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Cognition, emotion, and behaviour in women undergoing pregnancy termination for foetal anomaly: A grounded theory analysis

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ABSTRACT

Objective: To understand the cognition, emotions, and behaviour of women who had recently undergone termination due to a foetal anomaly. In this study, we developed and tested a theoretical model to describe how women went through the process after termination.

Study Design: A grounded theory study.

Setting: Three general hospitals and one special hospital in Changsha, Hunan, China.

Participants: 41 women who had recently undergone a pregnancy termination.

Methods: In-depth interviews were conducted from May to September 2017. A combination of convenience sampling and theoretical sampling was used, and conceptual depth criteria were used to measure the progress of the theoretical sampling.

Findings: This study developed a cognitive-behavioural experience framework of women undergoing pregnancy termination due to a foetal anomaly. The model included 4 phases: 1. Denial Phase, 2. Confirmation Phase, 3. Decision-making Phase and 4. Recovery Phase. Different cognitive appraisal, emotional, and behavioural reactions were included in each phase, and the different reactions influenced one another.

Key Conclusions & implications for practice: We built and tested a theoretical framework by interviewing women who had gone through a pregnancy termination. The framework describes their experiences more clearly from three dimensions, including cognitive appraisal, emotional reaction, and behavioural response in the different phases. This framework provides a basic understanding of the women's emotional process and, therefore, provides baseline data for developing an effective intervention to help women cope with termination stresses.

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Background

The reported incidence of congenital foetal anomalies was 3.8% worldwide (Babu and Pasula, 2013). Every year 150,000 women in the United States are diagnosed with a foetal anomaly, with 47% to 90% choosing to terminate their pregnancy (ACOG, 2017). The use of higher frequency transvaginal ultrasound probes and improvements in technology enhance the visualisation of anatomic

detail at earlier gestational ages (Luchi et al., 2012). Other studies have also noted that, with increasing detection rates of severe structural foetal anomaly, more women were requesting termination of pregnancy (TOP) (Wald and Kennard, 1998; Driscoll and Gross, 2009). Mental distress after TOP has proved to be a serious issue. Korenromp and his team found that 44% of women who had gone through TOP experienced a high level of posttraumatic stress, a level which was 10 times higher than the level in women who had a normal delivery (Korenromp and van den Bout, 2007). Furthermore, the levels of grief and persistence of posttraumatic stress symptoms observed in women who had undergone TOP due to a foetal anomaly remained constant when measured between two years and seven years after TOP (Korenromp et al., 2005).

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Fig. 1. Cognitive-Behavioural Model.

Several qualitative studies were conducted on the experiences of women who were diagnosed with a foetal anomaly (Gammeltoft et al., 2008; McCoyd, 2007; Hodgson et al., 2016; Maguire et al., 2015; Carlsson et al., 2016; Da Costa et al., 2005). Agonising wait, shocking disclosure, hardest feeling, (Hodgson et al., 2016) mythic expectations, excruciating dilemmas (McCoyd, 2007), sorrow and pain, guilt and fear, and uncertainty (Gammeltoft et al., 2008) were all ways that women described their experiences even two years after TOP. The women experienced mental suffering after foetal anomaly TOP, with feelings that included self-blame and guilt, as well as social isolation and a triggering of grief (Maguire et al., 2015). The feeling of grief was described before, during, and after TOP (Carlsson et al., 2016; Da Costa et al., 2005).

The five stages of grief model, established by Kübler-Ross in a famous qualitative research *On Death and Dying* (Kübler-Ross, 1969), was frequently used in programs of death education (Downe-Wamboldt and Tamlyn, 1997). It originally described the response of terminally ill patients to the awareness of their impending death: denial, anger, bargaining, depression, and acceptance. (Kübler-Ross, 1969) Later, researchers found the grief model can be widely used to describe feelings of grief in variety of conditions (Maciejewski et al., 2007), such as the process of adaptation to type 1 diabetes mellitus (Isla Pera et al., 2008), post-injury responses of competitive athletes (van der Poel and Nel, 2011), victim responses to an anticipated worksite closure (Blau, 2007), process of addiction recovery (Chambers and Wallingford, 2017) and so on. Kübler-Ross's model showed that the stages of grief can change constantly and regularly. However, studies on the stages of grief in women who have undergone TOP due to foetal anomaly are underreported.

