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## THE ROLE OF A DOULA DURING THE PROCESS OF PERINATAL LOSS IN THE U.S.

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### Abstract

Throughout the history, the approach to childbearing has been changing. It is also the same for miscarriage/stillbirth. In agricultural society, there were certain support systems for mothers who experienced miscarriage/stillbirth. However, in the current society mothers who lost baby over miscarriage/stillbirth tend to be out of support system. This can be a result of medicalization of pregnancy and value of individualism.

The purpose of this paper is to describe the role of doula in the U.S.. Doula is a certified assistant for pregnant women, although doula is not considered as medical staffs such as physician, midwife, nor nurse. Doula provides emotional and physical support for women and their family members. Although the number of doula is still limited, their role is getting attention. In 2015, we interviewed two doula to understand their roles and functions in medicalized pregnancy in the U.S..

From the interview, we learned that there are 2 types of doula. One is the live birth doula, another one is the bereavement doula. In this report, we will talk about doula especially for perinatal loss. To be certified as a bereavement doula, they need to go through a multiple programs to fully understand medical, cultural, psychological aspects of pregnancy. Doula is usually appointed by pregnant woman who seeks emotional support in the process of pregnancy. Especially in the case of miscarriage/stillbirth, doula plays the important role to share the information with women on what they can do with their baby (e.g., taking pictures, creating cloth, writing a letter). Doula also assists women to communicate with medical staffs. By doing so, doula supports women to save from loneliness over the loss of their baby.

Doula is not well-known in Japan. Traditionally women go back to their parents' home for childbearing. Because female family members take a role of doula in Japan, the occupation of doula may not be necessary. However, the number of nuclear family is increasing and the life styles have been changing across different generation;

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the doula can play the important role to assist pregnant women and their family members in Japan.

Key words: the role of doula in the U.S.; perinatal loss

### **1. Meaning of deaths during the perinatal period**

As modernization progresses, individualization and individualism have been advancing in conjunction with the diversification of values, which greatly impact people in terms of their relationship with others and society. This trend can also be applied to childbearing. Childbearing is an universal event for human beings, but how it is practiced or the philosophy behind it varies depending on the era and/or culture. Arguing that approaches to childrearing change over time, Matsuoka (2014) presents the changing characteristics of childbearing along with the shifting the forms of industry. The pre-modern period was a society before industrialization wherein products were home-made, and childbearing was also considered under the category of customs or mutual assistance. The modern period was a society of industrialization and mass production. Childbearing was centralized at the hospitals and handled by medical staffs, as a result expectant mothers are treated as patients. In the society where information communication became dominant, the concept of personalization became popular. During this time, people are interested in what is known as “active birth,” where pregnant women voluntarily try to give birth on their own at their homes or in maternity centers with minimum medical intervention, instead of completely entrusting the process of childbearing at the hospital. As the backdrop for this trend, there was a mental shift towards placing to value of the individual pregnant woman’s choice. Recently, what has become controversial when discussing childbearing at home or at maternity center is the issue of safety. They say that the perinatal period has a high risk that one can get to die (Nishida, 1997). This is why medical workers invest strenuous efforts to continue challenging death during the perinatal period. Gradually, the fatality rate of expectant and nursing mothers and neonatal mortality rate have been decreasing, and the perinatal mortality rate in Japan has become lower in comparison to other countries in the world.

According to Matsuoka (2014), in pre-modern society, death during the perinatal period, such as miscarriage and stillbirth, was considered as an uncontrollable event. People may even said that miscarriage and stillbirth are the consequence of parents’ bad behaviors. She adds that “in modern society, hospitals are considered to be the safest place for childbearing and the medical paradigm is considered to be correct; any problem occurring in hospitals are treated as unpredictable accidents.” Moreover, Matsuoka (2014: p.67-68) discussed that in medicalized society childbearing are managed and evaluated from the perspective of risk-based action.” However, it is difficult to consider that people will able to manage and manipulate the birth.

