Cross–cultural acceptability of interventions that may increase control at the end of life in people with dementia

Xu, J.

1

General introduction

A few years ago when I was visiting my family in East Asia, I asked S, a lovely lady in her late 70s, whether she had any preferences for her future care in case she becomes unable to make her own decisions. At that time, she has already witnessed more relatives deteriorate with dementia. "Oh, but I wouldn't want to make my own decisions anyway. My son will decide for me, whether my brains still work well or not." I was surprised, because she did decide on her own to undergo surgery for a tumor the year before. "Well, I would rather they didn't tell me about the illness. It was really stressful to make the decision and to think about the possibility of dying. If something like that happens again, just operate on me and lie to me that I would only need a minor intervention under narcosis. People are different," she said, "My husband wanted to know every detail of his medical care. I don't."

The complexity of control: people are different, cultures are different

Erich Fromm described a paradox in his book 'escape from freedom': while personal choice provides us with freedom and potentials for self-realization, it also brings anxiety and burdensome responsibility which people tend to escape from (1). On the other hand, according to another psychologist Ernest Becker, stiving for control can also be a means to deny death and escape from existential anxiety (2). People differ in how much control they would like to have over their lives. In the case of lady S, she was more comfortable handing over control to her family, while her husband attempted to retain it himself.

On a broader level, people with different cultural and historical backgrounds may have different tendencies when it comes to control. In the western world, control is seen as essential for a good death (3, 4). This emphasis on autonomy and personal control can be traced back to the start of modernity in the seventeenth century (5). However, in societies where values of modernity were introduced later and are less firmly rooted, control may not be the primary concern. In collective cultures, filial piety, for example, is an important value (6). This entails taking care of the parents, including taking over the responsibility and control of their medical decisions (7). Religious emphasis on sanctity of life, as well as historical events such as the Nazi regime also leave

marks on how certain countries perceive as appropriate amount of control that a person or their physicians can take (8).

Control in end-of-life care for people with dementia

Additional challenges and controversies around control exist in end-of-life care for people with dementia. Dementia is a neurocognitive syndrome currently affecting 55 million people worldwide, with more than half living in low-and middle-income countries (9). It is estimated that the number of people that live and die with dementia doubles each five years (10). At the end of life, control of the individual includes making preparations for death, influencing the time and place of dying, and managing distressing symptoms (4). These may all be very challenging for people with dementia because of the impairments in cognitive functions, decision-making, and communication (11), and changes in wishes as the disease progresses (12).

Interventions that may increase control

Several interventions may increase control at the end of life for people with dementia, including advance care planning (ACP), the use of technology to monitor distressing symptoms at the end of life, and euthanasia. ACP entails discussing "goals and preferences for future medical treatment and care" (13). There are diverse approaches to ACP. An approach focusing on making concrete treatment orders may help people gain more control over the medical treatments and distressing symptoms at the end of life, while an approach focusing on exploring values and generating global care goals leaves some room for family and healthcare professionals to decide on specific treatments. Both approaches allow people with dementia to prepare for future care and death and express their wishes when they are still able to consider and communicate what they want. Monitoring technology may help people gain control over distressing symptoms by detecting signs of discomfort, since people with dementia at the end of life are often no longer able to express themselves (14, 15). Euthanasia provides people with the possibility of controlling the timing and place of death, and end unbearable suffering brought by dementia or other comorbid conditions (16). In some countries, decisional capacity before

administration is required, which excludes people in later stages of dementia from euthanasia (17). In others, an advance euthanasia directive may provide people with an opportunity to exercise control over their future death (18).

These interventions may be received with diverse attitudes and controversies given the complexity of control in end-of-life care for people with dementia. Many current studies focus on the perspective of physicians, who are usually the ones carrying out the interventions. Regarding ACP, research suggest that physicians face moral challenges that influence their willingness to conduct these conversations with people with dementia (19). An examination of their ethical considerations throughout the ACP process, from initiation to enacting the plans, is needed to tailor suitable approaches of ACP for people with dementia. Studies on euthanasia demonstrated that physicians are less acceptive of euthanasia for people with dementia than the general public (20) and research on this topic has mainly been limited to countries where euthanasia is legal (20, 21). As more countries are debating and legalizing euthanasia (17), acceptability of physicians from countries with a variety of legalization is worth investigating. In terms of technology, although rapid development is taking place in devices that monitor possible distress (22, 23), a first step still needs to be set in mapping the available technologies that may be useful for the end of life. The acceptability of promising technologies can then be tested among the stakeholders.

Aims and outline of this dissertation

The aim of this dissertation is to provide insight into the acceptability of interventions that may increase control at the end of life for people with dementia. The research questions are:

1. Are advance care planning, the use of monitoring technology, and euthanasia acceptable in end-of-life care for people with dementia?
2. Are there cross-cultural differences in acceptability of these interventions?

Chapter 2 comprises the protocol of the CONT-END study: attempts to Control the End of Life in People with Dementia. This mixed-method vignette study investigates the acceptability of two approaches of ACP, the

use of monitoring technology at the end of life, and euthanasia among people with dementia, family caregivers, and physicians in six countries.

Chapters 3 and 4 report the results of the CONT-END study. Using interview data, **Chapter 3** examines the perspectives of Dutch and US physicians on two approaches of ACP for people with dementia. The following question was answered: What are ethical considerations of physicians from two high-income countries (the US and the Netherlands) on ACP for people with dementia? **Chapter 4** presents the quantitative results regarding the acceptability of euthanasia for people with dementia among physicians from six countries. The following questions were addressed: 1) Is euthanasia acceptable for people with dementia from the perspective of physicians in these six countries? 2) Are there differences in acceptability of euthanasia for people with dementia from the perspective of physicians between the countries? 3) Which personal characteristics of physicians are associated with the acceptability of euthanasia for people with dementia?

