

Dementia Caregivers' Experiences of Sleep Preparation and Sleep Participation

Sydney Kalin, OTS Division of Occupational Therapy and Occupational Science
University of North Carolina at Chapel Hill



THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

INTRODUCTION

- More than 34.2 million Americans provide unpaid care .¹
- By 2050 the number of Americans living with Alzheimer's is expected to double and so will need for informal caregivers.¹
- 40-64% of caregivers are not receiving adequate sleep, which is associated with higher levels of caregiver burnout, depression, and can be a major factor in placing loved one in higher level of care .^{2,3,4,5}

RESEARCH AIM

To explore the experiences of caregivers of persons with dementia surrounding the occupation of sleep preparation and sleep participation.

METHODS

- Qualitative Descriptive Design
- Purposive Sampling
- Caregivers of individuals with dementia
Mark: 63 y.o. son, Sophie: 87 y.o. wife
- Semi-structured Interviews
- Iterative Descriptive Coding
- Triangulation

RESULTS

Finding a Rhythm

"If it is early in the evening and I tell him to take off his clothes then he'll do it, but later on when he is tired... this is something where I had to change my routine."

Navigating Intertwined Nighttime Rhythm

"First I was wondering or thinking about whether that's a good night sleep for me or like sleep for her or really it's kind of both together"

Managing Temporal Influences

"I know that he wouldn't last because we sleep together...there wouldn't be someone there with him during the night to know if he needs to get up or to answer his questions. And things he says.. he apologizes because he thinks that he will leave me and then he gets upset."

DISCUSSION

- Perceived quality of sleep (subjective) and amount of sleep (objective) did not always differ as much of research had suggested.
- Caregivers' experience of sleep preparation and sleep participation is influenced by their temporal, cultural, physical, and social context.
- Even if a caregiver experiences poor subjective sleep quality, other factors influence whether or not a caregiver institutionalizes their loved one.

IMPLICATIONS

- Occupational therapists are well situated to understand and problem solve with caregivers to facilitate caregivers' shared rhythm with their loved one.
- Future research: occupation-based sleep assessment, more qualitative research about caregivers' intertwined sleep preparation and sleep participation rhythm

REFERENCES

1. Alzheimer's association, (2018) Alzheimer's Disease Facts and Figures.
2. Ar, Y., & Karanci, A. N. (2017). Turkish adult children as caregivers of parents with Alzheimer's disease: Perceptions and caregiving experiences. *Dementia*, 147130121769340. doi:10.1177/1471301217693400
3. Aslan, Ö, Sanisoğlu, Y., Akyol, M., & Yetkin, S. (2009). Quality of sleep in Turkish family caregivers of cancer patients. *Cancer Nursing*, 32(5), 370-377. doi:10.1097/ncc.0b013e3181a87fb
4. McCurry, S. M., Logsdon, R. G., Teri, L., & Vitiello, M. V. (2007). Sleep disturbances in caregivers of persons with dementia: Contributing factors and treatment implications. *Sleep Medicine Reviews*, 11(2), 143-153. doi.org/10.1016/j.smrv.2006.09.002
5. Peng, H., Lorentz, R. A., & Chang, Y. (2015). Sleep quality in family caregivers of individuals with dementia. *Clinical Nursing Research*, 25(4), 448-464. doi:10.1177/1054773815610747