Litz, Lee, & Maguen, 2005; Geerinck-Vercammen & Kanhai, 2003). However, a study by Hughes, Turton, Hopper, and Evans (2002) on psychological adjustment to stillbirth found that women who choose to see their baby adjust to their loss less easily than those who choose not to. Similarly, Green and Statham (2007) suggested that women who do not seek care

or engage in any form of ritual following TFA fare better psychologically than those who do. In light of this contrasted evidence, the UK National Institute for Health and Clinical Excellence (2007) issued guidelines about care in perinatal loss recommending not to routinely encourage mothers to spend time with their baby, but instead to leave the decision to parents. By highlighting the range of emotions associated with spending time with the baby, our findings support this clinical recommendation.

The third coping structure common to the procedure and its aftermath was avoidance. It included themes of self-distraction, dissociation, and avoidance, with the latter more prominent in post-termination coping. It was the least homogeneous structure, with some elements experienced as helpful and others unhelpful. Traditionally, self-distraction and dissociation have been linked to avoidant coping styles. Thus, they are considered maladaptive strategies, primarily because they are difficult to sustain (Folkman & Lazarus, 1988; Schnider et al., 2007). Nevertheless, in our study, both elements served an adaptive function, particularly during the procedure, by protecting women from further suffering. In contrast, most coping components of the avoidance theme in post termination coping involved various degrees of active denial and disengagement (actively trying not to think about the baby, drinking, getting busy to the point of exhaustion), which could be considered as maladaptive. These strategies are of limited use in the long term because they do not address the event and its effect in an individual's life (Carver & Connor-Smith, 2010).

The fourth common coping structure was meaning attribution. This included attributing meaning to the birth, deriving meaning, and experiencing growth as a result of TFA. This coping structure is echoed in the concept of resilience. Research in that field has shown that people can experience stress-related growth following a traumatic event (Bonanno, 2008). Research studies have established that the action of attributing meaning might lead to positive changes in people's

lives (Helgeson, Reynolds, & Tomich, 2006). Therefore, stress-related growth can be seen as a central part of the coping process rather than as a positive, unexpected outcome of a difficult experience. Our results show that, as a result of TFA, a number of women have discovered strengths they were unaware of having. Others have unearthed a drive to take control of their lives and fulfill their potentials.

Problem solving was a coping strategy used solely during the procedure. The benefit of preoperative information on levels of anxiety prior to surgery (McDonald, Hetrick, & Green, 2004) and on recovery has been documented (Shuldham, 1999). Focusing on the task rather than thinking about its meaning was also helpful. Both strategies were used as buffers against the stress and pain of the procedure. The strategy of looking to the future, not surprisingly, predominantly belonged to post-termination coping, although meaning attribution was common during both periods. It involved a return to normality and focusing on another pregnancy, and thus, reflected a drive to restore equilibrium and move forward.

The focus on a new pregnancy engendered mixed feelings. Many women experienced anxiety during their new pregnancy, a finding echoed in the literature (Rillstone & Hutchinson, 2001). This also raises a question about the recommended time between the termination and a subsequent pregnancy. A study by Hughes, Turton, and Evans (1999) in psychological adjustment to stillbirth suggests that women should preferably wait 12 months following their loss to conceive again. This has implications not only for the mother but also for the infant because anxiety and distress during pregnancy can negatively affect the well-being of the baby (Brouwers, van Baar, & Pop, 2001). To our knowledge such information applied in the context of TFA is lacking, and hence warrants further research.

Our research shows that women used coping strategies that are largely considered to be adaptive during and after the termination. According to the coping literature (Carver, 1997;

Carver & Connor-Smith, 2010; Folkman & Lazarus, 1988) seeking support, whether instrumental (e.g., aspects of care being provided by health professional) or emotional (e.g., derived from partner and/or friends) is an adaptive coping strategy. Similarly, acknowledging/remembering the baby, which is linked to the concept of acceptance, and meaning attribution, which is related to positive reframing and growth, are also considered adaptive. When traditionally labeled maladaptive strategies were used (self-distraction, dissociation, and avoidance), they either served an adaptive purpose of short-term protection and/or were used by only a few participants.

The debate about which coping strategy is adaptive and which is maladaptive is ongoing. Whether a strategy is adaptive or not is subjective. Carver (1997) himself advised against classifying coping strategies into discrete categories, such as problem-focused or emotional active/avoidant coping. His advice instead was to examine each aspect of coping independently. Coping with a traumatic event is a personal process, determined by individual (e.g., personality, personal history, attitudes, and beliefs) and situational factors (e.g., type of stressor, timing of event). Consequently, what is adaptive for some might not be so for others.

