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Abstract

A loss experienced during the perinatal period causes great sorrow and conflicts to the mother as well as those around her, and it tends to be treated as an event that is difficult to face. Recently, there has been a call for grief care in recent years, and it has started to be conducted in some professional institutions in a variety of approaches. However, it is undeniable that the quality and methods of grief care are currently different depending on the medical institute, and the staff. Also, grief work is provided actively by medical staff while the mother is in the hospital, but more than a few of these mothers who are discharged from hospital are placed in a state in which such support for expressing or outputting their negative feelings is unavailable. The purpose of this paper is to introducing mothers’ stories which were obtained through counseling and my investigations. Those stories will be opportunities to understand the emotional workings of mothers that are hardly spoken of while they are hospitalized, and serve as clinical clues for those involved in care during the perinatal period.

Key words: grief care, perinatal, clinical psychology

1. Introduction

The loss of a child is an experience that brings indescribable sorrow to not only the parents, but the family, those around them, and the medical staff. Particularly in the case of miscarriage, stillbirth, or neonatal death, there are very few numbers of people who knew of the existence of the baby, so the parents have a limited opportunity for sharing or expressing their sadness. When
we experience a loss of a loved one, any memory or memento of the person makes us reflect upon our loss and fall into a deep sadness. Gradually, we try to examine the reality that had been so difficult to understand, and eventually, despite going back and forth between acceptance and denial, we accept the truth: that the person is dead. Having someone around who one can share some time to talk about the dead often greatly helps a person suffering from the grief. Clinical psychologists, who are experts on mental health, listen to the complicated back-and-forth sways of individuals’ emotions and stay with them during their moments of deep sorrow. This symposium was planned through the generous support from Prof. Nobuhiko Suganuma, the president of the 52nd Japan Society of Maternal Health Study Meeting, and was such a success to the extent that the organizer of the meeting had to accommodate participant numbers that exceeded expectations by providing additional seating. This shows that social interest in grief care during the perinatal period is high. In this symposium, I briefly introduced mothers’ stories which were obtained through counseling and my investigations. I hope that those stories will be opportunities to understand the emotional workings of mothers that are hardly spoken of while they are hospitalized, and serve as clinical clues for those involved in care during the perinatal period.

2. The Current Situation of Grief Care during the Perinatal Period

In the case of a neonatal death, a baby should be recognized as “having lived” and subsequently “died” in the outside world, due to the baby’s experience of NICU or involvement with medical staff or relatives, albeit for a short amount of time, as well as social confirmation through registering of a name in the family register. Therefore, though the response from people surrounding the parents seems to differ, it can be considered that there would be the accompanying sorrow, suffering, or conflict in each instance of miscarriage, stillbirth, or neonatal death. Each of those deaths cannot all be handled under the same umbrella, but in any of these cases, materials pertaining to the baby are incredibly limited. Additionally, talking about the baby’s death is considered to be a taboo in society, and these cases are often treated as cases that “should not be touched upon”. It is possible that many people find it difficult to accept the fact of the death due to the overwhelming amount of sorrow. Because they do not know what to say, people often console the parents by saying “you should try to forget about this as quickly as possible.”

Moreover, the advance of modern medical technology has enabled medical staff to save those who would have lost their lives in the past, allowing most childbirths in Japan to be conducted safely. This is a remarkable development. However, people prone to forgetting the fact that the mortality rate during the perinatal period is still not zero, which causes the misunderstanding that once a woman becomes pregnant, a healthy baby will born and grow without any problems. It is difficult for people, other than healthcare professionals in particular, to realize how dangerous childbirth, an act of producing a life, is. Therefore, if a woman experiences a
miscarriage, stillbirth, or neonatal death, she is driven by feelings of self-blame, anger or envy such as “what did I do to deserve this?” “it probably happened because I pushed myself that one time” or “all my friends gave birth without any problems. Why am I the only one?” The parents tend to fall into a deep sorrow and undergo various inner conflicts.

