Kobe J. Med. Sci., Vol. 70, No. 1, pp. E1-E14, 2024

Spiritual Support to Improve Women's Mental Health after Miscarriage and Stillbirth: A Qualitative Study in Japan

YUKO ENDO[1,2,*] and IZUMI SAITO[1]

[1]*Department of Nursing, Kobe University Graduate School of Health Sciences, Kobe, Japan;*
[2]*College of Nursing Art and Science, University of Hyogo, Akashi, Japan*
**Corresponding author*

Received April 10, 2023/Accepted January 9, 2024

Keywords: Spiritual support, Perinatal grief care, Mental health, Miscarriage, Stillbirth, Bereavement care

PROBLEM: Miscarriage and stillbirth can severely impact maternal mental well-being. BACKGROUND: In Japan, local municipalities must prepare systems to provide mental and social-spiritual support to women after miscarriage or stillbirth. OBJECTIVE: To elucidate what spiritually supports the mental health of women who have experienced miscarriages and stillbirths. METHODS: This analysis included 25 women who had experienced miscarriage or stillbirth at least one month previously and participated in self-help group meetings at least twice. Data were collected from March 2020 to March 2021 using two narrative interviews and questionnaires. FINDINGS: The mothers led their lives "together" with their children. They derived spiritual support from others, such as "the presence of someone who is living now after having experienced anguish" and "others who acknowledge the presence of my child and me as a mother." Further elements of the support included "resigning myself to face my grief" and "strong links to deceased children." While facing their grief by accepting that this anguish cannot be replaced [with anything else] and resigning themselves to reality, their bond to their child is strengthened. CONCLUSION: What women perceive as support after a miscarriage or stillbirth will be an important clue to care.

Approximately 23 million miscarriages occur annually worldwide, and about one in 10 women experience miscarriages. Miscarriages are tragic events that change the lives of those who experience them, although their influence on women's mental health has been underestimated [1]. According to the results of demographic surveys, approximately 15% of all pregnancies end in miscarriage in Japan, and approximately 2% of all pregnancies end in stillbirth annually [2]. However, the psychological effects and grief after a miscarriage are not well understood by society [3–5].

The Japanese Ministry of Health, Labour and Welfare recently requested local municipalities to reexamine systems for mental and psychosocial support for women who have experienced miscarriage or stillbirth [6, 7]. Most women who have experienced a miscarriage or stillbirth end their medical care at the end of their one-month postpartum health checkup and live in the community. Despite being postpartum mothers, they are at high risk of falling into extreme isolation due to "unrecognized grief" [8] after the death of their child due to the lack of public social resources that have been provided. Such mothers need postnatal care to follow up on their physical and mental state. Therefore, perinatal loss care, which affects both physical and mental health, needs to be restored to how it should be now [9].

An epidemiological study conducted in the United Kingdom in 2006 evaluated 29 pregnant women who committed suicide and found that 17 of them (59%) had a history of psychiatric disease or severe depression, nine (31%) had experienced drug dependency, and three (10%) experienced a severe grief reaction [10]. Furthermore, a cohort study of 537 post-miscarriage women found that 18% satisfied the criteria for post-traumatic stress nine months after their loss, 17% had moderate to severe anxiety, and 6% experienced mild to severe depression [11]. Thus, there is a need to identify and provide the spiritual support required to deal with women's mental health issues after miscarriage or stillbirth, treating this condition as a severe problem. The anguish caused by bereavement grief is usually referred to as spiritual pain because it is an experience that goes beyond the spiritual level and shakes spirituality as well. We explore spiritual care for such distress.

This study aimed to understand what constitutes beneficial spiritual support for women who experience miscarriage or stillbirth and factors restoring mental strength and willpower. Spiritual support, which encompasses people, things, values, and others, that can offer support for spiritual pain, is not restricted to

Phone: +81-78-925-9441 Fax: +81-78-925-9441 E-mail: yuko.endog@gmail.com

external involvement by a third party. This study explores spiritual support by focusing on the grieving process of women rather than being limited to the conditions leading to the loss of a child.

MATERIALS AND METHODS

Definition of Terms

・Spiritual support

The concept of spirituality is greatly influenced by individual values, and the Japanese Society of Spiritual Care has not been able to establish a clear definition. Although the proposed revision of "spiritual well-being" to the Definition of Health was famously rejected, the WHO clearly states the presence of "spiritual pain" in its definition of palliative care [12]. In addition, spirituality is not something to be questioned only when facing death but is now considered to be something that transcends religion and should be faced throughout one's life. Kubodera, a leading expert on spiritual care in Japan and director of the Japan Society for Spiritual Care, defines spirituality as "the ability to seek out new sources of strength and hope, both within and without the self, when faced with a life crisis, and to find new meaning and purpose in life that has been lost" [13].

This study follows Kubodera's definition of spirituality based on the characteristics of the study subjects who experienced bereavement with their children. The definition of spiritual support in this study is as follows: Spiritual support refers to support that eases the distress (spiritual pain) that upsets the spirituality of the bereaved mothers. Anything and everything that is perceived by the person as support. It includes all people, things, events, perceptions, relationships, values, thoughts, and words, regardless of their form. The reason we use spiritual support rather than spiritual care here is to capture individual perceptions so that everything is covered and not limited to specific support from a third party.

Participants and recruitment

The study participants were women who met the following inclusion criteria: 1) those who had experienced miscarriage or stillbirth at least one month or more prior to the study, 2) those who were judged by the self-help group (SHG) representative to be voluntarily attended the SHG meeting at least twice, and 3) those who were judged by the SHG representative to be in the process of facing their own grief and in a situation where they could participate in the interview and verbalize their own feelings and thoughts. The exclusion criteria for participants included induced abortion, duration of less than one month of loss, those who did not voluntarily participate in the SHG for peer support, and those with social issues other than grief. The weeks of gestation at the loss were not restricted.

Data collection

The data collection method is shown in Figure 1. Data were collected from March 2020 to March 2021. Y.E. performed two narrative interviews with each participant. In addition, the participants were requested to fill out two questionnaires and a sheet with their demographic and other attributes.

The demographic characteristics and history of pregnancies form required the participants to provide the following information: age, marital status, divorce status, infertility treatment (yes versus no), history of pregnancy and childbirth, the experience of miscarriage or stillbirth, and the time of occurrence of these events, delivery style, cause of death, history of psychiatric examinations, history of participation in the SHG and the motivation for participating, and the daily habits that participants consciously engaged in.