Our findings have several practical implications, the main one being care provision. In view of the importance of support, it is key for health professionals to understand the nature of the loss to provide suitable care. Although different in nature, the grieving process in TFA has been compared to grieving after a stillbirth (Salvesen et al., 1997; Statham et al., 2001). If the unexpected nature of a stillbirth affects the grieving process, other elements might complicate the grieving process for a baby one has chosen not to have. White-Van Mourik and colleagues (1992) argued that most negative feelings inherent to TFA can be articulated around the loss of self-esteem: loss of biological self-esteem because of the pregnancy ending in a failure; loss of moral self-esteem caused by feelings of responsibility and sometimes guilt that accompany the

decision to end the pregnancy; finally, loss of social self-esteem derived by a perceived inability to bring a disabled child into the world and subsequent mixed feelings about what is "gained" from the loss. These issues alongside elements of guilt and self-blame, which have also surfaced in the data, must be taken into account. Research has also shown that women who undergo TFA often feel alienated and stigmatized in their loss (Bryar, 1997; McCoyd, 2010; Rillstone & Hutchinson, 2001), predominantly because TFA is still conceptualized within the abortion paradigm (McCoyd, 2010). In addition, because providing support to others, preparation, and experiential knowledge were experienced as helpful, early referral to support groups might be beneficial.

Our findings also point to the potential benefit of promoting coping strategies to women who undergo TFA, such as acceptance, positive reframing, and benefit finding. It might also be useful to emphasize psychological concepts such as self-esteem and resilience. Although controversial, the potential value of seeing the baby and creating memories might also be emphasized alongside suggestions of ways to achieve this. Conversely, women who express a desire to distance themselves from the event should be allowed to do so. Care needs to be open, sensitive, nondirective, and ultimately tailored to each woman's particular needs. Our study also revealed some inadequacies in aftercare, which might result in poor psychological adjustment. These could have significant consequences on women's quality of life and their well-being in subsequent pregnancies. Previous prenatal loss affects the mental health of women who conceive again, with typically higher levels of anxiety and depression being observed among those who have experienced a loss compared to those who have not (Blackmore et al., 2011). Similarly, women who conceive after TFA have reported a new pregnancy to trigger a "re-emergence of anguish" (Rillstone & Hutchinson, 2001). Consequently, it might be beneficial to monitor women who have undergone TFA during subsequent pregnancies.

One the many strengths of this study is the novel and prolific nature of the feedback gathered. The study also provided a welcomed opportunity for women to share their experiences, with many who indicated that their participation in the study had a therapeutic effect. By making a summary of the results available to all participants, we also endeavored to disseminate the results directly to the group most in need of this information and of the changes this information may bring. Our study was purposively exploratory, and thus, has limitations that warrant further research. First, the sample was limited to women who were, to various degrees, active members of a support group. Research has shown that the use of online groups can lead to personal empowerment, through the provision of a forum for self-expression and social support. This empowerment might act as a buffer against distress (Barak, Boniel-Nissim, & Suler, 2008) and influence coping processes. Consequently, further research based on women who are not using a support group is indicated.

In addition, as with many studies on TFA conducted in high-income countries, the sample in our study predominantly comprised White, well-educated participants. It is possible that women who are less articulate might find it more difficult to voice their feelings, which might influence the way they cope. Thus, widening the demographic profile of participants would be beneficial. This observation also raises the question of health literacy, given that TFA is a situation that involves a large exchange of complex information and often requires the input of many different health professionals (e.g., geneticists, neurologists, obstetricians).

Second, it is possible that some accounts reflect a social desirability bias (van de Mortel, 2008). Thus, some women might have under-reported the use of more maladaptive coping strategies. Similarly, some women might have felt under pressure to report their experience in a way they believed fit with society's stereotypes of motherhood. Comments from a few participants suggest that some women might feel inadequate if they are not overwhelmed by

sadness and pain. Hochschild (1983) suggested that society is governed by "feeling rules," which are sets of beliefs about how people think they ought to feel. These rules could also apply to TFA (McCoyd, 2009) and might influence the way coping processes are reported. Third, the retrospective nature of the study raises the possibility of a degree of post hoc rationalization. This is particularly relevant in the context of TFA because of the ethical issues it raises. Women might have post-rationalized their coping processes in light of the decision they made. This is suggested by some research studies in the field of abortion, antenatal screening, and prenatal sex identification, which have emphasized the concept of cognitive dissonance (Burke, 1992; Sandelowski & Borroso, 2005). Cognitive dissonance occurs when there is an uncomfortable conflict between ideas or feelings that are held simultaneously (Festinger, Riecken, & Schachter, 1956). The underlying assumption is that people are naturally driven to reduce this dissonance as much as possible by either changing their attitudes or rationalizing and justifying their actions.

The concept of cognitive dissonance is pertinent to TFA (Statham, H. personal communication, July 4, 2011) given that the pregnancy is, in most cases, wanted, and thus, the decision to end it is particularly complex (McCoyd, 2008). In some instances the decision strongly conflicts with personal religious beliefs, which accentuates the dissonance. It is therefore possible that when women recall their termination, they try, to some extent, to justify their decision by rationalizing it, and in turn, rationalizing the coping strategies involved. Ideally, further research would gather prospective data, from the time a fetal abnormality is detected to well after the termination. This study contributes to the knowledge in the area of pregnancy termination for fetal abnormality. In doing so, it has the potential to inform clinical practice, as well as to benefit women who are facing TFA. It also clearly represents a starting point rather than a conclusion, and thus might initiate exploration into new areas of research.

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