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Parental Competence among Parents with Autistic Children: A Qualitative Study

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ABSTRACT

Background: Parents of children with autism need to have unique competencies which are different from the competencies of parents with healthy children. Nurses and other health-care providers should know these competencies to be able to provide these parents with quality care and education. **Objectives:** This study aimed to define the concept of parental competence from the perspectives of parents with autistic children. The main question of the study was, “What does parental competence mean?” **Methods:** This qualitative study was done in 2016 on 20 parents (12 mothers and eight fathers) of 20 autistic children. Parents were purposively recruited from the Autism Association of Shiraz University of Medical Sciences, Shiraz, Iran. Data collection was done through 16 semi-structured interviews and two focus group discussions. Interviews and focus group discussions were digitally recorded, transcribed verbatim, and analyzed using conventional content analysis. **Results:** Data analysis led to the development of 13 subcategories, five main categories, and two main themes, namely, “restoration of family stability” and “excellence in child care.” The three main categories of the first theme were adaptation to the current situation, organization of family affairs, and improvement of satisfaction in the family. The second main theme also had two main categories, namely, self-confidence in child care and stability on the difficult path of child care. **Conclusion:** Parental competence among parents with autistic children is defined as “the ability to restore family stability and achieve excellence in child care.” Appropriate strategies are needed to evaluate and improve parental competence among parents with autistic children.

KEYWORDS: *Autism spectrum disorders, Child, Competence, Parents*

INTRODUCTION

Autism spectrum disorders (ASD) is a severe developmental disorder characterized by impairments in speech and social interactions.^[1] The global prevalence of ASD has increased to 6%, causing major challenges for the organizations which provide care services to children with ASD.^[2]

ASD-related behavioral, cognitive, and social problems negatively affect afflicted children’s and their parents’ lives,^[3] undermine parents’ caregiving competence, and cause parents and family members a wide range of physical, psychological, and social problems.^[4] Therefore, parents with autistic children suffer from great stress compared to parents with normal children.^[4]


Different studies have been conducted on parents with autistic children to evaluate their parental stress and coping strategies. Some studies reported that family members, particularly mothers, feel that they are ignored by healthcare and social organizations.^[5,6] Accordingly, health-care organizations should have stronger interactions with them and provide them with stronger professional support.^[7] Despite the wealth of studies into ASD, only one study in Iran explored the experiences

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How to cite this article: Mohammadi F, Rakhshan M, Molazem Z, Zareh N. Parental competence among parents with autistic children: A qualitative study. *Nurs Midwifery Stud* 2018;7:168-73.

Access this article online	
Quick Response Code: 	Website: www.nmsjournal.com
	DOI: 10.4103/nms.nms_8_18

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of parents with autistic children. It reported that these parents considered caregiving to their children as a top priority and hence, they attempted to help their children by relying on spirituality and transcendental beliefs. Moreover, that study highlighted that these parents need strong professional support.^[5] Some studies also assessed the effects of educational interventions on parents' competence. For instance, a study in Iran showed that a training program for parents with autistic children did not significantly improve their parental competence. Of course, the data collection tool in that study was a general competence-related questionnaire which did not address ASD-specific competence.^[8] Some other studies also attempted to define the concept of parental competence among parents with normal children.^[9,10] Yet, there is limited information on parental competence among parents with autistic children.

Objectives

This study aimed to define the concept of parental competence from the perspectives of parents with autistic children. The main question of the study was, "What does parental competence mean for parents of children with autism?"

METHODS

Design and participants

This qualitative study was done in 2016 using conventional content analysis method. Study participants were 20 parents (12 mothers and eight fathers) of 20 autistic children. They were recruited from the parents who referred to the Autism Association of Shiraz University of Medical Sciences, Shiraz, Iran. Sampling was undertaken purposively up to data saturation. Inclusion criteria were no history of mental illness, willingness to participate in the study, ability to speak Persian, a definite diagnosis of ASD for the child for at least 6 months, and no comorbid conditions for the child.

