

The Experiences of Mothers with Intrauterine Fetal Death/Demise (IUFD) in Indonesia

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ABSTRACT

Background: Intrauterine Fetal Death/Demise (IUFD) is a traumatic event for mothers. Mothers with IUFD have the risk of experiencing depression, anxiety, sadness, and sorrow in their lives. Research focusing on how mothers deal with such a traumatic experience is therefore necessary.

Purpose: This study aimed to explore the experiences of mothers with Intrauterine Fetal Death/Demise (IUFD) in Indonesia.

Methods: A descriptive qualitative study with a phenomenological approach was carried out to seven informants who were recruited using a purposive sampling technique. Data were collected through in-depth interviews and analyzed using the Colaizzi's method.

Result: The results showed four major themes, including the mothers' response to a loss such as painful and traumatic experience; moral support received by mother; negative behavior from others such as stigma and lack of support; and physical and psychological changes that interfere with the role as wife and mother.

Conclusion: The history of IUFD was a very traumatic experience and had quite a high emotional burden for mothers. Hence, it is necessary to integrate support and therapeutic communication into practice.

Keywords: Intrauterine fetal death; mothers' experiences; social support

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BACKGROUND

One of the high risks of the pregnancy is mothers with intrauterine fetal death/demise (IUFD). According to the American College of Physicians and Gynecologists (2002), IUFD is a dead fetus in the uterus with a fetus weighing 500 grams that often occurs in the twentieth week or more of the pregnancy. Furthermore, Cunningham et al. (2014) stated that perinatal outcome statistics cover fetuses who die and neonates born weighing 500 grams or more.

Data from the World Health Organization (2015) shows that the infant mortality rate (IMR) in ASEAN (Association of South East Asia Nations) countries such as in Indonesia

is 27/1000 live births. Furthermore, the results of the 2015 Interdental Population Survey (SUPAS) in Indonesia also showed that the total IMR was 22.23/1000 live births, and this statistic had reached the 2015 MDGs (Millennium Development Goals) target of 23/1000 live births (Depkes, 2015). This statistic should be a concern for not only the government and health care facilities but also the community to take necessary actions for preventions.

A stillbirth – death or loss of a baby before or during delivery, is a grief event for parents. Even with a high increase in quality of care in the health sector, there are still significant cases of IUFD caused by several factors, including mother, fetus and placenta (Kary & Oraif, 2017). Fetal death is shown by the fact that after separation, the fetus does not indicate life such as heart rate, umbilical cord pulses, muscle movements, and attempts to breathe (Patel, Thaker, Shah, & Majumder, 2014). IUFD often causes trauma to the mother and family. A mother who experiences IUFD is at risk of experiencing depression and feeling anxiety and sadness or grieving for more than six months. A study of 769 women who experienced IUFD reported that the women received support from families (91.7%), nurses (90%), and doctors (53.4%). Such support can reduce the level of depression and anxiety in mothers, while single women, divorced, and widows have a higher level of depression after experiencing IUFD (Temple & Smith, 2014). Furthermore, Brierley-Jones, Crawley, Lomax and Ayers (2015) reported that mothers who experienced IUFD felt that they were still stigmatized and ignored by people around them. Such condition becomes an emotional burden for the mothers which causes them to feel depressed and traumatized by the event and result in the disruption of their roles as mothers. Social stigma and loss of identity are commonly experienced by mothers with IUFD (Cacciatore, Froen & Killian, 2013; Hill, Cacciatore, Shreffler & Pritchard, 2017; Murphy, 2012;).

The phenomenon of stillbirth has been widely studied. Fewer studies, however, have been undertaken on the sociocultural aspects of stillbirth (Cheer, 2016). The struggle of whether to disclose the stillbirth or not is echoed in the literature by mothers who have experienced guilt, shame, social isolation, and exclusion from family, friends, colleagues, and strangers (Brierley-Jones et al., 2015; Cacciatore, 2010; Thompson, 2013). If the opportunities to share memories of their stillborn babies increases maternal wellbeing, if there was a social or perceived stigma surrounding stillbirth, and if there was a possibility of an expected finite grieving period, and overcoming those barriers are necessary to facilitate sharing opportunities (Keeble & Thorsteinsson, 2018). The mother and their families perceived stillbirth to be a very sudden, unexpected, confusing, and frustrating experience, as the exact cause was not explained to them clearly. They attributed various explanations, including superstitions, biomedical explanations, and blamed various persons in their lives for the occurrence (Gopichandran, Subramaniam & Kalsingh, 2018). Additionally, parents report adverse long-term effects on their ability to manage their jobs and their family life (Ryninks, Roberts-Collins, McKenzie-McHarg & Horsch, 2014). There is necessity to do research that examines the psychological response of mothers who experience IUFD, especially the cultures that greatly influences the lifestyle of pregnant women in Indonesia. Therefore, it is important to conduct such a study and understand this experience from all sides, including the changes that occur in mothers with IUFD.

