



Daily Occupational Balance of Mothers of a Child with Autism Spectrum Disorders

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Abstract

Background: Mothers of children with Autism Spectrum Disorder (ASD) are faced with enormous challenges, have difficulties integrating daily occupations and managing the needs of all family members.

Objective: The purpose of this study is to gain a thorough understanding of the daily occupational balance of mothers of a child with ASD, including their occupational pattern and challenges.

Methodology: A qualitative phenomenological approach was applied. Data were collected using in-depth interviews and observation of six mothers of a child with ASD and analyzed using thematic analysis.

Results: Four themes related to the daily occupational balance of mothers of a child with ASD were identified: occupational pattern; challenges in carrying out roles; coping and performing tasks within the roles; and achieving balance.

Conclusion: Occupational therapists should consider mothers' occupational patterns and help to create balance in mothers' daily occupation as a way of improving their well-being, quality of life, and general health.

Keywords: Occupational Balance; Mother; Children With ASD

Introduction

Autism is a spectrum of disorders that impairs multiple areas of a child's development, characterized by two core features-restricted social and communication skills and the presence of repetitive sensory-motor behaviors Khan, et al. [1], Lord, et al. [2]; Shangraw, et al. [3]. Though the severity of symptoms can range from very mild to severe, a lot of individuals with ASD require a lifelong support Lord, et al. [4].

Recent studies indicate that there is a significant increase of ASD prevalence in Asia as well as globally Chiarotti, et al. [5], Qiu, et al. [6]; WHO [7], although there is currently a lack of data regarding the prevalence of ASD in many low- and middle-income countries including Indonesia WHO [7]. Based on anecdotal evidence from over three decades of

experience in the field of pediatric occupational therapy in Indonesia, there seems to be a rise in the awareness of the nature of ASD and the need for professional intervention to address issues relating to the disability, as visibly more and more mothers or parents of children with ASD are accessing professional services in an attempt to understand and improve their child's condition.

A large number of studies suggested that despite the fact that mothers of children with ASD derived a sense of fulfillment from caring for their child, this caregiving greatly affected their lives in many ways Hoefman, et al. [8]. Mothers tend to have difficulty integrating childcare-related tasks with other daily/household tasks as well as managing the needs of their child and family Bonis, et al. [9], Hoefman, et al. [8]. Among the many challenges they faced, the fatigue caused by handling child's behavioral problems is one of the major

predictors of parenting-related stress and psychological distress Estes, et al. [10], Hayes, et al. [11]; Seymour, et al. [12]. Moreover, a large proportion of caregivers of a child with ASD experienced mental health problems such as depression which eventually led to the decrease in physical health and quality of life Bonis, et al. [9], Hayes, et al. [11]; Hoefman, et al. [8]; Jose, et al. [13].

Mothers of a child with ASD spent the majority of their time for childcare-related activities, including navigating professional services for their child, sacrificing their participation in other personally meaningful occupations as a result Behnia, et al. [14], Hodgetts, et al. [15]. These mothers are very prone to experiencing occupational imbalance Rizk, et al. [16], yet they don't have a lot of choices available, as having a child with such condition is something that's beyond their control Steele, et al. [17]. However, these mothers expressed the desire to maintain occupational balance in their lives in order to improve their well-being Hodgetts, et al. [15]. Through phenomenological approach, this study aimed to gain understanding of the occupational balance of mothers of a child with ASD, including their daily occupational pattern and challenges. Data was collected using in-depth interviews as well as observation and thematic analysis will be utilized to analyze the data.

Methods

Design

This study used qualitative approach to investigate occupational balance in the daily lives of mothers of a child with ASD. Qualitative research best suits the issues

being studied because its goal is to explore and understand how individuals or groups give meanings to a particular problem in their live Creswell, et al. [18]. Furthermore, phenomenological inquiry is utilized to obtain a rich description of the lived experiences of mothers of a child with ASD in performing daily occupations as told by the mothers themselves Creswell, et al. [18]. This description consists of "what" and "how" these mothers experience their occupations in relation to having a child with ASD, so that understanding of their occupational balance will be obtained Moustakas, et al. [19].

