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

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Summary

Introduction (Chapter 1)

This dissertation examined the acceptability of interventions that may increase control at the end of life of people with dementia. Dementia progressively affects cognition, decision-making, communication and physical functioning. These changes make it difficult for people with dementia to retain control at the end of life by expressing preferences, making decisions, or communicating discomfort and distressing symptoms. However, maximum control at the end of life may not be universally desirable. Some people prefer to remain closely involved in decisions about their care, while others prefer to delegate decisions to family members or professionals. Cultural, religious, legal and historical contexts may also shape how much control is considered appropriate, and who is expected to exercise it. In order to provide person-centered care to people with dementia and to shape education and policies regarding interventions that influence control, it is important to investigate people's attitudes towards such interventions.

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. Advance care planning entails communication about future care and treatment preferences, as well as values and goals of the person with dementia. ACP may help people with dementia express their wishes while they are still able to do so, thus exercising control over their care in the future. This dissertation investigated two ACP approaches, one focusing on concrete treatment orders (order-setting), and the other focusing on values and global care goals (goal-eliciting). Monitoring technology designed to monitor discomfort or distressing symptoms at the end of life may help people with dementia retain control over their well-being, and for family and physicians to monitor the symptoms when the person with dementia can no longer communicate it themselves. Euthanasia, where it is legally possible, may offer control over the timing and circumstances of death. It remains controversial in dementia care because the disease affects decision-making capacity and communication.

The aim of the dissertation was to provide insight into the acceptability of these interventions in end-of-life dementia care. Two research questions

guided the work: whether ACP, monitoring technology and euthanasia are acceptable in end-of-life care for people with dementia, and whether there are cross-cultural differences in their acceptability.

Chapter 2

Chapter 2 describes the protocol and pilot-testing of the CONT-END program, a cross-cultural mixed-methods vignette study on the interventions that may increase control at the end of life for people with dementia. The study was designed to assess the acceptability of the two ACP approaches, monitoring technology at the end of life and euthanasia. It included the perspectives of people with dementia, family caregivers and physicians in six countries: the Netherlands, Japan, Israel, the United States, Germany and Switzerland.

A central methodological feature of the CONT-END program was the use of short animated video vignettes. These vignettes explained the interventions in a standardized manner before participants were interviewed about acceptability. The study also collected information through questionnaire on demographic characteristics, life view, attitudes to dementia and dying, personality-related variables and professional background, depending on the participant group. A pilot testing was performed to check whether the vignettes and instruments were understandable, acceptable, feasible and not too burdensome. Based on participant feedback, the scripts were clarified, simplified and adjusted to be more neutral. The chapter therefore established the methodological foundation for the later empirical chapters.

Chapter 3

Chapter 3 reports the acceptability and ethical considerations on advance care planning for people living with dementia, from the perspectives of physicians in the United States and the Netherlands. The study included interviews with 50 Dutch physicians, 47 American physicians and three American nurse practitioners with medical responsibilities. Participants' views on two animation vignettes were included in this study: one about ACP focused on order-setting, such as resuscitation and hospital admission, and one about

ACP focused on getting to know the person and eliciting goals, such as maximizing comfort.

Both ACP approaches were regarded as acceptable by a large majority of participants in both countries. The analysis generated three ethical considerations that shaped physicians' views. The first was respecting the autonomy of the person with dementia. Physicians emphasized that, whenever possible, people with dementia should be heard and involved in decisions about their care, and that their preferences should remain central when families participate in ACP conversations. The second consideration was rationality as the basis for decisions and subsequent actions. Physicians did not view previously expressed wishes as the only relevant consideration; they also considered the clinical situation, feasibility, medical knowledge and the current best interests of the person with dementia. The third consideration was minimizing burden and suffering, both for the person with dementia and for those involved in care.

