CONFERENCE ABSTRACT

Family caregivers’ involvement in Decision-making processes regarding admission to nursing homes for persons with dementia

19th International Conference on Integrated Care, San Sebastian, 01-03 April 2019

Lill Sverresdatter Larsen¹², Bodil Hansen Blix¹², Torunn Hamran¹²

¹: UiT The Arctic University of Norway, Norway;
²: Centre for Care Research, Norway

Introduction: The large number of people affected by dementia diseases poses major challenges for public health, healthcare services and healthcare service providers. The Western health policy of ageing in place rests on a triad collaboration among patients, healthcare service providers and family caregivers. Such collaborations presuppose involvement in and influence on a vague juridical landscape. Several researchers have stated the need for knowledge about decision-making processes regarding admission to nursing homes for persons with dementia. The research question of this study is as follows: How do family caregivers experience involvement in and influence on the nursing home decision-making process for persons with dementia?

Theory/Methods: The data consist of twelve in-depth interviews with family caregivers to persons with dementia. By the use of positioning theory, we demonstrate how family caregivers strive to balance their assumed duty to take care of the person with their needs to take care of themselves.

Results: The family caregivers involvement (or non-involvement) in the complex decision-making process is demonstrated through seven positions: 1) the self-condemning determiner, 2) the dominant, 3) the proponent, 4) the saluting, 5) the pending, 6) the prisoner, and 7) the stooge.

Discussions: We discuss why expedient positions are more available for some individuals and the consequences that family caregivers’ various positions have on the healthcare policy aim of collaboration, and moreover, of equal healthcare services.

Conclusions: Health care policies regarding ageing in place rest on a third party: the family caregivers. This study contributes family caregivers’ experiences of involvement in and influence on the nursing home decision-making process for persons with dementia. Knowledge of how family caregivers present themselves and others within positions is useful in understanding how decisions regarding admission to nursing homes are made, and further, in evaluating individuals’ access to healthcare. This knowledge is important for Health care providers in order for them to provide tailored support and thus facilitate the involvement of family caregivers in nursing home decision-making processes for persons with dementia.

Lessons learned: To pinpoint the legislated user involvement for persons with dementia and reduce the family caregivers’ decisional burden, politicians and healthcare services must understand, acknowledge and emphasize family caregivers’ own needs. If the Health care providers are aware of potential positions in interactions with family caregivers of persons with dementia, they may enable more expedient positions for themselves and family caregivers. More expedient
positions may result in fewer conflicts and reduced decisional burden when demanding decisions as admission to nursing homes must be made.

**Limitations**: The study design is an exploratory, qualitative design based on an interactional perspective, where ‘reality’ is context bound and thus the results reflect one of several possible interpretations.

**Suggestions for future research**: Our model of family caregivers’ positions can be useful for further development of decisional aid to reduce conflicts and negative effects of care for family caregivers in home-based care.

**Keywords**: decision-making processes; dementia; family caregivers; involvement; home-based care; admission to nursing homes; positioning