Participants

The research was conducted at a pediatric occupational therapy center 'Budi Center' located in Surakarta, Central Java, Indonesia. Participants in this study were recruited through purposive sampling methods. To be eligible for this study the participants must meet the following inclusion criteria: 1) Mothers who have children diagnosed with ASD between age 3-20; 2) Residing in the city of Surakarta and its surroundings; 3) Able to speak Indonesian.

Invitations to participate in the study were sent through the clinic or school contact. Candidates who agreed to participate in this study were subsequently provided by the researcher with information regarding the purpose and nature of the study and requested for their informed consent. Finally, six mothers (aged 30-42) of children with ASD gave their informed consent to participate in the study. Participants' characteristics are summarized in Table 1. This study was reviewed and approved by the institutions ethics board.

Participant	Age, yr	Marital Status	Education Level	Job	Age of Child, yr	Diagnosis
1	35	Married	Bachelor's	Homemaker	6	ASD
2	38	Married	High school	Homemaker	8	ASD
3	38	Married	Bachelor's	Entrepreneur	11	ASD
4	40	Married	High school	Entrepreneur	10	ASD
5	42	Married	High school	Homemaker	7	ASD
6	42	Married	Bachelor's	Homemaker	8	ASD

Table 1: Participant Characteristics.

Data Collection

The data in this study were collected using in-depth interviews with the study participants as well as observation. The researcher asked questions related to balance in mothers' daily activities/occupations, including what efforts are made by mothers who have children with ASD to achieve balance in their daily occupations, as well as the things that

have prevented these mothers from participating in their personally meaningful occupations. The duration of the interviews was approximately one hour for each participant and the interview sessions were audiotaped.

To reach data saturation and to ensure the accuracy of the data, the researcher conducted second interview for each participant. To evaluate the validity of the findings as

well as to acquire a comprehensive understanding and to enrich the data, this study employs triangulation strategies Carter, et al. [20]. The type of triangulation used in this study was data source triangulation, which involves the collection and comparison of data obtained from different sources, at different times and places, and from different types of people Denzin, et al. [21], and method triangulation, which involves the use of more than one methods of data collection for the same phenomenon Polit, et al. [22].

Data Analysis

In-depth interview data were processed using thematic analysis, as it is a highly adaptable method that can be tailored to the needs of a variety of studies, resulting in a rich, informative, but complex account of data King, et al. [23]. According to Braun, et al. [24], the six stages carried out in the thematic analysis are as follows: 1) familiarizing with the data in details. In this first stage, researchers immerse themselves in the data to become acquainted with the depth and breadth of the content; 2) build the first set of codes. In this stage, researchers are suggested to work through the entire data set systematically, paying complete and fair attention to each data item, and look for interesting

features in the data items that might form the basis of trends across the data set; 3) look for ideas for themes. This process includes organizing and categorizing all of the coded data extracts that may be important into themes; 4) go over the themes again. During this stage, researchers examine the coded data extracts for each theme to see whether they have formed a logical pattern and individual themes are validated to ensure that they accurately reflect the meanings found in the collected data; 5) defining and naming the themes. During this stage, title names should be short and catchy, in order to give readers an immediate sense of the themes; 6) writing the analysis of data. In this final stage, the results of a thematic analysis should be presented in a succinct, logical, non-repetitive, and interesting manner.

Result and Discussion

From the thematic analysis that has been conducted, emerged four themes related to occupational balance of mothers of a child with ASD in their daily lives: occupational pattern; challenges in carrying out roles; coping and performing tasks within the roles; and achieving balance. The emerging themes as well as the subthemes are set out in Table 2 below.

Theme	Subtheme
Occupational pattern	1- Roles
	2- Social participation
	3- Leisure pursuit
	4- Rest & sleep
Challenges in carrying out roles	1- Stress
	2- Anxiety
	3- Emotional distress
	4- Health problems
Coping and performing tasks within the roles	1- Lifestyle Change
	2- Emotion-focused coping
	3- Problem-focused coping
Achieving balance	1- Spirituality
	2- Social support

Table 2: Theme and subtheme.