Data collection

Data were collected by holding 16 semi-structured interviews with four fathers and 12 mothers and two focus group discussions each with four fathers and six mothers. Interviews were started using a broad question, i.e. "What does parental competence mean to you?" Then, interviews were continued using follow-up questions such as "What competencies do you need to care for your child with autistic disorder?" "Was there any situation in which you felt incompetent for giving care to your child?" "Can you explain more?" "What do you mean?" "Why did you feel so?" Interviews were held in a quiet room in the study setting, lasted 60–90 min, and were recorded using a digital recorder.

However, one participating father and one participating mother did not consent to sound recording but allowed us to make notes of their speeches. Moreover, at the end of some interviews, parents provided explanations about some aspects of the study subject matter. Their explanations were written and added to their interviews. Interview data directed us toward holding two focus group discussions each with four fathers and 6 mothers. Focus groups were started by asking a general question such as, "How do you define the concept of parental competence for parenting a child with autism?" "What do you do to achieve these parental competences?" "What are the characteristics of a parent who is competent in giving care to an autistic child?" Pointed questions were also asked to explore different aspects of parental competence. These questions were, "Can you explain more about this?" "What do you mean by this?" "Can you clarify your perspective by describing your experiences?" "Why?" "How?" These questions helped us explore parental competence.

Data analysis and trustworthiness

The six-step conventional content analysis approach described by Graneheim and Lundman^[11] was employed to analyze the data simultaneously with data collection. Primarily, each interview was transcribed word by word and the transcript was read for several times in order to immerse in the data and obtain a detailed insight about them. Then, meaning units were identified and coded based on the aim of the study while taking the latent and the manifest content of the data into account. The codes were classified into broader subcategories and categories based on their similarities and differences. This process of data reduction and abstraction was continued until the themes were extracted. Table 1 shows an example of data analysis. The MAXQDA software (v. 10 R250412, Verbi® Verbi, Berlin, Germany) was employed to manage the data.

The credibility of the findings was ensured by performing data collection and analysis over a long 12 months period. Member checking and peer debriefing were also used to ensure credibility, in which four parents and two of our colleagues checked the data and the findings and confirmed that their understanding of the data conformed with our interpretations. In addition, preliminary literature review was performed only briefly to prevent researcher bias, i.e., to prevent our presumptions and mentalities from affecting data collection and analysis. Confirmability was also ensured through carefully recording the steps of data collection and analysis to facilitate others' scrutiny of our research activities.

Table 1: An example of data analysis

Meaning unit	Code	Subcategory	Category	Theme
I need to confide in myself and attempt to modify my child's behaviors. I can teach him good behaviors	Self-confidence in eliminating child's bad behaviors Self-confidence in shaping good behaviors	Self-confidence in child care and training	Self-confidence in child care	Excellence in care
I believe in my ability to help my child independently do his/her activities. Other mothers and I need to believe in our abilities to create a better future for our children	Self-confidence in promoting child's self-care ability Self-confidence in creating a better future for the child	Self-confidence in creating a better future for the child		
I change my daily plans to have adequate time to train my autistic child. I attempt to create a quiet and nondistracting environment and prepare necessary things for his/her training in order to promote his/her learning	Changes in personal plans for child training Creating a calm environment for learning Preparing necessary things for learning	Facilitating child training	Stability in the difficult path of child care	
Caring for this child is difficult and arduous. It needs great time and energy. You shouldn't get tired and give up	Persistence in the arduous path of child care	Stability in arduous care and training		
These children tardily learn things. Their training lasts neither one or 2 days nor 1 year; rather, you need to train them for a life. Parents need to train them with perseverance	Perseverance in child training			

Ethical considerations

The Ethics Committee of Shiraz University of Medical Sciences provided ethical approval for this study (approval number: 95.01.08.1168). At the beginning of the interviews, the interviewer, i.e., the first author, introduced herself to the interviewees, explained the aims of the study for them, guaranteed that the collected data would remain confidential, and ensured them that they could leave the study at will. All participants signed a written informed consent before taking part in the study.

