**Sub Article (Original article)** 

Resilience in Daily Occupations of Indonesian Mothers of Children

With Autism Spectrum Disorder

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### The aim of study

The aim study is to identify and describe processes influencing resilience in the context of daily occupations among Indonesian mothers of a child with ASD.

## Method

# **Participant**

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. This study was approved by the research ethics committee of Tokyo Metropolitan University.

### Data Collection

Focus groups were conducted to explore participants' experiences of resilience in daily occupations and were moderated by the principal investigator (PI). Two focus groups of approximately 90 to 120 min in duration, one consisting of 8 mothers and the other of 6 mothers, each convened each. An eight-question interview guide shaped both focus groups' discussions in the first session. 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. After initial coding, the PI —with support of the co-authors 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. 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. 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.

### Result

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.

## **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 provides 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 establishing 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.

#### References

- Barbour, R. (2007). *Doing focus groups*. London: Sage.
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, *51*,702–714. http://dx.doi.org/10.1111/j.1365-2788.2007.00960.x
- Charmas, K. (2006). Constructing grounded theory: A practice guide through qualitative analysis. London: Sage.
- Dababnah, S., & Parish, S. L. (2013). "At a moment, you could collapse": Raising children with autism in the West Bank. *Children and Youth Services Review*, *35*, 1670–1678. http://dx.doi.org/10.1016/j.childyouth.2013.07.007
- Dickerson, A. E. (2006). Securing samples for effective research across research design. In G. Kielhofner (Ed.), *Research in occupational therapy: Methods of inquiry for enhancing practice* (pp. 514-529). Philadelphia: F.A. Davis Company.
- Garcia-Dia, M. J., DiNapoli, J. M., Garcia-Ona, L., Jakubowski, R., & O'Flaherty, D. (2013). Concept analysis: Resilience. *Archives of Psychiatric Nursing*, 27, 264–270. http://dx.doi.org/10.1016/j.apnu.2013.07.003
- Glazzard, J., & Overall, K. (2012). Living with autistic spectrum disorder: Parental experiences of raising a child with autistic spectrum disorder (ASD). *Support for Learning*, 27,37–45. http://dx.doi.org/10.1111/j.1467-9604.2011.01505.x
- Greeff, A. P., &van der Walt, K. J. (2010). Resilience in families with an autistic child. *Education and Training in Autism and Developmental Disabilities*, 45, 347–355.
- Hastings, R. P., & Symes, M. D. (2002). Early intensive behavioral intervention for children with autism: Parental therapeutic self-efficacy. *Research in Developmental Disabilities*, 23, 332–341. http://dx.doi.org/10.1016/S0891-4222(02)00137-3
- Hodgetts, S., McConnell, D., Zwaigenbaum, L., & Nicholas, D. (2014). The impact of autism services on mothers' occupational balance and participation. *OTJR: Occupation, Participation and Health,34*,81–92. http://dx.doi.org/10.3928/15394492-20130109-01
- Koydemir, S., & Tosun, Ü. (2009). Impact of autistic children on the lives of mothers. *Procedia: Social and Behavioral Sciences*, *1*,2534–2540. http://dx.doi.org/10.1016/j.sbspro.2009.01.447
- Kuhaneck, H. M., Burroughs, T., Wright, J., Lemanczyk, T., & Darragh, A. R. (2010). A qualitative study of coping in mothers of children with an autism spectrum disorder. *Physical and Occupational Therapy in Pediatrics*, 30,340–350. http://dx.doi.org/10.3109/01942638.2010.481662
- Luong, J., Yoder, M. K., & Canham, D. (2009). Southeast Asian parents raising a child with autism: A qualitative investigation of coping styles. *Journal of School Nursing*, 25, 222–229. http://dx.doi.org/10.1177/1059840509334365
- Lutz, H. R., Patterson, B. J., & Klein, J. (2012). Coping with autism: A journey toward adaptation. *Journal of Pediatric Nursing*, 27, 206–213. http://dx.doi.org/10.1016/j.pedn.2011.03.013

