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

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General discussion

Main research findings

The studies in this dissertation investigated acceptability of interventions that may increase the sense of control when applied in dementia care. The following research questions were addressed: 1) Are advance care planning (ACP), 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 describes the design of the CONT-END study, which investigated the acceptability of these interventions among people with dementia, family caregivers, and physicians in 6 countries. It also reports on the development of animation vignettes to explain ACP, monitoring technology, and euthanasia to participants of the CONT-END study. **Chapter 3** found that ACP for people with dementia was highly acceptable for physicians in the first two countries where we completed the data collection: the Netherlands and USA. Participants from both countries shared similar ethical considerations regarding ACP for people with dementia, which included respecting the autonomy of the person with dementia, rationality as basis of decisions and subsequent actions, and minimizing burden and suffering. Tension existed among these ethical principles, especially between autonomy and rationality. While prioritizing autonomy means strictly following previous decisions made by the person with dementia, prioritizing rationality indicates providing room for decision making based on the current situation, which can deviate from decisions made during ACP. We can conclude that ACP is acceptable in dementia care, at least according to physicians. There were little cross-cultural differences in the acceptability of ACP among two western, high-income countries.

The use of technology and euthanasia is more controversial. Differences in the acceptability of euthanasia were observed among countries and individuals. **Chapter 4** illustrates that euthanasia for people with dementia was acceptable for nearly half of the participating physicians in the Netherlands, Switzerland, Germany, US, Japan, and Israel. The acceptability was higher in the Netherlands compared to the other countries. Being religious, training in palliative care, and the coping styles planning, religious coping, and using

emotional social support were associated with lower acceptability. **Chapter 5** presents a scoping review which identified a wide range of noninvasive monitoring technologies to detect discomfort that may occur at the end of life. Most technologies were designed to monitor sleep, level of consciousness, risk of pressure ulcers, urinary incontinence, agitation, or pain. Potential application of these technologies in end-of-life care, however, was under-researched. No studies on clinimetrics, feasibility, and acceptability of the technologies were reported in this setting except for Bispectral Index monitoring (BIS). In a case study, this technology to measure the level of consciousness was perceived as helpful and acceptable during palliative sedation. Driven by further enquiry of the acceptability of BIS in end-of-life care for dementia, **Chapter 6** demonstrated diverse opinions among people with dementia and family caregivers in the Netherlands. For people with dementia, there were different opinions regarding acceptability, although the participants did not experience the sensors of BIS as bothersome. For most family caregivers, BIS was evaluated as acceptable for medical situations such as palliative sedation and pain assessment. Considerations underlying the acceptability related to perceived effectiveness, ethicality, and usefulness of the device. More research is needed to investigate whether there are cross-cultural differences in the acceptability of technology.

Theoretical considerations

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

All of the interventions investigated in this dissertation may influence the sense of control for people with dementia (Chapter 2). Control at the end of life can consist of making preparations for death, influencing the time and place of dying, and managing distressing symptoms (1). Although control is an important element in good end-of-life care in the western world (2), retaining total control is not possible or desirable for many people with dementia, through interventions both ahead of time and at the end of life. According to a recent review, people with dementia live for a median of 4.8 years after diagnosis (IQR 4.0-6.0; 66 studies) (3). Only less than a third of people with dementia reach the advanced stage of dementia (4). For people who do, the disease can take an average of 5.3 years from mild to the advanced

stage. (Q-statistic 0.39-0.42; 2 studies) (5). In earlier stages of dementia, attempts to increase control around the end of life may take the form of euthanasia, especially in countries where it is legal. However, since euthanasia for people with dementia is not considered acceptable by all physicians that participated in our study regardless of its legal status (Chapter 4), euthanasia may not be an option for many who wish to control their end of life in this manner. Control in earlier stages of dementia can also be exerted by making arrangements for future treatments and care through ACP. However, total control of future medical treatments is not desirable either. This is reflected in the acceptability of relevant interventions investigated in this dissertation. According to the Dutch and American physicians from our study, flexibility for in-the-moment decisions is required to weigh in the patient's best interest (Chapter 3). They argued that not all situations can be discussed in detail during ACP, and the situations and best medical decisions can change. At the end of life, control by the person with dementia may be enhanced by giving them a voice to communicate discomfort through monitoring technologies. Such technologies are still being developed (Chapter 5) (6), and people with dementia have demonstrated mixed attitudes towards BIS (Chapter 6) (7).