PURPOSE

This study aimed to describe the experiences of mothers with Intrauterine Fetal Death/ Demise (IUFD) in Indonesia.

METHODS

A qualitative phenomenological research design was used in this study. The target population was mothers who had experienced intrauterine fetal death (IUFD) in South Lampung District, Indonesia. The participants were recruited using a purposive sampling method with the most variant samples (Polit & Beck, 2012). They were screened for eligibility to participate in this study based on the criteria of mothers who had experienced IUFD for more than six months according to the time in the loss process stage (Videbeck, 2011). The method was suitable because it can see the perspective of the informants to be interviewed, and through in-depth interviews, researchers can analyze the results of the meaning developed by mothers who experience IUFD. From the interview results, several similarities and differences in meaning were identified from some informants. The interview guidelines to be asked to the mothers were also formulated. The interview guide is generally more structured than informal conversation interviews, and there is still little discussion in its composition (Turner, 2010). The questions used in the interview examine more deeply the informants' responses to retell what they felt from their experiences of experiencing IUFD.

The interview was conducted in two cycles. The first cycle was carried out to find data in full for approximately 45 minutes using the Indonesian language and recorded using a tape recorder. In the second cycle, the participants were asked to validate the findings of the interviews. During the interview process, everything encountered by the researchers was noted. The informants' expressions, attitudes, and facial expressions when responding to the questions were included in the interview transcript. The Colaizzi's method was used to process and analyze the data assisted by software to obtain themes and descriptions of the experiences of mother participants.

Prior to the study, the researchers explained the purpose of the study as well as the rights and obligations as the participants. If they agreed, they signed informed consent. Their identities were also kept confidential. A code name of I1 to I7 was given to the participants according to the time of participation. The ethical approval of this study was received from the Ethical Committee of the Sint Carolus School of Health Sciences.

RESULTS

This study involved seven participants who had more than six months of IUFD experience according to the time in the loss process stage. Most of them were primipara (57.2%) and aged 26-40 (57.2%). Also, most of them lose their fetus at 8 – 9 months of pregnancy. Table 1 shows the participant demographic profile of the study.

Table 1. Demographic profile of participants

Demographic profile	<i>n</i>	%
Age		
18 – 25	3	42.8%

Demographic profile	<i>n</i>	%
26 – 40	4	57.2%
Parity		
Primipara	4	57.2%
Multipara	3	42.8%
Age of the fetus at death		
6 – 7 months	3	42.8%
8 – 9 months	4	57.2%

From this study, four themes were found which presented various experiences of mothers who experienced IUFD. These themes are discussed separately and interrelated with each other to reveal the experiences of mothers who experience IUFD and have been identified based on the research objectives.

Mothers' response to loss

The first theme developed in this study was the mothers' response to loss. In this theme, the informants stated that they had a painful experience when they had an IUFD. They stated that they felt a very deep sorrow and traumatic about the incident. The forms of grief experienced by informants included sadness, crying, anger, disappointment, and in time, the informants could accept the event. Some of the participants' expressions are quoted below:

“My reaction is immediately crying while looking at my baby, who had no hope. I was sad and did not believe that my child had died. I was disappointed as well. I wish someone had taken care of me at that time, but how else would it all be God's will.” (I₁).

“I was shocked, and I immediately cried, I couldn't take it anymore. I was very sad, angry, and disappointed with myself and blamed myself (laughing in tears). I wish I did not hear my mother's words, but I also could not blame my mother. If I said I was whole-hearted, what I would do, I was not whole-hearted. And I have to be whole-hearted. Everything has happened, and indeed it is not my child's fortune.” (I₆).

Furthermore, the informants also revealed a deep trauma to the event. Some of them even refused and postponed their next pregnancy. Some participants expressed the following:

“When it happened, I was traumatized, Ma'am, I didn't want to get pregnant again because it had happened for the third time.” (I₅).

“At that time, I was traumatized, whenever I heard baby's voice, I could not be happy, I immediately cried, especially when I was in the hospital when someone next to me had a baby.” (I₆).

Moral support received by mothers

The second theme raised the moral support received by the mothers. In this theme, it was revealed that some informants received support from people closest to them, such as from the family, medical teams, and community that could help informants' health recovery. Assistance received by the mothers can help them passed through the normal grieving

process. Besides, the assistance provided by the medical team, especially nurses, could help mothers find the meaning of the loss, and the family could understand the conditions that occurred in mothers with IUFD so that mothers could undergo normal activities.

