

The dynamic nature of participation

Experiences, strategies and conditions for occupations in daily life amongst persons with late effects of polio

Akademiska avhandling

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av

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- I. Santos Tavares I, Thorén-Jönsson A-L. Confidence in the future and hopelessness: Experiences in daily occupations of immigrants with late effects of polio. *Scand J Occup Ther* 2013; 20:1, 9-20.
- II. Santos Tavares Silva I, Thorén-Jönsson A-L. Struggling to be part of Swedish society: Strategies used by immigrants with late effects of polio. *Scand J Occup Ther* 2015; 22:6, 450-61.
- III. Santos Tavares Silva I, Thorén-Jönsson A-L, Sunnerhagen KS, Dahlin-Ivanoff S. Processes influencing participation in daily lives of immigrants with late effects of polio in Sweden. *Submitted for publication.*
- IV. Santos Tavares Silva I, Ottenvall Hammar I, Willén C, Sunnerhagen KS. Fatigue among persons with late effects of polio is a common, but hard to explain phenomenon - a cross-sectional study in Sweden. *Submitted for publication.*



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ABSTRACT

Aim: The overall aim of this thesis was to explore the conditions for daily occupations, and how these are reflected in the daily lives of people with the late effects of polio. Four studies (studies I–IV) are included in this research: three follow a qualitative approach exploring the experiences, strategies, and conditions for daily occupations among immigrants with the late effects of polio, and one follows a quantitative approach to explore the possible factors associated with fatigue among persons with the late effects of polio in Sweden.

Methods: The Grounded Theory (GT) method was used to explore experiences, strategies, and participation in daily occupations and how participation is reflected and can be understood in daily life. Twelve immigrants from Eastern Africa with the late effects of polio were interviewed and the interviews were analyzed according to GT (studies I–III). For study III, a secondary analysis of the interviews was conducted to probe deeper into the complexity of participation. In study IV, an explorative and cross-sectional method was used to explore possible factors associated with fatigue.

Results: Study I showed that experiences in daily occupations were highly varied. Thoughts, feelings, and reasoning about capacities and opportunities to live and do things like everybody else resulted in the identification of participants' conceptions of occupational self, which in turn affected their view of the future. Experiences were dependent upon participation in daily occupations where the social environment had a salient role. The findings in study II showed how participants used 14 different strategies to find a balance between physical capacity, meaningful occupations, and the conception of their own and others' norms and values and living conditions in Swedish society. This resulted in a struggle for occupational participation and normality. Occupations within different areas of life and social interaction appeared to be important. Based on the analysis in study III, participation proved to be an ongoing, dynamic, and interactive process influenced by five subprocesses that contributed to value and identity development. Different conditions in daily life shaped the participation process. The process could have different strengths and could lead to both a sense of participation and exclusion. Study IV showed that factors associated with fatigue such as age and the use of mobility assistive devices could partly explain fatigue among persons living with the late effects of polio in Sweden. Use of mobility assistive devices proved to be the factor most likely to explain fatigue among participants. Participants using mobility assistive devices reported less fatigue than non-users.

Conclusions: This thesis contributes to the understanding of conditions for daily occupations among immigrants with the late effects of polio. These conditions make participation an inconstant and changeable process.

Attention must be paid to those conditions that create possibilities to perform daily occupations and opportunities for occupations, conditions that lead to engagement in occupations, and how the conception of occupations emerges in interactions with others and the environment. To provide interventions that support the management of physical capacity and increase knowledge about the late effects of polio and its consequences in daily life is essential. To prevent fatigue and enhance participation in daily occupations, it is important to provide and demonstrate the importance of assistive devices to ensure the management of fatigue. Understanding participation as an interactional process helps to clarify the social political aspects of participation, which advocates for the consideration of conditions that influence the participation process both politically and socially. The results call for a critical approach when addressing and enhancing participation. Additionally, the findings in this thesis reinforce the importance of occupations for those at risk of social exclusion.

Keywords: Activities of daily living, Cross-sectional study, Fatigue, Grounded Theory, Immigrants, Occupational science, Occupational therapy, Post-polio syndrome, Qualitative study

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