Resilience in Daily Occupations of Indonesian Mothers of Children With Autism Spectrum Disorder

Tri Budi Santoso, Yuko Ito, Nobuo Ohshima, Mikiyo Hidaka, Peter Bontje

This qualitative study investigated how resilience functions in the context of daily occupations for mothers of children with autism spectrum disorder (ASD). Fourteen mothers of children with ASD participated in two focus groups that were used to elicit stories of the mothers' resilience in daily occupations. A constant comparative method was used for data analysis. A model of resilience in daily occupations of mothers of children with ASD was developed consisting of four categories: (1) creating and re-creating accepting conditions, (2) finding solutions, (3) striving for balance among daily occupations, and (4) thinking about the child's future. Sources of resilience were found to reside in both the mothers themselves and their social environments. Occupational therapy practitioners can use these findings in developing supportive approaches aimed at mothers, family members, and other people in the lives of children with ASD.


Raising children with autism spectrum disorder (ASD) can be challenging (Montes & Halterman, 2006). Examples of challenges include increased time required for nurturing the child (Smith et al., 2010); need to reorganize daily occupations around the child's special behaviors (Glazzard & Overall, 2012); lack of information regarding caring for and managing the child; and absence of support because of lack of acceptance among extended family members, social rejection, and lack of public awareness (Dababnah & Parish, 2013). Securing and managing educational and other services can be difficult; parents might have to take their child to therapy or school and carry out home exercise programs prescribed by therapists (Hodgetts, McConnell, Zwaigenbaum, & Nicholas, 2014). Finally, parents can be challenged by hectic schedules of activities devoted to their child’s needs (Stein, Foran, & Cermak, 2011). These demands can result in insufficient sleep (Myers, Mackintosh, & Goin-Kochel, 2009), fatigue and stress (Smith et al., 2010), reduced participation in stress-releasing occupations, and little time for oneself (Kuhoaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010).

The literature describes the plethora of challenges parents—specifically, mothers—of children with ASD might experience on a daily basis over the years of raising their child. Dealing with these continual challenges requires resilience, which, for the purpose of this study, we defined as a person’s capacity to rebound from difficult conditions (Garcia-Dia, DiNapoli, Garcia-Ona, Jakubowski, & O’Flaherty, 2013). Garcia-Dia and colleagues (2013) described resilience as processes consisting of rebounding, determination, social support, and self-efficacy. Rebounding is emotional and practical adaptation following the child’s ASD diagnosis (Koydemir & Tosun, 2009). Determination is persistence in finding solutions and resources (Lutz, Patterson, & Klein,
Self-efficacy, or belief in one’s ability to achieve goals, is affected by factors such as the severity of the child’s ASD (Rezendes & Scarpa, 2011), level of professional support (Hastings & Symes, 2002), and availability of early intervention (Reichow & Wolery, 2009).

Ungar (2011) suggested that resilience relies above all on access to resources relevant to one’s culture. However, Garcia-Dia et al. (2013) argued that external factors such as family, neighborhood, and financial resources influence how resilience processes occur. Weiss, Wongsiong, and Lunsky (2014) found that mothers’ ability to recover from difficult conditions was affected by lack of support from extended family, friends, and emergency services and financial problems.

The severity of challenges mothers of children with ASD face has thus been well documented. However, research has insufficiently addressed how resilience functions in the context of these mothers’ daily occupations. Therefore, the aim of this study was to identify and describe processes influencing resilience in the context of daily occupations among Indonesian mothers of a child with ASD.

Method

Participants

Fourteen mothers of a child with ASD were recruited through purposive sampling (Dickerson, 2006). Inclusion criteria were mother of a child with ASD age 18 yr or younger; residence around Jakarta City, Indonesia; and ability to speak Indonesian. Invitations to participate were sent to mothers through the Indonesian Autism Society and a pediatric clinic in Jakarta. Interested mothers contacted the principal investigator (PI; Santoso), who then explained the purpose and procedures of the focus groups, informed them that their participation was voluntary, and obtained their informed consent. This study was approved by the research ethics committee of Tokyo Metropolitan University. Table 1 summarizes the participants’ characteristics.

Data Collection

Focus groups were conducted to explore participants’ experiences of resilience in daily occupations and were moderated by the PI. In the moderator role, the PI encouraged mutual reflection on shared experiences by participants to elicit in-depth insight and greater meanings in the identified experiences (Barbour, 2007). Each of two focus groups of approximately 90 to 120 min in duration, one consisting of 8 mothers and the other of 6 mothers, convened twice.

An eight-question interview guide shaped both focus groups’ discussions in the first session. On the basis of a preliminary analysis of the first session’s content, a series of new questions were formulated for the second session. To encourage thick (i.e., rich, experiential) descriptions, the PI used probing questions to enhance in-depth explorations of the mothers’ stories. Both groups followed the same protocols to ensure consistency.