Additionally, perinatal mortality such as artificial termination of pregnancy due to prenatal diagnosis has been arising in Japan as a topic of discussion. When considering that “categorizing childrearing based on historical periods, such as pre-industrialization and post-industrialization, has nothing to do with medical advancements or improvement of safety” (Matsuoka, 2014: p.68). There are differences between people who lived in the pre-modern society and those who live in the modern society with respect to the way they face and experience prenatal mortality. A factor that contributed to these differences could be the change in society where opportunities for people to feel the graphic reality of life in death have decreased, and another could be the development in ultrasonic echo technology that displays fetuses in the mother’s womb, which was not possible in the past.

A reduction in the number of children born as well as individualism seems also to be involved in these changes. In the pre-modern society, there were functions in communities which supported the expectant and nursing mothers and their families who experience perinatal loss. With respect to Japan, for example, a group of women, sometimes in a community like a sorority, would console each other regarding their experiences with perinatal loss. In other cases, women would bury their child who they lost through miscarriage or stillbirth by putting them in a burial jar, or women would put the dead body of their child back in a burial jar as a symbolic gesture of putting them back in their mother’s womb to pray for their rebirth (Hirukawa, 2010).

In the societal rules written in the, “Engi Shiki,” which was compiled according to the order of Emperor Daigo during the mid-Heian era, and also in the encyclopedia “Shugaisho” which was compiled in the period of the Northern and Southern Dynasties, a categorized confinement period after miscarriage is prescribed. In the Hachiman Usagu Bukkiryo (a confinement order) in 1235, confinement periods related to childbearing were prescribed. The statement “fearful deference comes from the human heart” was written after the description of the period of confinement after birth had been set forth, and it is notable in that this statement emphasizes spiritual aspects. When considering the denotation of these spiritual aspects, these orders seem not only to be a way for people to evade blood or death, but also to consider the physical and mental condition of the woman who experienced childbearing or miscarriage by keeping them away from the outside world (Sugao, 2013). This was not a system to isolate the woman, but was a function for the community as a whole to address perinatal loss so that the parents or the family that experienced the loss were supported psychologically.

Today, the traditional courtesy and wisdom for stabilizing a woman’s physical and psychological condition during childbearing has become neglected, and since childbearing has become incorporated in medical exercises in particular, interest in the mother and child’s mental health during perinatal care has heightened in various countries. In this context, those who will become directly involved in perinatal loss are not people in the community who live close to expectant and nursing mothers like in the pre-modern period, but medical staffs such as doctors, midwives, nurses, and other co-medical individuals. Additionally, doulas, who are active

professionals in the United States and Europe including the U.K. and Germany, can be one of those who are directly involved in the process of childrearing. Doulas play a supportive role for expectant and nursing mothers at the time of their childbearing, but research showed that there are doulas who work exclusively for perinatal loss. This paper will focus on doulas who work exclusively for perinatal loss. Furthermore, we summarize the interviews that we conducted with doula regarding the following questions (1) what kinds of support are available for expectant and nursing mothers? and, (2) what are the roles of doula?

## **2. Definition and current status of perinatal loss**

Prior to discussion of how doulas get involved with mothers during the period of perinatal loss, some of the terminology used in this paper should be clearly defined and the current status of Japan should be explained. Perinatal loss is literally the experience of loss during the perinatal period. In a broader scope, whatever experiences a woman has during the perinatal period, such as changes and disappearances that occur to the pre-childbearing-self or relationships that the women had before their pregnancy can be, in a sense, considered an experience of loss. However, in a narrower scope, it can refer to death of child during the perinatal period. This paper uses the term perinatal loss exclusively in cases of fetus deaths or the death of a newborn baby due to circumstances such as miscarriage, stillbirth (including artificial termination of pregnancy), and neonatal death.

