Perceived Support in the Shadow of Death: Near-Miss Mothers' Experience of Being Supported

Sedigheh Abdollahpour
Mashhad University of Medical Sciences https://orcid.org/0000-0002-6112-0052
Abbas Heydari
Mashhad University of Medical Sciences
Hosein Ebrahimipour
Mashhad University of Medical Sciences
Farhad Faridhoseini
Mashhad University of Medical Sciences
Talat Khadivzadeh (Khadivzadeht@mums.ac.ir)
Mashhad University of Medical Sciences

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Abstract

Background: A maternal near miss (MNM) is an event in which a pregnant woman comes close to maternal death, but does not die. The aim of this study was therefore to understanding meaning of NMM lived experiences of being supported on the social and cultural context of Iran.

Methods: This qualitative study utilized a hermeneutic phenomenology study. The study was conducted in in multicenter hospitals, where usually handle the NMMs. The sampling was purposeful with maximum variation of eleven NMM. Data collection used unstructured in-depth interview that analyzed with Diekelmann, Allen, and Tanner analysis approach.

Results: The two main themes emerging from the data were "Perceived Social Support" and "Perceived Care Support". 910 code, eleven sub sub-theme, six sub-themes emerged, and they were grouped into two themes that help us to understand the experience of MNM mothers from supporting.

Conclusions: Findings demonstrate that mother's experience of supporting, can be effective in reducing the psychological-emotional, social, economic, and cultural burden of pregnancy and childbirth complications, and future planning should aim to reduce such complications based on mother's support. Therefore, targeted training programs, especially for the spouse, family, and medical team can be of great help to millions of near-miss mothers.

Background

A maternal near miss (MNM) is an event in pregnancy up to 42 days after delivery which a woman comes close to death, but does not die [1]. According to the World Health Organization(WHO), if a woman present any life threatening conditions due to maternal morbidities and survive, she is considered as a maternal near miss case [2]. Maternal deaths just are the tip of the iceberg of maternal morbidities, because for every mother who dies, several mothers experience lifelong disability due to maternal complications [2].

In a large systematic review and meta-analysis study, the worldwide prevalence of MNM, was 18.67/1000 live birth[3]. It is estimated that this rate is 1/1000 in countries such as the United Kingdom and Iran [4] [5] and it is in Tanzania and Uganda 17.9 and 40, respectively, per 1000 live birth[6]. The event of MNM is more common than the maternal death, and because these mothers are available to us, we can learn from interviewing them how to improve quality of care [2, 3, 5]. It is very important to hear these mothers' voices about the physical, psychological, social, and spiritual aspects of them, because it helps health providers to reduce the burden of maternal complications and improve women's health [7, 8].

Results of an extensive systematic review study that addresses the needs of women who have experiences MNM, show that the Social and Psychosocial support, is the key to programming for providing high-quality care [9]. Most of the qualitative studies obtained from interviews with mothers who have experienced MNM, have aimed to explore the meaning of quality care from their perspective [10, 11,

12]. No research has been published on mothers' perceptions of perceived support through family, community, and health care providers. The only similar study is the Hinton study, which emphasizes that long-term support for mothers and their families in primary care should be available to all [10, 13]. To achieve this goal, it is necessary to investigate their experience of being supported by interviewing mothers over a longer period of MNM event. Therefore, the aim of this study was to understand the lived experience of near miss mothers of supporting.

Methods

Aim

The objective of this study is to understand the experiences and perceptions of MNM mothers of supporting from individuals and health providers within one year after the MNM event. **Design and setting**

This qualitative naturalistic research was designed based on Dickelmann's hermeneutic phenomenology [14]. In this study, the goal of Heidegger's hermeneutic approach is to gain understanding by discovering the hidden meanings of the everyday mothers' life experiences. The meaning of personal experience reflects how mothers interact with others in the situations in which they engage themselves in context life [15].

Population and participants

The study was carried out in Ghaem and Imam Reza Hospitals, in Mashhad, Razavi Khorasan province, Iran. They are both Educational, Research and Treatment Center public hospitals.

