INTERNATIONAL JOURNAL OF NURSING KNOWLEDGE
The Official Journal of NANDA International, Inc.

Emotional Reactions of Mothers Diagnosed With Down Syndrome Baby

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Search terms:
Amniocentesis, Down syndrome, nursing, qualitative research, Turkey

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Conflict of interest: The authors declare no conflict of interest.
Funding: This study was supported by the Research Fund of Karamanoglu Mehmetbey University. Project No.43-M-12.

PURPOSE: The aim of this study was to explore a deeper insight into experiences of Turkish mothers living with/diagnosed with Down syndrome (DS) baby.
METHODS: Individual and audiotaped interviews were carried out with 11 women after amniocentesis in Karaman city of Turkey between August 2012 and February 2013. Transcribed semistructured interviews were qualitatively and analyzed using a thematic analysis approach to code and categorize emerging themes.
RESULTS: Three principal themes emerged from the study: mothers' emotional reaction after diagnosed DS, mother and healthcare professional interactions, and mother's coping with diagnosed DS.
CONCLUSIONS: Understanding the experiences of women living with/diagnosed with DS baby enables nurses to devise appropriate strategies to provide better support at every stage and thus helping them to cope with daily life.
AMAÇ: Bu çalışmanın amacı gebeliğinde Down sendromu tanısı konmuş kadınların derin bir bakışla deneyimlerini saptamaktır.
YÖNTEM: Çalışma Karaman'da Ağustos 2012 ve Şubat 2013 tarihleri arasında yapılmıştır. Yarı yapılandırılmış görüşme formu ile kişiye özel ses kayıtları alınarak yapılan çalışmada tematik analiz kullanılarak veriler kodlanmış ve kategorize edilmiştir.
BULGULAR: Çalışma sonunda sptanan temalar: tanı sonrası kadınların duygusal durumları, anne- sağlık personeli ilişkisi, tanı sonrası başetme yollarıdır.
SONUÇLAR: Kadınların hislerini anlamak, bu sürecin her aşamasında hemşirelerin daha iyi destek vermek için uygun stratejileri geliştirmelerini sağlayarak, onların günlük yaşamlarını kolaylaştırılabilir.

Introduction

Although a number of methods are currently available to detect chromosomal congenital malformations, amniocentesis is one of the oldest invasive methods of fetal evaluation. Amniocentesis is used to obtain amniotic fluid for the diagnosis of variety of disorders through enzymatic analysis and DNA testing. The test has a much lower false positive rate than the screening tests; therefore, they are more reliable in establishing the diagnosis of Down syndrome (DS) (Littleton-Gibbs & Engebretson, 2002).

DS is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21. DS is the most common aneuploidy compatible with development to full term with a reasonable quality of postnatal life. Physical and mental abnormalities vary enormously in spectrum. Mean intelligence quotient is 50 (70 and below is defined as the cutoff for intellectual disability), with a range 25–75 (Lozano, 2012). In spite of medical developments, life expectancy is still shortened, with 22% dying in the first decade, mostly from heterogenic malignancies and cardiac defect (Littleton-Gibbs & Engebretson, 2002). Approximately 1 of every 800–1,000 live births has DS, and this prevalence rate is known to be similar in all racial groups (Skotko & Bedia, 2005). In Turkey, there is no full record.

Numerous studies have been conducted to examine factors that influence pregnant women's decision-making processes (Choi, Riper, & Thoyre, 2012; Park & Mathews, 2009; Reid, Sinclair, Barr, Dobbs, & Crealey, 2009), and their knowledge (Etchegary et al., 2008; Hwa, Huang, Hsieh, & Chow, 2010) and/or attitudes toward prenatal screening (Seror & Ville, 2009) and testing (Brajenovic-Milic et al., 2008). On the other hand, very little is known about women's emotional status and decision making following a prenatal diagnosis of DS. The research has addressed emotions and experiences of mothers living with/diagnosed with DS baby after amniocentesis in Turkey. In this article, we designed a qualitative, face-to-face interview-based study. We believe that better understanding of these emo-

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tional reactions of mothers could contribute to improving nursing support and developing nursing care strategies.