Previous research suggests that we still know little about attitudes towards control in people with dementia (8). The need for control may differ per person. Some people with dementia would prefer to focus on the current situation instead of the future, where the physical and mental level of functioning is difficult to know or imagine (9). Some people with dementia make adaptations to the new challenges in their lives, as a way to cope with the disease (10). Some researchers even argue that quality of life for people with dementia is defined by how well they cope and adapt to the situation (11). Only a small group of people with mild dementia from a British study expressed a wish to take control by making plans for the future (12). Thus, stakeholders in dementia care need to recognize that control may not be the most important issue. Interventions that aim to maximize control of the person with dementia, such as ACP focused on making concrete treatment orders, can be offered as an option but if the person with dementia does not want to participate, other intervention or support need to be provided. For the group for whom control is of critical importance, the limitations of retaining control at the end of life

may need to be addressed, such as explaining limitations of advance euthanasia directives.

Identity

Besides the possibility and desirability of control, the changing identity in dementia poses additional challenges in the exertion of control on a future end of life (13). Main components of identity, which is what makes any person to be themselves, includes personality traits (14), morality (13), and memory (15). As dementia progresses, the personality often changes towards more neuroticism, less extraversion, and less conscientiousness (16). Moral capacities can be damaged due to the dementia, leading to family members perceiving a change in the person with dementia (13). People with dementia in later stages may no longer be able maintain a continuous sense of identity based on past experiences and life story (17).

I support the opinion that instead of one single identity, people have "successive selves" which continuously change (18). It is questionable how legitimate it is to exercise absolute control over a future self, when this future self may in many ways be a different person. However, people typically cling to an illusion that their identity is continuous and consistent, and it is difficult to reconcile with changes in identity when planning for the future (19). It may be a role of ACP and public education to challenge the assumption of a continuous, consistent identity and facilitate the acceptance of change. For example, during ACP, some people with dementia may express a wish to end their life in certain future situations, like many Dutch participant with dementia of the CONT-END study. The healthcare professional engaged in the ACP can start a discussion on how the person with dementia sees themself in the future, and explain that many professionals observe an adaptation and change in attitudes of people with dementia as the disease progresses (Chapter 3). If the person with dementia expresses a fear for losing the self, it may be beneficial to explain that the experiential self remains even in later stages of dementia, which means that the person still experiences the world through their senses moment by moment, although this self may not be continuous (19). If people with dementia are open to the idea of a changing self and changing interests,

they can be encouraged to consider the moral responsibility of making prudent decisions, respecting the rights and agency of future selves (20).

Good death

One important aim of retaining control around the end of life and to provide interventions that are acceptable for the stakeholders is to ensure a good death (21). Essential elements of a good death in dementia include being pain-free, having comfort, peace and dignity, being surrounded by familiar things and people, person-centered communication, spirituality, having a completed life, and receiving only preferred interventions (22). These elements are similar to the definition of a good death in general (23). The interventions investigated in the CONT-END study mainly contribute to the first and last elements of a good death. However, the psychological and spiritual elements are also crucial components of a good death and should be addressed when there is a need (22, 24). This can be part of ACP, especially the approach of getting to know what is important for the person which we investigated in Chapter 3. However, this is not yet a wide-spread practice, as people with young-onset dementia made a suggestion in a recent study to include existential issues in ACP conversations (25). In Dutch end-of-life care, although spiritual caregivers are often involved, psychological and social services were used less frequently (26). In dementia care, psychologists are usually an integral part of the multidisciplinary team and often functions as the practitioner in charge together with a physician. I suggest that psychological care to be better integrated in the end-of-life care of other illnesses too. In the future, I believe, there is also a potential for technologies to assist caregivers in many routine tasks, such as monitoring the patient and helping with activities of daily living. Caregivers can thus use more of their time in providing human contact and attending to psychological and spiritual needs of the patient and family. The current generation of older people in Western countries may still feel uncomfortable for technology to assist with their activities of daily living, but the acceptance is higher in younger generations, suggesting a potential change in the future (27).

Methodological considerations

The strengths of the studies included in this dissertation were the involvement of a variety of perspectives on the controversial topics of end-of-life care for people with dementia. We not only involved voices from different countries, but also the different stakeholders including physicians, family caregivers, and most importantly, people with dementia.