Effective intervention for women undergoing TOP for foetal anomaly is urgently needed and crucial in easing the women's mental suffering. Women who have gone through TOP need professional support (Asplin et al., 2012; Lotto et al., 2016; Fisher and Lafarge, 2015). The cognitive-behavioural model (CBM) (Fig. 1), one which could be a useful part of that professional support, is the basic model of CBT. Cognitive-behavioural therapy (CBT) is a psychotherapy approach with two central themes: 1. Cognition can control emotions and behaviour; and 2. Behaviour can strongly affect thought patterns and emotions (Jesse, 2005). In CBM, cognitive processing is essential, because humans continuously appraise the events in the environment around them, and cognition is associated with emotional reactions and behavioural response (Jesse, 2005). This CBM is guiding clinicians to understand the relationship between thoughts, emotions, and behaviours, and can be used to develop an effective intervention (Jesse, 2005).

Therefore, a deep understanding of cognition, emotion, and behaviour is urgently needed for women who have undergone TOP due to foetal anomaly. In this paper, we developed a framework made up of the different phases of women's reactions after TOP. With this theoretical model, providers can develop effective interventions to decrease mental stress. We used grounded theory to reveal the changes in women's cognition, emotions, and behaviour, and to show the relationship between these variables.

Methods

Aim

The aim of this study was to establish a model to explain women's experiences of cognitive, emotional, and behavioural reactions before, during, and after TOP due to a foetal anomaly.

Setting and participants

Forty-one women who went through the TOP process were recruited. Several outpatient clinics, including three Xiangya hospitals and Hunan Provincial Maternal and Child Health Care Hospital in Hunan, China, were used as the study sites from May to September 2017. The inclusion criteria were: 1. Pregnant women who had decided to undergo TOP due to a foetal anomaly; 2. Able to write and speak Chinese; 3. Had access to the Internet and telephone; and 4. Able to complete the follow-up surveys. Pregnant women with severe complications (e.g., heart failure, severe pre-eclampsia, eclampsia, and/or massive haemorrhage) or diagnosed with a severe mental illness (e.g., psychosis, schizophrenia) were excluded because of the possibility that those issues might affect their decision to undergo TOP.

A combination of convenience sampling and theoretical sampling was used. Theoretical sampling, where data collection and analysis occur together, was used to guide the recruitment to ensure the development of the theory (Charmaz, 2006). A special feature of grounded theory is theoretical sampling, which can be used to constantly make comparisons, directing the researcher to seek pertinent data to illuminate emergent categories and dimensions (Glaser, 1998).

Conceptual depth criteria were used to measure the process of reaching saturation during theoretical sampling (Nelson, 2017). "Conceptual depth" is defined as an appropriate way to set a point where the researcher stops the theory search and participant recruitment (Nelson, 2017). To reach conceptual depth is to reach a sufficient depth of understanding that can allow the researcher to build a theory, not only to reach a final limit that no new concepts was presented. The conceptual depth scale included five criteria: range, complexity, subtlety, resonance, and validity (Nelson, 2017).

During the data collection process, we contacted 45 women who had decided to terminate their pregnancy due to a foetal anomaly. Four refused to participate for personal reasons. Therefore, a total of 41 participants were recruited, with a 91% acceptance rate. The mean age of the women was 30.8 years (range 21–44 years), the mean gestational age of the foetus was 22.5 weeks (range 13–28 weeks), and 19 of 41 foetuses (46.3%) had structural and chromosomal anomalies. A detailed diagnosis is shown in Table 1.

Data collection and analysis

We interviewed each participant four different times.

The first encounter was an in-depth interview, and it took place after the pregnant woman decided to terminate her pregnancy and her healthcare providers referred her to the research staff. All in-depth interviews were conducted using a semi-structured inter-

Table 1
Participants diagnoses.

Diagnosis	N = 41 (%)
Multiple malformation	11 (26.8)
Cardiac malformation	7 (17.1)
Cleft lip and palate	7 (17.1)
Renal malformations	4 (9.8)
Cerebral malformation	2 (4.9)
Spine malformation	2 (4.9)
Strephenopodia	1 (2.4)
Osteogenesis imperfecta	1 (2.4)
Duodenal obstruction	1 (2.4)
Diaphragmatic hernia	1 (2.4)
Severe thalassemia	1 (2.4)
Biliary atresia	1 (2.4)
Acromphalus	1 (2.4)
Genital malformation	1 (2.4)

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view guide encompassing participants' experiences with receiving the diagnosis, counselling, discussion of options, potential decision factors, and coping after the termination procedure was performed. During the interview, open-ended questions were used, and participants were guided in describing their experience of TOP.

The second encounter was held on the sixth day after TOP. The third encounter occurred one month after TOP, and the last encounter was held three months after TOP.

The first, in-depth, interview lasted 30 to 90 minutes, depending on the study participant's condition. All in-depth interviews were conducted in person in a private space that provided adequate privacy for the participants. The follow-up interviews were conducted over the telephone and lasted approximately 20 minutes. Of the 41 participants, 28 completed all 4 interviews, 2 completed 3 interviews, 7 completed 2 interviews, and 4 only completed the first interview.