“The response of the nurses was concerned about my condition; they gave spirit and hope.” (I₁)

“The doctors and nurses are good, always give support to stay strong and not stressed, and give hope and advice that I take part in the pregnancy program ...” (I₅)

A family is a group of person who is close to an informant who is always there at all times in providing support. Support provided by the family was expressed by the informants, as well as the support they received from the community:

“Husbands and parents are good with me; they are very patient in taking care of me.” (I₄)

“The great strength that I received was from my family ...” (I₅)

“For families, they are very attentive, especially my husband and child ...” (I₆)

“People like my neighbors and community are good, they visit me and give encouragement, support, and prayer ...” (I₁)

“For good neighbors, I came home from the hospital, and they immediately visited me to give me support ...” (I₄)

Negative behaviors from people around the mothers

This theme raised the negative behavior from people around the mothers. In this study, the mothers perceived that the treatment they received was not good, including from the family, medical team, and the community, such as getting a negative stigma, rejection, and even a lack of communication delivered by the nurse.

“The response of the midwife/nurse is normal after the action is done; there is nothing to say.” (I₂, I₃)

“The family of my husband (brothers) gave no care about me; instead, they are becoming suspicious and stay away from me.” (I₁)

“...there are people who talk about me, slamming compared to their experiences....” (I₅)

Physical and psychological changes that interfere with the role of wife and mother

This theme raises physical and psychological changes that interfere with the role of wife and mother, which reveals the changes experienced by mothers after experiencing IUFD. The informants revealed that many physical and psychological problems occurred so that they experienced obstacles in carrying out daily activities that interfered with their role as wife or mother.

“After the incident of fetal death that I experienced, I said I’m unconscious, dizzy, and tense. I often get sick because I always think of my fetus.” (I₁)

“All my needs were met by my husband; my job was replaced by him because I must not have too much strength and a lot of thoughts because I was often dizzy and tense.” (I₄)

“I often cry, daydream like crazy. I like being sensitive to people and not responding to them. I often get angry with my husband.” (I₁)

“I was traumatized until I didn’t want to see the baby’s clothes and hear the baby’s voice. I cried myself, often had trouble sleeping, was nervous. I am not excited to do activities and chat with neighbors ...” (I₆)

DISCUSSION

This study aimed to investigate the experiences of mothers with IUFD. Seven mothers having the experience of IUFD for more than six months were interviewed in this study. Four major themes were developed, including mothers’ response to a loss, moral support received by mothers, negative behavior from others, and physical and psychological changes that interfere with the role as wife and mother.

The first theme in this study was the mothers’ response to loss. This incident made some participants experience a deep trauma so that they cried and felt sad when they recalled the incident. The informant stated that the incident was so traumatizing that they were afraid to get pregnant again, even though it had been more than two years. The trauma response expressed by the informants included feeling guilty for all the actions they had taken before IUFD, feeling that God had left them, and regretted the pregnancy. A previous study reported that after one year of infant death, a woman will postpone her pregnancy and have an excessive awareness of the next pregnancy (Daurgirdaite, Akker, & Purewal, 2015). Another study found a difference in the loss response experienced by mothers, from the age of mothers who are 18 years old with mothers over 30 years of age. Informants aged 30 years and over have a deeper loss response, and expectations for subsequent pregnancies are smaller than informants aged 18 or 20 years. At this age difference, seen from maternal factors, mothers over 35 years old have a high risk of developing IUFD (Cunningham et al., 2014).

The second theme described the support received by the mothers. This was expressed by the participants that the support they received from those around them, such as family, medical team, and community, could help their mental health recovery. Health professionals face difficult choices about what issues should be raised with parents at this sensitive time and the optimal timing to inform them of the decisions they will face (Sun, Rei & Sheu, 2014). The support of the medical team, especially nurses, is highly needed by mothers who experience IUFD. In this study, the mothers revealed the support provided by nurses included enthusiasm, attention, and hope. According to Crawley, Lomax, and Ayers (2013), the support received by mothers from a professional medical team about mental health outcomes after the mother experiences fetal death while the mother was at the hospital or after going home, it was something meaningful to motivate mothers. Previous research conducted by Temple and Smith (2014) stated that support from families, nurses, and doctors received by women with IUFD is very helpful in reducing depression and anxiety in women with IUFD, compared to single, divorced, and widowed women who have depression rates higher after experiencing IUFD. In this research, there is also a form of social support provided by people around the mother. Participants revealed that in addition to support from the medical team and their families, they also received support from the community such as prayer and encouragement. Allahdadian, Irajpour, Kazemi and Kheirabadi (2016) stated that the women expressed

their need for family support during these hard times and mourn stages. Furthermore, Mills, Ricklesford, Cooke, Heazell, Whitworth and Lavender (2014) also reported that participation in tailored support programs was considered to have significant benefits, the importance of emphasizing high-quality psychosocial support to parents who are saddened in labor.