Involvement of people with dementia in research

Patient and public involvement (PPI) in research is crucial because we ultimately want to provide care that address the needs of the most important stakeholders (28). In the CONT-END and BIS studies, the most important stakeholders are people with dementia. We strived to give voice to people with dementia by including them as participants, both in the actual study (Chapter 6) and during pilot testing (Chapter 2).

We faced many challenges recruiting people with dementia. Aside from the Covid-19 pandemic, a major obstacle we encountered was the well-meant protection from professional caregivers and also from family. Many perceived the topic as confronting and burdensome for people with dementia and protected them by not informing the people with dementia of this research. In some countries, like Israel, we were informed by our collaborator that people with dementia are generally protected from the news of their diagnosis, which make them ineligible to partake in the CONT-END study. Based on my experience while conducting the study, the concern of the protecting caregivers is not totally grounded. Although some potential participants refused to take part because they did not want to talk about the end of life or did not have room in their life for research, many agreed to participate when they were contacted directly by the researchers. Some interviews were indeed emotional for the participants, but they expressed that it was not more stressful than their current life with dementia. Many conveyed that they were very glad to be able to contribute in research on a subject that is of crucial importance for them. A number of participants also expressed gratitude for being able to talk about end-of-life topics freely and being listened to with full attention.

Another major obstacle was the timing of approaching people with dementia in research that require a substantial level of cognitive capacity. From our experience, the window is variable and can be small between receiving a dementia diagnosis to losing the capacity to contemplate on and articulate complicated issues such as ACP and euthanasia. In some countries, dementia is typically diagnosed late, which exacerbated the problem (29). Even when it is diagnosed timely, the current clinical criteria for the diagnosis of dementia require a considerable loss of cognitive capacity, which may already make it challenging to participate in an interview study (30). The turmoil of practical and emotional adjustments in the period directly after the diagnosis was also the reason for some people with dementia and family caregivers not to participate in our studies.

From our experience with tackling these challenges, I recommend better integrating research into dementia care. For example, memory clinics can register the willingness to be approached for research when a person gets a diagnosis. Informing people with dementia of potential research can be integrated into the tasks of professional caregivers, accompanied by sufficient training. Previous research suggested that training related to the research limited gate-keeping (31). Of course, the freedom to deny participation should be guaranteed. For research in late stage dementia, professional caregivers can also assist researchers to acquire consent of participation in advance (31).

Due to the difficulty in timing of involving people with dementia in research that require reasoning and elaboration of thoughts of people with dementia, I recommend that such research can include people with mild cognitive impairment (MCI) as well. A recent study showed that more than 90% of people with MCI ultimately progress to dementia (32). People with MCI are also experiencing cognitive decline and have thoughts about a possible future with dementia. The involvement of this group opens up the window of participation, although researchers should be aware that the experience and opinions of these participants may change as the disease progresses.

I also recommend more involvement of people with dementia in the whole research process. The role of the public and patients in research can range from listener, co-thinker, advisor, partner, to decision-maker (33). They

can be involved in one or more research stages (33). In our studies, people with dementia were mainly involved as listener and co-thinker during the execution phase of the research (28). We could have involved them more intensively throughout the research cycle as co-researchers instead of only participants. A review has demonstrated that this is feasible, for example by involving people with dementia in a lay advisory group or using interviews or focus groups to formulate a research agenda, co-create an intervention, or interpret qualitative data (34). However, the type of grant supporting the CONT-END study limited our options in involving people with dementia as co-researchers. I suggest funding bodies provide more room for public and patient involvement in all kinds of grants they provide. Researchers can also facilitate the involvement of people with dementia by building a trusting relationship, co-creating a clearly defined role, ensuring adequate resources, employing a flexible research design, valuing the lived experience of people with dementia, providing support if needed, and reflecting on their involvement (35). I hope that with these measures, more people with cognitive decline will get a chance to contribute to research and have their voice heard.

Mixed methods studies

The CONT-END study used a mixed methods methodology, combining interview with questionnaires, and closed questions with open-ended questions (Chapter 2). The quantitative data enabled us to compare the acceptability of the interventions across countries and groups of participants, as well as to explore factors that are related to the acceptability. The qualitative data helped us gain a deeper understanding of the reasons and situations where the participants considered a certain intervention (not) acceptable. Employing the mixed methods methodology in the CONT-END study provided us the possibility to answer a range of research questions that are not possible be answered by a qualitative or quantitative study alone (36).