Data Analysis

Constant comparison was used to analyze the data (Charmaz, 2006). To ensure accuracy of the data, the PI transcribed the data verbatim from audio recordings and added observed gestures he recorded in field notes and verified from video recordings. Repetitive reading of the transcripts facilitated a comprehensive understanding of the data. After initial coding, the PI—with support of the coauthors who either collaborated in the coding and categorizing or critically reviewed the data—identified and developed categories and subcategories by comparing data with data, case with case, event with event, and code with code.

These categories were solidified by memo writing, in which the PI explained their properties, including the conditions and consequences of each category and subcategory and the ways in which these components conveyed meaning to each other. Relationships between categories and subcategories also were constructed by memo writing and by drawing graphic representations until a model began to emerge.

Study Rigor

Saturation of data was assumed when the second group session did not provide any new insights. Sufficient data were gathered to answer the research aim of identifying and describing processes influencing resilience in the context of daily occupations among Indonesian mothers of a child with ASD. The results of the study were presented to another group of mothers with characteristics similar to those of the mothers in the focus groups. This group verified that the results reflected their experiences. Rigor was further established through peer debriefing (Robson, 2002) consisting of discussion of the analysis and conclusions among the coauthors, presentation at scientific meetings in which feedback from audiences indicated validity, and presentation to a group of four psychologists who also agreed with the interpretation of the results.
Results

Analysis results are illustrated in Figure 1. The figure depicts the children’s future as the main domain of the participants’ concerns. Creating and re-creating accepting conditions forms a solid base for the participants’ resilience in daily occupations. However, this base can easily be destabilized by problems in any of four underlying factors. Resilience was also called on when the structure was destabilized by problems caring for the child or negative influences from the environment.

Resilience, as conceptualized in this study, served to help participants find solutions to problems and strive for balance among daily occupations. The dynamics of mothers’ resilience were influenced not only by internal factors within the home environment, such as family cohesiveness and financial resources, but also by external factors such as social support, stigma, and availability of professional services. These dynamics influenced and complemented each other. Thus, resilience consists of complex processes mothers used to gain access to strengths and resources, which functioned to counterbalance threats to balance in their daily occupations and to their coping with the challenges of raising a child with ASD.

Creating and Re-creating Accepting Conditions

The results show that creating and re-creating accepting conditions is fundamental to mothers’ resilience by easing their emotional and practical burdens. Accepting conditions include practical and emotional support from family members and other people in the environment. The family’s acceptance of the child, the involvement of the father in the child’s care, and understanding of the child’s condition among extended family all contributed to creating and re-creating accepting conditions. The mothers’ resilience was enhanced when their husbands, family members, and other people in the environment accepted the child’s condition and provided practical or emotional support. One mother noted, “First our husband must support us to make us stronger, . . . then the other people around us.”

Involving their husbands in the child’s care could be demanding. One participant described how she practiced patience and lowered her expectations of her husband, who did not involve himself much in the child’s care. At first she facilitated his involvement by writing daily child care schedules and asking him to take on certain tasks. She told of the burden her husband’s uninvolvment added to their child’s care:

At that time, my son was 5 years old and hyperactive, . . . but when he reached 6 years old, . . . my husband just kept quiet. . . . I cried for 2 years. . . . So one thing that made me annoyed was not my child but my husband. . . . Finally, with extraordinary effort, I involved my husband in caring for my child.

Later, this mother’s child successfully played his instrument in a music performance for an audience of parents of children with ASD, including her husband. Other parents asked how they had encouraged their child’s music skills, and the husband realized the importance of parents’ role when only his wife could answer the other parents’ questions. This mother reported that after this experience, her husband committed himself to assisting with their child’s care.

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<table>
<thead>
<tr>
<th>Participant</th>
<th>Age, yr</th>
<th>Marital Status</th>
<th>Education Level</th>
<th>Job</th>
<th>Age of Child, yr</th>
<th>Diagnosis</th>
</tr>
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<tr>
<td>1</td>
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<td>Homemaker</td>
<td>7</td>
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<td>Master’s</td>
<td>Lawyer</td>
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<tr>
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<td>Bachelor’s</td>
<td>Homemaker</td>
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<tr>
<td>5</td>
<td>38</td>
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<td>Master’s</td>
<td>Dentist</td>
<td>5</td>
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<td>Bachelor’s</td>
<td>Homemaker</td>
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<td>ASD</td>
</tr>
<tr>
<td>7</td>
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<td>Married</td>
<td>Bachelor’s</td>
<td>Private employer</td>
<td>7</td>
<td>ASD</td>
</tr>
<tr>
<td>8</td>
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<td>Homemaker</td>
<td>12</td>
<td>ASD</td>
</tr>
<tr>
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<td>Private employer</td>
<td>12</td>
<td>ASD</td>
</tr>
<tr>
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<td>Some college</td>
<td>Homemaker</td>
<td>10</td>
<td>ASD</td>
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<tr>
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<td>Some college</td>
<td>Private business</td>
<td>13</td>
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<tr>
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<td>13</td>
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<td>Some college</td>
<td>Homemaker</td>
<td>5</td>
<td>ASD</td>
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Note. ASD = autism spectrum disorder.
the grandmother attended a seminar about children with ASD; as a result, she developed similar perspectives on the child’s care, reducing the participant’s need to spend her resources of resilience on getting her mother to understand her perspective.