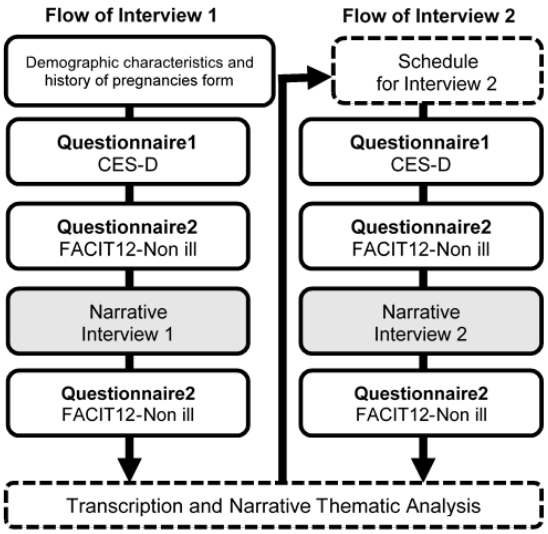


Figure 1. Data collection method
CES-D: Questions on mental health: Center for Epidemiologic Studies Depression Scale.
FACIT12-Non-Ill: Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being, a modified version for non-illness questionnaire contains 12 questions.

Questionnaire and Interview

・Questionnaire 1. Questions on mental health: Center for Epidemiologic Studies Depression Scale (CES-D)

CES-D is a scale developed for epidemiological studies of depression developed in the United States [14, 15]. We used the Japanese version of the CES-D, which is prototypical of the National Institute of Mental Health (NIMH) version, has a smaller number of items, a lower response burden, and has been shown to be clinically useful [16–18]. It consists of 20 items: 16 symptom-present items (depressive mood, physical symptoms, and interpersonal relationships) and 4 symptom-absent items (positive mood). The frequency of symptoms in the past week is asked, and the respondent selects from four options: "none," "1 to 2 days," "3 to 4 days," or "5 or more days" [14, 15, 17, 18]. Participants were asked to complete this questionnaire to determine their depressive symptoms before each interview.

・Questionnaire 2. Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being, a modified version for non-illness (FACIT-Sp-Non-Illness) ver. 4, Japanese-language version

The FACIT-Sp-Non-Illness (user license from FACIT. org on May 1, 2019) contains 12 questions regarding spirituality with responses on a 4-point Likert-type scale (0: not at all – 4: very much) [19–21]. The questions were divided into two groups, with eight questions in the "Meaning/Peace" group and four questions in the "Faith" group. Higher scores indicate a more positive spiritual condition. Individual pre- and post-interview questionnaire 2 scores were compared to assess whether participants were not distressed enough by the interview to have their spirituality shaken.

・Narrative interview

Participants were asked the following narrative generation question: "You have gone through the most difficult experience in your life, and what kind of spiritual support do you think has kept you alive today?" Y.E. was careful not to interrupt the participants while talking, and the primary focus was to listen even when the participants got sidetracked. Only when the participants finished talking, Y.E. asked questions to clarify unclear points or confirm responses.

All narratives from the first interview were transcribed into text. Y.E. then repeatedly read the transcribed narratives and prepared a summary of the "content and meaning" of the first interview narratives as captured by the interviewer. After preparing a verbatim transcript and summary of the first interview, Y.E. made an appointment for the second interview. The second interview was conducted to address missed or misunderstood aspects of participants' initial responses during the first interviews. Additional questions were asked if required. In the second interview, we gave them a summary of the first interview and confirmed that the content was correct. Participant reaffirmed their perceptions of support by receiving their narratives of the first interview through the author's voice.

Data analyses

This study used thematic narrative analysis based on Riesman's idea that the subject of narrative analysis is the "story being told" [22–24]. Narrative analysis focused on individual narratives and concentrated on finding spiritual support by focusing on "what" was told, rather than pursuing the meaning of who and for what purpose. The specific procedure was based on the thematic narrative analysis procedure by Ewick & Silbey [22–24].

First, verbatim transcripts were created from the recorded narrative data. The created verbatim transcripts were read repeatedly to extract all spiritual support while retaining the overall storyline without compromising the coherent sequence of each semantic content of the narrative regarding spiritual support. We were careful not to subdivide by coding or mix multiple cases, as in the grounded theory approach. Areas in which specific episodes of support were not described were excluded from the analysis. Themes were extracted by carefully finding commonalities for each content that fell under the definition of spiritual support presented in the individual narratives. After all themes have been identified, we had focused on differences, similarities, and relationships among the themes to try to capture the overall picture of the narratives regarding spiritual support.

The English translation of the manuscript, including the Japanese narrative, was done by native English proofreaders with extensive experience in translating medical manuscripts. Y.E., who was responsible for the interviews, repeatedly proofread the manuscript more than 20 times by multiple proofreaders, checking the translated English text for mistranslations and differences in nuance from the Japanese text. Finally, we received a quality certification statement from native proofreaders and submitted this manuscript. In this translation work, no back-translation by a third party was performed.

The scores obtained from the questionnaire were subjected to a paired t-test and p-values were calculated.

Ethical considerations

This study was conducted with the approval of the Ethics Committee of the Graduate School of Health Sciences, Kobe University (Approval No. 911). Y.E. provided the candidates with verbal and written

explanations of the study. In addition to obtaining permission to record the interviews, Y.E. obtained informed consent from the study participants that they did not have to answer questions they did not want to answer in the interviews, that all information would be used only for research purposes, and that the information would be thoroughly managed to prevent disclosure. Consent was also obtained to disclose the results of the study in a form that would not personally identify any individual.

The setting was critical in getting participants to talk about their experiences of loss. Participants can only speak in an environment that is familiar to them and in which they can build trust with the interviewer [22–24]. To build rapport and obtain genuine narratives, Y.E. became an integral member of the SHG staff and continued participating in activities. When the candidates revisited the SHG, Y.E. consulted with the candidates regarding participation in the study. By fostering relationships with participants and providing sufficient explanations of research requests, we worked to create an environment in which participants could refuse research requests at any time of their own volition.

To extract compelling narratives, Y.E. spent three and half years gaining specialized knowledge about loss and grief, underwent training for effective listening, and obtained professional certifications in bereavement care before conducting the interviews. Informed consent was obtained to record the interviews. All data obtained from the participants was handled with care for confidentiality.

RESULTS

Overview of the participants

The SHG representative, who was familiar with the participants' situation, assisted in the candidate selection. As a result, all 25 participants met the inclusion criteria, and consent was obtained from all. No one dropped out during the entire research process. Their demographic characteristics are shown in Tables I and II. Fifteen participants had experienced multiple perinatal losses. The total number of perinatal losses experienced by the participants was 46, with an additional four experiencing neonatal death. The gestational age at the time of their loss ranged from the early to the late gestational period (5 to 41 weeks), and 67% had experienced loss before 22 weeks. In addition, 10 participants had experienced a loss within 3 years, seven within 3 to 5 years, and eight between 5 to 25 years after their first loss. The elapsed time since the first loss is indicated because the grief process that a person continues to face is important, even if woman has experienced multiple losses. 12% of those who reported having religious faith indicated that they had been religious since childhood, regardless of their perinatal loss experience.

The mean duration of the first and the second interviews was 1 hour 26 minutes and 1 hour 18 minutes. The mean time between the first and second interviews was 112 days (19 to 203 days).