The in-depth interviews were conducted, audio-recorded, and then transcribed in Chinese. ATLAS.ti software (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany version 7), was used to code and analyse the data. Data were analysed using initial, focused, and axial coding (Charmaz, 2006). Using the constant comparison method of data analysis, incidents and concepts in the data were compared in order to develop categories; these categories were later used to formulate our theory (Glaser, 1998).

Team analysis, memo writing, and member checking were used to ensure study rigour (Anselm and Strauss, 1998). Team analysis was done every two weeks with a multi-perspective research group to ensure that assumptions and biases were revealed and discussed until the theme was settled. The team in this study included experts in nursing, clinical medicine, and psychology. Team members discussed and compared constantly. After the discussions, interrogative sentences were used to describe the cognition of the participants. One of the important aspects of this team analysis was to explore possible different stages that could later assist in intervention design. During the team analysis, the theoretical framework converted from self-regulation decision making model to five stages of grief and CBM. Memo writing helped in sorting the categories and completing the framework. Member checking with participants was conducted by asking them their opinions about emerging concepts and categories, ensuring the researchers had a thorough understanding of participants' experiences.

Use of the literature and theoretical framework

Salient issues and concepts are not known until they emerge in the data when using grounded theory (Glaser, 1998), and literature is not searched in-depth until later in the research process for fear that knowledge of existing literature could constrain model development. But the constant comparison method of grounded theory cannot be stopped until the completion of data analysis. Literature and theoretical frameworks are valuable resources for comparison. Comparison with previous literature and theoretical frameworks is necessary for expanding and exceeding the theoretical framework (Charmaz, 2006).

After the main categories, such as “heartbreak”, “mythic expectation”, “denial”, “researching information, reassessing”, and “triggered” developed from the data, the researchers sought literature that was generally focused on the emotional reactions and process experience of women undergoing TOP due to foetal anomaly, and the professional care required by the women, with intervention provided by healthcare staff. After continued comparisons and discussions by our team, the five stages of grief and CBM were chosen to be the theoretical frameworks for this study.

Ethical considerations

The study received approval from the Central South University and Yale University Institutional Review Boards. Pregnant women who met the inclusion criteria and were interested in participating in the study met with the research staff to further discuss this study. After the research staff members explained the study, they answered questions, and then obtained verbal consent from all study participants.

Findings

A cognitive-emotional-behavioural framework was developed for women undergoing TOP due to a foetal anomaly (Fig. 2). The model included four stages: 1. Denial Phase; 2. Confirmation Phase; 3. Decision-making Phase and 4. Recovery Phase. Different cognitive appraisal, emotional, and behavioural reactions were included in each stage, and these reactions influenced one another. The specific behaviours influenced a new cognitive appraisal for the next stage. The **cognitive** appraisal was at the centre of each stage, because it had a controlling influence on emotional and behavioural reactions. For example, a woman might think the following things: 1. “My baby is fine. How can it be abnormal?” 2. “Is my baby really abnormal? Is this an incorrect diagnosis?” 3. “My baby is abnormal. What should I do?” 4. “I lost my baby. How do I adjust? What about the next pregnancy?” The main **emotional** reactions in the different stages included 1. Heartbreak, 2. Mythic Expectation, 3. Anguished, 4. Triggered.

The feelings of grief in the first phase (Denial Phase) and the third stage (Decision-making Phase) were more serious than in the other two stages (Confirmation Phase and Recovery Phase). **Behavioural** reactions in the different phases included the following: 1. Denial and doubting the diagnosis; 2. Researching information and reassessing; 3. Gathering pros and cons, decision making; and 4. Adjusting and recovering.

Denial phase

Cognitive appraisal - My baby is fine. How can it be abnormal? The diagnosis of a foetal anomaly happened suddenly, and the women did not expect this result when they visited their healthcare providers. When they were first told about the diagnosis, the participants thought the diagnosis must be wrong because all of

Fig. 2. A cognitive-emotional-behavioural framework of Women Undergoing Termination of Pregnancy for Fetal Anomaly

Note: One circle indicated one phase. The cognitive appraisal, emotional and behavioural reaction of each stage stayed in one circle and influenced each other. The arrows represented the development after being diagnosed as fetal anomaly. The deep color meant that the emotional reactions in these stages were more serious than others.

their previous results appeared normal. Most of them expressed repeatedly that it was unbelievable.