RESULTS

The mean of parents' age was 38.52 ± 2.37 , with a range of 18–51 years. Most participating parents were female (60%) and married (80%) and had a secondary diploma (50%), a male child (65%), and an average monthly income equal to 200–300 US dollars.

Data analysis led to the development of 1011 codes which were categorized into 13 subcategories, five main categories, and two main themes. The themes were “restoration of family stability” and “excellence in child care” [Figure 1]. These themes are described in the following.

Restoration of family stability

According to participants' experiences, restoration of family stability is one of the most important aspects of parental competence among parents with autistic children. This theme included three main categories, namely, adaptation to the current situation, organization

of family affairs, and improvement of satisfaction in the family.

Adaptation to the current situation

Study participants equated competence with the ability to adapt to the current situation. Accordingly, they attempted to cope with the psychological tensions associated with the illness of their children to accept the illness and to patiently continue caregiving to their children. Their main strategies for promoting their coping ability were information seeking and patience. One of the participants commented: “*You should accept that your child is ill and should search for strategies to improve his conditions. Thus, you need to obtain accurate information about the illness and its treatments from informed individuals such as doctors and nurses, and the internet. Moreover, you need to be patient and manage all fears, concerns, discomforts, and depression in order to cope with the situation*” (P. 13).

Organization of family affairs

The second main category of the “restoration of family stability” main theme was the organization of family affairs. According to the participants, parents with autistic children need to develop appropriate plans to fulfill their own needs, their autistic children's needs, and the needs of the other family members. Moreover, they need to improve the interactions of their autistic children with other family members, relatives, and people. One of the parents said: “*I continuously talk to my both children and explain the situation for them in*



Figure 1: Parental competence among parents with autistic children

order to establish a closer relationship between them and help them better understand of each other. I attempt to pay attention to the affairs of all family members, to organize all aspects of my life, to improve my ill child's interactions with others, and to teach him how to accurately communicate with others. In this way, I can help my family members have better feelings and be not ashamed of having an autistic member" (P. 2).

Improvement of satisfaction in the family

Another key component of family stability restoration and parental competence promotion was to improve satisfaction in the family. According to the participants, satisfaction in the family is improved through giving quality care to the ill child and fulfilling the needs of the other family members. A participant articulated: "I heartily help my child to improve his recovery. I'm satisfied to be effective in teaching him, giving care to him, and improving his recovery. My engagement in her care and teaching has also made my husband happy and satisfied and has enabled him to actively engage in childcare. Similarly, it has given our children feelings of happiness and satisfaction and has prevented their separation from the family" (P. 16).

Excellence in child care

The second main theme of parental competence was excellence in child care. This main theme holds that parental competence is gradually promoted over time up to excellence achievement. To achieve excellence, parents need to have firm beliefs in their abilities to improve the well-being of their ill children and also to have stability and persistence. The two main categories of this theme were self-confidence in child care and stability in the difficult path of child care.

Self-confidence in child care

Self-confidence was a key component of achieving excellent parental competence. According to the

participants, firm beliefs in one's own ability to teach and promote healthy behaviors in autistic children can significantly contribute to the health and well-being of the afflicted child. Self-confidence can also help parents follow treatments and achieve excellence in child care. However, participants noted that due to the difficult and time-consuming process of training autistic children and the long time needed to achieve the ultimate goals of caregiving, parents with autistic children usually do not believe in their own abilities to promote healthy behaviors in their afflicted children. One of the participants commented: "A mother needs to believe and trust in her abilities to teach her child and improve his/her interactions so that he/she can independently do his/her daily activities. This belief is the most effective factor behind giving quality care and achieving competence" (P. 10).

Stability in the difficult path of child care

Rearing an autistic child is a very long and arduous journey and hence, parents need to have long-term stability and perseverance to achieve excellence and desired outcomes. In fact, stability shows that parents have achieved competence and excellence in child care. One of the parents said: "I always attempt to allocate adequate time to the training of my child. I attempt to create a quiet and nondistracting environment for his training in order to promote his learning. I also accompany him to the Autism Association in order to learn how to treat him. I do these things every day. It is arduous; but I always attempt to provide educations on time. I have stood patiently and persistently and will follow this path to the end" (P. 2).