Table I. The demographic characteristics and history of pregnancies of the study participants (n = 25)

Mother's age at time of 1st interview	n	Number of pregnancy loss experiences	n	Time passed since 1st perinatal loss	n	Number of times of participating in SHG meetings (in times)	n	Any other circumstances at the time of the interviews	n
26–30	2	1 time	10	Within a year	1	2–5	13	Undergoing	
31–35	5	2 times	9	1–3 years	9	6–10	6	infertility treatment	3
36–40	6	3 times	6	3–5 years	7	11–15	3	Pregnant	2
41–45	10			5–10 years	4	16–20	2	No children	2
46–50	1			10–15 years	2	21 or more	1	None	18
51–55	1			15–20 years	1				
				21–25 years	1				

Number of deliveries before the loss	n	Number of deliveries after the loss	n	Religion	n	History of psychiatric care related to perinatal loss	n
0 Births	16	0 Births	10	No faith	22	Yes (no pharmacotherapy)	1
1 Birth	5	1 Birth	14	Christian	1	Yes (with pharmacotherapy)	9
2 Births	2	2 Births	1	Other	2	No	15
3 Births	2	3 Births	0				

Table II. Individual loss experiences of the study participants (n = 46)

Year of perinatal loss	n	Gestation of perinatal loss (in weeks)	n
2020	1	Less than 12	26
2019	9	12–21	5
2018	7	22–27	4
2017	11	28–31	1
2016	5	32–35	1
2010–2015	10	36–39	7
2000–2009	1	40–42	2
1990–1999	2		

Questionnaire survey results

・**Questionnaire 1. Questions on mental health (depressive symptoms)**

Figure 2 shows the pre-interview CES-D scores, which were categorized as Normal (under 16 points), Mild (16 to 20 points), Moderate (21 to 25 points), and Severe (26 points and higher). More than 30% of participant responses were 16 points or higher, indicating that those who experience grief often have depressive symptoms to the extent that they are diagnosed with depression. The results of a paired t-test with a mean score of 13.78 points (0 to 40 points) for the first interview and a mean score of 13.08 points (1 to 25 points) for the second, showed no significant difference (p-value = 0.377).

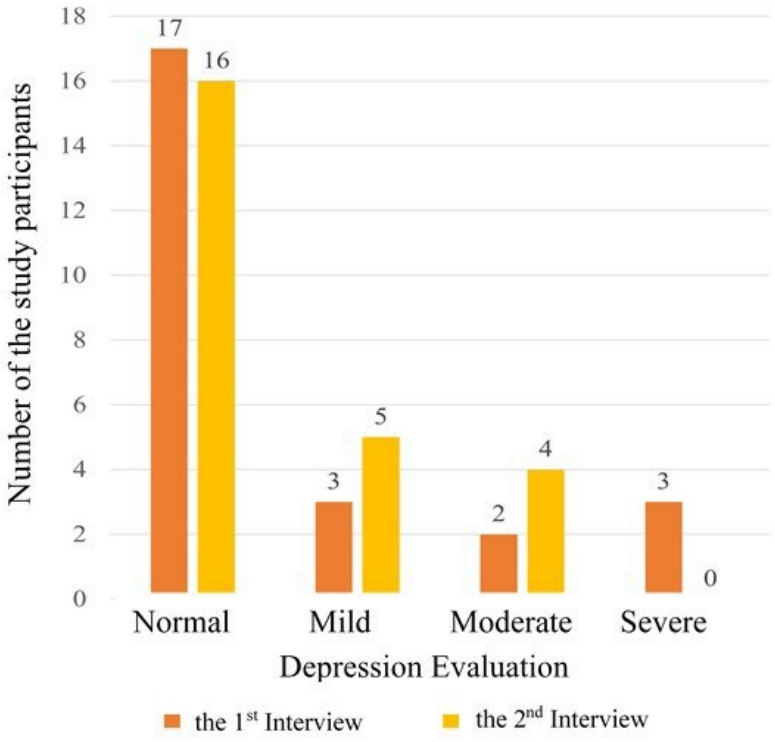
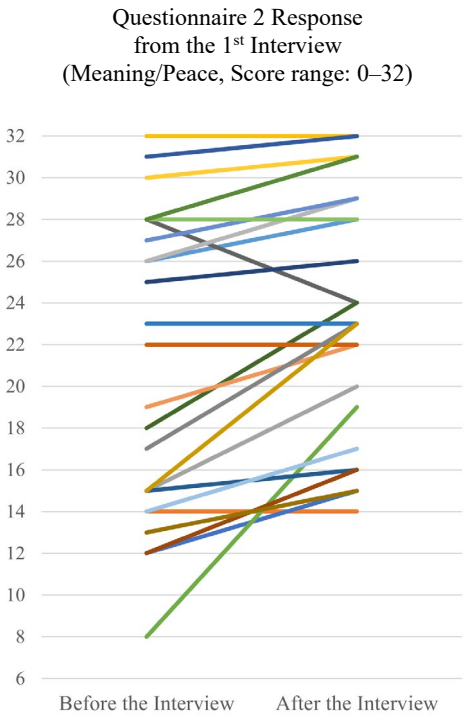


Figure 2. Questionnaire 1 response
Pre-interview CES-D depression scores, which were categorized as below.
1. Normal (under 16 points)
2. Mild (16 to 20 points)
3. Moderate (21 to 25 points)
4. Severe (26 points and higher)

・**Questionnaire 2. The FACIT-Sp-Non-Illness Spirituality scale**

A comparison of the scores for Questionnaire 2 completed before and after each interview is shown below. The scores of several participants increased after they recalled and talked about their experiences of loss. Individual differences in this score itself were found to be significant. Therefore, individual scores and their trends are shown in the figures. Figures 3 through 6 show the score trends for each group (Meaning/Peace, Faith) in Questionnaire 2. Among these, the mean increase in the scores of the "Meaning/Peace" group was 2.44 points (1st interview) and 3.84 points (2nd interview). Although the scores in the "Faith" group increased in many cases, the average increase was 1.24 points (1st interview) and 1.32 points (2nd interview), which was small. The p-values of each are 0.0031 (1st) and 0.0004 (2nd), without any significant difference. The p-values of the t-tests before and after each interview for each group were as follows: interview 1 (Meaning/Peace group: 0.00028, Faith group: 0.0031, Total: 0.00016) and interview 2 (Meaning/Peace group: 0. 000026, Faith group: 0.0004,

Total: 0.000014), all of which showed significant differences. The results of the t-test between interview 1 and interview 2 showed no significant difference (p-value = 0.22).