Methods

In our study, performed using in-depth interviews, we used a semistructured questionnaire as the most appropriate research tool. A qualitative descriptive approach is considered ideal when the information is limited on a topic because the aim is to provide rich description of the phenomena in the study. The target in qualitative approach is to obtain the understanding of experiences from the perspective of participants rather than the generalization of findings (Yildirim & Simsek, 2011). In the light of literature, we aimed to explore a deeper insight into the experiences of Turkish mothers living with/diagnosed with DS baby via a qualitative approach.

Sampling

The selected study sample was based on the following inclusion criteria: being agreed to participate in the study, having no difficulty in communication, and presence of a diagnosis of DS after amniocentesis. In our hospital, after receipt of the amniocentesis results, families are informed by telephone, and it is ensured that families have their test results generally within 1 week. The attending doctor informs the women about the results of amniocentesis. After this process, the participants have been invited by the third researcher to the clinic within 2 weeks by the phone and been informed about the purpose of the study. Twelve women diagnosed with DS were selected to undergo an in-depth interview about their emotions. Of 12 women, one rejected to participate in the study. Accordingly, the study group consisted of 11 women.

Ethical Considerations

The study was approved by the Ethics Committee of the Faculty of Medicine of Selcuk University. Both verbal and written informed consents were obtained from the study participants. The study was approved by the Ethics Committee of Selçuk University Faculty of Medicine (Issue Date: January 11, 2012; Number: 287). Official permission was obtained from an Obstetrics and Gynecology Clinic in Karaman to conduct the study. All participants were informed about the fact that the interview would be taped and transcribed, and their names would be kept confidential before collecting data.

Data Collection

Semistructured interviews were employed in a private room to collect face-to-face in-depth data. A review of the relevant literature was performed before the interview, and a semistructured interview form was developed in accordance with the literature (Askelsdóttir, Conroy, & Rempel, 2008; Dinç & Terzioğlu, 2006; Sahin & Gungor, 2008; Sandelowski & Barroso, 2005). Face-to-face interviews used an open-ended introductory question: "Can you explore deeply: 'Please tell me about your amniocentesis experience?' " "How did you feel when you first realized your baby had problem?" "How was your relationship with health professionals during this process?" "What is your plan after now?" "What major factors affected your decision to continue/to end the pregnancy?" These questions were used to encourage deeper exploration of these issues. Each interview lasted approximately for 25–35 min. Medical terminology was avoided as much as possible in order to communicate with a common language and to avoid possible confusions. The methods of tape recording and taking notes were used for data collection during the interviews. Interview was terminated when data that had been close to the results were obtained.

Data Analysis

Comments recorded were first transcribed and analyzed via a thematic analysis approach suggested by Yildirim and Simsek (2011). Widely used in scientific research, thematic analysis aims to systematically organize and report key elements of participants' accounts across an entire data set into transcribing, comprehending, synthesizing, and forming themes (Kumbetoglu, 2008; Sonmez & Alacapinar, 2011; Yildirim & Simsek, 2011). The target is to provide with a rich and detailed account of reflecting the experiences of participants in the study. An initial thematic analysis of participants' primary experiences were described, organized, and then interpreted from their perspectives (Boyatzis, 1998). Interviews were audio recorded, transcribed verbatim, and analyzed concurrently with the process of conducting interviews. Descriptive categories were constructed according to data-coding processes where initial categories were identified and summarized. Additional coding developed as other meaningful categories were recognized and traced across interviews. This process was undertaken by the team who discussed the themes and elaborated categories. The content and meanings of these categories were illustrated by quotes extracted from the interviews to preserve the personal perspectives, a crucial aspect of thematic analysis (Boyatzis, 1998). Finally, to guarantee the rigor of the data analysis, each interview was verbally summarized for the participants to validate the researchers' primary interpretation. Of total 11 interviews, the ninth interview indicated completeness and convergence of data with no evidence of new themes emerging. The analysis of two further interview transcripts supported our existing categories and revealed no new emerging themes, confirming that data convergence was reached.