Additionally, in the 10th edition of the International Statistical Classification of Diseases and Related Health Problems (ICD-10), the perinatal period is defined as the period between the 22nd week into a woman's pregnancy until the days after giving a birth. However, Hashimoto (2006, p. 732) stated that the "perinatal period of the mind commences on the day the woman finds out about her pregnancy," and continued that this period should be considered to start at the early period of pregnancy and last for a while after birth, without restricting it as prescribed in the ICD-10 (the period between the 22nd week into a woman's pregnancy and before the 7th completed day after birth). Furthermore, medical services conducted before and after the perinatal period determined by the ICD-10 is also referred to as perinatal care. Despite the fact that pregnancy and childbearing are not considered to be illnesses, there is a risk for mothers, fetuses, and newborn babies to face death from complications, as well as asphyxia for the newborn during this period. In order to prepare for such sporadic incidents of emergency, a comprehensive and consistent system of obstetrics and pediatrics are necessary. This is why, in recent years, some clinical departments that cover a broader field including care for mothers, fetuses, and newborn babies, as well children who are past the newborn stage, under the name of prenatal centers. The Ministry of Health, Labour and Welfare (MHLW)'s prenatal care system policy also prescribed in 2010 that clinical psychologists must be stationed in general perinatal Mother and Child medical centers or regional perinatal Mother and Child medical centers.

According to this, it is clear that the perinatal period requires not only physical but also psychological support. Although clinical psychology engineers are rarely stationed in suburban areas, mental and physical transitions do happen through the pregnancy period, and transitions in the mothers' self-identities, as well as the self-identities of her partner, the father of the child, will result in a reconstruction of new identities with respect to various relationships. In some cases, this process gets confused or complicated by the event of perinatal loss. Specifically speaking, if a mother and father lose their child in ways such as miscarriage or stillbirth, their experiences tend to be easily hidden and treated as something that did not happen. Though they cannot be handled in the same way as miscarriages and stillbirths because of factors such as age and circumstance, neonatal deaths also tend to be treated as taboos.

According to Nubo et al. (2000) and the Japan Association of Obstetricians and Gynecologists (1997), miscarriages comprised 10–20% of all pregnancies. The MHLW's statistics show that there were 23,524 stillbirths in 2014: 10,905 of them were natural fetal deaths and 12,619 of them were artificial fetal deaths. It is worth noting that artificial fetal deaths outnumber natural fetal deaths. The reason for this circumstance can be attributed to the accuracy of prenatal diagnosis through advancing medical technologies, etc.

### **3. Role and significance of doulas**

#### *3-1. Who are doulas?*

Doulas are attendants that are experienced in childbirths and who provide psychological and physical support to the parturient woman and her partner throughout the pregnancy (Klaus et al., 2002/2006). Doulas have been established as an occupation in the United States. Because doulas are not on duty at obstetric clinics but rather are individuals who provide independent services or individuals who belong to associations which dispatch doulas (Sugao, 2016), they assist the expectant and nursing mother upon request from her or her family. Medical staffs allow doulas to come into the birthing room as well as other parts of the clinic at the expectant and nursing mother's request. Researchers reported positive medical impacts including reduction of the use of medicine such as painkillers or ecboic, and decrease in the frequency of caesarean sections when a doula was present with the expectant and nursing mother at the time of childbirth (Scott et al., 1999). The presence of doula also encourage to shorten the time of childbirth (Kennell et al., 1991). Other research shows that marital relationships can be improved after childbirth when couples receive support from doula even if this improvement is not with respect to medical effectiveness (Klaus et al., 1993/1996).

#### *3-2. Interview survey*

We conducted two interviews in the mid-western areas of the United States, in February 2015. Interviews were approximately one hour each. The interview was recorded and transcribed into

a form of a script with the approval of the cooperators. The following is the summary of the interviews.