...It is difficult to accept. It is unimaginable. P1T1 (27 years, 28 weeks, first pregnancy)/P22T1 (27 years, 16 weeks, first pregnancy)

Everything is good. All results are normal. How can it (diagnosis of foetal anomaly) happen to me? P7T1 (29 years, 24 weeks, second pregnancy)

I visited my obstetrician regularly for antenatal care. Nothing is wrong. No anomaly. No complications. I never prepared for this (foetal anomaly) diagnosis. P14T1 (41 years, 16 weeks, second pregnancy)

Emotional reaction - heartbreak

The emotional reaction in the first phase, accompanied by cognition, was heartbreak. Our participants described the chaos of their shattered world in different ways, using words like “dazed”, “shocked”, “complex feeling” and “very painful” to express their feelings. Most said that their tears were out of control at that time.

I feel so cold, so cold that my body starts to chill when I get the information. P8T1 (34 years, 21 weeks, second pregnancy)

I felt heartbreak when the healthcare provider told me the result. It was heartbreaking information. P17T1 (27 years, 24 weeks, first pregnancy)

...I lose consciousness at that time. I feel like the sky is falling. I faint. I stand there without consciousness, no mental activity, no thoughts. P33T1 (35 years, 25 weeks, second pregnancy)

I am tearing up all day. I have never had so many tears. P7T1 (29 years, 24 weeks, second pregnancy)

I am crying all the time during the process when she (the healthcare provider) explained the diagnosis to me. P24T1 (28 years, 25 weeks, second pregnancy)

Behavioural reaction - denial and doubting the diagnosis

Most participants didn't accept the diagnosis of foetal anomaly, and began to recall the behaviour recorded in their memories, and collected that information to support their view that the foetus was normal. But at the same time, they could name some of the high-risk issues that might cause the foetal anomaly.

We (I and my workmates) were working overtime every day to apply for “good community” when I had a positive pregnancy test. I thought everything was okay, because I was healthy. But I know

I am in a high-risk age group for pregnancy. P12T1 (44 years, 24 weeks, second pregnancy)

Neither my family nor my husband's family have these genes (anomaly). We (my husband and I) are designers, so we used computers in our job. The computers had radiation, which could hurt the foetus...but we had many workmates... (Their babies were all normal.) How could it have happened to me? P38T1 (24 years, 27 weeks, second pregnancy)

...I got the hepatitis B vaccine (at the time I didn't know I was pregnant). The doctor said that it's okay to continue with the pregnancy. I took all of the medicines or tests needed for a healthy pregnancy. No problems had been found before. P33T1 (35 years, 25 weeks, second pregnancy)

In our participants' experiences, this phase was short, lasting only about half a day or a day. The behavioural response affected cognition, and led to the new cognitive appraisal of the next phase.

Confirmation phase

Cognitive appraisal - Is my baby really abnormal? Is this an incorrect diagnosis? Unlike the denial phase, participants began facing the diagnosis of foetal anomaly in this phase. They still didn't accept that their baby had an anomaly, but they started to think about what was wrong. They asked whether it was a misdiagnosis. Was the level of the healthcare providers' knowledge or skills not high enough? Were the healthcare providers irresponsible? Was the medical equipment not advanced enough?

(My husband and I are) unwilling to believe the diagnosis. We don't believe in the competency of the county hospital. Is it a misdiagnosis? P7T1 (29 years, 24 weeks, second pregnancy)

...(I) doubted the diagnosis based on the B ultrasound. It must be wrong. ... I still thought that it was a misdiagnosis after I got the results of the amniocentesis test... P20T1 (37 years, 28 weeks, second pregnancy)

Emotional reaction - mythic expectation

In this phase, the participants rekindled their hope. They hoped that they must be lucky. They hoped that evidence somewhere could be used to prove that the diagnosis of foetal anomaly was incorrect.

...I feel better when others say that your baby still has a chance to be diagnosed as normal and the proportion was 60%. ... I hope it (the diagnosis of foetal anomaly) is wrong. P8T1 (34 years, 21 weeks, second pregnancy)

I know it is impossible when I calm down. But I still keep a little hope in my mind. I expect a miracle. P14T1 (41 years, 16 weeks, second pregnancy)

I find it difficult to give up my expectations. I mean, maybe something is wrong, maybe they (healthcare providers) gave me the results of another pregnant woman. P36T1 (33 years, 13 weeks, second pregnancy)

Behavioural reaction - researching information, reassessing

Participants made extensive efforts to collect information for reassessing, because they held on to hope in their mind, even if their hope was unrealistic. They researched related information on websites to check whether the information on the website was the same as what the healthcare provider had said. They visited different healthcare providers to see if the opinion of each provider was similar. And they also asked for professional advice at different hospitals in different cities to confirm the diagnosis. Participants in this study visited different doctors at two to five hospitals.