Results

The minimum and maximum age levels ranged from 33 to 44 months, and the pregnancy week was between 15 and 20 weeks. Among these participants, the average number of pregnancies was 3.09 ± 1.38; the average number of abortions was 0.45 ± 0.93. The demographic characteristics of participants are presented in Table 1. The main and subthemes after doing analyses have been summarized in Table 2. The responses from women have been stated as in the following.

Mothers' Emotional Reaction After Diagnosed DS

According to the expressions of the participants, after designated with DS, intense fear, anxiety, and guilt have occurred. Except guilt, the women felt them in close relationship. The intensity of these feelings could also change before or after amniocentesis.

About the feelings before amniocentesis one participant (35 years old, 20 weeks of gestation) mentioned that: "The doctor gave us one week time for our decision after he recommended amniocentesis following the results of triple test. People around me said that the baby's heart could suddenly stop during amniocentesis and the baby could die. This scared me. It was a tough decision for us. Even so, I decided to have the test. I was in doubt if I made a wrong decision. I didn't have a sleep for one week and asked myself 'can such thing happen?' I felt nervous all the time."

During the waiting time for amniocentesis, a participant explained their feelings as follows: A 38-year-old participant at 20th week of gestation said that: "It was very very stressful while waiting for the amniocentesis results. Something was wrong in double and triple tests. Waiting is as much as stressful as the negative results. My husband has relatives with Down syndrome. But I don't even think about curettage. I can't stand any more losing my baby."

Another participant (33 years old, 16 weeks of gestation) said that: "It is very hard to wait for amniocentesis results. I felt like dying. I counted the days. It was very, very stressful. I wish I had never got it done."

When she first heard the result of amniocentesis, one participant (34 years old, 18 weeks of gestation) said that: "I was shocked for a moment when I first heard the result. I already have another child with genetic disorders. I am going to face same problems. I am so sad, how I can cope with all these."

Another participant (35 years old, 20 weeks of gestation) said cryingly: "It was said that the risk of Down syndrome is high. Where am I going to now? I feel like that I have nothing to do."

One participant (38 years old, 20 weeks of gestation) said that: "I was afraid of an unfavorable result. I was scared when I first heard. It is scary to expect a child with Down syndrome. I wonder what it looks like. Is the face of my baby scary? Is anyone going to be scared when looking at my baby? How can I help my baby?"

All of the participants were anxious and desperate. A participant (36 years old, 15 weeks of gestation) expressed the following: "My first baby. . . Hope to have a normal baby, cries normally, reacts normally, walks, goes to school and becomes successful. . . In other words, everything begins with dreams about the baby. But, I know my baby will not be totally normal due to this disorder. I know my baby will be mentally disordered and will have an average 30 years of lifespan. I can't stop thinking that my child will die before me. They don't live so long. I feel terrible when I think of such things."

Another participant (33 years old, 20 weeks of gestation) said that: "I can look after this baby as long as I live. But if I die, what happens to my baby. Who is going to take care of my baby? I keep thinking about this. It would be worse if it becomes disabled. This is a very hard experience for us."

One participant (33 years old, 20 weeks of gestation) said: "I cried a lot when the disabled has been found. I was told that my baby would be both mentally and physically handicapped. Cried a lot. Well. . . I can take care of the baby but what will happen when it grows up. . . As I said. . . What will happen to my child when I die? I have fears. . . This is a terrible feeling. . . You carry another life attached to your life. And your whole life totally dependency on its life. It feels very different, beyond words."