This study shows two forms of support received by participants, namely emotional support and information support. Emotional and information support were shown in the form of family assistance at the hospital or home, how long, and how easy it was for them to talk or obtain information from health workers around them. The information given to mother and family members was examined by asking whether their opinions were appreciated if the information was adequate, and who had provided the information (Kirk, Fallon, Fraser, Robinson, & Vassallo, 2015; Majasaari, Sarajarvi, Koskien, Autere & Paavilainen, 2005). When care was not delivered well, mothers were further distressed, on top of their grief for their baby, with unpredictable long-term consequences. However, when this one chance was seized and used to its full capacity, the benefits appeared to be significant and long term. Parents were particularly negative about perceived emotional distance on the part of health professionals (Downe, Schmidt, Kingdon & Heazell, 2013). The communication and openness look very important; the family and the closest person become the biggest support system for the mother is facing uncomfortable conditions. Thus, any support given by the health professional, family, and community to mothers who experience IUFD can help mothers pass through the grieving process that is experienced and can take mean from loss so that mothers can continue their normal activities.

The third theme describes the negative behavior of people around the mother. This was revealed by informants that they get negative behavior from people around like, negative stigma even to accept rejection. In the study of Brierley-Jones et al. (2015), the mothers who experience the stigma of infant mortality and stigma come from families, professional medical personnel, friends, coworkers, and strangers, even from the mothers themselves. They assume the mother deliberately did not maintain her pregnancy so that IUFD occurred. Blame the mother for not doing regular pregnancy checks and maintaining inadequate food. They recounted experiences that suggested that relationships with others had been changed irrevocably and that other peoples' attitudes towards them had altered too (Murphy, 2012). Mother has an increasingly greater sense of guilt because of that. Lack of knowledge and understanding of family or community about IUFD causes negative stigma so that the behavior can slow down the recovery process and worsen the mental condition of the mother.

The last theme reveals the physical and psychological changes that disrupted the role of wife and mother. This can disturb the relationship between mother and family and the surrounding community, both in terms of communication and socialization. Also, the activities and role of informants as wives and mothers were disrupted due to delays in the process of receiving IUFD incidents experienced by the informants. The previous study by Huberty, Coleman, Rolfsmeier, and Wu (2014) mentioned that women who had after infant death have barriers to physical activity such as emotional symptoms, lack of motivation, feeling tired, and feeling guilty. Psychological changes often occur in mothers

who experience fetal death. This period occurs to the mother after experiencing the death of the baby, and the mother has major consequences in showing the results of psychological symptoms such as sadness, anxiety, fear, and suffering. According to Heazell et al. (2016), mothers who experience IUFD often reported experiences of negative psychological symptoms, including depression, anxiety, posttraumatic stress, panic, phobia, and even with the idea of suicide. Because there were physical and psychological changes, the mother cannot fulfill her normal role as a wife or mother. The grief literature indicates that people expect there to be an endpoint to the period of grief, and that grief symptoms should decrease over time (Penman, Breen, Hewitt & Prigerson, 2014). Some couples reported experiencing conflicting emotional reactions to sexual relationships. Women, more frequently than men, reported guilt and disturbing images, thoughts, and feelings that interfered with sex (Burden et al., 2016). Thus, the role of health care providers in physical activity is needed by women who experience infant mortality for the importance of physical activities such as working, exercising, and maintaining a healthy body and their weight, and can help improve emotional and mental health in mothers.

CONCLUSION

This study revealed four themes that described the experiences of mothers with IUFD, including the mothers' response to loss, moral support received by mothers, negative behavior from people around the mothers, and physical and psychological changes that affected mothers' roles. The findings in this study are expected to increase the knowledge of health/community cadres about mothers' experiences of IUFD. It is hoped that the community will not have a negative stigma and judge women with IUFD experiences, and be more sensitive in providing support for maternal psychological conditions. It is also expected that to improve healthcare services, nurses should increase their knowledge and understanding of nursing in medical and psychological care with therapeutic communication for mothers with IUFD, as well as increase their certifications to enhance their competences.

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CONFLICT OF INTEREST

None

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