



Occupational Participation of Mothers of Children with Autism Spectrum Disorder

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Abstract

Background: Mothers of children with ASD are faced by great challenges trying to follow and establish a daily routine. Participation in personally meaningful occupations is often sacrificed to focus their time on providing the needs related to child care/child rearing.

Objectives: This study aimed to obtain a deep understanding of occupational participation of mothers of children with ASD as well as the challenges they faced and how they cope with those challenges. A qualitative research method was adopted. Method: Using phenomenological approach, data were gathered through in-depth, semi-structured interviews with six mothers.

Results: Five themes related to occupational participation of mothers of children with ASD emerged from the thematic analysis that has been conducted, which are (1) being constantly occupied, (2) restricted participation in meaningful occupations, (3) challenges of raising a child with autism spectrum disorder, (4) impact on mother, and (5) coping and support.

Conclusion: Mothers of children with ASD find it difficult to participate in occupations that are meaningful to them. Hence, there is a need for occupational therapists to support them in improving satisfaction and engagement in meaningful occupations.

Keywords: Occupational Participation; Mother; Autism Spectrum Disorder

Introduction

Children with autism spectrum disorder (ASD) are characterized by significant deficits in social-communication skills, including poor eye contact, difficulty maintaining conversation, lack of relationships with peers, as well as the occurrence of restricted and repetitive patterns of behaviors such as stereotypical behavior, hypo or hypersensitivity, and interest in things that are unusual [1]. As the caregiver of children with ASD, in caring for their children, mothers are faced with a plethora of challenges and difficulties, which includes the caregiving burden itself [2,3]. Child's lack of daily living skill requires mothers to continuously assist and supervise their children at home, restricting them from leaving home and doing other activities [3]. Mothers are faced by challenging tasks of dealing with children's abnormal

behavior [4-7], teaching their children to communicate and perform basic life skills, protecting their children from danger, as well as preparing for their children's future [4]. On top of that, they also have to deal with negative response and stigma that persist in the community [3,8], which could result in mothers of children with ASD choosing to hide their children and limit their social interaction [8,9].

Although some mothers may feel satisfied with the role as the primary caregiver of a child with ASD, having such role can limit mothers' ability to participate in other meaningful or important occupations or activities. Mothers of children with ASD tend to spend more time performing tasks related to child care, thus they have limited time to engage in self-care, rest/sleep, work, social participation, and leisure activities [10,11]. They are also more inclined to have a negative view

regarding everyday life, especially when compared with mothers of children with typical development [11].

Participating in daily routine and finding time to engage in occupation that is beneficial to them is an immense challenge for mothers of children with ASD [11-14]. Most of these mothers sacrifice their participation in their personally meaningful occupations and focus their time on seeking and participating in professional services for their children as well as meeting the needs related to the care of their children [15-17].

The purpose of this study is to understand occupational participation of mothers of children with ASD, including the challenges they face and how they deal with those challenges. In order to obtain a deep understanding of mothers' experience, a phenomenological approach was used in this study.

Method

Design

To thoroughly investigate the occupational participation of mothers of children with ASD and the challenges

experienced as well as how mothers cope with them, a phenomenological approach was chosen. A phenomenological study "describes the meaning for several individuals of their lived experiences of a concept or a phenomenon" [18]. This approach allows for identifying the essential quality of conscious experiences by means of an in-depth and careful analysis [19]. Furthermore, in phenomenology the goal is not to search for cause-effect relationships nor is it to generalize [20]. Instead it is a process of observing and analyzing "the things themselves" [21].

Participants

Six mothers of children with ASD aged 3 years and older were purposefully recruited through two centers providing services for children with disabilities in Central Java Province of Indonesia. Participants who were also caring for other individual(s) with disability apart from their children with ASD were excluded from this study. Participants' ages ranged from 25 to 39 years ($M= 30.5, SD= 5.47$) with various educational backgrounds (high school to bachelor level). The children with ASD were aged between 3.5 and 12 years. Three participants quit their full time job, one of them transitioned to a more flexible job, an entrepreneur (Table 1).