(I) used the Baidu search engine to research messages about foetal anomaly every day, and expected to find much more supportive information for my baby. P12T1 (44 years, 24 weeks, second pregnancy)

I asked many people, visited many hospitals (including) Xiangya Hospital, Hunan Provincial Maternal and Child Health Care Hospital, 301 Hospital, and 307 Hospital. P18T1 (32 years, 26 weeks, second pregnancy)

... One more time to check, one more time to make an effort, trying my hardest until the day I can do nothing more. P19T1 (28 years, 25 weeks, first pregnancy)

However, after tremendous effort, all hopes were dashed, and then the next phase presented itself. The duration of this phase differed widely (ranging from three to 54 days in this study), mainly according to the method or time used for reassessing.

Although I knew that little hope existed, I kept a glimmer of hope until it was broken by all the rechecking. P14T1 (41 years, 16 weeks, second pregnancy)

I really maintained high expectations. Hopefulness alternated with hopelessness. ... In the end, the results didn't meet my expectations. P2T1 (22 years, 23 weeks, first pregnancy)

Decision-making phase

Cognitive appraisal - My baby is abnormal. What should I do? After rechecking the diagnosis over and over in the confirmation phase, participants eventually accepted the diagnosis of foetal anomaly. The main issue that lay ahead was whether to continue the pregnancy or to terminate the pregnancy.

I just accept the truth now. (Healthcare providers) say that I can continue my pregnancy if it is remediable, but my baby (is too severely affected). I really want to continue. P11T1 (26 years, 18 weeks, first pregnancy)

... continuing or terminating, it is most difficult for me... P21T1 (28 years, 25 weeks, second pregnancy)

I want to turn this page quickly, but am afraid to start. I think I have already admitted it, but I cry again because of my regret. P27T1 (33 years, 19 weeks, second pregnancy)

Behavioural reaction - gathering pros and cons, decision making

Our participants had all chosen TOP (this was one of our inclusion criteria). The factors they considered when deciding whether to choose TOP included the severity, lethality, and remediability of the anomaly, and quality of life of the baby after delivery. During

our interviews, we found that the most important references for the participants' decisions were similar examples from websites, friends, doctors, or the news.

A sister of my friend delivered a baby with an anomaly. ... The baby has dysgnosia. ... An unhealthy baby brings so many difficulties for families and society. ... My baby has multi-malformations, so we must give up. P6T1 (34 years, 14 weeks, first pregnancy)

The healthcare provider told us about an example where the operation was a failure, so we chose TOP. P13T1 (36 years, 16 weeks, second pregnancy)

It is the truth. ... Competition in modern society is fierce. As a normal person, I lived in stress. I could not think about what it would be like if I had a congenitally abnormal child. P33T1 (35 years, 25 weeks, second pregnancy)

Emotional reaction - anguished

From the participants' descriptions, we identified that the emotional reactions of the denial and decision-making phases were more intense than the other phases. In this decision-making phase, the pain covered the feelings of helplessness after the patients' hopes were dashed, and the desperation they felt during the baby's disappearance. It was described as great pain, of both body and mind. The duration of this phase was approximately one week.

I cried for two days out of hopelessness. ... I lost my appetite, couldn't sleep, had a headache and chest pain. P17T1 (27 years, 24 weeks, first pregnancy)

... The pain of the body has never achieved the level of pain of the mind. ... My baby in my body acted weaker and weaker, and vanished. P7T1 (29 years, 24 weeks, second pregnancy)

Recovery phase

Cognitive appraisal - I lost my baby. How do I adjust? What about the next pregnancy? The foetus had been delivered in this phase. The participants recognised that they had already lost their baby, and that their health had been impaired, both physically and mentally. They found that in this phase, they needed to recover from the termination. Some participants also hoped to analyse the factors related to the foetal anomaly, in order to adequately prepare for the next pregnancy. However, some were not yet ready to think about the next pregnancy.

Every person faced difficulties on the growing process... I hope to recover quickly. The key is adjustment in my own way. P1T2 (27 years, 28 weeks, first pregnancy)

I am always wondering what went wrong during the previous pregnancy, and what I need to do better for the next pregnancy. I yearn for a healthy baby. P7T3 (29 years, 24 weeks, second pregnancy)

I accepted frankly at last. I must relax myself. It's no benefit to immerse myself in painful or stressful feelings. ... P36T4 (33 years, 13 weeks, second pregnancy)

Emotional reaction - triggered

A few participants had already recovered to a normal emotional status. But most participants said that it was impossible to return to the time before the diagnosis of a foetal anomaly. Baby clothes, pregnant women, or babies in the vicinity, and even things about babies mentioned by others, would trigger their grief.