This would provide a broad sample based on WHO criteria in defining organ failure (MNM) and ensure that the experience would be remembered with sufficient detail and intensity.

The inclusion criteria were: organ failure in accordance with the World Health Organization approach[2] and passing at least one year from the event after discharge from hospital. Telephone contacts and residential addresses were obtained from the electronic file archived at the hospital. After setting the appointment, interview was conducted in a quiet room at the mother's at woman’s house. They were told that their participation in the study was voluntary and that they could leave the study at any time. It was explained that the data obtained are kept confidential and in accordance with ethical regulations. Finally, 11 NMMs were interviewed Insert Table 1.

Table 1
Characteristics of study participants

Participant	Type of organ failure	Mother's job	Husband's job	Number of previous children	Education
1	Uterine Failure - Hematology	housewife	Insurance agent	2	Diploma
2	Uterine dysfunction	housewife	electrical engineer	1	Bachelor
3	Neurological failure	housewife	self-employed	1	Diploma
4	Neurological failure	housewife	Health worker	0	Diploma
5	Uterine and bladder failure s	housewife	Hospital Paramedic	0	middle School degree
6	Respiratory failure / preeclampsia / hematological failure / advanced lung cancer	housewife	Locomotive driver	1	Bachelor
7	Uterine dysfunction / hematological failure / gastrointestinal failure	Employed	Baker	1	middle School degree
8	Cardiovascular Failure / Respiratory Failure / Renal Failure	housewife	self-employed	0	Bachelor
9	Kidney failure / hematological failure	housewife	Driver	2	Diploma
10	Kidney failure / hematological failure	Employed	Worker	1	Bachelor
11	Kidney failure / hematological failure	housewife	Painter	0	middle School degree

Data collection

In this study, one of the common sampling methods in qualitative studies called purposeful sampling was used. In-depth face-to-face interviews were used to collect data. Interviews were conducted between May 2019 and January 2020. The first researcher telephoned participants and invited them to participate in the study. According to the hermeneutic method, the interpretation of the interviews and the analysis of the data were performed once independently and then jointly by two researchers who have PhDs in Reproductive Health familiar with the methodology of phenomenology. Each interview lasted between 60 and 100 minutes, and each one was recorded to be typed in the next step. During the interviews, the

researcher considered field notes and body language. When the researchers found that no new issues were emerging and the extracted codes were being repeated, data saturation was announced and data collection stopped. The interview started with an open-ended, general question: "What is your experience of being supported?" or "Describe your experience of being supported?" or "Explain an example of supporting yourself during hospitalization or after hospital discharge". Subsequently, other questions were asked following the protocol used and based on the natural flow of the conversation. The final question in each interview was: “Do you have anything else you would like to add?”

Data analysis

The analysis process was performed using the seven-step method of Diekelman and Allen, to emerge themes with a description of the development of the final constitutive patterns [14]. The process of interpretation begins with an understanding of the one's background, and with the deepens into the participants' layers of experience, an essence emerges [16]. To reach this stage, first the audio file must be transcribed audio file to the text and immersed in the data, and in the next stage, narrative summaries must be written. It is important for researchers to use consensus and discuss about narrative text and quotations to support emerging themes during the interpretation process. Also, after participants' responses for confirmation, data saturation of each theme was created. The analysis process continued by developing a constitutive pattern that obtain the essence of the experience [14].

Rigor

In order to ensure the rigor of the study, four Lincoln and Goba criteria including credibility, confirmability, dependability, and transferability were used. Here are some examples of these methods: Participants confirmed the results of the study, such as units of meaning, sub-themes and themes. Additionally, all the participants’ experiences were represented. In this study, the researcher listened to the audio file several times and read the texts repeatedly to become more familiar with the participants' narratives after immersion. She also compared the data to examine their similarities and differences [17].