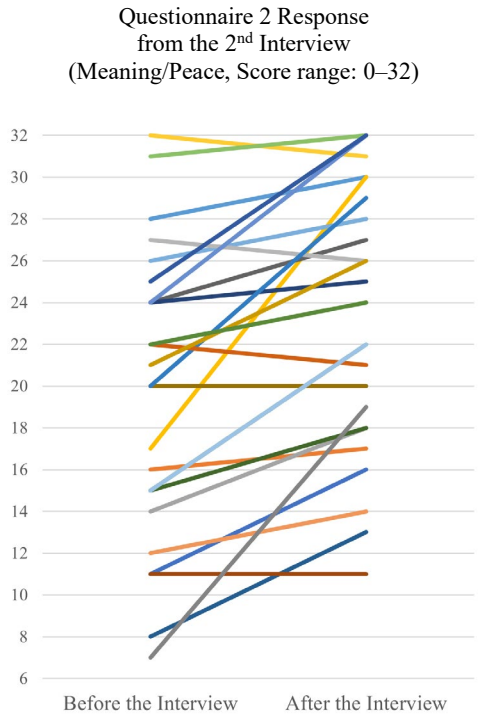
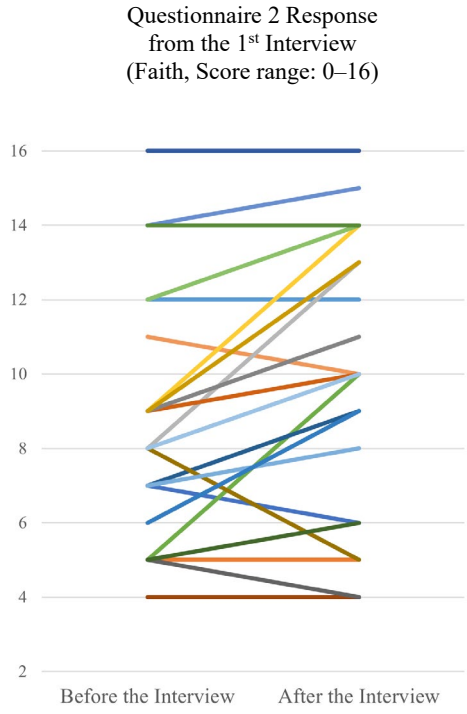


Figure 3 (left side). Scores of the **Meaning/Peace** group of the questionnaire 2 responses before and after the **1st** interview

Figure 4 (right side). Scores of the **Meaning/Peace** group of the questionnaire 2 responses before and after the **2nd** interview



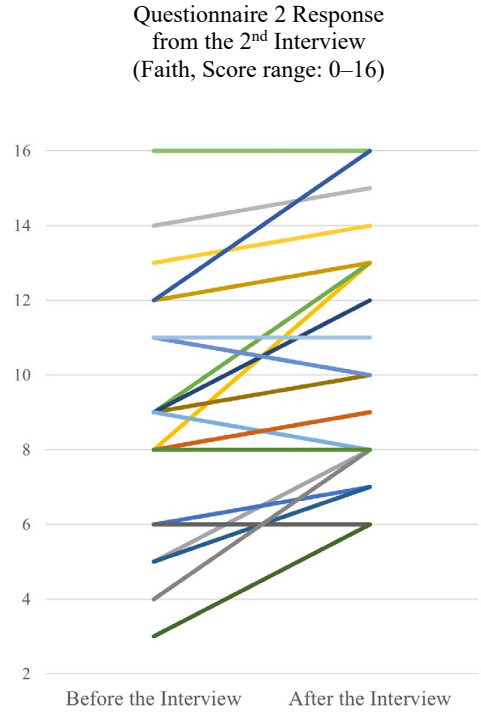


Figure 5 (left side). Scores of the **Faith** group of the questionnaire 2 responses before and after the **1st** interview

Figure 6 (right side). Scores of the **Faith** group of the questionnaire 2 responses before and after the **2nd** interview

Results of thematic narrative analysis

As a result of seeking similarities while keeping in mind the importance of every statement made by the participants, we identified the following seven themes that served as spiritual support for the mental health of those who had experienced miscarriage or stillbirth: 1) The presence of someone who is living now after having experienced anguish, 2) others who recognized the existence of their deceased children, 3) others who

recognized the participants as mothers, 4) resignation to the fact that participants had to face their sadness alone, 5) the presence of deceased children who were the subject of their sadness and love, 6) the presence of deceased children who helped them grow, and 7) strong links to their deceased children.

The participants who told on each theme are shown in Table III. The main excerpts from the narratives were used as specific examples of each of the seven themes and are presented below without altering the participants' statements. Narratives that did not make sense in the excerpts were edited by changing expressions or omitting parts of them.

Focusing on the differences, similarities, and relationships among the themes identified, two key elements were ultimately extracted as an overall picture of the narratives related to spiritual support: 1) providing them with hope to continue living after experiencing, and 2) helping mothers regain their self-esteem. An association map of two key elements with seven themes is shown in Figure 7.

Table III. Availability of narratives applicable to each theme for each participant (n = 25)

Study participant ID	Number of perinatal loss experiences	Time passed since the 1st loss (year/month)	**Theme1:** The presence of someone who is living now after having experienced anguish	**Theme2:** Others who recognized the existence of [their] deceased children	**Theme3:** Others who recognized [them] as mothers	**Theme4:** Resignation to the fact that [they] had to face [their] sadness alone	**Theme5:** The presence of deceased children who were the subject of [their] sadness and love	**Theme6:** The presence of deceased children who helped [them] grow	**Theme7:** Strong links to [their] deceased children
A	1	2y 9m	●	●	●				
B	2	2y 7m	●	●					
C	1	1y 3m	●	●	●				
D	3	10 yrs		●	●	●			●
E	1	1y 0m	●	●	●		●	●	●
F	3	10m		●	●	●	●	●	●
G	1	1y 0m		●	●			●	
H	1	2y 5m		●	●	●	●	●	●
I	1	6y 0m	●	●	●				●
J	3	4y 2m		●			●		
K	2	4y 2m	●	●	●		●	●	●
L	2	6y 0m		●	●		●		
M	2	3y 8m		●	●		●	●	
N	1	20 yrs		●	●		●		●
O	2	1y11m	●	●		●		●	●
P	2	3y 7m		●	●	●		●	
Q	2	5y 8m		●			●	●	●
R	3	2y 0m		●	●		●	●	●
S	2	10y9m	●	●	●	●	●	●	●
T	1	3y 6m		●					●
U	1	3y 3m		●	●		●		●
V	2	2y 3m	●	●	●			●	●
W	3	25 yrs		●	●	●		●	●
X	3	5y 5m		●	●		●		●
Y	1	3y 3m	●	●	●	●	●	●	●
Number of participants for each theme:			10	25	20	8	14	14	17