Chapter 5 and 6 investigate the role of monitoring technology in end-of-life care for people with dementia. With a scoping review, **Chapter 5** addresses the following questions: 1) What noninvasive monitoring technologies are available or under development that identify discomfort and distressing symptoms which can occur at the end of life? 2)What is known about the clinimetric properties (e.g., validity, reliability, sensitivity, specificity, responsiveness) of these technologies? 3) What is known about the acceptability and feasibility of these technologies for persons with limited communication? **Chapter 6** presents a first step in exploring the acceptability of a well-developed technology, Bispectral Index monitoring (BIS), in end-of-life care for dementia, using focus groups with people with dementia and family caregivers living in the Netherlands. The following questions were investigated: Is BIS at the end of life of people with dementia acceptable from the perspective of people with dementia and their family caregivers? In which situations it is considered acceptable and why?

The dissertation is concluded with a general discussion in **Chapter 7**, with summarized findings, methodological considerations, and recommendations for the practice and future research.

References

1. Fromm E. The escape from freedom. An introduction to theories of personality: Psychology Press; 2014. p. 121-35.
2. Becker E. The denial of death: Simon and Schuster; 1997.
3. Coret M, Martimianakis MAT. Conceptualizations of "good death" and their relationship to technology: A scoping review and discourse analysis. Health Sci Rep. 2023;6(7):e1374.
4. Cottrell L, Duggleby W. The "good death": An integrative literature review. Palliat Support Care. 2016;14(6):686-712.
5. Monatschrift B, ist Aufklärung W. Michel Foucault. What is Enlightenment. The Foucault Reader New York: Pantheon Books. 1984.
6. Li WW, Singh S, Keerthigha C. A Cross-Cultural Study of Filial Piety and Palliative Care Knowledge: Moderating Effect of Culture and Universality of Filial Piety. Front Psychol. 2021;12:787724.
7. Badanta B, González-Cano-Caballero M, Suárez-Reina P, Lucchetti G, de Diego-Cordero R. How Does Confucianism Influence Health Behaviors, Health Outcomes and Medical Decisions? A Scoping Review. J Relig Health. 2022;61(4):2679-725.
8. Schicktanz S, Raz A, Shalev C. The Cultural Context of End-of-Life Ethics: A Comparison of Germany and Israel. Camb Q Healthc Ethic. 2010;19(3):381-94.
9. Organization WH. Dementia 2023 [updated 15 March 2023; cited 2024 04 April]. Available from: https://www.who.int/news-room/fact-sheets/detail/dementia.
10. Cao Q, Tan CC, Xu W, Hu H, Cao XP, Dong Q, et al. The Prevalence of Dementia: A Systematic Review and Meta-Analysis. J Alzheimers Dis. 2020;73(3):1157-66.
11. Nakanishi M, Martins Pereira S, Van den Block L, Parker D, Harrison-Dening K, Di Giulio P, et al. Future policy and research for advance care planning in dementia: consensus recommendations from an international Delphi panel of the European Association for Palliative Care. Lancet Healthy Longev. 2024;5(5):e370-e8.
12. Walsh E. Cognitive Transformation, Dementia, and the Moral Weight of Advance Directives. Am J Bioeth. 2020;20(8):54-64.
13. Rietjens JAC, Sudore RL, Connolly M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. Lancet Oncol. 2017 Sep;18(9):e543-e551.
14. O'Connor T, Paterson C, Gibson J, Strickland K. The conscious state of the dying patient: An integrative review. Palliat Support Care. 2022;20(5):731-43.
15. Schmidt H, Eisenmann Y, Golla H, Voltz R, Perrar KM. Needs of people with advanced dementia in their final phase of life: A multi-perspective qualitative study in nursing homes. Palliative Med. 2018;32(3):657-67.
16. Mangino DR, Nicolini ME, De Vries RG, Kim SYH. Euthanasia and Assisted Suicide of Persons With Dementia in the Netherlands. Am J Geriatr Psychiatry. 2020;28(4):466-77.
17. Richardson S. An international expansion in voluntary euthanasia/assisted dying: The implications for nursing. Int Nurs Rev. 2023;70(1):117-26.

18. Miller DG, Dresser R, Kim SYH. Advance euthanasia directives: a controversial case and its ethical implications. Journal of Medical Ethics. 2019;45(2):84-9.
19. Keijzer-van Laarhoven AJ, Touwen DP, Tilburgs B, van Tilborg-den Boeft M, Pees C, Achterberg WP, et al. Which moral barriers and facilitators do physicians encounter in advance care planning conversations about the end of life of persons with dementia? A meta-review of systematic reviews and primary studies. BMJ open. 2020;10(11):e038528.
20. Brinkman-Stoppelenburg A, Evenblij K, Pasman HRW, van Delden JJM, Onwuteaka-Philipsen BD, van der Heide A. Physicians' and Public Attitudes Toward Euthanasia in People with Advanced Dementia. J Am Geriatr Soc. 2020;68(10):2319-28.
21. Bravo G, Trottier L, Arcand M. Physicians' Characteristics and Attitudes Towards Medically Assisted Dying for Non-Competent Patients with Dementia. Can J Aging. 2022;41(1):135-42.
22. Khan SS, Ye B, Taati B, Mihailidis A. Detecting agitation and aggression in people with dementia using sensors—a systematic review. Alzheimer's & Dementia. 2018;14(6):824-32.
23. Nair P, Subha V, editors. Facial expression analysis for distress detection. 2018 Second International Conference on Electronics, Communication and Aerospace Technology (ICECA); 2018: IEEE.