As mentioned above, a loss experienced during the perinatal period causes great sorrow and conflicts to the mother as well as those around her, and it tends to be treated as an event that is difficult to face. However, there has been a call for grief care in recent years, and it has started to be conducted in some professional institutions in a variety of approaches, such as setting a time for interviews with clinical psychologists, providing families with time or space to spend with their deceased child as much as possible, giving the families the baby’s umbilical cord, taking pictures of the baby, making baby clothes or blankets, taking the baby’s handprints and footprints, or making messages card for the baby. Furthermore, self-help groups over the Internet such as a parents’ association have been becoming more active and expanding their scope.

However, it is undeniable that the quality and methods of grief care are currently different depending on the medical institute. Some hospitals are active in their support undertakings, while some do not. Furthermore, there is a difference in the quality or perception of, along with motivations towards, grief care among staff even belonging to the same institution, which may cause the staff themselves to undergo difficult emotional states. Also, grief work is provided actively by medical staff while the mother is in the hospital, but more than a few of these mothers who are discharged from the hospital are placed in a state in which such support for expressing or outputting their negative feelings is unavailable. Once a mother who lost her baby is discharged from the hospital, the medical staff do not have much opportunity to obtain feedback on mentality of the patient, and many of them seem to continue their work while repeatedly questioning themselves regarding the method of care, such as “did I do well?” or “couldn’t I have said something better?”

3. For Providing Grief Care during the Perinatal Period

Medical staff members who have been in charge for miscarriages, stillbirths, or neonatal deaths also undergo various feelings. These individuals confessed at a seminar or workshop that “I think mental care is necessary and want to do something, but do not know what to do,” “There is a woman who I have been concerned about even after her discharge, but I haven’t gotten in touch with her,” “A baby in my charge passed away. I felt very sad and did not know what to say to the parents. I feel conflicted about just going about my daily work,” “I’m forced to work within an organization. I’m tired of trying to figure out how to gain understanding from the other staff members.” The answer for this question of what to do and how to provide grief care can be found in problems or conflicts that the medical staff members who actually work in such workplaces experience themselves. Medical staff members also have a difficult time accepting
the death of a baby. However, it is precisely because they themselves have felt various feelings of conflict or suffering that it is possible for them to provide useful grief care to their patients.

Because emotional counseling is an intangible concept, it can cause confusion and make it difficult to gain understanding from others. It is difficult to guess how the words or actions of staff can influence a patient from the patient’s response at that precise moment in time. However, sometimes one word or action by a staff member can become emotional support for a patient later on in life. As an example, I will briefly present some mothers’ stories about an event that occurred while they were in the hospital: “Shortly after delivery, a midwife brought my baby to me and let me hold it in my arms. She said, ‘You can meet your baby anytime, so feel free to call for me at any time.’” (miscarriage at 16 weeks of pregnancy), “They said many kind words to me, such as you don’t have to bear it all, you can have a good cry, or you can take medication if you need it. They were so kind to me... it almost made me feel even more pained. I couldn’t even say anything in return, I just kept crying. I appreciate their kindness, of course. All I have for them is gratitude.” (induced abortion at 19 weeks of pregnancy), “My midwife carefully listened to me, so I didn’t mind the facilities too much even though it was a shared room.” (natural miscarriage at 20 weeks of pregnancy) “I just recalled something that I’ve remembered all this time. I remember a medical intern stroking my shoulder gently, even during my ultrasonography in the last examination. Even when taking the baby to the dissection room, the intern seemed more in pain than me. I think that, the intern stroked my shoulders for such a long time because he/she wanted to be able to do something for me.” (induced abortion at 20 weeks of pregnancy), “At my health check one month after the fact, a midwife who I met almost for the first time asked me, ‘How is it going?’, and that made me realize that it was alright to talk about it” (neonatal death at 28 weeks of pregnancy). These stories indicate that the words or actions of staff members gave a sense of safety to the mothers upon knowing that there is a person who would warmly watch over their sadness and share in it, even though the mothers themselves cannot respond or do anything but cry at that time. Kawai says that “death is so great that it cannot be kept away merely through adult consideration.”

Death is so overwhelming that we cannot control it or escape from its deep sorrow. Probably the only thing that can be done under such situations is to treat the deceased baby as “a precious, one and only individual” and share honest emotions with the parents, rather than keeping the death at a distance or bottling up the sadness or suffering.