In this study, four women had first-degree consanguineous marriage. In addition to the feeling of anxiety, women of consanguineous marriage also had feelings of guilt. Women of nonconsanguineous marriage did not express such feelings of guilt.

Table 1. The Participants' Characteristics

Educational status	Primary school	4 (36.4)
	University	7 (63.6)
Husband educational status	High school	5 (45.5)
	University	6 (54.5)
Working status	Working	8 (72.7)
	No working	3 (27.3)
Income status	Low income	1 (9.1)
	Average income	9 (81.8)
	High income	1 (9.1)

Table 2. The Main and Subthemes

Principal themes	Subthemes
Mothers' emotional reaction after diagnosed Down syndrome	Fear, anxiety, and guilt
Mother and healthcare professional interactions	Lack of nursing support and not giving enough information
Mother's coping with diagnosed Down syndrome	Fatalism and submission

One participant (38 years old, 20 weeks of gestation) said that: "My husband is also my cousin. My husband has relatives with Down syndrome. And now it happens to us. This wouldn't happen if I didn't marry. This is all because of me."

Other mothers explained their feelings as follows: A 38-year-old participant at 20th week of gestation said that: "It was very very stressful while waiting for the amniocentesis results. Something was wrong in double and triple tests. Waiting is as much as stressful as the negative results. My husband has relatives with Down syndrome. But I don't even think about curettage. I can't stand any more losing my baby."

Another participant (33 years old, 16 weeks of gestation) said that: "It is very hard to wait for amniocentesis results. I felt like dying. I counted the days. It was very, very stressful. I wish I had never got it done."

Mother and Healthcare Professional Interactions

All participants have stated that they have not taken any professional support from health professionals except husbands and some relatives. The women primarily defined the health professionals as nurses. The professional support was especially to give a psychological support and a sufficient information at each stage.

One participant (44 years old, 15 weeks of gestation) expressed: "I had nobody to support me when I needed at most. No nurses. The doctor quickly told everything in a few minutes. I desperately went to see another doctor. Nothing has changed. I searched on the web, no idea about how much true."

Another participant (36 years old, 16 weeks of gestation) mentioned: "One should be in awareness. Particularly, nurses must increase our awareness on this matter. Coping with it psychologically. . . They also must give a clear guidance in the tests and also in other means. They must support rather emotionally. Support. . . More Support. . . Moral support. . ."

Another participant (36 years old, 16 weeks of gestation) said that: "As a result it is an intervention from outside. There is a high risk of abortion. This has to be explained but this never happens. This is never told. This should be definitely a something told. The people have their own rights. They only go for their own rights. There are things that need to be done, and they are all that is done."

One participant (38 years old, 20 weeks of gestation) said that: "I wonder what it looks like. Is the face of my baby scary? Is anyone going to be scared when looking at my baby? How can I help my baby?"

One participant (34 years old, 19 weeks of gestation) said that: "What is amniocentesis? How is it done? Is it risky? What is Down syndrome? Why do we have it? How many people have it? What are we going to? No doctors and no nurses answered about these questions. Just you asked us how we feel."

Mother's Coping With Diagnosed DS

All participants decided to give birth. The fatalism and submission were subthemes.

One participant (43 years old, 18 weeks of gestation) in our study explained the following: "My triple test result showed high risk for Down syndrome. My doctor recommended amniocentesis. The result was positive for the second time. Even so, I will deliver this baby. This is the law of nature. God examines me in this way. God gives me patience when the baby is born. I trust God."

Another participant (36 years old, 17 weeks of gestation) said the following: "If the God decided so, even if the test result is normal, if I am supposed to have this. . . Even if the test result is good but something happens to the baby after delivery, that's what I am supposed to have. If it is destined, it is inevitable."

Another participant (36 years old, 18 weeks of gestation) expressed the following: "I feel that I am a lucky soul of God. I am a chosen person. If I take good care of the baby, God will reward me with heaven."