In short, both family cohesiveness and community supports are required for creating and re-creating accepting conditions. Creating accepting conditions, in turn, facilitates mothers’ resilience.

Finding Solutions

The participants used various strategies in finding solutions to problems, including participating in spiritual activities, using external resources, sharing problem-solving techniques with other mothers of children with ASD, and creating household management systems. Finding solutions enhanced their resources of resilience and freed available resources of resilience to deal with other aspects of the child’s care and with their own daily occupations.

One participant told how she dealt with solving the problem of her child’s rejection by several schools. A combination of persistence in applying to different schools and diligent prayer resulted in her child being accepted at a school: “Every night, I prayed to Allah requesting my child to be accepted at the right school for him. Finally, 2 weeks later, my request was granted.”

These mothers also used external resources such as pediatric clinics to promote their child’s functioning. One mother noted that therapy enhanced her communication with her child: “With the help from the therapist, my...
child is now able to follow my instruction.” As a result, her child started showing more developmental progress, increased abilities, and fewer problems, which in turn reduced the mother’s need to spend resources of resilience on the challenge of instructing her child.

The participants agreed that sharing experiences with others helped them deal with problems and enhanced their resilience. Sharing lowered mothers’ stress and exposed them to new practical knowledge, increasing their repertoire of problem-solving strategies. As one mother stated, “I feel sharing with other mothers is more effective rather than reading” about caring for a child with autism.

Finally, the mothers created household management systems to deal with problems in daily occupations. For example, they provided instructions for family members and nannies to ensure the child’s safety, planned their days and weeks while building in flexibility for dealing with emerging problems or the child’s needs (e.g., by having alternative plans in place), and established house rules. In particular, good child care systems were deemed helpful; as one mother stated, “I believe we all often experience irregularities and stumble in daily life [when we cannot execute] the plan already set in advance; finally, we create a system which makes us comfortable.” Thus, household management systems helped mothers regulate their daily occupations and lessened their burden.

**Striving for Balance Among Daily Occupations**

The mothers made efforts to establish balance among their daily occupations. The following strategies replenished and recharged their energy, helping them maintain this balance: getting enough sleep, engaging in leisure activities to expose themselves to different environments and get away from the daily routine, and obtaining support from their husband.

Getting enough sleep was very important for participants to stay healthy. One mother noted the need “to relax and be refreshed,” and another stressed sleep quality as important: “For me, enough rest is a luxury; the important thing is the quality.”

Participating in leisure activities helped these mothers recover and manage their available sources of strength. Leisure activities that provided the experience of belonging, such as family gatherings, were energizing and provided another source of resilience. A mother described the advantage of playing basketball with her friends to support her life balance “because I want to change to a different environment.” Another mother noted that her hobby of sewing, done after her child went to bed, was an enjoyable way to recover resilience. The mothers agreed that their own health was an important source of strength, and they participated in activities to support their health and well-being such as doing yoga, getting massage, or going to a beauty salon.

These mothers obtained support from others, such as their husbands, when striving for balance among daily occupations. One mother explained that on weekends her husband woke up early to take their child for a walk so she could use the time for herself. For another mother, healthy activities also provided a necessary escape from stress factors at home, and her husband expressed his support: “My husband told me, ‘You don’t have enough time for yourself; you have to go out.’” Having the child driven to and from school or looked after by a skillful nanny freed the mothers to do chores or take a break from caring for their child.

**Thinking About the Child’s Future**

In their stories, the participants voiced their worries and hopes for their child’s future. Creating and re-creating accepting conditions, finding solutions to problems, and enhancing balance among their occupations allowed the mothers sufficient mental and practical resources to work on their child’s future. In other words, when mothers were making effective use of personal and external resources, they were able to plan for and think about their child’s future. Accordingly, thinking about their child’s future was an indicator of mothers’ resilience in daily occupations. One mother noted that her ability to balance her occupations enabled her to plan for her child’s future: “I have to make a good plan . . . organize my time so that I can make real plans suitable for his condition.”

Accepting conditions and support also facilitated the mothers’ thinking about their child’s future. A participant told how she instructed her other children to support their brother with ASD, such as by training him in practical life skills. Several mothers told how they worked toward their child’s future; for example, one said, “I may explore, What are his talents? Maybe in music, photography or [an]other thing.”