The chapter shows that ACP is ethically complex, even when it is generally acceptable. There is tension among the ethical considerations, especially between autonomy and rationality. Prioritizing autonomy may imply strict following of prior decisions, which may conflict with rationality based on current clinical judgment. This chapter therefore argues for an ACP approach centered on the values of the person with dementia, while allowing flexibility in future decision-making. Rather than treating ACP only as a way to secure goal-concordant care through fixed instructions, ACP should also support well-being, adjustment to dementia and communication among the person with dementia, family and professionals.

Chapter 4

Chapter 4 examines the acceptability of euthanasia for people with dementia from the perspective of clinicians in the six countries included in the CONT-END program. Differences in the acceptability between countries and associations between acceptability and personal characteristics were also investigated. Participants consisted of 202 physicians and three nurse specialists with similar medical responsibilities.

Across the six countries, 44% of the participants considered euthanasia acceptable for people with dementia, and 38% were willing to perform euthanasia upon request of a person with dementia. Acceptability was highest in the Netherlands, where 66% considered euthanasia acceptable. In the other countries, the proportion ranged from 23% to 44%. Dutch clinicians were also more often willing to perform euthanasia upon request of a person with dementia than clinicians in most other countries. We also found associations between acceptability and personal characteristics and coping styles. Planning as a coping style and religious coping were associated with lower acceptability of euthanasia. Willingness to perform euthanasia upon request of a person with dementia was associated with reporting no religion, no training in palliative care and less use of emotional social support as a coping style.

These findings show that opinions on euthanasia for people with dementia varied substantially between countries and individuals. Policy may need to consider the wishes and needs of clinicians both for and against this practice. Changes in the acceptability of euthanasia may be expected as palliative care becomes more widespread or when religiosity changes in a country. Research is needed to explore the mechanism of associations between coping strategies and acceptability of euthanasia.

Chapter 5

Chapter 5 presents a scoping review of non-invasive monitoring technologies that may identify discomfort and distressing symptoms in people with limited communication at the end of life. The review addressed the fact that people near the end of life may have difficulty expressing discomfort because of fatigue, sedation, delirium, cognitive impairment, loss of consciousness or communication problems. In current practice, recognition of discomfort often depends on observations by professional caregivers and family, but continuous observation is not always feasible.

The review comprised searches in nine databases and consultation of experts. Manuscripts were eligible when they described a non-invasive technology that measured discomfort, distressing symptoms or level of consciousness; could be administered continuously for at least four hours; and was potentially

applicable to bedridden people. Of 3,414 identified manuscripts, 229 met the eligibility criteria. The review identified a variety of technologies, including actigraphy, brain activity monitoring, electrocardiography, electrodermal activity monitoring, surface electromyography, incontinence sensors, multimodal systems and noncontact monitoring systems. The main indicators of discomfort measured by these technologies were sleep, level of consciousness, risk of pressure ulcers, urinary incontinence, agitation and pain.

The chapter concludes that many relevant technologies exist or are under development, but their application in end-of-life care remains under-researched. One study reported that brain activity monitors may be helpful and acceptable for monitoring level of consciousness during palliative sedation. For the other technologies, however, no manuscripts reported clinimetrics, feasibility or acceptability specifically in the end-of-life phase. It maps the field and identifies the need for future research to further develop monitoring technologies for end-of-life care, and to evaluate their usefulness, feasibility and acceptability in this context.

Chapter 6

Chapter 6 investigates the acceptability of Bispectral Index monitoring (BIS) in end-of-life care for dementia. BIS is a noninvasive bedside technology that uses brain activity to indicate level of consciousness. It is routinely used during surgery to monitor depth of anesthesia and may be relevant in palliative care, for example during palliative sedation or when consciousness and discomfort are difficult to assess. The study used focus groups and interviews with demonstrations of BIS monitoring and included 17 people with dementia and 24 family caregivers in the Netherlands.

