Abstract

Background

South Korea was the first East Asian country to implement hospice and palliative care, introduced by a group of Catholic nuns from Australia in 1963. Hospice and palliative care in South Korea have been primarily targeted at terminal cancer patients as part of the Cancer Control Act of 2004. However, according to government statistics on cause of death in 2019, dementia ranked 7th in South Korea, up from 13th a decade previously. As the role of home for dementia care is decreasing due to the falling fertility rate and the increase in the elderly population in South Korea, the government has announced a policy to relieve the burden on families of the elderly with chronic illnesses such as dementia. Hence, there is an increasing need for end-of-life care for people with advanced dementia, while at the same time, the provision of care is increasingly being provided by healthcare professionals and family members. Therefore, it is necessary to explore the experiences of family members and healthcare professionals in their provision of hospice and palliative care for people with advanced dementia.

Aim

The purpose of this study is to explore the ethical dilemmas of family members, nurses, and doctors involved in making decisions for people with advanced dementia in South Korea

Methodology

A qualitative research project designed to explore family members' and healthcare professionals' experiences of decision-making, the barriers they faced in their decision-

making, and supports for their decision-making, was undertaken using Hermeneutic Phenomenology as the research methodology. A total of 18 participants were recruited and interviewed for the project. Template Analysis (TA) was conducted to determine the significant issues in the data from the perspective of family members, nurses, and doctors with experience in caring for patients with advanced dementia.

Findings

Four themes were identified from the data collected from nurses who take care of patients with advanced dementia: communication barriers, lack of education, care for people with advanced dementia, and stressful ethical dilemmas. The nurses were actively involved in caregiving activities for patients with advanced dementia, but they felt that education on dementia care was insufficient. Their active expressions of intentions were often hindered when communicating with doctors, and they experienced ethical dilemmas when they disagreed with other healthcare professionals. Four themes from the doctors' experiences were derived: difficulties managing patients with advanced dementia, financial difficulties of patients with advanced dementia, the effects of decision-making, and healthcare professionals' lack of knowledge about dementia. The doctors experienced limitations in their scope of treatment because it was difficult to ensure patient cooperation due to the nature of dementia. Under some circumstances, there were cases where the doctors had to make decisions for patients with advanced dementia, while mental health specialists felt that other healthcare professionals lacked knowledge of these patients' condition. Finally, four themes were identified in the data from family members of people with advanced dementia: care for people with advanced dementia, experiencing conflict, decision-making for people with advanced dementia, and poor quality of life. The family members in this study made a

considerable contribution to caring for their relatives with advanced dementia, but they also experienced conflict with them, other family members, and healthcare professionals, particularly in relation to treatments for people with advanced dementia. As the next of kin, family members are often involved in making decisions for relatives with advanced dementia.

Conclusion

Understanding the experiences of family members, nurses, and doctors in caring for people with advanced dementia in South Korea assists with the identification of their ethical dilemmas. By highlighting what is and what is not known about the decision-making of family members and healthcare professionals for people with advanced dementia in South Korea, a range of educational support and policy development needs were identified. A number of suggestions are made at the end of the thesis for future research as well as for family members and healthcare professionals engaged in dementia care.

Key words: advanced dementia, decision-making, end-of-life care, ethical dilemma, doctors, family members, nurses, palliative care, South Korea