Participant	Age, year	Marital Status	Education Level	Job	Age of Child, year	Diagnosis
1	25	Married	High School	Homemaker	5	ASD
2	26	Married	Bachelor's	Homemaker	3.5	ASD
3	27	Married	High School	Homemaker	4	ASD
4	34	Married	Bachelor's	Homemaker	8	ASD
5	39	Married	Some college	Civil servant	12	ASD
6	32	Married	Some college	Entrepreneur	5	ASD

Table 1: Participant Characteristics.

Data Collection

Data collection was done through in-depth, semi-structured interviews, and was supported by the use of an audio recorder during the interview process so that interview data can be captured effectively. Interviews were conducted at least twice (or approximately 180 minutes) for each participant to achieve data saturation and to allow participants to expand and clarify their description of their experiences. The primary questions asked were the following:

1. Please describe your experience starting from the first time being told about your child's condition.
2. How does your child's condition affect you and your daily life? What changes have you experienced?
3. What are the day to day challenges that you faced?

(Prompt participants to describe the challenges during participation in areas of occupation)

4. How do you cope with those challenges and what are the things that had helped you cope?
5. What are your concerns currently?
6. Please describe how society and relatives respond/react upon discovering your child's condition.

Probes were used in order to evoke more in-depth answers, to follow up on points of interest, and to get clarification.

Ethical Consideration

The study was reviewed and approved by ethical research committee of Department of Occupational Therapy of the Ministry of Health. Information about the purpose and the method of the study were provided for all participants

prior to the interview. They were informed that participation in the study was voluntary and that they could refuse to participate or withdraw from the study at any time without any repercussions. The participants were reassured that their responses would be confidential and their identities would not be revealed in research report and publications. Finally, the author obtained written consent from the participating mothers. Each interview was audio recorded with permission that has been given by all participants.

Data Analysis

Data analysis was started with transcribing the audiotaped interviews into verbatim. In this study thematic analysis was conducted as a technique for identifying, analyzing and interpreting patterns of meaning or “themes” within qualitative data [22]. The thematic analysis consisted of six phases according to Braun, et al. [22]; (1) getting familiar with the data by repeatedly and carefully reading the transcripts, focusing on identifying the patterns that occur; (2) generating initial codes through the process called data reduction in which data were collapsed into labels as a means of creating categories for more efficient analysis, this process involves making inferences about what the codes mean; (3) combining codes into comprehensive themes

that accurately represent the data; (4) determining whether the themes already support the data and the overarching theoretical perspective and, if the analysis seems incomplete, subsequently going back to find what is missing; (5) defining the meaning of each theme, as well as providing explanation about which aspects of data are being captured and what is interesting about the themes; (6) deciding which themes make meaningful contributions to the understanding of what’s going on within the data, this phase includes conducting member checking by going back to the participants to know if the description/interpretation is accurately represented. Therefore ultimately a thick description of the results would be obtained. Apart from “member checking”, to ensure the reliability and validity of the research results, during the process of data analysis, weekly meetings were held between the researchers to discuss the emerging results and draw consensus regarding coding and themes related to the research objectives.

Results

Five themes related to occupational participation of mother of children with ASD emerged from the thematic analysis that has been conducted. The emerging themes as well as the subthemes are set out in Table 2 below.

Theme	Subtheme
Being constantly occupied	1- Child rearing
	2- Activities of daily living
	3- Work
	4- Leisure activities
Restricted participation in meaningful occupations	1- Restricted participation in meaningful occupations
Challenges in raising children with ASD	1- Time burden
	2- Financial burden
	3- Factors contributing to caregiving burden
	4- Lack of knowledge
	5- Negative attitude/response
	6- Lack of support
Impact on mother	1- Positive impact
	2- Negative impact
Coping and support	1- Coping Strategies
	2- External support

Table 2: Theme and subtheme.

