Translation and cross-cultural adaptation of a family booklet on comfort care in dementia: sensitive topics revised before implementation

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ABSTRACT

Introduction Families of patients with dementia may need support in difficult end-of-life decision making. Such guidance may be culturally sensitive.

Methods To support families in Canada, a booklet was developed to aid decision making on palliative care issues. For reasons of cost effectiveness and promising effects, we prepared for its implementation in Italy, the Netherlands and Japan. Local teams translated and adapted the booklet to local ethical, legal and medical standards where needed, retaining guidance on palliative care. Using qualitative content analyses, we grouped and compared adaptations to understand culturally sensitive aspects.

Results Three themes emerged: (1) relationships among patient, physician and other professionals—the authority of the physician was more explicit in adapted versions; (2) patient rights and family position—adding detail about local regulations; and (3) typology of treatments and decisions. Considerations underlying palliative care decisions were detailed (Dutch and Italian versions), and the Japanese version frequently referred to professional and legal standards, and life-prolongation was a competing goal. Text on artificial feeding or fluids and euthanasia was revised extensively.

Conclusions Providing artificial feeding and fluids and discussing euthanasia may be particularly sensitive topics, and guidance on these subjects needs careful consideration of ethical aspects and possible adaptations to local standards and practice. The findings may promote cross-national debate on sensitive, core issues regarding end-of-life care in dementia.

INTRODUCTION

Dementia is a progressive illness which limits prognosis. In the course of the disease trajectory, patients and families frequently develop palliative care needs.1 Family members are usually involved in care and support of patients with dementia, including in end-of-life decision making. This may present ethical and emotional dilemmas. To support their decision making, families need adequate and customised information about dementia and the natural evolution of the progressive disease, and on care and treatment options including on comfort or palliative care which are often used as synonyms.1 2

To support family, a guide was developed in French and English in Canada in 2005 in the form of a booklet on comfort care at the end of life with dementia3 (box 1).

This booklet was intended primarily to support family members and relatives of people with dementia residing in institutional settings. It was based on the international literature, but also on specific needs elicited in qualitative research into decision making in Quebec.4 It explains treatment options, but was written explicitly from the perspective of palliative care. It provides guidance based on the assumption that dementia is a terminal disease and palliative care therefore applies, rather than providing neutral information on treatment options—including life-prolonging interventions—which is common for decision aids.5 The booklet concerned sensitive information tailored to the Canadian situation but the terminal nature of the dementia and families’ information needs may be universal to some extent. We decided to adapt the booklet to other countries rather than developing new booklets for each country for a number of reasons that relate to better cost-effectiveness.6 First, it was based on thorough qualitative research on family experiences;7 second, preliminary evidence of effectiveness was available: it was shown to improve communication between nursing staff and family in the area of development;8 third, it appeared well balanced with the limitation that there was no accepted concept of what comprises palliative care in dementia at that time as appeared recently;9 10 and fourth, it was well written for non-academics. Finally, at that time, to our best knowledge, no other such booklet had been developed. There are, however, considerable cultural differences between end-of-life decision making and caregiving practices, for example, between South European countries such as Italy versus other, more Northern European countries,9 10 and between Western countries and Japan,11 12 such as on the role of professional and family caregivers, and the value attached to living as long as possible.

An international team prepared for its implementation in Italy, Japan and the Netherlands and found, as others,5 that translation alone would not suffice. The booklet was translated and adaptations deemed necessary for local acceptability were carried through. Substantial adaptations in several booklets were necessary to guarantee a basic level of acceptability, for example, to meet different legal frameworks/regulations. This mostly reflects the ‘sensitive’ nature of the matter. In this
implementation study, we categorise and compare textual and substantive revisions made to the three new versions of the booklet. We aim at understanding which aspects are sensitive from an ethical and cultural point of view within the respective cultural contexts in giving shape to palliative care in dementia.

METHODS

Local teams (all including researchers, ethicists and physicians) in dementia palliative care first translated the original English version of the Canadian booklet. Subsequently, the rather literally translated text was modified for fluency to match the language more commonly used in each of the three countries. It was further adjusted to applicable medical, ethical and legal standards and views in the country involved, if needed, in consultation with local experts (eg, Alzheimer’s Association, legal expert). The starting point was to retain the structure and the central message of the booklet—dementia is a terminal disease and palliative care therefore applies—and to stay close to the original text where possible.

The booklet was then back-translated by professional translators. All back-translations were evaluated by the developer of the booklet for adherence to the central message. The local teams included any subsequent adaptations in the final text in English for analyses, distinguishing deletions, additions, revisions and style adaptations, and indicated reasons for any substantial modification of the original text.

The adaptations and the reasons why these were made were then inventoried by the members of the Dutch team. In an iterative process of qualitative content analysis and discussion, the adaptations were analysed and categorised into themes. Preliminary findings were evaluated by the responsible researchers of the other countries and the Canadian author.

Further, an international acceptability study was initiated, evaluating and comparing acceptability and usefulness of the adapted and original versions among families and practitioners. Briefly, acceptability was the highest in the Quebec area of development, and—despite the adaptations—lowest in the most distant culture (Japan). The study resulted in second revised versions in two of the three countries.