Results

Eleven women, all with an experienced of MNM event took part in the study. Data analysis using MAXQDA10 software. 910 code, eleven sub sub-theme, six sub-themes emerged, and they were grouped into two themes that help us to understand the experience of MNM mothers from supporting. The two main themes emerging from the data were "Perceived Social Support" and "Perceived Care Support", each consisting of six sub-themes. Sub-themes in "perceived social support" included "Spouse Support", "Family Support" and "Community and Relative Support", and "perceived care support" sub-themes included "Behavioral Support" and "Information Support", and "Functional Support". Each theme was perceived both positively and negatively by the mothers. (Fig. 1).

Perceived Social Support

The experience of mothers participating in this study indicates that perceived social support means receiving tangible support such as physical and behavioral support, emotional support such as empathy

and encouragement to express feelings, kindness, and expression of love and affection. All mothers said that they perceived their positive and negative social support in some way as spouse support, family support, and community support.

Spouse Support

Most mothers said that their husbands played an important role in their feeling of support because the complication caused by the pregnancy and childbirth was the result of a joined decision by the couple. The fact that these mothers thought their organ failure was the result of childbearing further highlighted the need for support and understanding on the part of their husbands. Therefore, husbands who showed their support by reassuring mothers, and providing them with unconditional support and acceptance in the most critical life situations, created a positive sense of support in the mothers' experiences, and the "Staying Together" sub-themes emerged. Mothers who experienced a sense of not being understood, lack of empathy, and scant attention from their husbands following the ordeal which occurred to them, felt "Not Being Seen" and in fact perceived negative support from their husbands.

Regarding the sub-themes of "staying together", a [20–25] year-old mother who underwent an emergency hysterectomy due to placenta accreta says:

"My husband gave me a lot of support. I will never forget that he told me: 'I am with you in any situation'. I told her even with no womb?' He said, "in any case, you are the same wife for me".

Regarding the sub-themes of "not being seen", a [35–40] year-old mother who is on dialysis due to postpartum hemorrhage says:

"My husband does not lift a hand at home; I do all the chores myself. He never takes me to dialysis to know what infliction I undergo every day. But he refuses to come and see how I am feeling."

Family support

All mothers felt more support from their parents, and they felt that since childhood their family, with their constant positive support, were a shoulder to cry on, and a tower of strength to them, and they can rely on them in tough situations. Therefore, the sub-themes of "A Constant Tower of Strength" appeared. In this regard, a [20–25] year-old mother who has been in the intensive care unit for three months following an intestinal perforation in an emergency cesarean section says

"After my release, my father slaughtered four sheep as a sacrifice and shared the charity among people. I lost weight from 90 kg to 40 kg in the hospital, but my father and mother took care of my nutrition so much that I returned to my first place."

Sometimes the mother had expectations of her relatives and family, and when these were taken into account, the negative effects of the disease perhaps reduced for her, but sometimes the family, especially the husband's family, did not live to the expectations, and mothers did not receive support in all recent

problems, and the sub-themes of "Unkind Responses to Expectations" emerged. In this regard, a [30–35] year-old mother who has suffered from kidney failure following severe preeclampsia says:

"At that time, the whole family were saying that we would raise money and buy her a kidney so that she could have a kidney transplant. It was all just paying lip service. No one was a man of a deed. If they had helped that time, I would not be suffering so much pain now".

A 40-year-old mother who suffered from kidney failure after the first childbirth also says:

"My mother keeps saying that if your husband had paid and you had gone to a private hospital, this would not have happened to you."

Community Support

Most mothers had received positive or negative support from the community. In positive support, they had experienced a sense of understanding and sympathetic behavior that was enhanced their mental health, because the mother felt important to other people and realized that her survival was important to them, and had a good feeling of the second chance of life. Therefore, in the positive community support, the sub-themes of "Enthusiasm for Living in the Community" emerged. In this regard, a [20–25] year-old mother who was hospitalized in the intensive care unit for two months due to a neurological disorder, says

"When I was released and returned to our village, it was as if someone was coming from Karbala; the whole village came into our alley to welcome me. All of them. No one believed I would survive. I was very happy to be received so warmly."