Being Constantly Occupied

Participants reported to have a very hectic daily life as a result of the high demand of child rearing activities,

accompanied by other domestic responsibilities. Being the mothers of children with ASD, participants are obliged to continuously supervise and assist their children throughout the day, as well as seeking professional help for their children

and caring for their children's educational needs. Aside of child-related activities, there is also the overwhelming household chores to attend to. Additionally, one participant who has a full time job expressed her desire to quit her job and focus more on her children; however she doesn't have a choice due to the high financial need of having three school-aged children. The other participants had either quit, or shifted to other forms income-generating activities that require less time, effort, and focus so that they can put most attention for their children with ASD, and one participant has been a housewife since her marriage.

There were times where I had to continue at night after the kids are asleep (doing household chores), sometimes until 1 am, and then I slept.

Restricted Participation in Meaningful Occupations

Participants in this study indicated that they experience imbalance in their occupations, with child care related activities always being prioritized, resulting in disrupted and limited participation in other areas of occupation such as rest/sleep, self-care, work, leisure, social activities, and religious activities. Despite the wish and enjoyment of participating in paid employment, four mothers quit their full time job as it was not possible to maintain those jobs when the caregiving demand associated with having a child with ASD is too high. Several participants expressed their discontentment of being restricted or unable to participate in activities such as leisure and social activities. Such activities serve as relief and alleviation of their tough and stressful life.

To be honest I'd prefer to have a job, because I enjoy it. But what can I do. Well I just really hope that he could be normal again so I can work.

Challenges of Raising A Child With Autism Spectrum Disorder

Mothers in this study experienced many challenges in the course of their day to day life. Among those challenges are time and financial burden; caregiving burden; lack of knowledge regarding child's condition and the actions to take in order to cope with the associated problems; negative response of extended family members and neighbors; as well as a lack of support from spouse, family, and community. Caregiving burden is one of the greatest challenges that they faced. Many things contribute to the high caregiving burden including child's problematic behaviors, rigid routine, lack of communication and interaction skill, low on independence, eating/feeding problems, sleep problems, problems with sibling(s), the presence of a baby, and lastly the issues relating to participation in professional services for the child.

Well R need to go to therapy twice a week. Thursday till Saturday I have to take him to school. For the whole week I don't even have time to rest, being lazy, or do things (that I want).

Impact on Mother

Having a child with ASD can impact mother negatively and positively. Unsurprisingly, there are some consequences of bearing the role as the primary caregiver of a child with ASD which include fatigue, disrupted sleep, restrictions and challenges to participate in meaningful occupations, and also psychological distress. Along with those negative impacts, these mothers acknowledged that there are also some positive impacts of having a child with ASD. They described that they have better resilience, better self-control, and that the presence of their children had allow them to gain more knowledge and experience and also the ability to see things from more positive and optimistic perspectives. In addition, they experience "positive moments of reward" each time they managed to tackle one issue that they face, including when their children showed little improvements or when they were no longer ashamed to introduce their children. These mothers also feel a stronger mother-child bond and stronger bond with their spouses, and several participants mentioned that they become more spiritual and closer to God.

I think I'm better at controlling myself now. People would mock and humiliate me, but I'll just focus on how to make his condition improve, whatever it takes, I can do anything, travel anywhere, pay no matter how expensive. Other people might confront or get angry when they're being mocked, but not for me, I have patience.

Coping and Support

Among the coping strategies that the mothers in this study used were emotion-focused coping strategies, problem-focused coping strategies, and the use of spiritual beliefs, task-oriented coping strategies, and lastly maladaptive coping strategies. Other than problem-focused coping strategies, emotion-focused and spiritual coping strategies were also quite frequently used. All participants in this study had, at some points during their experience of being a mother of a child with ASD, used some forms of maladaptive coping strategies such as self-blaming, denial, as well as avoidance and withdrawal from social interactions. Apart from the various coping strategies utilized by mothers, what had helped them get through difficult situations are the support from their spouses, other family members, and society.