### **(1) Types of doulas**

In order to become a doula, it is absolutely necessary to be certified by an accreditation body, such as DONA international. There are many criterias to achieve to be certified as a doula: reading theses, writing reports on practical lessons, and attending childbirths and receiving evaluations from the mother, the doctor, the midwife, and the nurses. Since doulas are, as explained above, women who have the role of being with and supporting mothers over a certain period of time, there might be a general idea of doulas as a person who provides support right before and soon after the childbirth. However, our interviews revealed that there are different types of doulas. First, doulas can be categorized into Live birth doulas and Bereavement doulas. The former's job is to stay with mothers before and after the child birth to provide support. Live birth doulas can also be subcategorized into Pre-birth doula, Actual birth doula, and Postpartum doula, depending on which phase of the pregnancy process they provide support for. Needless to say, during the course of the pregnancy, unforeseen miscarriage or stillbirth might occur.

Doulas also provide support as the situation calls for it. On the other hand, Bereavement doulas also have experience attending live births during the accreditation process, they also receive special training on how to handle death. In the United States, some accreditation bodies such as Loss Doulas International (LDI) and Still Birth Day exist, which specialize in training Bereavement doulas. All of these accreditation bodies have drawn up almost identical curriculums, and prospective doulas are required to complete a series of courses. These courses consist primarily of reading documents on specific cases, watching visual records, and taking clinical classes and exams. The following are examples of possible questions that are asked: what could happen during the development phase? What should you be ready for during this phase? What are things you must be aware of to save a person who experienced either a miscarriage or a stillbirth? How should you handle a woman who must face the reality of a limited lifespan? The targets for Bereavement doulas are mothers who are going through the following three circumstances: miscarriage by 20 weeks of pregnancy (or occasionally 24 weeks), stillbirth by 20 to 24 weeks or up to 40 weeks of pregnancy, and the death of an infant after the childbirth with 40 weeks or later pregnancy until a year later. Doulas call the mother who they are assigned to a "client," not a "patient." This is likely because, much like clinical psychologists, the target is first and foremost regarded as a mother, not a patient.

Two doulas who participated for this interview were specialized as a Live birth doula and Bereavement doula. The job frequency seems to vary depending on the doula, but according to the Live birth doula that we interviewed, she usually meets 2 to 3 clients a month, though she could meet up to four times per month. The reason is because being a doula is strenuous work and consumes a considerable amount of mental and physical energy. It takes about 24 to 48 hours to restore one's energy after completing work for one client. In other words, exhausted



energy must be recharged to prepare for the next client. The time of childbearing differs from client by client, and lingering cases can take days. On top of this, childbearing means something different from person to person; how to live one's life until childbirth or what to feel about the experience differs from individual to individual.

A doula can meet with 100 different clients, and they would experience 100 different cases of childbirth. Doulas are present for each one of these cases and approach each one with extreme care. Even for deliveries which are expected to be easy, doulas must be unceasingly attentive to each individual detail. It is not difficult to imagine how much mental and physical energy is consumed during this time. The other cooperator, the Bereavement doula, said that she handles one client or so a month. The reason for this is that miscarriages and stillbirths are outnumbered by regular childbirth; however, the other reason is that the work of a Bereavement doula must consume a huge amount of energy because these doulas must not only directly face generally so-called negative emotions such as grief and anger, but must also try to work alongside these emotions without negating or avoiding them. Considering that there is no framework for doulas similar to counseling which is provided by a certified clinical psychologist, and considering that there is no work shift like those applied to midwives, nurses, and doctors for doulas either, it seems natural for the monthly number of clients that a doula takes on to be limited.

## **(2) Involvement of Bereavement doulas and non-medical staffs**

During the interview, the Bereavement doula described mothers who have experienced perinatal losses as follows: “Since people consider [miscarriages or stillbirths] as taboo, these women do not ask outsiders for help. They believe that they are not eligible, or do not need help. These mothers did not receive support from doulas at the time of childbirth.—(omitted)—Getting over the experience [of perinatal loss] is important. These mothers should talk about their experiences with someone, and know that it is ok to talk about it. Grieving and feeling sorrow is not a bad thing. I think there is a tendency in the States to think that the death of baby is shameful, and that these experiences should be buried in oblivion, and should not talk about.” As mentioned above, the tendency in the States to treat miscarriages and stillbirths as something that did not happen and something to forget about as soon as possible is shared in Japan as well. A Bereavement doula listens to and accepts these tabooed experiences.