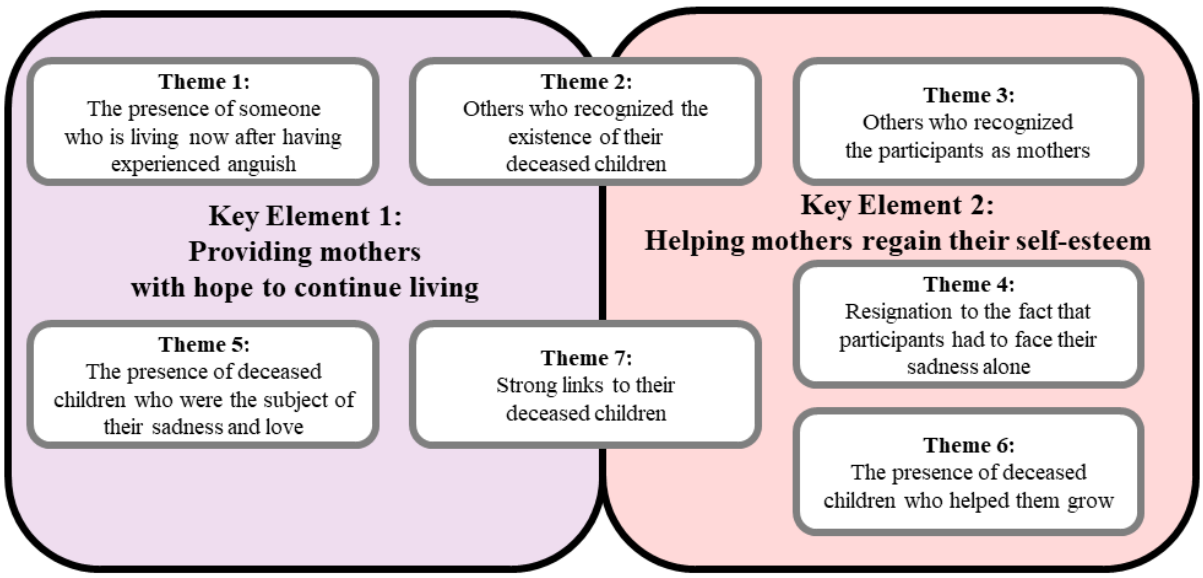


Figure 7. Result of thematic narrative analysis. Association map of two key elements with seven themes

• **Theme 1: The presence of someone who is living now after having experienced anguish**

Ten out of the 25 women said they did not know how to live after the death of their children. When they had nearly lost their confidence and willpower to live, the presence of someone with similar experiences, who had moved past the mental and emotional turbulence, gave them hope in their lives.

Ms. S came across someone with the same experience in a publication.

"When I wondered what others had done in the wake of the shock of realizing that such misery existed in the world that I – a health care provider – never knew existed, a head nurse lent me a book to read. This book contained people's experiences. I realized that there were people who had continued living their lives all by themselves after such terrible things had happened to them, and I was grateful to have found this out. Through this book, I came across people who had had the same experience."

Ms. O spoke of how someone with the same experience acted as a signpost indicating how to live her life when she was in the depths of darkness with no view of her future.

"Even among people who have had the same experience, the various circumstances [they are in] differ. I wanted to share my feelings of anguish with someone who suffered in the same way. But that was not enough. I wanted those who were a little further along in their experience to act as a signpost to show me how I could continue living and spiritually support me. When I was at my worst, when I had no idea how to go on living, the person I wanted to meet was someone who had had the same experience and was a little further along than me."

• **Theme 2: Others who recognized the existence of their deceased children**

All participants confirmed that the existence of others who recognized the fact that they were indeed pregnant, and the child was alive in the womb was a factor that was important for spiritual support.

Ms. X spoke of being spiritually supported by the SHG.

"I am thankful [for those who] consider it as important as I think of my child as being alive. There isn't a single day when I don't think of my deceased child. I don't hold back my tears. I was saved by [the existence of] a place [i.e., the SHG] where the children here on earth and heaven could be together. So, visiting the SHG and venting regularly is what I needed more than anything else. The time I spend here [at the SHG] feels like the time I spend with my child, and people want to talk to me about my child. Having a place where people accept my child's existence is a [source of] spiritual support."

Ms. L gave the following account: An environment (people, location, and time) giving importance to the existence of children is an important source of spiritual support that prevents mothers from becoming mentally isolated.

"I am blessed by my family, friends, and even the hospital. Everyone cherishes my child and is concerned about me. They worry about [what would happen if] I had a painful experience…. The fact that I have not had such

an experience is a great [source of] spiritual support. I could not understand the circumstances surrounding the fact that my daughter died while still in the hospital, and I couldn't even cry. So, I even lost interest in making memories. But, to prevent me from regrets later, a midwife took the time to make memories with me and my daughter and husband since these memories cannot be made later. Being able to have made memories that way was a major [source of] spiritual support in my subsequent life."

- **Theme 3: Others who recognized the participants as mothers**

Twenty of the 25 women stated that the presence of individuals who recognized them as mothers gave them the strength to adjust to the loss.

Ms. I spoke of how important it was to be recognized as a mother.

"After the stillbirth, all I did all day was stay at home and cry in front of the Buddhist altar from morning until night. My mother said, 'You are a mother, so cook food [for your child].' At that moment, I suddenly realized, 'That's right: I am a mother!' From that point, I gradually became able to cook food for my child and make offerings of food on the Buddhist altar.… While I was still in the hospital, no one on the medical staff ever referred to me as a 'mother.' Only the man in the morgue naturally called me a mother when he said, 'The mother should come this way.' When I was treated that way, I was happy because it felt like approval that I deserved to think of myself as a mother. [The fact that] When my next child was born safely, I finally felt confident that I am a mother.

Nevertheless, since no one could see my [first] child, no one treated me like a parent. Instead, they treated my child only as a child who had died. There wasn't even a record of my child's existence in the Family Register. Every time I experienced something like this, I thought to myself, 'But I'm a mother!'"

Ms. K spoke of her experience of being treated like a mother at the SHG.

"Until I started participating in the SHG [activities], no one thought of me as a mother even though I had given birth to a child. People who had had the same experience listened to me when I talked about my child because they understood. So, it was very significant that they referred to us as '[baby's name] Mom.' I have never forgotten how happy I was the first time someone called me 'mother'… Because I am a mother, regardless of my child being in heaven."

- **Theme 4: Resignation to the fact that participants had to face their sadness alone**

Eight of the 25 participants' narratives fell under this theme. They stated that to adjust to bereavement with a child, it is important to be prepared to face oneself.

Ms. H spoke of her experience of unjust or unfair treatment from God.

"Beliefs? In my case, beliefs provided no spiritual support whatsoever. How could that be possible? Do gods or Buddhas even exist? I realized that the only thing I could do was face my suffering by myself."

Ms. W shared their experience of confronting themselves.

"I think I was scared because I never really had a solid sense of myself. When my child died, my already unstable base became even more unstable due to my grief. The experience of that sadness led me to the task of looking at my inner self. It wasn't easy, but I looked carefully at what kind of person I was and took back [the version of] myself that did not waver no matter what others said to me. So, now I am not affected no matter what others think of me. I strove to accept myself and [finally] accepted my life. [So now], I am living a life I am satisfied with. It was a terrible experience, but when I thought that maybe this experience could be of use to other people, I finally could stand on my own two feet."

- **Theme 5: The presence of deceased children who were the subject of their sadness and love**

Statements made by 14 of the 25 women shared similarities with this theme. For mothers, the love for their children and the grief of losing them were inseparable.

Ms. F expressed ambivalence in the grief after child loss.