All the neighbors support and accept his condition. They're all helping me figuring out about how to make my

child improve, they would play and tease him, trying to make him make sound (speak).

However, such support is not always available for each of these mothers. One participant regretfully stated that had her husband provided more support and taken more share of the parenting and household load, things would have felt easier for her.

Discussion

This study found that every day mothers are faced with high demands related to childcare tasks, domestic activities, and also work, and often these are not matched by the availability of time and support received by mothers. Findings from previous studies had indicated that the mother's daily life is identical with high and relentless demands related to child care [23]. In addition, Behnia, et al. [10] revealed that mothers are faced with a lot of household chores but there is not enough time to finish them. As a result, every day mothers are forced to be constantly involved in activities to fulfill these various responsibilities, which in turn will contribute to limited participation in occupations that are meaningful to them and cause fatigue and stress in these mothers. An older study disclosed that mothers of children with ASD felt overwhelmed in meeting these high demands [24].

As the results suggest, mother's participation in meaningful occupations such as leisure activities, family activities, social activities, and religious activities are generally limited and mothers are faced with various challenges during the involvement with these occupations. Participation in these activities is often sacrificed to accommodate the time needed for more prioritized activities such as caring for children and doing household chores. Gona, et al. [3] found in their study that parents of children with ASD find it difficult to leave home and carry out other activities because of responsibility for their children who have autism. In order to be able to fulfill tasks related to household activities mothers often sacrifice recreational activities and activities that are less prioritized, participation in social activities is also generally very low [3].

Furthermore, it was found that during raising a child with ASD mothers are faced with various challenges, one of which is the time burden, as most of the mothers' time is spent on their children who have ASD. This is as also found in Crowe, et al. [11] study that mothers' time is mostly spent on child care, and is least used for recreational activities. Having children with ASD also has an impact on the high financial burden, due to the need to undergo examinations, treatment, therapy, education, and these findings are consistent with the previous [7,11,25,26]. The next challenge is the caregiving burden, which is primarily caused by behavioral problems in

children [6,7] and child's low independence [27]. In addition, other challenges faced by mothers are a lack of knowledge; understanding about the child's condition; facing negative attitudes/responses from the community/family; as well as the low level of support received.

Raising children with ASD accompanied by various challenges can affect mothers positively and negatively. The negative effects of having children with ASD include fatigue, as mothers of ASD children experience higher levels of fatigue when compared to mothers of normal children [28]. Another negative impact is the disruption of mothers' rest and sleep, in a study it was found that as many as 80% of parents of children with ASD reported experiencing sleep disturbances caused by difficulty in sleeping in their children [29]. Moreover having a child with ASD can also contribute to psychological distress in mothers. As suggested by previous studies, various factors related to the care of children with ASD have the potential to cause negative psychological or emotional impacts such as stress, anxiety, and depression in the mother [30,31].

Regardless of the magnitude of the challenges faced, raising a child with ASD can also have some positive impacts on mother. One is mother's resilience, as discovered in Twoy, Connolly, et al. [32] study, parents of children with ASD show resilience in adapting to the challenges associated with caring for and raising children with ASD. Another positive impact is that mothers feel closer to children; this is consistent with previous studies suggesting that having children with ASD can increase closeness between family members [33]. Receiving negative attitude from the community could eventually make mothers develop better self-control, this is consistent with the results of Cashin's, et al. [34] research that one of the positive effects experienced by mothers is that mothers reported to be more patient in reacting to negative attitude from the community. Furthermore, Ludlow, et al. [7] found that the mothers can also experience what is called positive moments of reward, which manifested in the feeling of happiness or satisfaction when there is progress in children's development even only as small as when a child began to be able to write her nickname.