However, I noticed that the mixed methods design posed limitations on the quality and efficiency of this particular study. We chose to formulate interview questions openly, so that instead of being restricted by specific situations described in the questions, participants could come up with important situations themselves of when the intervention was (not) acceptable.

However, in order to conduct quantitative comparisons in the CONT-END study, the questions need to be well-defined and the interpretations should be limited. Acceptability can be highly dependent on the specific situation, for example the stage of dementia, decisional capacity, and concomitant diseases (37). After the initial interviews, we realized that the participants interpreted the questions very differently and this made it challenging to interpret the quantitative results. We partially addressed it by specifying some concepts in the questions and adding them to a comprehensive guide for interviewers. Interviewers were instructed to redirect participants if they noticed that the participants had a different interpretation of the questions. However, this was not systematically checked for each participant, and some ambiguity remained in the interview questions. Thus, accurate interpretation of the quantitative results remains challenging.

We also met challenges of feasibility with the original concurrent design, collecting both qualitative and quantitative data from a single assessment. The power analysis based on the quantitative analysis resulted in 900 participants. This number is larger than what a qualitative study would require to reach data saturation. Although we decided to stop asking follow-up questions after reaching data saturation in each country and group, the interviews and subsequent data analysis were still time-consuming and had little added value. The study team then decided to provide a questionnaire-only version for physicians, so that they could view the video's and answer the questions on their own. This increased the efficiency of the study, limited the participant burden, and facilitated participation of busy physicians.

Upon reflection, I think that the CONT-END study could have benefited from a sequential design, so that the advantage of both approaches could be maximized, and the time could be spent efficiently. If I were to conduct the study again, I would have started with qualitative in-depth interviews with a small sample from each country to identify important reasons for and situations where the interventions were considered (not) acceptable. A questionnaire with more specific questions would be devised based on these situations, and distributed to a larger group of physicians and family caregivers.

This could have contributed to a more efficient use of the project time and better interpretable results from the quantitative data.

Positionality

The PhD trajectory has been a journey of continuous exploration and reflection on my positionality. I grew up in China and studied psychology in Hong Kong and Leiden. The education I received was largely based on (post-)positivism. There was a strong emphasis on gaining knowledge about an objective reality through quantitative methods, avoiding or reducing biases as much as possible during the investigation. While I recognize its value in natural sciences, I did not feel comfortable applying it to the subject that I'm interested in, which is the individual experience of human beings. Beyond the formal education, growing up in China also exposed me to idealistic views of the world from Buddhism. Although I do not adhere to any religious tradition, I felt affinity with the idea that each individual's subjective world is largely based on their unique perception and interpretation of their experiences.

I got into contact with constructionism through a sociology course during my Bachelor training, and later, in a course on qualitative research in the early phase of my PhD trajectory. I agreed with the epistemological assumption that knowledge in social sciences is created through human interactions (38). In the years afterwards, I experienced many internal conflicts reflecting on the research methods that I have used during my research, which were not all based on constructionism. I gradually realized that a key struggle was finding an ontological position between relativism and realism. My current reflection on this issue is that relativism and realism is not dichotomous, but a continuum. Objects of investigation vary in the extent they are affected by context and humans. The laws of physics, like gravity, are realities independent of the observer and human activity, although when the context drastically changes on a quantum scale, another set of laws will apply. Social phenomena are more dependent on human activities. Concepts of happiness, love, and end of life can be highly dependent on the social and historical context, while constantly being shaped by how people interact with each other and talk about these topics. Individual opinions on a certain topic can evolve continuously in the small context created by the interaction with the researcher.

My position in the CONT-END study is around the middle of the relativism-realism continuum, leaning slightly towards the realism side. This is based on my observation and assumption that most participants in this study seem to have a pre-existing general attitude towards topics like planning for future care, technology, and euthanasia. Although I recognize that their opinions can be more concretely formed during the participation in the study, influenced by how the interventions are portrait in the animation vignettes, how the interviewers ask the questions and how they respond to the answers. I also noticed that people who had more prior exposure to these interventions, especially experienced physicians, had stronger pre-existing views. A few other participants, however, developed new insights and modified or clarified their original view as they elaborated their opinions and gave deeper thoughts on these topics during the interviews. I recognize that we, investigators, play a role in the data that we get, but the opinions of the participants at the time of the study are also realities that are largely knowable and expressed.