"It seems strange, but even though my deceased child is the source of my painful feelings, I am oddly comforted by the presence of [that same] deceased child.… This huge contradiction is something that only someone who has had an experience like this can understand. The more time passes, the more I am convinced of this. From the perspective of those around me, the only thing they can understand is that my child 'makes [me] suffer and feel sad and is the cause of [my] painful feelings.' This seems strange to me.… The presence that makes me suffer is, at the same time, the same presence that gives me resilience against that suffering. Even I find this

mysterious. So, I have never even once thought of my child, 'If I had never been blessed with you, I would not have suffered like this.' Society only sees the sad aspect, but my child's presence is a [source of joy] for my husband and me. Our child is a living hope that gives us happiness."

Ms. U spoke of her complex feelings about facing her sadness.

"Facing the death of my child was something that I honestly wanted to give up on because it was so difficult.… But if I were to do that, it would make it seem as though my child had never existed, which would lead to extremely complex feelings, and I would fall into self-loathing. So, I think I am spiritually supported by my child's presence. I don't want to think of my child because doing so causes me to suffer, but I can't not think of my child, and putting my child out of my mind is something that I absolutely should never do. I can never and do not want to ever forget. I love my deceased child the same as [her] siblings."

- **Theme 6: The presence of deceased children who helped them grow**

Fourteen of the 25 participants felt that their deceased children helped them grow. Instead of living attached to their physical bodies, mothers gained the ability to sense the presence of their children, who were not physically visible.

Ms. K spoke forcefully of her child, giving her hope.

"My child did not come [into this world] to make me sad. I believe my child came [into this world] to bring me many gifts. My child showed me what I thought was difficult in my life and that I wasn't living as myself. Then, I could live as myself without worrying about what other people thought of me and without holding myself back. Since my child is in heaven, I am not even afraid of death anymore. I now live my life happily and positively with my child. I have nothing but thanks and appreciation for my child. I will live proudly until the day comes when I am reunited with my child."

Ms. S spoke of her child, providing her with many realizations.

"It was a challenging period for me, but these last ten years have been years that I learned a lot of things. If I hadn't had this experience, there would have been many things I would never have realized. I thought about several things because of my son and my son taught me so many things. I have my son to thank for the fact that I became happy, and I am thankful to him. My experience became one in which I realized different kinds of happiness, and I became thankful for the fact that I am alive.… I changed my sense of values as I identified things that were important to me, and through this experience, I realized that I was connected to others. After a child dies, those who think their lives are over find connections with someone and continue living. The fact that there is a warm, welcoming place where that is allowed is something I learned from others. So, in a sense, my child got me to revise the way I was living.… My child took away the pain I used to have in my life due to a variety of things. I think his coming into the world had this meaning for me. Through him, I came to understand many things, many things became visible to me, I started thinking about many things, and I realized what is really important. Thus, it became easier than before for me to live my life."

- **Theme 7: Strong links to their deceased children**

Seventeen of the 25 mothers felt strong links to their children. Through the task of facing their grief, they affirmed the belief that their children resided within themselves, and as a result, their bonds with their deceased children grew, although the approaches toward arriving at this conclusion were different. It could be concluded that the relationship between mother and child continues long after the child's death and that this is a source of mental and emotional strength for the mother.

Ms. N experienced her first miscarriage over 20 years ago. At that time, there were no SHGs, so she had no opportunity to face her sadness. Instead, she had to put away her sadness for a long time, but she told of how she finally found a place for her child.

"Over twenty years have passed now.… Even those who have lost a child and thought their lives were over can connect with someone and realize that it is okay to live. I learned from others that there is a warm place (SHG) in this world where we can naturally support each other. Things were so difficult that I didn't know what to do before that. I just cried and cried when I attended memorial services for miscarried children.… All I did was say 'I'm sorry' repeatedly to my child. But I no longer go to memorial services for miscarried children, and I think I'm all right. Since I discovered that there was a place for my child, I now know that my child is always with me."

Ms. H spoke of her wish that her child's life would continue.

"The midwife taking care of me taught me something. She said, 'People die twice. The first time is when the body dies. The second time is when they disappear from memory.' The death of the body filled me with deep sadness. So, I thought that there was no way I would allow my son's memory to disappear. After I die, [my son's] life would be over. [To avoid this], I got my other children to remember [my deceased child]. I thought that this way [my deceased child's] life would not come to an end. So, we always talk about [my deceased child] in my family."

Ms. S spoke of invisible links to her child.
"I still suddenly burst out crying sometimes, even now. But my child currently resides within me.… I believe the child-mother relationship is 'one flesh.' In particular, the infant is part of the mother. And so, my son is, without a doubt, part of me.… For a mother, I think the greatest source of power is the presence of the deceased child. Once I become able to place my child within myself, this affects how I see everything in my life. So, it gives me the power to live or perhaps makes me think that I can live life to the fullest."

DISCUSSION

Main findings

From the seven themes derived from this study, two important key elements of spiritual support for women experiencing perinatal loss were identified. The first is providing them with hope to continue living after experiencing sudden child loss. Previous studies have reported a strong association between miscarriage and anxiety, depression, and suicide [10], and that women who experience miscarriage and stillbirth face significant mental health crises. In the results of Questionnaire 1 (Figure 2), more than 30% of the mothers who had lost a child were depressed. Furthermore, a comparison of the results of Questionnaire 2 before and after each interview showed that many of the respondents improved their spirituality scores. In some cases, scores before the second interview were lower than those after the first interview, but since the grief process changes slowly, moving forward and backward, receiving external stimuli, it is impossible to say whether the fluctuation in scores between interviews was a short-term effect or due to other factors. Nevertheless, what can be said from this is that talking to others about the experience of loss in a safe place has a more positive impact on spirituality. This study indicates that the presence of others who had undergone the same experiences and were continuing with their lives, as well as the presence of those who recognized the participants as mothers inspired them to continue living until they could be reunited with their deceased child. This idea is common to the spirit of Japanese culture, which bonds with the deceased [25, 26]. This inspiration is related to the extracted themes 1, 2, 5, and 7, which provided them with the mental and emotional strength to continue living (Figure 7). Having a strong bond with their deceased child and the very presence of the child they love serve as unmistakable sources of hope to continue living.

The second key element is helping mothers regain their self-esteem. The presence of others, who recognize the mother of the child and their belief that the soul of their precious child continues to live on, as in themes 2, 3, 4, 6, and 7 extracted in this study, provided the mothers the opportunity to regain the self-esteem they were on the verge of losing (Figure 7). When spending their days in grief, mothers may tend to be obsessed with how weak and powerless they are. It has been well documented that women who experience bereavement during childbirth become lonely and unable to seek help due to a lack of understanding or care [4, 8, 27]. Recovering their self-esteem inspired these women to prepare themselves to believe in their strength and face their anguish again. While they were facing their grief, as difficult as it was, they experienced revelations and growth because of their experience of child loss. Overall, this study was able to derive specific spiritual support that focused on the perceptions of the women involved. These can provide suggestions for how to provide support to women who have experienced miscarriage and stillbirth.