Coping strategies used by participants including emotion-focused coping strategies (focus on controlling emotional distress [35], problem-focused coping strategies (based on problem solving to try to control stressful situations [35], the use of spiritual beliefs (belief in God and destiny [36], task-oriented coping strategies (active involvement to relieve stress [37] and maladaptive coping strategies (controlling stress with less effective efforts such as self-blame, anger, and denial [38].

In addition, receiving support from other people

has helped mothers through difficult situations and face challenges. Such support can come from the community, family, and husband. Based on the results of previous studies, the use of support systems is one of the coping methods that is often used which consists of support from spouse/husband, family support, and support groups [6,7,39]. Based on the research by Mackintosh, Myers, et al. [40] the sources of support received by parents of children with ASD include other parents who have children with ASD, spouses, family members, friends, neighbors, religious communities, as well as professionals such as doctors, teacher, and therapist. In mothers of children with ASD, receiving informal support can reduce the stress experienced [2,41,42].

Implications for Occupational Therapy Practice

Mothers of children with ASD are faced by many challenges in raising their children as well as in participating in meaningful occupations. Success and satisfaction in participation in meaningful occupations influence mothers' health and well-being. Undeniably, such thing worth the attention of occupational therapy practitioners in line with the implication of family-centered intervention, by which mothers' occupational needs and participation in meaningful occupations should be taken into consideration. Thus occupational therapy practitioners need to supply themselves with information regarding occupational participation of mothers of children with ASD.

Knowledge such as the things that contribute to mothers' satisfaction in their occupations, the effective strategies to cope with challenges associated with raising a child with ASD and how to live day to day life positively and satisfactorily, is important in designing a suitable, family-centered based, intervention program. The proper intervention program is one that supports and facilitates mothers' occupational participation, instead of one that disrupts mothers' participation in meaningful occupations. Furthermore, the program should be designed in collaboration with mother and/or other family caregivers.

Limitations and Future Studies

This study has several limitations. First, there are some variables that this study hasn't been able to cover, that might influence mothers' occupational participation, for instance child's gender, economical status of the family, and the severity of child's condition. Second, the unavailability of information regarding the intimacy and sexual relationship between mother and father, which is a component of mothers' occupational participation that also influences their health and well-being. Therefore, there is a need to conduct a more comprehensive and detailed study with bigger sample size. Future studies might need to consider how different cultural

backgrounds impact and manifest in the occupational participation of mothers' of children with ASD.

Conclusion

Every day mothers of children with ASD are faced with high demands related to child care tasks, domestic activities, work and other occupational areas and often the high demands are not facilitated by the time available and the support they received. Therefore mothers of children with ASD experience limitations in participating in a number of meaningful occupations such as work, leisure, family activities, social activities, and religious activities.

Throughout the experience of raising a child with ASD, mothers were faced with various challenges such as time burden, financial burden, caregiving burden, lack of knowledge/understanding related to the child's condition, negative attitude/response from community/family, as well as the lack of support received. Raising children with ASD has a negative and positive impact on mothers. Negative impacts felt by mothers include fatigue, disruption of rest/sleep, and high psychological distress. Whereas some of the positive impacts were that mothers becoming more resilient, have closer bond with their children, have better self-control, and more appreciative toward every little good thing.

To overcome challenges, various strategies have been used by mothers, including emotion-focused coping strategies, problem-focused coping strategies, and the use of spiritual beliefs, task-oriented coping strategies, and maladaptive coping strategies. Various forms of external support were also received by the mother and have helped those overcoming challenges. This support is obtained from the community (neighbors/friends), family, and husband.

In accordance with the results of this study, it is important for occupational therapists who work with mothers of children with ASD to support mothers and help increasing satisfaction and meaningful involvement in occupation so that it can further improve the health and well-being of mother.

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