RESULTS

First adapted versions: three themes in revisions

Three themes emerged on which the four versions of the booklet differed substantially from each other. These themes are described below, and include: relationships among the patient, physician and other professional caregivers; patient rights and the position of the family members/next of kin (surrogate decision maker); and typology of treatments and decisions at the end of life. Small adaptations concerned modest rephrasing (eg, preferred use of passive voice in the Japanese version, illustrated in box 2), and larger adaptations mostly concerned additions rather than deletions. The Italian version follows the original text most closely; adding some underlying considerations, whereas the Dutch and Japanese text extended considerably on underlying considerations (Dutch version) or legal and professional standards (Japanese version). Overall, the Japanese version was adapted most extensively.

Relationship among the patient, physician and other professional caregivers

As the dementia progresses, various professionals become involved with the patient. In institutional settings, the healthcare team plays an important role. As obvious from the text of the booklets, nurses do not generally make medical decisions in any of the four settings under study, but they are involved in the considerations of physicians and family.

The four versions differ with regard to how these complex relationships are expressed. In the Canadian version, a—not very explicit—distinction is made between the physician and the nurses when it comes to formulating medical decisions. The Canadian text focuses mainly on generating a broad consensus.

The Dutch and Italian versions distinguish more explicitly among the roles of the physician, nurse (aid) and patient, with a focus on clarifying and separating responsibilities and positions rather than on consensus. Both versions state that physicians make the medical decisions, albeit in consultation with the patient or his/her representative. In the Italian version, compared with the Dutch version, the physician has more authority to make a decision, especially when there is no legally appointed representative. The Japanese version focuses mainly on the physician–patient relationship and on responsibility for medical decision making, in which nursing staff and careworkers (nurse aids) play no role.

Patient rights and the position of the family members/next of kin (surrogate decision maker)

As a rule, patients need to be informed and they must consent to medical treatment. This will become a problem at some point in the case of patients who suffer from dementia. The required informed consent for treatment will then have to be provided through a surrogate decision maker instead of the patient. Nevertheless, the relevance of protecting and guaranteeing the autonomy and privacy of the patient is a central concern in all four versions of the booklet.

The versions of the booklet, however, reflect differences in legal context with respect to the position and power of the patient’s representative as surrogate decision maker. In Canada

Global medical ethics

Box 1 Contents of the original and all (first) adapted versions of the family booklet on comfort care in dementia

- Natural evolution of Alzheimer disease and related disorders in advanced stages
  - Eating and drinking difficulties
  - Repeated infections especially pneumonia
  - Appropriateness of hospital transfer and cardiopulmonary resuscitation
  - Relevance of comfort/palliative care approach
- Decisions at the end of life
  - Role of the family and the physician
  - What to do in case of conflict?
  - Withholding or withdrawing life-prolonging treatments
  - Active life termination
- Relief of symptoms and decisions
  - Relief of breathing difficulties, pain and anxiety
  - Usefulness of antibiotics for pneumonia
  - Intravenous fluids for dehydration
  - Feeding tubes
  - Myths about the use of morphine and other opioids
- Final moments
- After death

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  - Role of the family and the physician
  - What to do in case of conflict?
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  - Appropriateness of hospital transfer and cardiopulmonary resuscitation
  - Relevance of comfort/palliative care approach

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and Japan, the representative does not make a medical decision but provides consent. The Italian and Dutch versions detail on regulations on family members representing the patient in decision making and how a legal representative may be appointed.

**Box 2 Text fragments from the four versions of the booklet on intake problems and withdrawing of tube feeding**

**Original Canadian version and (first adapted) Dutch version:**
“What to do if the person already has a feeding tube?”

Even though some might have trouble understanding this concept, experts in the field of ethics consider that the decision to stop tube feedings is essentially the same as not inserting a feeding tube. Thus, after discussing with the family representative or mandatory,* it is possible to stop the tube feeding at any time that it is judged to be in the best interest of the patient. The tube does not need to be removed because the procedure is usually uncomfortable. Although this may seem inhumane, as ethics experts point out, why should people suffer for a longer time than before the advent of current technological advances?

**Italian version:**

Addition to original text: ‘Thus, after discussing with the family representative or with a legal-representative (a ‘tutore’ (guardian) or a ‘amministratore di sostegno’ (a support administrator)), if the disease is near to the end or if there are more frequent complications of the feeding tube (vomiting, ‘ab ingestis’, decubitus ulcer, patient’s intolerance of the gavage tube), it is possible to stop the feeding tube.’

**Japanese (first adapted) version:**
“What can be done for a patient who already has a feeding tube?”

Addition to original text:
‘The decision to stop artificial feeding is certainly a difficult one and can cause distress and guilt feelings. However, it will be greatly influenced by the professional caregiver’s attitude. Professional caregivers should present this as one of options and discuss with family members in their legal and ethical context and relevant in this patient’s situation.