My heart would tremble if I recalled this thing (TOP). I feel uncomfortable when my mother-in-law talks about the baby next door. ... P2T4 (22 years, 23 weeks, first pregnancy)

I feel irritated that there are many infants in our community. ... Some people are so stupid to ask me about my baby. P8T3 (34 years, 21 weeks, second pregnancy)

(It) is always in my mind, sometimes coming out in my dreams, so sad. P27T4 (22 years, 23 weeks, first pregnancy)

Behavioural reaction - adjusting and recovering

Different participants chose different methods to relieve their grief, such as asking for social support, looking for similar references, facing it positively, diverting attention from the experience, or avoiding every related event. The duration of this phase differed according to the individual.

I returned to work as soon as possible, and then I had no time to be entangled in it (TOP). P11T3 (26 years, 18 weeks, first pregnancy)

I refuse to talk about it with family or friends. I discuss it with people who have had the same experience. P27T2 (22 years, 23 weeks, first pregnancy)

I am avoiding it completely. I have closed all doors on it (TOP). P33T4 (35 years, 25 weeks, second pregnancy)

Discussion

A cognitive-behavioural framework of women undergoing TOP due to foetal anomaly was established in this grounded theory study. This model clearly described the cognitive appraisal, emotional reaction, and behavioural reaction of the women in four phases (denial phase, confirmation phase, decision-making phase, and recovery phase), from the first day of the prenatal diagnosis up to three months after TOP. This study provided a framework for laying out the women's reactions during the grief process, as they slowly recuperated.

The finding that women who had undergone TOP experienced four phases (including denial, confirmation, decision-making, and recovery) was based on Kübler-Ross's model of the five stages of grief and the CBM. Our framework and Kübler-Ross's model were both used to describe the experience after an event that caused grief (Kübler-Ross, 1969). The significance of this framework was that we also introduced CBM to more clearly describe each phase. According to the central tenets of CBM, our cognitions have a controlling influence on our emotions and behaviour, and how we behave can strongly affect our thought patterns and emotions (Jesse, 2005). So in our four-phase theoretical framework, cognitive appraisal influenced behaviour in the same phase, and then the behavioural response changed the cognition to the next phase, different emotional response accompanied with different cognition and behaviour.

Cognition is "the mental action or process of acquiring knowledge and understanding through thought, experience, and the senses (Definition of cognition in English, 2018)." Cognitive processing is given a central role in the CBM because humans continually appraise the significance of events in the environment around and within them associated with behavioural and emotional reactions (Jesse, 2005). Therefore, understanding the cognitive processes of women who had undergone TOP for foetal anomaly was the beginning of understanding their psychological experiences, but it was underreported in previous studies. After being discussed among the research team, interrogative sentences were selected to describe the cognitive process, including thinking and evaluating.

In this framework, after being diagnosed with a foetal anomaly, women's behaviour changed with the development of the events under the interactive influence with cognition. This process was similar to the description in Da Costa and his team's study (Da Costa et al., 2005). The main difference was researching information and reassessing in the confirmation phase between the processes changed from denial of the foetal anomaly diagnosis to the decision to terminate the pregnancy. One possible reason was that the previous study paid more attention on the negative emotional reaction, and the mythic expectation covered the grief temporarily in the confirmation phase. Our results showed that the women's behaviour was special while researching information and reassessing, and they tried to collect information from anywhere

they could, such as different hospitals, doctors, and websites. Study participants in this project visited two to five hospitals just to confirm the diagnosis. Besides providing information for women to understand the diagnosis of foetal anomaly, our study also suggested that providing adequate time to process the diagnosis is important for women going through a TOP decision. Another difference between their results and ours was the process of requesting legal authorization, which does not apply to women in China.

Emotion changed with cognition and behaviour in different phases. Words like "shock" and "pain" were used to describe their emotional reaction which were the same words used in other qualitative research (Gammeltoft et al., 2008; Carlsson et al., 2016). However, other studies didn't consider the changes according to the events development. The emotional reactions during the denial and decision-making phases were more severe than the other two phases in our framework. In a literature review, Statham et al. extracted two of the phases as "initial response to diagnosis" and "making decisions" after receiving a prenatal diagnosis (Statham et al., 2000). These correspond to our denial phase and decision-making phase. That said, these phases are important for women who have gone through the TOP process. The mythic expectations in the confirmation phase were described as bringing temporary relief from grief, as the expectations help one escape from reality. Therefore, the mythic expectations should be studied more in the future.

