Women's Needs related to Obstetric Services: Viewpoints of Mothers of Children with Disabilities in Japan

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Abstract

The overall aim of the present study was to investigate needs in obstetric services among mothers of children with disabilities in Japan. This paper reports on the results obtained midway through the survey, also identifying the needs of these mothers through free descriptions. Corporation with parents associations of children with disabilities throughout the Japan, self-administrated questionnaire has been distributed mothers of children with disabilities since January to March in 2016. The free descriptions obtained showed that the needs of these mothers could be divided into three: needs for diagnosis and information about disabilities, needs for networks and hope, and needs for sensitivity through words and deeds. I suggested that medical staff providing obstetric services give adequate information about possible disability; act as mediators, introducing mothers to counselors, peer groups, and social support; avoid insensitive words and deeds; and use positive terms when talking to these mothers.

Introduction

The experiences of pregnancy and childbirth are considered important events in a woman's life. Especially, memories related to pregnancy and childbirth may be painful to some mothers of children with disabilities. I previously interviewed mothers of children with disabilities in Japan, and found that most of them had had unpleasant experiences at obstetrics and gynecology hospitals, and long-term difficulties with forgetting such memories (Kimura, 2012; Kimura & Yamazaki, 2013). In addition, low levels of maternal satisfaction with childbirth were related to high levels of psychological distress (Sato, Kato, Ito, Gu, & Kakee, 2008) and a higher postpartum stress response (Sekizuka, 2005). Therefore, there is a need for the provision of adequate obstetric services that meet women's needs. To facilitate this, it is important to identify women's needs and consider practical implications of obstetric services. The overall aim of the present study was to investigate the obstetric-service-related needs of mothers of children with disabilities in Japan. Midway through this survey, I present a report mainly focusing on the extracted needs of the mothers, based on free descriptions.

Methods

In cooperation with several parents' associations of children with disabilities throughout Japan, self-administrated questionnaires started being distributed to mothers of children with disabilities from January to March in 2016.

Ethical considerations

This study was approved by the review board of St. Marianna University School of Medicine.

Results

As of March 15, 2016, 798 questionnaires had been returned, and 265 of these were filled with free descriptions. Most mothers wrote about severe childbirth experiences and troubling issues with the diagnosis of their children, but some mothers expressed positive feelings concerning their relationships with the obstetric services medical staff. In particular, when an infant's disability can be detected during the early stages of pregnancy or delivery, the words and deeds of medical professionals strongly affect the psychological well-being of mothers of children with disabilities. These mothers' needs were identified and were divided into three categories, namely, needs for diagnosis and information about disabilities, needs for networks and hope, and needs for sensitivity through words and deeds.

Needs for diagnosis and information about disabilities

> *After the delivery, I suspected ... my baby would have Down syndrome. The doctor did not say anything about the disability, and I ... couldn't ask him..., because I was scared ... he would say "yes." I had a hard time and couldn't stop my tears. If the doctor explained ... the possibility of the disability well, I could have expressed my feelings and calmed down.*
> *(#70 Mother of child with Down syndrome)*

> *Just after the birth, I noticed my baby's disability. I asked the doctor, but I could not get any answer. (#61 Mother of child with Down syndrome)*

These are typical claims mothers of children with Down syndrome make. These mothers needed certain explanations of the disabilities, but they could not get them. Thus, they considered their obstetricians to be intentionally hiding information about their infants' disabilities. However, although infants with Down syndrome have some distinguishing characteristics, most obstetricians might hesitate to talk about the possibility of disability because genetic testing takes some time to complete. In addition, definitive diagnosis is the role of pediatricians in Japan.

On the other hand, some mothers do learn of their infants' diagnoses at an early stage.

> *Just after the birth, the doctor let me know of my baby's disability. But the doctor did not explain about my baby's condition, how to raise such a baby, [or even] what ... Down syndrome is. Thus, I was anxious during my hospitalization.*
> *(#23 Mother of child with Down syndrome)*

This description illustrated how even mothers who receive diagnosis experience increased anxiety in response to a lack of information and support. Therefore, it is important to provide not only a diagnosis, but also related information.

Needs for networks and hope

> *When I was 8 months pregnant, I received amniocentesis and was shocked that my baby had Down syndrome. But I felt relieved a little bit, because the pent-up feelings in my mind were lessened. I collected information about the disability and ... prayed for the birth. The nurse and the doctor told me that disability was one of the characteristics of babies and Down syndrome babies were very cute, and there were various sources of support available. I was really lucky.*
> *(#16 Mother of child with Down syndrome)*

> *I believe it is important for doctors and medical staff to try to understand our sadness and encourage us by saying ... there must be a ray of hope. Whether such mothers and their families are able to have hope ... depends on the doctor.*
> *(#85 Mother of child with Down syndrome)*

> *I was very happy because the doctor introduced me to the counseling system, and I could receive counseling once a week. In addition, since the doctor called the leader of the parents association for disabled children, the leader came to my house and listened to my story.*
> *(#44 Mother of child with Down syndrome/West syndrome)*

These descriptions used positive words such as "lucky" and "happy" and clearly presented how obstetric services medical staff can support mothers who are in the depths of grief following the diagnosis of their babies.

Needs for sensitivity of words and deeds

> *I was convinced of the disability of my baby because of the doctor's/nurse's attitudes. They didn't want to care for my baby. I felt that I delivered an unpleasant baby.*
> *(# 18 Mother of child with Down syndrome)*
>
> *Since my breast nipples were dented, breastfeeding was a very hard task for me. My doctor said to me, "Your nipples will never be able to play the role of breastfeeding." I was so shocked, and I can't forget it.*
> *(#92 Mother of child with autism spectrum disorder)*

The above comments expressed how the words and deeds of the medical staff transmit negative messages to these mothers. Although such words and deeds were unintentional, the mothers might have felt that they were denying the infant's existence or the mother's own motherhood. Thus, obstetric services medical staff need to be sensitive in their communication and interactions with mothers and infants.

Conclusion

I conclude that women's needs (especially those of mothers of children with disabilities) related to obstetric services offered in Japan are as follows:

1. **To obtain certain information about an infant's disability as soon as possible following the delivery.**
   To do this, it will be necessary for obstetric services medical staff to provide mothers with adequate information about the possible disability, explain the roles of specialists (e.g., the obstetricians and pediatricians), and offer advice for ensuring optimal mother-child conditions and interactions.

2. **To obtain support networks and hope.**
   To do this, obstetric services medical staff will need to act as mediators, introducing mothers to counselors, peer groups, and social support. In addition, it is strongly recommended that staff members use positive words when talking to these mothers.

3. **For their medical providers to avoid insensitive words and deeds.**
   To do this, obstetric services medical staff members need to understand mothers' difficulties and feelings, and they should be conscious of the effects their own words and deeds may have on such mothers.

Since this report was written midway through the survey, I am unable to show details of all important free descriptions and their analyses. In the future, I will perform content analyses of this survey and explore how obstetric services both positively and negatively influence the psychological well-being of mothers who have children with disabilities.

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