But sometimes the support received from the community was negatively experienced, and the behavior and words of those around made it difficult for the mother to cope with her organ failure and illness, or suffer from a guilty conscience and feelings of guilt, or seclude herself from the community. Therefore, the sub-themes of "destruction of social relations" emerged. A [40–45] year-old mother, who underwent a hysterectomy after two previous cesarean sections, says in this regard:

"People who came to visit me did not understand me. They did not understand, for example, what I was saying or what happened to me. They were trying to belittle my problem. I also preferred not to explain anything to them anymore."

Perceived care support

The statements of the mothers participating in this study imply that the meaning of support from the medical team was closely tied to the provision of quality services because it was the quality of care that led to the sense of support, and if the mother had not perceived support, it was as if she had not received quality care. In other words, if the staff had efficient behavior and performance, mothers experienced a

sense of support. Thus, the sense of support from the medical staff was experienced as "behavioral support", "information support" and "functional support" which could be positive or negative.

Behavioral support

All near-miss mothers who had perceived staff behavior in that difficult situation as ego-boosting or pacifying attempts had a strong sense of positive emotional support. This personnel tried to reduce the psychological burden of what happened to the mother through effective communication and empathetic interaction with her. Therefore, the mothers saw this personnel as angels who saved their lives in difficult circumstances. Thus, the mothers' experience of the behavioral support from the personnel led to the emergence of the sub-themes of "Angels of Salvation". In this regard, a [20–25] year-old mother who has been hospitalized in the intensive care unit for a month following a heart-respiratory disorder says

"My doctor was so heartening that she would come and sit next to me, talk to me, ask me 'why are you crying now? Why are you upset?' she would talk to me a lot. So much that I cannot describe."

But some of the staff only paid attention to the physical dimension of the mothers and did not consider other aspects of the care of the mother who has been on the verge of death and provided the required services mostly with the aim of performing legal duties. These health workers treated mothers coldly, dispassionately and instrumentally, and did not adjust their behavior to the mother's circumstances, resulting in the emergence of the sub-themes of "Instrumental Look". In this regard, a [30–35] year-old mother who, following preeclampsia, had a failure in both kidneys, says:

"Very, very frankly, the doctor came over my head and told my husband and mother that 'your daughter has lost both of her kidneys' and left. At that moment, we were all broke into pieces and reduced to tears. Is it really right to break bad news like kidney failure in this way?"

Information Support

In this study, since the health care staff did not fully inform the mothers of the cause of their problem, all of them were looking for the cause helplessly. They had been given contradictory information by different parties and this made it difficult for the mother to accept and adapt to her new organ failure. The experience of mothers shows that they did not have a reliable reference to ask their questions and clear their mental ambiguities and did not receive the necessary training about their problem neither in the hospital nor the healthcare center after discharge, and they did not perceive good support from the staff to promote self-care. Therefore, after a year, the vast majority of these mothers were still looking for the cause of the near-death accident, and no one was available to answer their questions. The mothers stated that long after the incident, they still had a lack of information and they did not know why this problem occurred to them, and they had not received a precise explanation from the medical team. Therefore, the sub-themes of "Looking for the Cause" emerged. In this regard, a [40–45] year-old mother who has had a hysterectomy due to placenta percreta says

"I always wanted to know why. Some said it was because of the c-section. But I said I had seen people who had five c-sections with no problem, but why did it just happen to me? Some others said you had an infection. No one was there to give us the right answer."

A [15–20] year-old mother with a neurological disorder who was admitted to the intensive care unit due to a coma says:

"I did not remember anything after the coma. There was no one to support me. There was not even one person to answer my questions. There was no one to tell me why I was here and why I became like this".

Functional Support

In this study, most of the mothers under the study said that they perceived the experience of being supported by the performance of the staff when the staff assured the mothers that they had provided the service skillfully and in accordance with the scientific standards. In this case, the mother had experienced appropriate support to save her life and get through life-threatening conditions. Hence the sub-themes of "Healing Skill" emerged. In this regard, a [20–25] year-old mother who suffered from cerebral hemorrhage during pregnancy, after discharge from the hospital, says

"The midwife from the healthcare center supported me a lot. She came to my house and took the baby's heartbeat carefully. She checked my blood pressure. She knew the ropes, and she knew exactly what to do."