The mothers also highlighted the importance of financial independence in preparing for a future in which they could no longer support their child. One mother noted, “I would like to have a place . . . so that I can open a business for my child.”

In short, the processes influencing the resilience of the participants were complex and challenging. The mothers’ ability to cope with their child’s difficult condition required enormous perseverance, effective strategies, and empowering resources to overcome their daily occupational problems. When they were functioning adequately, however, they were able to plan for their child’s future.
Discussion

This qualitative study resulted in the development of a model of resilience in daily occupations of mothers of children with ASD. Resilience in everyday occupations was enacted in four ways: (1) creating and re-creating accepting conditions, (2) finding solutions to problems, (3) striving for balance among daily occupations, and (4) thinking about the child’s future.

Creating and Re-Creating Accepting Conditions

Creating and re-creating accepting conditions was the foundation of the participants’ resilience. This foundation’s stability depended on family members, particularly husbands, and other people involved with the child (e.g., teachers). In another resilience study, Bayat (2007) reported that parents of children with ASD require flexibility from their family members in accepting the condition and meeting the demands that follow the child’s diagnosis. Acceptance of the condition facilitates the family’s adjustment and adaptation to the child’s problems and capacity to discover harmony (Luong, Yoder, & Canham, 2009). Furthermore, Greeff and van der Walt (2010) highlighted the importance of open communication within the family to facilitate adjustment to the needs of a child with ASD. Other research findings that lack of acceptance and support increase stress add support to our finding that acceptance and support strengthen mothers’ resilience (Bayat, 2007).

Finding Solutions

The mothers in this study used various strategies to overcome problems in their daily occupations. Our finding that participating in religious practices increased mothers’ inner strength is supported by other studies highlighting spiritual or religious activity as a resource in dealing with daily problems (Dababnah & Parish, 2013; Muniroh, 2010). These mothers also used external resources to find solutions, such as respite, professional support, and educational seminars. This finding is in line with Mackintosh, Myers, and Goin-Kochel (2005), who documented personal and professional connections, including with other parents of children with ASD, as a major source of information and support. Further, the mothers highlighted that household management strategies, including planning and work prioritizing, were helpful in overcoming problems, similar to the theme of “fighting all the way” identified by Woodgate, Ateah, and Secco (2008, p. 1081).

Striving for Balance Among Daily Occupations

Our findings show that effective daily plans assisted mothers in getting their occupations running smoothly. Kuhaneck et al. (2010) similarly demonstrated that continuous planning by mothers facilitated orderly daily routines. We also found that life balance was facilitated by family support and resources such as nannies, drivers, and adequate schools for the children. However, mothers with limited financial resources might have difficulty striving for their life balance; further study is needed to investigate the impact of social class on resilience. A qualitative study by Woodgate et al. (2008) highlighted the importance of taking time off from daily routines related to child care demands for parents of children with ASD to achieve healthy life balance. Our findings also show that these measures allow mothers more time for themselves.

Thinking About the Child’s Future

Our study showed that thinking about the child’s future was an indicator of resilience in daily occupations. When the two pillars of finding solutions and striving for balance among daily occupations in the model had enough stability, mothers had enhanced capacity for thinking about their child’s future. The wishes of the mothers in this study were similar to those found in other studies and included the expectation that their child would live independently, pursue an education, hold a job, and raise a family (Dababnah & Parish, 2013; Watson, Hayes, Radford-Paz, & Coons, 2013). The current study shows that the dynamics of resilience present in the mothers facilitated their thinking about their child’s future.

Future Methodological Considerations

Further research is warranted among mothers from other geographic regions and social groups, such as rural areas and families who are financially unable to obtain household help. Additional research might further develop the model and the categories. Observing and interviewing mothers in their everyday contexts provide practitioners with more direct access to the means by which resilience is enacted and functions in specific situations.

Implications for Occupational Therapy Practice

The results of this study suggest that occupational therapy practitioners can use individualized approaches to enhance various aspects of mothers’ resilience by

- Providing instruction to family members, teachers, and friends of the child with ASD;
- Educating families about how resilience functions in daily occupations and where to obtain resources for support services, perhaps through groups that include
mothers of children with ASD, their family members, and other involved persons and that use peer support principles; and

- Providing skills training in mitigating problems in mothers’ daily occupations, establishing balance in daily occupations, and preparing for the child’s future.

Conclusion

Resilience in daily occupations of mothers of children with ASD is enhanced when they understand and accept the child with ASD and have practical support from family members and social networks. Establishing such conditions provides a good foundation and source of strength for mothers in creating a balanced occupational life and dealing with difficult situations they experience on a daily basis over the years of raising their child. When mothers have sufficient resources of resilience, they are better able to plan for their child’s future.

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References


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