As the doulas stated in our interview, they “[doulas] have a totally different point of view from medical experts, and that is important.” Doulas are differentiated from medical staffs such as doctors, midwives, and nurses, all of whom are involved in medical intervention. Medical staffs are asked to provide medical intervention for the purpose of the mother and child's safety, but doulas are asked to stay by the expectant and nursing mothers' sides to provide emotional support. This does not mean that doulas and these other occupations are on opposing sides, but rather that one end of the spectrum fulfills its own role so that the other side of the spectrum can do the same.

Furthermore, the doula claimed that “another reason for me [a doula] to be in hospitals is to



help nurses and doctors.” Perinatal loss, is a painful and mentally strenuous experience that medical staffs, not to mention the mother and her family, go through. As a comment on medical staffs who grapple with life and death every day, the doula said that “though they may not experience death every single day, there are bound to be some times when they can’t help but cry. I am there for occasions like these.” Aside from making efforts to maintain good relationships with medical staffs and cooperating with them, doulas attempt to pay close attention to everyone involved in the situation surrounding the mother. In the U.S., this aforementioned attempt by not only medical staffs but also non-medical agents to support to the individual experiencing perinatal loss is conducted in a way that suits.

In cases where miscarriages or stillbirths are acknowledged in advance and there is time before they happen, forms and checklists are used to hear the mother’s wishes and share them. Preparations can be made ahead in cases like these, but cases like these where information can be obtained in advance are rare. Most cases do not allow time to prepare, so doulas must address the situation after the miscarriage or stillbirth. Table 1 as follows is a list of example questions that mothers are asked with respect to stillbirths, as obtained during this interview.

Some of above questions are occasionally asked in Japan primarily by midwives or nurses. Medical staffs engaged in clinical duties in institutes felt the need to provide psychological care for perinatal loss and have tailored their responses, which were developed through daily practices, for each institute. However, these practices are only conducted in hospitals in which grief care is proactively provided, and not applied to every miscarriage and stillbirth. The reality is that the type of service provided differs among institutes and staffs.

As a form of involvement of non-medical individuals in the U.S., there are professional photographers who take photos for particular situations such as stillbirths. They provide support for grief care as well. This group is called Now I Lay Me Down to Sleep, which was established in Denver as a certified organization of volunteer photographers. Photographers from this organization propose points to consider when a family in perinatal loss decides to take photos with the deceased baby, as well as how to pose for photos and even taking the photos for the

TABLE 1. Checklist of a mother’s wishes (for miscarriages), examples

Who do you want to be with you?
What kind of childbirth do you prefer, natural childbirth or caesarean section?
What have you been told from your doctor? (e.g.: It will possibly be a caesarean section.)
Who do you want to be with you in the case above?
Would you like to take a photo?
Would you like to hire a professional photographer to take a special photo in case of a stillbirth?
Do you want to meet your baby after birth?
Do you want to take a handprint or footprint?
Do you want to have a funeral hall be arranged?
Is there anything you would like us to do?

families. Photos are usually in black and white; color photos are rarely taken. After modifying the photos taken as necessary, they are given to the family who lost baby. If the parents ask for it, photo data is given to them in a CD.

Right after perinatal loss, people experience various emotions which they need to cope with. Due to fear, hardship, or other complicated emotions and situations, some families refuse to or cannot bear to hold or come face-to-face with their own baby after the birth. There are many parents who are unable to even look at a picture of their own lost child. In cases of late miscarriage or stillbirths, the baby must be buried, which makes the time to be together with the baby. Meeting, holding, or taking photos of the baby are not always the desirable courses of action. The request from the party concerned should be prioritized, but it is true that some express regrets afterwards, such as “I should have stayed longer,” or “I should have taken photos.” If the data is given to the family, it is not necessary for them to look at it right away, and it is possible to store the data until one is ready to look at them.