The results show that people with dementia did not find the BIS sensors bothersome, but acceptability differed across participants and situations. Family caregivers generally considered BIS monitoring acceptable in medical situations, especially during palliative sedation and for pain assessment. Reasons for acceptability included the potential to improve care, support symptom monitoring, facilitate communication, assist decision-making and help family caregivers accept difficult situations.

At the same time, participants raised important concerns. Some questioned the added value of BIS compared with existing observation, communication and professional judgment. Others were concerned about feasibility, including signal quality and whether people with dementia would remove them if they are agitated or do not want sensors on their heads. The use of BIS was more controversial in non-medical situations, such as natural sleep. Participants also emphasized that the technology should not replace human care or human decision-making. The chapter concludes that BIS or similar technologies should only be implemented if they have sufficient added value, if people with dementia and family caregivers are well informed, and if the use of the technology remains supplementary to professional and family care. Future research should validate BIS monitoring in people with dementia and test its efficacy, feasibility and acceptability in the situations that participants considered most acceptable.

Discussion (Chapter 7)

Chapter 7 integrates and reflects on the findings, and discusses theoretical, methodological and practical implications. Returning to the topic of control, this chapter concludes that total control is indeed not possible or desirable for many people with dementia. ACP may increase control over future care, but physicians emphasized that future decisions require flexibility because circumstances and best interests may change. Monitoring technologies may support control by helping to detect discomfort when communication is limited, but the evidence base and acceptability remain incomplete. Euthanasia was not acceptable to many clinicians in the six-country study regardless of permissive legislation, leaving it inaccessible to many people with dementia as a means to exert control.

The discussion also addresses identity and the idea of a good death. Dementia can change memory, personality and moral capacities, which complicates the question of how far earlier wishes should travel in attempting to control future care. The dissertation suggests that ACP and education of the general public may help people reflect on possible changes in identity and accept uncertainty. A good death involves more elements than control, such

as being free from pain, comfort, dignity, familiar people and surroundings, person-centered communication, spirituality, a sense of completion and receiving preferred interventions. Although the interventions studied in this dissertation related to several of these elements, it is argued psychological and spiritual dimensions of a good death require attention in future research.

The methodological discussion highlights the importance and difficulty of including people with dementia in research on end-of-life care. The recruitment of people with dementia for studies in this dissertation was challenging. Professional and family caregivers sometimes acted as gatekeepers because they perceived the topic as too confronting or burdensome. The dissertation argues that this protection was not always supported by the actual experience of participants, many of whom valued the opportunity to contribute. Another challenge was timing: the period between diagnosis and loss of capacity to reflect on complex topics may be short or variable. The dissertation therefore recommends better integration of research into dementia care and more involvement of people with dementia throughout the research process.

For policy and practice, the dissertation recommends improving public awareness of end-of-life situations and choices in dementia, including realistic information about nursing home care, the changing needs of people with dementia and the limits of future control. It also recommends involving people with dementia in the development of technologies for end-of-life care and protecting people who have lost decision-making capacity from unwanted interventions, including non-preferred care technologies. For professionals, the dissertation recommends regular reflection on ethical dilemmas, for example through intervision or moral case deliberation, and greater involvement of psychologists and spiritual carers in end-of-life care to discuss fears and to facilitate living with uncertainties. For education, future healthcare professionals should be trained to reflect on conflicting ethical principles, their own values, identity, good death and the role of technology.

Conclusion

This dissertation shows that acceptability of interventions intended to increase control at the end of life for people with dementia varies. ACP was

generally acceptable to physicians yet ethically complex. Euthanasia was more controversial and acceptability varied substantially between physicians within and across countries. Monitoring technologies may support symptom recognition, but require further development, stronger evidence and careful implementation. End-of-life dementia care should therefore not aim to maximize control in a uniform way. Offering tailored control in an uncertain situation can be helpful, but foremost, we should strive to align care with the person's values, current needs, legal context and professional responsibilities.