In our study, one participant (44 years old, 15 weeks of gestation) explained the following: "Having such a child will be a burden for our family and for the community. But I don't want to sacrifice his life."

Discussion

Mothers' Emotional Reaction After Diagnosed DS

In this study, all participants said that that they experienced anxiety before, during, and after amniocentesis. This is confirmed by other studies documenting that genetic testing is a stressful experience for people (Dinç & Terzioğlu, 2006; Feeny et al., 2002; Pilnick & Dingwall, 2001).

Fear is another emotional reaction that couples face while having tests for prenatal diagnosis, waiting for the results, and coping with possible unfavorable results. Indeed, fear and anxiety have complex nature, and it is difficult to separate from each other. One affects the other and causes an increase in the level strength of the other (Kowalcek et al., 2003; Ng, Lai, & Yeo, 2004). In the study by Sahin and Gungor (2008), it has been found that the fear and anxiety increased with increasing lack of knowledge on the test results and their consequences. In addition, no lack of knowledge has been proved to reduce the level of potential anxiety (Dinç & Terzioğlu, 2006; Ng et al., 2004; Sahin & Gungor, 2008).

A positive test result will have a lifelong physical, psychological, and social effect on the children and the family. DS is a physical and mental disorder. The cost of care for children with DS is higher due to diminished self-care, long-term need for special education, and much dependence on family (Lessick & Faux, 1998; Williams & Lessick, 1996). Therefore, the mothers are worried about the future for their children. The families need the support and detailed

information about where, when, and how to have the diagnostic and screening tests performed, possible complications, time period the results will appear, and interpretation of the results. The interesting and disappointing finding in this study was that all participants emphasized was their demand for more nursing care before, during, and after amniocentesis, and they also said that they have not got nursing care. In addition, women who explained their desire to get information from the doctor were complaining about the limited time spent with the doctor.

The women who had consanguineous marriage were feeling guilty. Consanguineous marriage can cause an increase in the risk of autosomal recessive disorder (Teeuw et al., 2010). Thus, genetic counseling should certainly be provided with consanguineous couples wishing to have a child. However, there are no certain standards in Turkey determining which genetic diagnostic and counseling services would be provided by which institutions except for university hospitals and private hospitals. Furthermore, only families with higher socio-economic status receive services from these centers.

Mother and Healthcare Professional Interactions

Even though amniocentesis can make accurate prenatal diagnosis of DS, the majority of families learn about their children's diagnosis after the birth (Skotko & Bedia, 2005). The situation where parents first learned about their children's condition and the attitude of healthcare providers, such as answering parents' questions and providing anticipatory guidance, strengthening families' abilities to care for their children, and establishing rapport, have an effect on families' reactions to the diagnosis (Garwick, Patterson, Bennett, & Blum, 1995; Van Riper, 2000). Parents who reported better relationships with healthcare providers also reported more positive attitudes and higher satisfaction with their infants' care and a higher level of adaptation (Miles, Holditch-Davis, Burchinal, & Nelson, 1999; Van Riper, 2000). As a result, in the studies the mothers who received the information emphasizing the positive aspects of DS were more positive and optimistic about raising their children (Choi, Lee, & Yoo, 2011; Skotko & Bedia, 2005). Optimistic feelings will promote healthy parent–child relationships and optimum growth and development of the child (Van Riper, Pridham, & Ryff, 1992).

Initial interactions with nurses and physicians may influence the way the parents respond to their children's diagnosis (Skotko & Bedia, 2005). Many healthcare providers, especially obstetricians practicing in the community, as also determined in our study, have little or no contact with individuals with disabilities in their practices (Seligman & Darling, 1989). Because of their lack of training and exposure, they may be ignorant or insensitive to the fear and anxiety of these parents. In the study of Choi et al. (2011), it has been indicated that they cannot or do not provide necessary information or emotional support for the parents who are in shock and despair. This was compatible with that of ours.