The PhD journey has also helped me clarify my thoughts on agency. I interpret agency as the freedom to make choices and to act. It has been one of my core values, formed from frustrations and powerlessness growing up in an authoritarian environment. I have now gradually realized an accepted the limitations to it. I believe that our agency and number of available choices are limited by our cognitive and physical capacities, our societal context, and choices made by our previous selves.

I reflected on my own opinions on ACP, technology, and euthanasia throughout the study and observed them develop as I encountered the participants and literature. My view on ACP evolved from embracing it in all forms to seeing it as a way to communicate current values and needs. I began to adhere more value to the well-being of a later self. In a care context where there is enough attention to the needs of a person, and where maximum life extension is not the default, I even think that ACP may not always be necessary. My opinions towards technology changed from indifferent and slightly negative to more permissive, especially after finding monitoring systems in the review that do not require any contact with the person. I also changed my views on euthanasia from being totally supportive, from a respect to autonomy,

to more conservative, after hearing about the emotional burden it can have on physicians. During interviews, I tried to bracket my own views and react with a similar openness and curiosity towards all answers, although I noticed myself asking more questions when the opinion of the participant did not corresponded with mine. To facilitate reflexivity of the whole research team, I also set up a questionnaire for all investigators involved to reflect on their own opinions on the investigated topics and included such reflections in the training of all interviewers. Our opinions played a larger role in the presentation of the results and the recommendations that we give in the articles, for example the emphasis on leaving room for future decision making in Chapter 3.

Being a young, female researcher employed by a Dutch university with a Chinese appearance, I might have been seen as an outsider by most participants and it prompted them to explain their care system and cultural context in more details to me. I myself take an eclectic stance towards the cultures that I have lived in or am exposed to. Without feeling particular affiliations with any one of them. I observe and interact largely as an outsider. At the same time, being able to speak Dutch and English fluently, looking East-Asian in Japan, and being involved in the subject of dementia may have let participants to see me partly as an insider, enough to share their genuine view on the topics. Having lived long enough in both Asia and West-Europe, I also gained cultural experience that helped me understand participants' narratives as an insider. Many students and research assistants were also involved in this study, acting as insiders in interviews and during interpretation of data. This combination of insiders and outsiders allowed the study to enjoy the benefits of both.

Implications and recommendations

The results of this dissertation demonstrated that interventions that may increase the sense of control are controversial in the context of end-of-life care for people with dementia (Chapters 4 and 6). Even the highly acceptable intervention ACP entails complex ethical considerations with conflicting principles (Chapter 3). Therefore, interventions should be tailored for individual situations and preferences. Considerations and controversies surrounding the interventions and end-of-life care for people with dementia

can be made explicit for stakeholders to make more informed choices. Measures can be taken to support all stakeholders in the process of implementing the interventions when they are considered acceptable.

Implications for policy

I recommend policy to improve public awareness of end-of-life situations and choices in dementia. This is particularly relevant because ACP is recommended to start informally among the person with dementia and family (25). So quality information needs to be easily available before a healthcare professional gets involved in the discussion. In addition to making use of existing resources that encourage the discussion and documentation of treatment options and values (39-41), different views on identity can be presented to the public to stimulate reflection and formulation of their own thoughts. Campaigns can promote a realistic image of life in nursing homes, the end of life and the recognition that the needs of the person with dementia can change as the disease progresses. I believe that this may help people develop more realistic expectations, for example about moving to a nursing home or future euthanasia, and allow more flexibility when they or their family need to consider and document wishes for future care with dementia. This in turn will contribute to more suitable care at the end of life for people with dementia, and reduce ethical dilemmas of healthcare professionals and family.

I also recommend policy-makers to encourage the involvement of people with dementia in the development of technologies for end-of-life care. Our review found a large number of technologies that can potentially monitor distressing symptoms, but very limited research and application of monitoring technology in end-of-life care for dementia (Chapter 5). Our focus study on BIS monitoring demonstrated that some people with dementia and family were open to the use of technology in some, but not all situations at the end of life (Chapter 6). There is potential to better support care for people with dementia at the end of life with technology and suitable technologies need to be identified and further developed together with the stakeholders to best address their needs.