On the other hand, for mothers who did not experience support, their problem was belittled and their clinical symptoms were overlooked and their diagnosis and treatment were not timely and efficient. Thus, the lack of adequate support often stemmed from inadequate skills in obstetric emergencies. In this situation, the sub-themes of "Belittling the Problem" emerged. A [20–25] year-old mother who has been on dialysis due to lack of attention to heart and lung edema and increased blood creatinine following preeclampsia says:

"I went to the emergency ward and said I did not feel well. They said, "it is not something important. Go home". Then I went to the specialist and she said, you are in a very bad situation. You have been treated like an elderly. Blood pressure treatment of an old lady is different from that of a pregnant mother. You need to be hospitalized." If they had taken my problem seriously at first and paid adequate attention to the signs and symptoms, my case would not have been so deteriorated."

Finally, the results of this study show that near-miss mothers had a range of positive and negative experiences of being supported. If the perceived social support and care, was experienced positively, it was beneficial to the mother and, if it was negative, it was considered detrimental to the mother. Therefore, the experience of mothers' support, including perceived social support from the spouse, family, community, and relatives, as well as behavior, information, and functional support from service providers, play an important role in the mother's mental perspective.

Discussion

The purpose of this phenomenological study was to explore the lived experience of MNM mothers from supporting. Eleven women, after one years of MNM event diagnosis, were asked to describe their experience from hospital to after discharge. In this study, the meaning of mothers' experience of being supported by the two main themes of "perceived social support" and "perceived caring support" was formed.

In this study, mothers received positive or negative support from their spouse, family, and community in the critical condition of life threatening and achieving success on the circumstances of the death. The feeling of being supported in harsh conditions is created when "perceived social support" is increased, in this regard in Premji study that explores mothers' experience of caring for their late preterm infants in the community, fathers, family, and friends provided important sources of social and emotional support to mothers [18]. The need for social support is also seen in other aspects of the postpartum phase, such as breastfeeding, as the Pounds study emphasizes that the partners, close friends, and family members are most likely to form the support system when the mother is experiencing an episode of acute need [19].

One aspect of "perceived caring support" was functional support and providing quality of care by health providers. Consistent with this result, in Hinton study, women who were received very good care and support after discharge, were cared and reassured by GPs and midwives [13]. In this study, support for the mother's experience of support varied from positive to negative. This result is also suggested in Hinton's study that some mother felt that the support from their local health visitors was excellent, while others would have liked more support after such a traumatic time in hospital [13]. Another aspect of this study was information support by health providers, because there was no available information source and mothers were looking for the cause of their problem. Also in Premji study, public health nurses represent a source of informational support for managing neonatal morbidities associated with being late preterm; but seeing multiple care providers, information support was not always effective, given inconsistent guidance to care [18], which is in line with the present study.

Other studies of MNM mothers experience indicate their need for support; If a “Maternal Near-Miss Syndrome’ occurs, full social support should be implemented and a companion of the woman’s choice should be allowed to remain with her[8] or ‘Between life and death’ health professionals hold a pivotal role in supporting women and keeping them informed during or following an emergency hysterectomy[20] and finally in the acute obstetric crisis, social networks and friends and relatives can provide critical financial and emotional support for survivors [21]. Therefore, the importance of needing to support these mothers was understood by listening the voice of the participants in this study.

Strengths and limitations

The strengths of this study are as follows: First, this study is the first to examine the concept of support from the perspective of MNM mothers. Second, there was maximum geographical or cultural variation in

the sample. Third, interviews in this study performed a broad timeline of discharge and the meaning of support was examined in the long term.

One of the limitations of this study is that there are relatively few studies worldwide that have reported MNM mother's experience of supporting. For this reason, there are limitations in comparison with previous studies of concurrent and inconsistent studies.

Implications for practice, policy and future research

It is recommended that a support program be developed in accordance with the concept of support from the viewpoint of near-miss mothers. It is also recommended that clinical trials and further research examine the effect of support for mothers by various social groups and service providers on the quality of life of these mothers.