Occupational Pattern

The Occupational pattern is “occupations, activities, and actions organized in range, direction, frequency and number of repetitions, and performed in a social and physical environment, over time ... these occupations, activities, and actions are interconnected with an overriding meaningful theme, a unifying motivation and goal, and value given by the

individual and the social environment” Bendixen, et al. [25]. Participants in this study possess numerous roles, such as being a mother/caregiver, a housewife, a wife, and a worker, and they are obliged to carry out tasks associated with each role on daily basis within the limited time that they have. Among those roles, being the caregiver of a child who has ASD is the most time-consuming.

Being in possession of multiple roles, mothers reported that they experience difficulties in social and leisure participation. One mother said, "I have to make a plan whenever I got an invitation from my friends, I have to adjust the appointment according to my child's schedule for therapy sessions. Since I have limited opportunity to go outside, I need to manage my time efficiently to be able to exercise or hang out with my friends, but I am always in a hurry".

On the other hand, Santoso, et al. [26] highlighted that mother's participation in activities outside the house can improve their health and life balance. Moreover, mothers also described that they experience a lack of rest and sleep. As one mother stated, "I might not have the appropriate amount of sleep, but sleep quality is really important for me".

In short, occupational patterns of mothers of children with ASD encompass the possession of multiples roles, the lack of social and leisure participation along with the lack of rest of sleep, which influence the achievement of life balance.

Challenges in Carrying out Roles

The demands associated with child care/child-rearing are extremely high as they have to provide for their child's needs, constantly assist and supervise the child, take the child to therapies and school, and so on. Consequently, they have little to no time to fulfill other responsibilities such as doing household chores. As one mother noted, "My child has a very tight daily schedule of therapy sessions, and I also have to cook, go shopping, and the other domestic chores ... I don't even have the time to clean the house". This is consistent with the findings of previous studies which suggested that the daily life of mothers of a child with ASD goes hand in hand with the high and constant demands related to child care, making it difficult for them to perform other daily tasks Bourke Taylor, et al. [27], Gona, et al. [28], Hoogsteen, et al. [29]; Stein, et al. [30] suggested that such imbalances experienced by mothers contribute to an array of negative psychological consequences, such as stress, anxiety, depression, functional limitations, as well as health problems such as hypertension or diabetes. One mother said that, "my husband goes to work in the morning and comes home at night every day, I am very physically and mentally tired because of both caring for my child and doing other domestic activities, ... and I feel very sad when I got sick".

Coping and Performing Tasks Within the Roles

Having a child with ASD forced a considerable change in mothers' lifestyle and occupational pattern, in which mother sacrificed their participation in paid work and social participation or other areas in order to focus their time on caring and seeking professional help for their child.

Participants also reported that they don't have enough time for rest and sleep due to sleep problems in their child. A lot of children with ASD have co-occurring sleep disturbances Aathira, et al. [31], Singh, et al. [32], Souders, et al. [33]; Tzischinsky, et al. [34], and as a consequence mothers have to adjust their bed time and lose some portion of their sleep, which will inevitably impact the quality in performing other daily occupations Crowe, et al. [35], Polimeni, et al. [36]. As much as 80% of mothers of a child with ASD have a reduced time and quality of sleep, while sleep quality is found to be a predictor of psychological health Meltzer, et al. [37], Polimeni, et al. [36]. In addition, mothers' participation in social activities are limited because of the duties related to child care, comparable to what Sen, et al. [38] had found in their study that over 70% of mothers of a child with ASD experience a significant change in their social life. As one mother stated, "It is difficult for me to manage the time if I want to go outside because I have to cook twice, every morning and evening ... and I still need to help my other son with his homework".