Furthermore, regulation should protect people who have lost capacity from interventions that they may not want to receive, including care technologies. In the Netherlands, this is regulated with the law Care and Coercion (in Dutch: Zorg en Dwang), which advises against interventions if there is no consent or if the person with dementia shows signs of resistance, and requires regular evaluation to find alternatives or reduce the involuntary care. However, practical challenges in the implementation are reported, and the rights of people who are not resisting against involuntary care may still be under-protected (42). Other countries that are designing or modifying similar laws can make use of the experiences in the Netherlands.

Implications for practice

To facilitate practitioners to deal with ethical challenges inherent in caring for people with dementia at the end of life, I recommend that they hold regular intervision sessions to discuss their doubts, reflect on their own value systems, and support each other. This can be done in a comprehensive moral case deliberation in groups with 8-12 participants (43), or in quick simple steps on a small scale (44).

I also recommend more involvement of psychologists and spiritual carers in end-of-life care. In my opinion, the fear of death and fear of discomfort can play an important role in the choices people make for their (future) care including end-of-life care (45). These fears should not be discarded as psychological disfunction and used as reasons to disqualify someone from making their own decision. Rather, as the existential psychotherapists stated, these fears can be opportunities to stare at our existence straight in the eyes and open possibilities of living a richer and more fulfilling life (46). I argue, as a psychologist myself, that my colleagues and spiritual carers can play a more important role in end-of-life care whenever possible, to prepare people by exploring their attitudes towards life and death, before they discuss and document their wishes regarding medical care with medical professionals. In my opinion, psychological intervention to facilitate acceptance and adjustment should be available and recommended when the fear for future deterioration is expressed as the main reason for an euthanasia request or an advance euthanasia directive.

Implications for education

Educational programs can prepare healthcare professionals for their future career by increasing their awareness and reflections on the complexities in end-of-life care for dementia. They can be introduced to the conflicting ethical principles, and the possible integration of more technologies in dementia care. Future healthcare professionals should be encouraged to reflect on their own values, theirs view on identity, good death, and technology in order to make conscious choices and state their personal preferences and limitations to their future clients.

Future research

The findings presented in this dissertation point to many directions for future research. For example, acceptability of interventions affecting the end of life for people with dementia should be examined among the stakeholders in middle- and low-income countries, and different cultural groups within one country. Studies can also be conducted to further develop and implement monitoring technologies to detect distressing symptoms at the end of life. My personal interest lies in exploring interventions that address the need of control, identity, and facilitate acceptance of death and decline in people with cognitive impairment. I'm interested in whether this acceptance would affect their choices for the end of life, and attitudes towards interventions investigated in this dissertation.

Recent reviews reported that psychological interventions (such as problem-focused and meaning-focused therapies) may have a positive effect on the acceptance of the disease, depression, and quality of life in people with cognitive impairment (47, 48). However, research on this topic is limited and the quality of many of the studies was low (47, 48). I suggest co-creating an intervention together with people with cognitive decline, case managers, and psychologists working with this population, aiming at reducing fear for future decline and enhancing the acceptance of uncertainties. The intervention can then be implemented in a randomized controlled trial. People with subjective cognitive decline and mild cognitive impairment can be recruited through patient organizations, memory clinics that receive consultations regarding cognitive decline, general practitioners, nurses, and other professional

caregivers who work with community-dwelling people with dementia. People who experience stress and fear for future decline can self-identify or be referred to this intervention by healthcare professionals. Depending on the country, psychologists, social workers, and case managers can be trained to provide the intervention, because they are trained to provide psychosocial interventions and usually work in an interdisciplinary team together with the medical care professionals who would perform the referral. The attitude towards future changes and decline, current quality of life, and goals of care can be measured as outcome. The intervention can start in one region in one country, for example the Netherlands. If successful, it can be expanded to other regions or combined with psychosocial interventions designed for family caregivers such as acceptance and commitment therapy (49). It may also be interesting to investigate whether such an intervention would be applicable to other cultures and countries.

Epilogue

Last year, I talked with the lovely East-Asian lady again about her wishes for the future "Now that I'm above 80, I accept death and do not mind talking about it at all," she said lightheartedly, "I think it helps my family if they know what I want". In the presence of her children, we went over her wishes and several common treatment options at the end of life. Her decisions were documented. It was challenging, however, to explain to her that we would not follow her wish to feed her a bunch of sleeping pills to end her life once she is too ill to take care of herself. She was not totally satisfied, but accepted our promise that we would do our best to ensure comfort and quality of life.

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