Conclusion

Near-miss mothers are in a very special situation and the experience of life-threatening conditions, as well as organ failure, make them have a different perception of support from healthy people. Depending on the meaning of the near-miss mother's experience of support, the spouse, family, and community can create positive or negative "perceived social support" for the mother. Behavior, functional, and information support from service providers can also provide "perceived care support." Undoubtedly, the mother's experience of being supported, regardless of the source of support, can be effective in reducing the psychological-emotional, social, economic, and cultural burden of pregnancy and childbirth complications, and future planning should aim to reduce such complications based on mother’s support. Therefore, targeted training programs, especially for the spouse, family, and medical team can be of great help to millions of near-miss mothers.

Abbreviations

NMM: Near Miss Mother; MNM: maternal near-miss

Declarations

Ethics approval and consent to participate

The study was approved by the Ethics Committee of Mashhad University of Medical Sciences (IR.MUMS.NURSE.REC.1398.009). All participants were given oral information about the goal of study, and written consent was obtained from all of the participants. Anonymity were secured, and participants were informed that they could withdraw from the study at any time.

Consent for publication

We have received written consent from participants to publish the results.

Availability of data and material

Data could be available upon a reasonable request and with the permission of Mashhad University of Medical Science ethical committee.

Competing interests

The authors declare no conflict of interests.

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Authors' contributions

SA, AH and TKH contributed to the study conception and design, Data analysis and interpretation, and Critical revision of the article.

SA, AH, HE and TKH conducted the interviews and collect the data. SA, AH, FF and TKH wrote and revised the first draft. All authors read and approved the final manuscript.

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Authors' Information

[1] PhD Student in Reproductive Health. [2] Ph.D of Nursing. [3] PhD in Management of Social Determinants of Health.[4] Psychiatrist.[5] PhD in Reproductive Health

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Figures

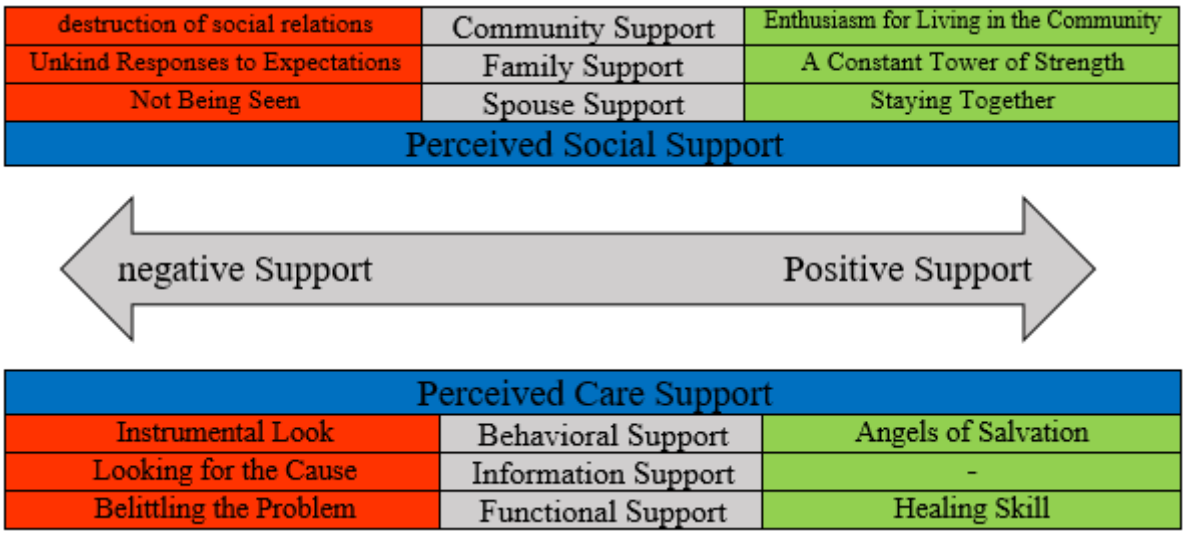

Figure 1

Emergent Themes of Participant's experience