Women who had undergone TOP showed high levels of grief (Korenromp and van den Bout, 2007; Korenromp et al., 2005; Gammeltoft et al., 2008; McCoyd, 2007; Hodgson et al., 2016). Psychological intervention was urgently needed (Asplin et al., 2012; Lotto et al., 2016). Recently, several researchers have conducted interventions to provide relief for women who were suffering from serious grief (Gorayeb et al., 2013; Markin, 2017), and their research has shown that being cared for in a protected environment can enhance the recovery process for such women (Fisher and Lafarge, 2015). On the other hand, as an effective therapy for mental suffering, (Jesse, 2005) a cognitive-behavioural intervention should be encouraged and developed. Therefore, our research framework with phases of different cognitive appraisal, emotional reaction, and behavioural reaction can serve as the basis for constructing an effective intervention for women who have gone through TOP due to a foetal anomaly. The main content of the effective intervention would be an online format integrating CBT and medical information which the women needed in different phases.

Limitations

There were several limitations in this study: First, our participants were pregnant women undergoing TOP because of a foetal anomaly. Pregnant women facing foetal loss might have different experiences than individuals who are facing other serious health issues (e.g., those who have had an operation to remove carcinoma). Therefore, it would be difficult to generalise the findings of this study model to other illnesses. Second, we did not recruit family members in this study. Family members' viewpoints might be different from the viewpoints of women who have gone through the TOP process. Future studies should include family members, since family support plays an important role in Chinese culture to soothe women during times of discomfort. Third, in the recovery phase, different individuals chose different methods to decrease their grief. In this paper, we did not categorise their grief processes. Also, we did not analyse the relationship between coping strategies and recovery speed. These things should be focused on in follow-up studies. Fourth, some women diagnosed with foetal anomaly choose to keep the baby. Since this project is only focus on the TOP, we did not recruit women who chose to maintain the pregnancy. Finally, in this study, we

did not analyse the effects of mental distress such as depression and/or anxiety. The next project can include these variables in the analysis.

Conclusion

In this study, we established a cognitive-behavioural framework for women who underwent TOP due to foetal anomaly. This framework describes women's experiences before, during, and after TOP in three dimensions, including cognitive appraisal, emotional reaction, and behavioural reaction over time. Based on this framework, healthcare providers can provide key information for interventions designed to target women who have gone through this process. Future studies should focus on designing a format including effective intervention method that can be used to help women who have gone through TOP due to a foetal anomaly.

Conflict of interest

The authors report no conflict of interest.

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Ethical approval

The study received approval from the Central South University (2017-S205) and Yale University Institutional Review Boards (2,000,020,337).

Clinical trial registry and registration number

Not a clinical trial

Author contributions

Qin, CX and Tang, SY conceived, planned, and designed the study. Qin, CX wrote the first draft of the manuscript. Chen, WT and Deng, YL supervised the project, interpreted the data, oversaw the writing of the paper, and edited the manuscript. Li, Y collected data and abstracted the dataset. Sun, LL validated and analysed the data under the supervision of Mi, CM. All authors contributed to the data analysis, interpretation of the results, and manuscript revisions. All authors reviewed and approved the submitted manuscript.

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References

- ACOG, 2007. Practice Bulletin No. 77: screening for fetal chromosomal abnormalities. *Obstet. Gynecol.* 109 (1), 217–227.
- Anselm, C., Strauss, J.C., 1998. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. SAGE Publications, Inc., Newbury Park.