DISCUSSION

This study aimed to define the concept of parental competence from the perspectives of parents with autistic children. Based on the findings, parental

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competence among parents with autistic children can be defined as “the ability to restore family stability and achieve excellence in child care.”

Study findings showed the restoration of family stability as one of the important aspects of parental competence. To restore family stability, parents with autistic children need to accept the illness of their children, patiently adapt to the psychological tensions associated with the illness, and attempt to obtain accurate information about the illness and how to give care to their afflicted children. An earlier study also reported that parents with autistic children attempt to adapt to their children’s illness by adopting an optimistic view about the future of their children, making use of educational and supportive opportunities, and enduring bravely. These strategies help parents manage the psychological tensions associated with the illness of their children and enable them to give care to their children.^[12] Another study also reported that the mothers of autistic children face different challenges in managing their stress and concerns about the future of their children and also in getting support and acceptance from their families and societies.^[4]

Our findings also indicated that when parents with autistic children accept the illness of their children and obtain necessary information for quality child care, they will be able to organize their interests and life schedules as well as the interests and plans of their ill children and other family members. Moreover, they will be able to improve the interactions of their ill children with family members and other people, improve satisfaction in their families, and create a calm and stable life. However, an earlier study showed that these parents have numerous difficulties in balancing their roles, managing their feelings and emotions, regulating their ill children’s behaviors, and bringing peace and stability to the family, and thus, they need adequate professional help, support, and counseling.^[4] Another study reported that having an autistic child negatively affects their family members’ personal and social lives, work, and marriage and therefore, parents need to adopt different strategies to minimize these effects with the help of other family members and healthcare professionals. Besides, they need to adopt optimistic views about their lives and their autistic children.^[13] Similarly, a study reported that the mothers of autistic children experience considerable stress regarding their parental roles and hence, they need extensive education and professional support.^[14] Moreover, these parents face challenges in allocating time to take care of themselves and to manage their daily activities. Therefore, they need to learn management skills to organize their familial relationships and improve

satisfaction in their families.^[12] All these findings highlight the importance of extensive family, social, and professional support for parents with autistic children to improve their competence in child care.

The findings of the present study also revealed that excellence in child care is a key aspect and the final step in achieving parental competence. Excellence in child care results from adaptation to the current situation, organization of family affairs, improvement of satisfaction in the family, development of self-confidence in child care, and achievement of long-term stability in the difficult path of child care. Parents’ stability and perseverance can improve self-care ability in autistic children’s. Similarly, a study reported that although caregiving to autistic children is tough, painstaking, and long-lasting, their mothers attempt to do it through relying on their emotions and spirituality.^[5]

To the best of our knowledge, this was the first study into the definition of the concept of parental competence among parents with autistic children. Despite our attempts to conduct a sound study, we faced some limitations. For instance, most parents had school-aged or younger autistic children; therefore, we could not explore the experiences of parents with adolescent or older children. Moreover, although the children of participants suffered from different types of ASD, this study did not differentiate parents respecting the type of their children’s ASD.

CONCLUSION

This study defines the concept of parental competence among parents with autistic children as “the ability to restore family stability and achieve excellence in child care.” This concept has different components, namely, adaptation to the current situation, organization of family affairs, improvement of satisfaction in the family, development of self-confidence in child care, and achievement of stability in the difficult path of child care. In this regard, it seems that health authorities and policymakers should also consider the findings of this study to provide a suitable support environment for these parents. As competence is a multidimensional and context-bound concept, further quantitative and qualitative studies are required for its evaluation and definition based on the immediate sociocultural contexts.

Acknowledgement

This article was derived from a PhD thesis with project number 95.01.08.1168, Shiraz University of Medical Sciences, Shiraz, Iran. The authors would like to acknowledge the research deputy at Shiraz University of medical sciences for their support. We also are thankful of all parents who participated in this study.

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Financial support and sponsorship

This study was supported by research deputy at Shiraz University of Medical Sciences.

Conflicts of interest

There are no conflicts of interest.

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