On the other hand, there are also negative remarks as follows: “I cannot forget that I heard a sound, a clanging, when the baby was born. The sound still remains in my head, going round and round. I couldn’t ask to see the baby or even ask whether it was a boy or girl. On the last day, I gathered the courage to ask a midwife if I could see the baby. She said, ‘Do you? It won’t be what you imagined it to look like.’ Those weren’t the words you would use to speak about a human being, but I couldn’t say anything, and I felt so disappointed with myself. She brought the baby to me in one hand. My breasts started to ache and my breast milk was flowing, but the
nurse only said ‘Oh, it’ll be OK.’ When I left the hospital, they didn’t give me any information or explanations about my future, except for a piece of paper. What? I told them, ‘I’m leaving the hospital, what about my baby?’ They said ‘Professionals of cremation will take care of the rest.’ I really regret that I couldn’t do anything. They haven’t contacted me after that, except for sending me a piece of paper that looked like a certificate” (induced abortion at 17 weeks of pregnancy). Another mother said: “The staff’s way of working looked like an assembly line at a plant… They probably didn’t know what to say, but it was very businesslike, so there was no atmosphere to ask them to listen to me” (neonatal death at 39 weeks of pregnancy), and “All the clinical psychologist who came to me did was talk about chromosomal abnormality or the parents’ association, even though my doctor had never mentioned anything about these things. I was really annoyed with the psychologist because it was a one-way conversation rather than being listened to or responding to my sense of suffering” (induced abortion at 17 weeks of pregnancy).

Parents who can cry loudly and complain about insomnia or hardships in front of medical staff after losing their baby are likely easier to support on the part of said staff. However, regarding parents who do not cry, say “I’m alright,” or are seemingly fine, staff often evaluate them as being “returned to a relaxed state of mind.” Certainly, some of them may have returned to this relaxed state, but some of them, after leaving the hospital, visit counselors to complain about their suffering, saying “I thought I should not cry” or “I didn’t want to trouble the staff.” Also, in another case, after seeing a mother crying loudly and becoming incredibly upset upon hearing words of comfort from a medical staff member, the rest of the staff felt that she should be left alone and not be triggered foolhardily, after she finally calmed down. However, it is cases like these that require attention. Providing care does not always mean that parents will not undergo strong grief. On the contrary, providing care sometimes encourages this grief to be expressed on a far greater level than we expect. It can be said that grief is deepened through care processes like this, and that the parents can eventually accept this sense of sorrow over time. It is necessary for medical staff involved in grief care to understand this process.

4. Conclusion

It has been pointed out that there are two perspectives for care during the perinatal period: “physical care” and “emotional care.” From the perspective of physical care, medical staff can provide their patient with precise information and objective facts, letting them obtain a feeling of security based on scientific and medical knowledge. Meanwhile, from the perspective of emotional care, subjective facts are often considered as more valuable than objective facts or information, and psychological support is required depending on the condition of the patient. Both perspectives of the affected party and the staff are held and can be said to be important as well as necessary without viewing it as a matter of which one is more important or superior to
the other. It is important to provide care while recognizing that both the staff and the patient have
their own perspectives in both categories, even though they are in different positions.

As Hashimoto\(^6\) says, “We have no choice other than to continue care focusing on the ‘here
and now’, while paying close attention to family members who all have different stories of their
own.” This means that there is no way to standardize grief care during the perinatal period. A
manualized program or guideline for grief care may be created in the future. This will promise
a certain level of effectiveness in the sense that it will help medical staff prepare for providing
care. However, simply following what is written in the manual cannot be considered true care.
Care should be provided on the premise that the staff has understood the background or the
reason why these manuals were created, and, as much as possible, from the perspective of
emotional care. By coming to understand the real feelings or inner experiences of a family who
has lost its baby through direct communication, sympathetic feelings such as “what can I do for
her?” or “what are the right words to say?” are generated, and led to practice. Although this task
requires considerable preparation as well as inner strength, perhaps that is the kind of care that
is in great demand. To accept the overwhelming experience of a death, it is believed that it is
necessary for the entirety of the individual to work towards acceptance, rather than looking for
effectiveness through external operations. It is required that staff involved in care listen to each
parent and stay with them to share the pain of losing a baby, and staff members themselves
should think about their own feelings. That will serve as a foundation for providing care.

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