Unfortunately, the genetic courses have been incorporated into obstetrics-gynecology and pediatrics nursing care classes in nursing undergraduate programs in Turkey. However, there is no information regarding the scope and duration of the genetic courses. Genetics is a rapidly evolving area, and nurses need to translate their knowledge on genetics into clinical practice (Terzioğlu & Dinç, 2004). As we observed in our study, because of deficient and outdated knowledge, nurses may be refraining themselves from taking active role in order to avoid making mistakes and doing harmful sayings and behavior to the patient.

Mother's Coping With Diagnosed DS

In a study of pregnant women from the United States who tested positive for DS, 90% made a decision to terminate the pregnancy (Britt et al., 2000), while in a similar study of pregnant women in Uruguay, 89% decided on the termination of pregnancy (Quadrelli et al., 2007). Pregnant women from Hong Kong, China, who had a religious background, were less likely to accept termination of pregnancy due to DS than those who did not (Leung et al., 2004). None of our participants wished to end their pregnancy whatever the cause would be. The women perceived this duration as fate and submission. Devotion to God's will lies under the roots of the word "Islam," and the general belief of the Muslims is that everything happens in virtue of God's will (Hunfeld et al., 1993). The study by Bryant, Green, and Hewison (2006) in Pakistan showed similar results. In that particular study, one participant said: "It may be an abnormality but certainly not an error of nature. Allah made it this way and we should not interfere with his plans." In the same study another participant explained the following: "I would not have a termination because I would never disrupt the will of God. I trust Him and I love Him. Whatever He wills for me, whatever He decides for me I am fine with it."

Participants in the study by Bryant et al. (2006) and our participants used even similar words in their expressions. The Islamic morals formed their common language by which they explained their infinite devotion to God. This way of thinking might help families to better cope with this problem. Muslims generally feel that curettage is a rebellion against God. Furthermore, salvation can be achieved by taking care of a malformed baby. This is an invaluable earning because, according to the Islamic morals and values, this world is mortal (temporary) and the other is eternal (permanent). More interestingly, the studies on non-Muslim individuals showed also similar devotion to God. In a study on families of children with a congenital anomaly in Brazil, one participant said the following: "I also have God's support . . . I guess that God comes first, then the family, because I guess that everything is in His hands. So, if I want advice I have to ask Him. . . Anything my family cannot supply, I guess that only God can, you know" (Guiller, Dupas,

& Pettengill, 2009). Another study in the same country assessing the experiences of a father with a malformed child showed that the father passed the remedy and his own pain onto God (Baumann & Braddick, 1999). In the study by Bryant et al., one group of women was considering DS as "a child with DS is 'the will of god' but a burden to their family." A participant: "God gives a trial to everyone one way or another. If someone has a child with DS he will be tested socially as well as religiously on the matter of acceptance of the child."

While giving nursing services to women who are Muslim or not during this time, the ways of coping with the problems should be determined properly. The families can be directed to get an efficient and healthy ways of coping with the problems.

Limitation of this study includes the small sample size and the choice of a convenience sample from only one public hospital in Karaman. The participants were not followed after they obtained the results of amniocentesis. That is why no meaningful tests have been carried out. Therefore, it is not feasible to make our results general.

Conclusion

In this study, all women have been complaining about not having professional health care in any stage of prenatal diagnosis and screening tests. The nurses should give the necessary and sufficient information and physiological support before/after and during prenatal screening tests. The families should be directed to the gene experts to take much more wide and comprehensive information and counseling. The interaction with parents would be helpful in understanding their coping mechanisms and would help in providing appropriate interventional programs for parents of children with DS. The health professionals can help the families on healthy coping strategies instead of fatalism and submission.

Acknowledgments. The authors thank the women who agreed to participate in this study for their effort and contribution.

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