- Mackintosh, V., Myers, B., & Goin-Kochel, R. (2005). Sources of information and support used by parents of children with autism spectrum disorders. *Journal on Developmental Disabilities*, 12,41–51.
- Montes, G., & Halterman, J. S. (2006). Characteristics of school-age children with autism. *Journal of Developmental and Behavioral Pediatrics*, 27,379–385. http://dx.doi.org/10.1097/00004703-200610000-00002
- Muniroh, S. M. (2010). Dinamika resiliensi orang tua anak autis (the Dynamic of resilience parents of children with ASD). *JurnalPenelitian (Journal of Research)*, 7(9), 1–11. Retrieved fromhttp://download.portalgaruda.org/article.php?article=251292&val=6751&title=DI NAMIKA%20RESILIENSI%20ORANG%20TUA%20ANAK%20AUTIS
- Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). "My greatest joy and my greatest heartache": Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, *3*,670–684. http://dx.doi.org/10.1016/j.rasd.2009.01.004
- Reichow, B., & Wolery, M. (2009). Comprehensive synthesis of early intensive behavioral interventions for young children with autism based on the UCLA Young Autism Project model. *Journal of Autism and Developmental Disorders*, 39,23–41. http://dx.doi.org/10.1007/s10803-008-0596-0
- Rezendes, D. L., & Scarpa, A. (2011). Associations between parental anxiety/depression and child behavior problems related to autism spectrum disorders: The roles of parenting stress and parenting self-efficacy. *Autism Research and Treatment*, 2011, 395190. http://dx.doi.org/10.1155/2011/395190
- Robson, C. (2002). *Real world research* (2<sup>nd</sup> ed.). Oxford, England: Blackwell.
- Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 40, 167–178. http://dx.doi.org/10.1007/s10803-009-0844-y
- Stein, L. I., Foran, A. C., & Cermak, S. (2011). Occupational patterns of children with autistic spectrum disorder: Revisiting Matuska and Christiansen's model of lifestyle balance. *Journal of Occupational Science*, *18*, 115–130. http://dx.doi.org/10.1080/14427591.2011.575762
- Ungar, M. (2011). The social ecology of resilience: Addressing contextual and cultural ambiguity of a nascent construct. *American Journal of Orthopsychiatry*, 81,1–17. http://dx.doi.org/10.1111/j.1939-0025.2010.01067.x
- Watson, S., Hayes, S., Radford-Paz, E., & Coons, K. (2013). "I'm hoping, I'm hoping . . .": Thoughts about the future from families of children with autism or fetal alcohol spectrum disorder in Ontario. *Journal on Developmental Disabilities*, 19,76–93.
- Weiss, J. A., Wingsiong, A., &Lunsky, Y. (2014). Defining crisis in families of individuals with autism spectrum disorders. *Autism*, *18*, 985–995. http://dx.doi.org/10.1177/1362361313508024
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, *18*, 1075–1083. http://dx.doi.org/10.1177/1049732308320112

Table 1. Participant Characteristics

Participant	Age, yr	Marital Status	Education Level	Job	Age of Child, yr	Diagnosis
1	43	Married	Bachelor's	Homemaker	7	ASD
2	45	Married	Master's	Lawyer	6	ASD
3	40	Married	Bachelor's	Homemaker	6	ASD
4	43	Married	Bachelor's	Homemaker	8	ASD
5	38	Married	Master's	Dentist	5	ASD
6	38	Married	Bachelor's	Homemaker	7	ASD
7	43	Married	Bachelor's	Private employer	7	ASD
8	40	Married	Bachelor's	Homemaker	12	ASD
9	42	Married	Bachelor's	Private employer	12	ASD
10	40	Married	Some college	Homemaker	10	ASD
11	37	Married	Some college	Private business	13	ASD
12	46	Married	Bachelor's	Homemaker	6	ASD
13	36	Married	Bachelor's	Homemaker	7	ASD
14	33	Married	Some college	Homemaker	5	ASD

*Note.* ASD = autism spectrum disorder.

Figure 1. Model of resilience in daily occupations.