This study found that mothers of a child with ASD faced a great number of challenges in orchestrating the many roles that they have. Among those challenges were the presence of stress and anxiety, emotional distress, and health problems. Challenges that mothers faced are primarily the result of behavioral problems in children with ASD, which is supported by the findings of previous studies Estes, et al. [10], Lecavalier, et al. [39], Myers, et al. [40], Seymour, et al. [12]; Tomanik, et al. [41]. Because of the children's problematic behaviors mothers were too anxious to leave their child unobserved, they became overly protective of their children. One mother remarked, "I can't leave my son alone at home". This is in line with Larson's, et al. [42] findings that mothers of children with ASD had to remain vigilant throughout the day and it is exhausting for them. Having to give constant supervision, mothers became restricted from doing other things including other responsibilities and personally meaningful occupations. Furthermore, stress and anxiety experienced by mothers affected the quality of child care and their performance in daily occupations. According to National Institute of Mental Health [43], higher levels of psychological and emotional problems is associated with impaired social, work, physical, and role function in addition to lower well-being, quality of life, and general health.

Mothers in this study tend to blame themselves for what happened to their child, they believe that their child's condition is the result of their failure in protecting their child. However, they also showed eagerness to better understand their child's condition, through reading the literature regarding ASD from medical, biomedical, rehabilitative, as well as other point of views. It is in accordance with what has been suggested by previous studies in which mothers

gathered information relating to their child's diagnosis as a way to cope with challenges of raising a child of that condition Hall, et al. [44], Kuhaneck, et al. [45]. By gaining knowledge and understanding of ASD, mothers have better judgment on the right actions to take in order to improve their child's health and life. As a result of the improved condition, child could be less dependent and the mother would have more time to perform her other tasks and roles. Matuska, et al. [46] argued that as life is constantly changing, people have to be able to face the challenges with new, innovative ways that allow them to keep growing as an individual.

Achieving Balance

In facing all the obstacles in their day-to-day life as mothers of a child with such diagnosis, participants described that they became more spiritual, as in seeing the situation as a fate designated by God, believing that their child is a precious gift from God that has to be loved and protected regardless of the medical condition, and that God will show them the way. Thus these mothers became more accepting and optimistic and able to feel a sense of satisfaction and fulfillment from their role as a mother of a child with ASD. Comparable with what has been reported by previous studies, in which mothers of a child with ASD employed spiritual beliefs as a way to cope with challenges Gona, et al. [28], Gray, et al. [47]; Tway, et al. [48]. In addition, Heydari, et al. [49] suggested that mothers of a child with ASD who experienced an elevated spirituality are able to provide better care for their child as well as to help themselves throughout the process and grow as an individual.

Participants need assistance from other people in carrying out tasks and help them in achieving balance in daily occupations. Such support came primarily from their spouse, family and neighbors in the shape of emotional, physical, and material support. As stated by one participant, "...when I feel really tired I ask my husband to take over and take care of my son". In spite of all the limitations, participants tried to maintain their social relationships by keeping in touch with their friends by any means possible, such as through social media or finding time to meet friends. Social support and positive relationship with other people are important aspects in someone's life and could increase psychological and physical well-being Matuska, et al. [46]. Tobing dan Glenwick, et al. [50] also found that satisfaction with the support that mothers received is associated with lower psychological distress in mothers of a child with ASD.

Conclusion

In-depth interviews as well as analysis procedures that have been conducted resulted in four themes that explain the occupational balance of mothers of a child with ASD, those

themes are: occupational pattern (consists of subthemes roles, social participation, leisure pursuit, and rest & sleep); challenges in carrying out roles (consists of subthemes stress, anxiety, emotional distress, and health problems); coping and performing tasks within the roles (consists of subthemes lifestyle change, emotion-focused coping, and problem-focused coping); and lastly, achieving balance (consists of subthemes spirituality and social support).

The results of this study showed that mothers of a child with ASD experienced changes in lifestyle and daily occupational pattern. Mothers have many duties associated with multiple roles that they have, yet having relatively limited time available, hence they sacrificed participation in paid work, social participation, rest and sleep, as well as other areas of occupation in order to focus their time on child care. To cope with daily challenges, mothers made use of various coping strategies which also helped them to achieve balance in their life. Occupational therapists who work with this group of people should take into consideration mothers' occupational pattern and help creating balance in mothers' daily occupation, in order to improve their well-being, quality of life, and general health.

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