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# Redefining the meanings of daily-occupations and life quality amongst mothers living with their autistic children



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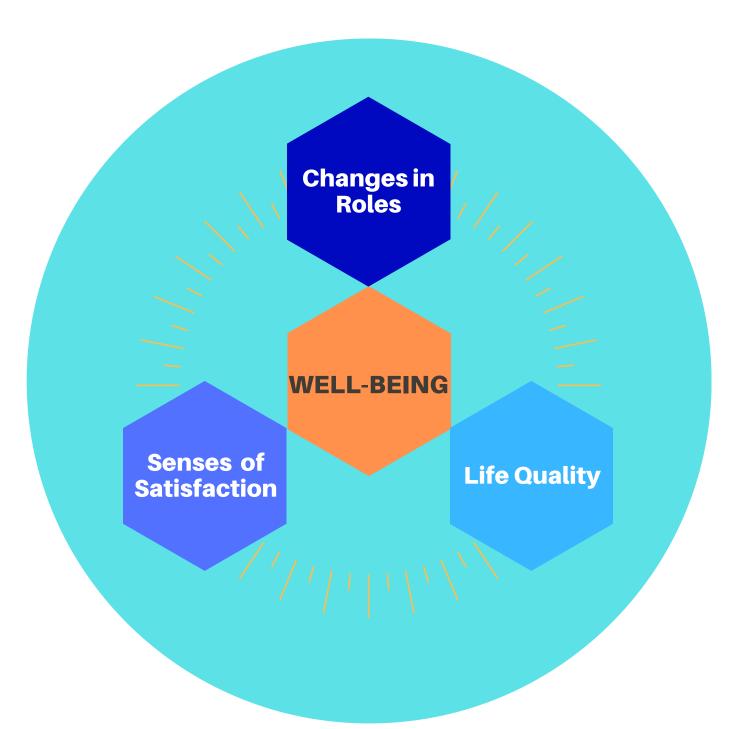
## Abstract

Raising children with autism is very challenging for mothers due to changes on how occupational performance and occupational roles are performed. This circumstance demands these mothers to redefine the meaning of doing occupations and how they perceive their well-being in general. This study empirically investigates how mothers redefine the meaning of daily activities and self-report their well-being. The study employs in-depth interviews and formulates specific themes of findings. The study uses the phenomenology approach to investigate the dynamics of meanings experienced by the respondents and how they construct the new version of well-being from raising the autistic children.

## Method

This study is qualitative research with a phenomenological approach designed to reveal particular ideas over numerous data collection. The studies by of Thorne (2000), Alhamdani (2016), and Suton & Austin (2015) were all adopted within the investigation. The theoretical construct of the theories leads the study to concentrate the analysis on the similarity of experiences, reported by the participants. The study conducted at ASA Club Clinic Jakarta (Indonesia) in 2018 and it involved four participants recruited via purposive sampling process. The selection process applied both inclusive and exclusive criteria aimed to capture desired information with maximum accuracy (Thorne, 2000 & Yin, 2016). Participants were within the age range of 30 to 50 year old, with education background varies from high school to bachelor degrees graduates. All four participants are working as housewives, while only one participant mentioned a fulltime job beside her first roles as a housewife. All of the participants are the primary caregivers of their autistic children. A collection of data had compiled through interviews, observations, and audio-visual materials such as photos, videotapes and recorded audios. The captured data were then analysed and codified into three major themes. The results then tested for validity through the triangulation process, member checking, and peer-debriefing.

# Results and Findings



# **Daily Occupations**

This study emerged with three themes as the results of data analysis processes. The constructed data themes are 1) the change in life quality, 2) the significant changing on occupational-roles, and 3) the sense of satisfaction to the roles experienced by the participants. The first theme describes the memento where life starts to transform in term of meaning and also the alteration of family systems, which then reform their quality of life in general. This perceived-changes, later play a significant part in how these participants interpreted their role as mothers in general and then redefined the importance of their roles within the family. Finally, the new meanings of doing occupations determine the satisfaction level of the participants, especially in performing their role as caregivers. The dynamic in interpreting the definition of the daily activities and perceiving life quality is pretty much understandable as fostering autistic children may deliver various challenges on coping strategies, achievements and expectations of their mothers.

## Summary



Occupational therapists are to employ cognitive-based approaches when working with mothers living with autistic children. The programs could be delivered through training and counselling, focused on adapting into new roles experienced by the caregivers (e.g., parent, family).

It will further allow occupational therapists to help their clients best prepare for the physically and psychologically challenges along with the adaptation processes. Other strategies to reduce psychological and emotional distress include designing appropriate home activity programs and providing psychological supports. These strategies are to help clients in preserving their life quality. Not to mention, occupational therapists may provide feedback to effectively maintain family dynamics, caregiver wellbeing, and ongoing treatments for the children.

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