The doula who participated in this interview said that “some parents make a hard copy of the data to post on their wall,” which is similar to what we heard in a survey which targeted mothers in Japan who had experienced perinatal loss. The photographers belonging to this organization receive counseling as necessary and are trained in appropriate issues. Furthermore, this organization holds an event called the Remembrance Walk for parents or families who experienced perinatal loss, and provides opportunities for parties concerned to remember their baby and share their feelings even after time has passed since being discharged from hospitals.

### **(3) Things that Bereavement doulas are asked for**

In our interviews, we asked “what do people expect from you?” The answer was that “they [the mothers] want to make sure that they are not alone.” As an example, once in a while when counting the number of their children, a parent who has experienced perinatal loss includes the baby who lost due to miscarriage or stillbirth. They wonder why they unconsciously count the baby knowing that the baby doesn’t exist. While they can’t help but think that “I do this because I must be crazy,” they also have an urge to ask anyone around them “how do I seem to you?” or “why do I...” in order to make sure that “thinking the way they think is not strange.” Under such states of mind, being told that “the body instinctively feels that there should be a third child; there is no reason for it. There is no reason for you to think that you should not count the third child. There is absolutely nothing wrong with you,” or that “you are not crazy” can confirm, for the mother, that there is someone who understands them. Then, obtaining the sense of security that they are not on their own can provide them with distance from a sense of solitude. We believe that mothers obtain this sense of security by receiving acknowledgment of their lost child’s existence.

When facing perinatal loss, mothers suffer from a significant emotional shock resulting in a state of confusion without knowing what to do. In order to “drag them out” of the situation, backup support is necessary. The doula stated that “they [mothers] are restless and fall into negative thoughts, but giving them a hand in making memories with their baby, as well as

sparing time for mothers to spend with their baby and take pictures together can help them. People tend to forget, but actions like these soothe them.” Mothers felt warmth as long as she had time to spend with her lost child, and the experience of having done something for her child as a parent can support her. When people are overtaken by overwhelming circumstances, it is important for them to feel some sense of independent accomplishment in order to heal. When these accomplishment happen, “what happened becomes less harsh for them” despite their sorrow still being deep.

#### **4. Conclusion**

A doula’s job in the U.S. is to provide services that hospitals do not provide. Doulas are not medical staffs, nor are they family members or friends. Doulas, who are not exactly close with the mothers, are able to stay calm to address situation without getting too emotional. They are able to stay by the individual’s side as someone who can handle situations while holding an unique relational position. The concept of doulas has not permeated in Japan, one may infer from Japanese culture in which mothers go back to her parents’ home for childbearing, it is common for close kin such as the mother’s mother or sisters to lend a helping hand. Perhaps this is why post-birth doulas and similar occupations are still difficult to establish in Japan. However, there seems to be a possibility for the concept of doulas to take root as an option in Japan in the future, considering changing forms of family and people’s life styles with respect to perinatal loss. Of course, this does not mean that a doula can handle all cases of perinatal loss. A doula who we interviewed described the problem of perinatal loss as something “like an onion. Another layer waits beneath the first peeled-off layer. This continues forever. ” There are multiple types of care that can be provided specifically depending on the position that the individual occupies, such as care which can be provided by medical staffs, psychologists, the family, friends, and care which can only be provided to oneself by the individual concerned. These various types of care help to pull individuals out of their solitude, however minimally, and allow them to spend their precious time to cherish their deceased loved ones. Precisely because current society is information-oriented, differentiated, and individualized, having places where an individual can access multiple types of care is considered to be effective as a social system that supports situations involving deaths during the perinatal period.

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