Interpretations

Yamamoto et al. researched whether religious and cultural ancestor worship influenced differences in the grieving process [25]. Japanese women who were war widows were less depressed and anxious than their Western counterparts. They showed that Japanese people have almost universal Japanese customs of Shintoism and Buddhism and maintain ties with the deceased after bereavement [25]. In Japan, there is a tradition of installing shelves set up in homes and workplaces to worship the gods, called "kamidana." The custom of placing a "kamidana" at the center of daily life enshrines not only the gods rooted in the country and land but also the soul of the family, protecting family harmony and order and strengthening family ties. The primary claim of the "continuing bonds model" advocated in the Japanese culture is that deceased people continue to live on in the hearts and minds of their surviving relatives and that maintaining bonds with the deceased [26], which is a belief that promotes the grief process. All the women interviewed in this study indicated a deep affection for

their children from the time of conception to the present, regardless of the time elapsed since the loss of the child. Mothers never forget their children, even temporarily, for the rest of their lives [27, 28].

Famous grief studies include Westberg's good grief, which was compiled based on Eric Lindemann's research, Kübler-Ross's five-step death acceptance process, and Alfons-Deeken's 12 stages of the grieving process [29–31], among others. These theories of the grief process treat the dead as no longer having a physical presence and focus on a process designed to sever the emotional relationship with the deceased and move toward restoration [32, 33]. In contrast, a theory known as the "Continuing Bonds Model," which was first advocated in the 1990s, describes the idea that the bonds with the deceased continue and that the deceased is transformed into an internal representation within the hearts and minds of the surviving family members, where it lives on [26, 32]. Understanding and accepting the feelings of mothers who have experienced miscarriage or stillbirth and their bond with their deceased child is an essential attitude for spiritual support. Shimazono stated, "In today's society, religious culture, which once played a major role, has receded, and resources for grief care are dwindling. Grief care is needed more than ever" [32]. The results of this study will provide valuable insight into how participants feel about their bond with the deceased in these days where death is becoming increasingly distant.

The idea that "losing the deceased even from memory is true death" mentioned by Ms. H in Theme 7 is common to "the Japanese view of life and death" [34], which has never severed life and death. Finding a place within herself to safeguard the presence of her deceased child assists in a mother's ability to consider herself as a parent and remain confident. Once this feeling solidifies, she becomes impervious to insensitive remarks. In addition, women who have experienced miscarriage or stillbirth gained a sense of their child as the subject of "sadness and love," "their own growth," "appreciation for their child," "parent-child bonds," and "happiness" as they face their grief. When a parent who has lost a child lives with their grief, they experience a process in which they share their grief, "let go of their pain, and instead gain a strong bond to their deceased child," and "have a place in their hearts where their deceased child can remain, and they can accept themselves as a person who will continue living with grief" [32, 35]. The way that Japanese people face the sadness of bereavement includes both positive and negative factors in the form of pain and happiness [36]. The fact that a person continues a relationship with a deceased child is a positive factor that provides the person with a sense of meaning and growth while helping them gain strength to accept their sadness, which allows the mothers to continue living. The Japanese word "sadness" has the meaning of "so deeply ingrained, dear, and attractive that I cannot stand it" as well as "so terrible that I want to cry; my heart pains me so much that I cannot stand it" [37]. Thus, the meaning of the Japanese word "sadness" itself hints at how to face grief in Japanese culture.

Strengths and limitations

As the study participants were recruited at the single SHG, a selection bias toward specific populations might have been present. It is necessary to continue the study with other SHG participants and women who do not participate in SHGs to generalize the results of this study. As exclusion criteria based on the number of weeks of pregnancy or the number of years that passed since the death was not set, the participants' narratives over a wide range of circumstances were obtained. Identifying similarities in cases with different periods of loss allowed the identification of common experiences and ideas. Thus, individualized results for understanding grief without being limited by the number of weeks of gestation at the time of loss could be obtained. Furthermore, we placed importance on the narratives of those who experienced early miscarriages, which have been neglected in the past. However, a limitation of this study was that it was difficult to differentiate between the experiences of loss in early pregnancy and those who have multiple experiences of loss, as many of the participants of this study experienced the death of their child at a point under 12 weeks of pregnancy and had also undergone multiple experiences of loss. Interviewing participants about their past perinatal losses may have created a certain recall bias. In this study, a second interview was conducted after a time interval. The procedure of confirming the participants' narratives from the first interview may have helped to reduce recall bias.

Since the study participants were Japanese women, the study also focused on the relationship with Japanese culture. Although the sample size is small, the narratives of the 25 women who experienced grief in this study are individually valuable materials and are expected to be useful in the construction of a Japan-specific grief care theory. Since grief is highly individualized, reflecting culture and values, a grief process constructed from various cultural backgrounds is required. In the future, by accumulating further research results, we hope to construct a theory of the grief process specific to parents who have lost a child and that respects the deceased child's continued existence in a different form.

CONCLUSION

In conclusion, women who have experienced miscarriage or stillbirth found spiritual support that helped them to recover their will to continue living and regain the self-esteem they were on the verge of losing. In

addition, while immersed in a mental state in which they resigned themselves to the fact that no one could take on their anguish, they began to come to terms with their sadness, after which they began feeling affection for and a relationship with their deceased child. The mothers realized that their children had a place in their hearts and felt strong bonds with their deceased children as they continued living with their surviving as well as deceased children.

Spiritual support for women's mental health is important when dealing with miscarriage or stillbirth in a way that encourages them to regain their self-esteem and will to live. Specifically, it is important to accept the love for the child that coexists with the grief of loss and to protect the dignity of both the deceased child and the mother who lives with the child in her heart. Accepting and understanding the affection toward her child that exists simultaneously with sadness increases the mother's ability to face her grief. Caregivers need to understand the affection that is at the heart of grief and loss and have an attitude of negative capability, which is the ability to be amid uncertainty, wonder, and skepticism, without impatiently seeking facts and reasons [38, 39], allowing them to believe in the power women have to face their grief as they assist them. Dealing with mothers while trusting in the mother and child bond and capabilities the mother possesses leads to spiritual support that aids the mothers in their grief work and strengthens their mental health.

ACKNOWLEDGMENTS

We deeply appreciate the representative of the self-help group and all mothers who participated in this study. We also thank the Grant-in-Aid for Scientific Research (Proposal No. 21K10857) for recognizing the significance of this research. Finally, we would like to express my sincere gratitude to my dear families, friends, and colleagues of the team "Perinatal grief care, Hachidori Project" [7].

AUTHOR CONTRIBUTIONS

Y.E. designed the study; Y.E. collected and analyzed the data and wrote the manuscript. I.S. supervised the study implementation. All authors reviewed the manuscript and approved the final version.

DECLARATION OF INTEREST

There are no conflicts of interest to declare, and both authors agree to this submission.

