CONFERENCE ABSTRACT

The Need for Advance Care Planning for Individuals with Dementia in South Korea

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Introduction: Despite growing attention to dignified death and end-of-life care decision making in Korea, little effort has been made to help persons with dementia (PwD) and their family caregivers engage in advance care planning (ACP) or discussions on end-of-life care. This study examined the felt needs for ACP among social workers working with PwDs and their families and the factors that need to be considered in introducing and utilizing ACP in dementia care.

Methods: We conducted in-depth interviews with 7 social workers who work at day care centers (n=2), hospitals (n=3), and nursing homes (n=2) in Seoul and its vicinity in South Korea. We asked about participants’ opinion about ACP for PwDs, whether and how they engage in discussions on end-of-life care, obstacles in their efforts to engage in these discussions, suggestions for improving end-of-life care and decision making for PwDs. We conducted content analysis and extracted themes relevant to our research questions.

Results: Participants viewed ACP as a useful tool to engage individuals with dementia in decision making before they lose cognitive abilities. However, they pointed out many obstacles in implementing ACP, such as ‘gap between cognitive and physical death,’ ‘difficulty in assessing decision making capacity among individuals with dementia,’ ‘death-avoiding culture,’ and ‘people’s reluctance to discuss end-of-life care issues when individuals with dementia have decision-making capacity.’ They suggested that, in order for ACP to be helpful for persons with dementia, various individual, family, cultural, and societal-level factors should be taken into account in its implementation.

Discussions, conclusion, lessons learned: Findings suggest that, despite the benefits of ACP, practitioners felt limited in their capacity to engage in discussions on end-of-life care because of the cultural contexts, in which death is a taboo topic and families tend to make important decisions on behalf of older patients. Also, the lack of people’s readiness to discuss end-of-life care issues when patients are physically well-functioning was an obstacle. While changing the death-avoiding culture is important, providing more information about the process of cognitive decline and care options available at each stage can empower PwDs and their families to think about different choices they can make at the end of life.

Limitations and suggestions for future research: Our research participants were limited to social workers. In order to better understand the needs of persons with dementia and their families, future research should include these people who are directly affected by dementia. Also, examining the perspectives of other professionals, such as physicians, nurses, and bereavement counsellors
would extend the current research findings. Future studies should also look into ways to support and enhance decision-making capacity among individuals with MCI or mild dementia.