- Asplin, N., Wessel, H., Marions, L., Ohman, S.G., 2012. Pregnant women's experiences, needs, and preferences regarding information about malformations detected by ultrasound scan. *Sex. Reprod. Healthcare* 3 (2), 73–78.
- Babu, R.S., Pasula, S., 2013. Frequency of foetal anomalies in a tertiary care centre. *J. Clin. Diagn. Res. JCDR* 7 (7), 1276–1279.
- Blau, G., 2007. Partially testing a process model for understanding victim responses to an anticipated worksite closure. *J. Vocat. Behav.* 71 (3), 401–428.
- Carlsson, T., Bergman, G., Carlsson, A., Wadensten, B., Mattsson, E., 2016. Experiences of termination of pregnancy for a fetal anomaly: A qualitative study of virtual community messages. *Midwifery* 41, 54–60.
- Chambers, R.A., Wallingford, S.C., 2017. On mourning and recovery: integrating stages of grief and change toward a neuroscience-based model of attachment adaptation in addiction treatment. *Psychodyn. Psychiatr.* 45 (4), 451–473.
- Charmaz, K., 2006. *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*, 1st ed SAGE Publication Inc., London.
- Da Costa, L., Hardy, E., Osis, M., Faundes, A., 2005. Termination of pregnancy for fetal abnormality incompatible with life: Women's experiences in Brazil. *Reprod. Health Matters* 13, 139–146 PII S0968-8080(02)26198-026.
- Definition of cognition in English. [2018*2018: 2018 Oxford University Press.
- Downe-Wamboldt, B., Tamlyn, D., 1997. An international survey of death education trends in faculties of nursing and medicine. *Death Stud.* 21 (2), 177–188.
- Driscoll, D.A., Gross, S., 2009. Prenatal Screening for Aneuploidy. *New Engl. J. Med.* 360 (24), 2556–2562.
- Fisher, J., Lafarge, C., 2015. Women's experience of care when undergoing termination of pregnancy for fetal anomaly in England. *J. Reprod. Infant Psychol.* 33 (1), 69–87.
- Gammeltoft, T., Hang, T.M., Hiep, N.T., Hanh, N.T.T., 2008. Late-term abortion for fetal anomaly: Vietnamese women's experiences. *Reprod. Health Matters* 16S, 46–56 PII S0968-8080(08)31373-131.
- Glaser, B.G., 1998. *Doing Grounded Theory: Issues & Discussion*. Sociology Press, Mill Valley.
- Goarayeb, R.P., Goarayeb, R., Berezowski, A.T., Duarte, G., 2013. Effectiveness of psychological intervention for treating symptoms of anxiety and depression among pregnant women diagnosed with fetal malformation. *Int. J. Gynecol. Obstet.* 121 (2), 123–126.
- Hodgson, J., Pitt, P., Metcalfe, S., et al., 2016. Experiences of prenatal diagnosis and decision-making about termination of pregnancy: A qualitative study. *Aust. N. Z. J. Obstet. Gyn.* 56 (6), 605–613.
- Isla Pera, P., Moncho Vasallo, J., Guasch Andreu, O., Torras Rabasa, A., 2008. Alignment of the Kubler-Ross grief cycle phases with the process of adaptation to type 1 diabetes mellitus. *Endocrinología y nutrición: organo de la Sociedad Española de Endocrinología y Nutrición* 55 (2), 78–83.
- Jesse, H.Wright MRBM, 2005. *Learning Cognitive-Behavior Therapy: An Illustrated Guide*. American Psychiatric Publishing, Inc., Washington, D.C.
- Kübler-Ross, E., 1969. *On Death and Dying*. MacMillan Publishing, New York.
- Korenromp, M.J., van den Bout, J., et al., 2007. A prospective study on parental coping 4 months after termination of pregnancy for fetal anomalies. *Prenatal Diag.* 27 (8), 709–716.
- Korenromp, M.J., Christiaens, G., van den Bout, J., et al., 2005. Long-term psychological consequences of pregnancy termination for fetal abnormality: a cross-sectional study. *Prenatal Diag.* 25 (3), 253–260.
- Lotto, R., Armstrong, N., Smith, L.K., 2016. Care provision during termination of pregnancy following diagnosis of a severe congenital anomaly - A qualitative study of what is important to parents. *Midwifery* 43, 14–20.
- Luchi, C., Schifano, M., Sacchini, C., et al., 2012. Detailed fetal anatomy assessment in the first trimester at 11, 12 and 13 weeks of gestation. *J. Matern-Fetal Neo.* 25 (6), 675–678.
- Maciejewski, P.K., Zhang, B., Block, S.D., Prigerson, H.G., 2007. An empirical examination of the stage theory of grief. *J. Am. Med. Assoc.* 297 (7), 716–723.
- Maguire, M., Light, A., Kuppermann, M., Dalton, V.K., Steinauer, J.E., Kerns, J.L., 2015. Grief after second-trimester termination for fetal anomaly: a qualitative study. *Contraception* 91 (3), 234–239.
- Markin, R.D., 2017. An introduction to the special section on psychotherapy for pregnancy loss: review of issues, clinical applications, and future research direction. *Psychotherapy* 54 (4), 367–372.
- McCoy, J.L.M., 2007. Pregnancy interrupted: loss of a desired pregnancy after diagnosis of fetal anomaly. *J. Psychosom. Obstet. Gynecol.* 28 (1), 37–48.
- Nelson, J., 2017. Using conceptual depth criteria: addressing the challenge of reaching saturation in qualitative research. *Qual. Res.* 17 (5), 554–570.
- Statham, H., Solomou, W., Chitty, L., 2000. Prenatal diagnosis of fetal abnormality: psychological effects on women in low-risk pregnancies. *Best Pract. Res. CL OB* 14 (4), 731–747.
- van der Poel, J., Nel, P., 2011. Relevance of the Kubler-Ross model to the post-injury responses of competitive athletes. *S. Afr. J. Res. Sport Phys. Educ. Recreat.* 33 (1), 151–163.
- Wald, N., Kennard, A., 1998. Routine ultrasound scanning for congenital abnormalities. *Ann. N. Y. Acad. Sci.* 847, 173–180 1998-06-18.