REFERENCES

1. Quenby S, Gallos ID, Dhillon-Smith RK, Podesek M, Stephenson MD, Fisher J, et al. Miscarriage matters: the epidemiological, physical, psychological, and economic costs of early pregnancy loss. Lancet. 2021;397(10285):1658–1667.
2. Ministry of Health, Labour and Welfare, Japan [Internet]. Demographics Survey vol. 2020; c2020 [cited 2022 Mar 1]. Available from: https://www.mhlw.go.jp/toukei/saikin/hw/jinkou/kakutei20/dl/03_h1.pdf.
3. The Lancet. Miscarriage: Worldwide reform of care is needed. Lancet. 2021;397(10285):1597.
4. Smith LK, Dickens J, Bender AR, Bevan C, Fisher J, Hinton L. Parents' experiences of care following the loss of a baby at the margins between miscarriage, stillbirth, and neonatal death: A UK qualitative study. BJOG. 2020;127(7):868–874.
5. Tommy's. (n.d.) [Internet]. Miscarriage matters: Findings from the Lancet miscarriage series and implications for policy with recommendations; c2021 [cited 2022 Mar 1]. Available from: https://www.tommys.org/sites/default/files/2021-04/Miscarriage_Matters%20policy%20report%20FINAL%20without%20page%20numbers.pdf.
6. Ministry of Health, Labour and Welfare, Japan [Internet]. Psychosocial support for women who have experienced miscarriage and stillbirth (notification); c2021 [cited 2021 Mar 31]. Available from: https://www.jsog.or.jp/news/pdf/20210602_kourousho.pdf.
7. Endo Y, Otake M, Sugawara M. Seven Requests to the National and Local Governments from Parents Bereaved of their Children: Practical report on delivering the results of the parent questionnaire to the Ministry of Health, Labour and Welfare, Japan. Japanese Journal of Grief and Bereavement Research. 2023;4(1):79–86.
8. Doka KJ. Disenfranchised grief: New directions, challenges, and strategies for practice. Illinois: Research Press; 2002.
9. Heazell AE, Siassakos D, Blencowe H, Burden C, Bhutta ZA, Cacciatore J, et al. Lancet Ending Preventable Stillbirths investigator group. Stillbirths: economic and psychosocial consequences. Lancet. 2016;387(10018):604–616.
10. Cantwell R, Clutton-Brock T, Cooper G, Dawson A, Drife J, Garrod D, et al. Saving Mothers' Lives:

Reviewing maternal deaths to make motherhood safer: 2006-2008. The Eighth Report of the Confidential Enquiries into Maternal Deaths in the United Kingdom. BJOG. 2011;118(1):143–203.
11. Farren J, Jalmbrant M, Ameye L, Joash K, Mitchell-Jones N, Tapp S, et al. Post-traumatic stress, anxiety, and depression following miscarriage or ectopic pregnancy: a prospective cohort study. BMJ Open. 2016;6(11):e011864.
12. World Health Organization (WHO) [Internet]. Definition of palliative care in Fact Sheets; 2020 [cited 2023 Sep 4]. Available from: https://www.who.int/news-room/fact-sheets.
13. Kubodera T. Introduction to Spirituality Care. Tokyo: Miwa Publications; 2000. Japanese.
14. National Institute of Mental Health (NIMH). Center for Epidemiologic Studies, National Institute of Mental Health. Center for Epidemiologic Studies Depression Scale (CES-D). NIMH; 1971.
15. Radloff LS. The CES-D scale: A self-report depression scale for research in the general population. Applied Psychological Measurement. 1977;1(3):385–401.
16. Shima S, Shikano T, Kitamura T, Asai M. New Self-Rating Scales for Depression. Clinical Psychiatry. 1985;27(6):717–723. Japanese.
17. Shima S. CES-D Instructions for Use. Tokyo: Chiba Test Center; 1998. Japanese.
18. Shima S. NIMH/The center for epidemiologic studies depression scale: CES-D Scale (Japanese version). Tokyo: Chiba Test Center; 2008.
19. Bredle JM, Salsman JM, Debb SM, Arnold BJ, Cella D. Spiritual well-being as a component of health-related quality of life: The functional assessment of chronic illness therapy—spiritual well-being scale (FACIT-Sp). Religions. 2011;2(1):77–94.
20. FACIT. org [Internet]. FACIT-Sp-Non-Illness; c2021 [cited 2022 Mar 1]. Available from: https://www.facit.org/measures/FACIT-Sp-Non-Illness.
21. Irie W, Shiwaku H, Suzuki Y, Inoue Y, Aizumi I. Functional assessment of chronic illness therapy-spiritual well-being-non-illness (Facit-sp-non-illness): Examination of the reliability and validity of the Japanese-language version. Archives of Tohoku Bunka Gakuen University Nursing. 2016;5(1):1–8. Japanese.
22. Ewick P, Silbey S. Narrating social structure: Stories of resistance to legal authority. Am. J. Socil. 2003;108(6):1328–1372.
23. Riessman CK. Narrative Methods for the Human Sciences. Translated by Okubo N, Miyasaka M. Tokyo: Quality Care; 2014. Japanese.
24. Riessman CK. Narrative Methods for the Human Sciences. Sage Publications; 2007.
25. Yamamoto J, Okonogi K, Iwasaki T, Yoshimura S. Mourning in Japan. Am. J. Psychiatry. 1969;125(12):1660–1665.
26. Klass D, Silverman PR, Nickman SL, editors. Continuing bonds: New understandings of grief. New York, London: Taylor & Francis; 1996.
27. Flenady V, Boyle F, Koopmans L, Wilson T, Stones W, Cacciatore J. Meeting the needs of parents after a stillbirth or neonatal death. BJOG. 2014;121(Suppl 4):137–140.
28. Saiki-Craighill S. The grieving process of Japanese mothers who have lost a child to cancer, part II: Establishing a new relationship from the memories. J Pediatr Oncol Nurs. 2001;18(6):268–275.
29. Deeken A. The grieving process: Care for surviving family members. Tokyo: Medical Friend; 1986.
30. Kübler-Ross E. On Death and Dying. New York: Scribner Book Company; 1969.
31. Westberg GE. Good grief: A constructive approach to the problem of loss. Minneapolis: Fortress Press; 1993.
32. Shimazono S. Living with grief: The history and culture of grief care. Tokyo: Asahi Shimbun Publications; 2019. Japanese.
33. Worden JW. Grief counseling and grief therapy: A handbook for the mental health practitioner. 4th ed. New York: Springer Publishing Company; 2008.
34. Takeuchi S. ‘Sadness’ and Japanese people. Tokyo: NHK Publishing; 2007. Japanese.
35. Klass D. The inner representations of the dead child in the psychic and social narratives of bereaved parents. In Neimeyer RA (Ed.), Meaning reconstruction & the experience of loss. APA. 2001:77–94.
36. Yoshida T. Accept sadness: Grief care notices. Tokyo: Nihon Hyoron-sha; 2013. Japanese.
37. Shinmura I. Kojien. 6th ed. Tokyo: Iwanami Shoten Publishers; 2008. Japanese.
38. Keats J. The complete poetical works of Keats. Houghton, Mifflin, and Company; 1900.
39. Hahakigi H. Negative capability - Ability to withstand unanswerable situations. Tokyo: Asahi Shimbun Publications; 2018. Japanese.