Note: In the judicial precedent and medical ethics, there is no difference legally or ethically between ‘withholding’ and ‘withdrawal’ of care. In many cases, people involved in care often feel differently between the two. It is emotionally difficult to remove a feeding tube for artificial nutrition from patients who can otherwise live a few months or even more than a year with artificial fluid and nutritional supply. Such an act can arouse a deep sense of guilt.

Removal of a feeding tube is considered the same as ‘withholding life-prolonging treatment.’ In present Japan, it is considered necessary to satisfy all of the requirements of futility of treatment, prior intent of the patient, consent of the family and appropriate procedure.

The patient and the family can experience great psychological and emotional conflicts in making a decision to ‘withhold or withdraw life-prolonging treatment.’ If the measure that they decided is implemented, then it can cause further conflicts. The implementation is even more difficult and painful than making the decision. Even if the family is aware of the patient’s wish, they could be hesitant to implement it.’

*A mandatory may be similar to an ‘attorney’ or ‘guardian,’ terms that may be more commonly used in some countries other than Canada.

**Typology of treatments and decisions at the end of life**

The original guide and the translations conceptualise (advanced) dementia as a terminal disease and the primary orientation of the treatment should therefore be palliative. Within the context of this explicit orientation all versions of the booklet discuss how to provide comfort, as well as possible withholding or withdrawing (life-prolonging) treatments, and euthanasia. Only the Dutch version addresses palliative sedation because of possible information needs due to the topiality in the Netherlands. The text on artificial hydration and nutrition, and on euthanasia was revised most thoroughly as we point out below.

The original Canadian version mentions the possible life-prolonging treatments describing them as frequently useless or ineffective because they prolong the suffering of the patient, even though considered in a case-to-case approach. The purport is not to prolong life unnecessarily, reassuring that this is an acceptable option, and briefly mentioning underlying considerations regarding these decisions.

The Italian version adopts much of the Canadian version. The recommendations regarding dehydration and intravenous fluids are the same (box 5). The Dutch version provides more information about the considerations underlying the decision. In the Japanese version, a different ethical context emerges in which maintaining and protecting life is another leading general principle including for terminal diseases such as dementia. The decisions that are to be considered and are described in this version must always be seen in this light, dealing also with families’ expectations (box 3). This makes the tendency towards life-prolonging treatments stronger. Furthermore, the Japanese version does consider the palliative options, but lets the scope of treatments and care, and the process of end-of-life decision making be determined mainly by the framework outlined by professional associations and health insurance schemes:

‘In present Japan, the indication for morphine is only for ‘cancer pain’.

In the framework of health insurance, morphine cannot be used for breathing difficulty at the end of life. Additionally, the associations formulate clear guidelines with regard to what is and what is not allowed, which limits the possibility of choosing a different option. The guidelines are included as multiple footnotes and text boxes throughout the booklet. The original text on tube feeding was revised in the Italian and Japanese versions only, adding text alluding to acceptability of tube feeding in certain cases (box 2).

Euthanasia is discussed separately in all four versions. It is pointed out that withholding useless or ineffective life-prolonging treatment is possible at all times. The original Canadian version mentions that many family members may

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feel that suffering should end. This is retained in the Japanese and Dutch versions, but dropped in the Italian version, in which it was emphasised that euthanasia is ‘absolutely forbidden’. A euthanasia law was thought to have negative rather than positive consequences in all versions but this was omitted in the Dutch version. Herein, euthanasia is outlined in accordance with the rules and legislation in force in the Netherlands. The Dutch definition of euthanasia implies that euthanasia is not a feasible option in severe dementia. The Japanese version distinguishes between active euthanasia, the intention to end a person’s life, and passive euthanasia, not taking action to save a person’s life. Both are prohibited by law as they imply life-terminating action in the eyes of the Japanese. Not starting or withdrawing a treatment in light of the patient’s wishes is possible because in this case there is no intention to terminate life.

Second adapted versions

The Dutch and Japanese versions were revised in response to results of the acceptability studies on which articles appeared in local professional journals. Suggestions provided by professional caregivers (and families, Dutch version) in open-ended items were particularly helpful. The Dutch version added a table of contents to facilitate navigating through the booklet and, with help of professional language services, simplified language to a European Standard B1 level. Regarding content, adding of psychosocial issues to the medically oriented booklet was repeatedly suggested. However, to avoid adding pages, we rather referred to other sources, such as the national Alzheimer’s Association, for this. Further, we provided some more detail on the course of the dementia, and in particular on how this could vary between patients, which the Japanese version had added already in the first round, similar as with the index of contents.

The Japanese version was revised in response to the acceptability study as well, considering the responses of nursing home staff, for example, the term ‘palliative care’ needed more introduction. Language was an issue also in the Japanese version, and the use of medical terms was avoided to better suit the level of Japanese care workers who do not always have a clinical background. Further, the information on what could be done preparing for death was extended to encourage care workers in their caregiving without life-sustaining treatment.

DISCUSSION

In this study, we described and compared international adaptations with an originally Canadian booklet for families on end of life with dementia. Local teams, in consultation with local experts of three countries with substantially varying end-of-life decision making practices, Italy, the Netherlands and Japan, deemed these adaptations necessary before implementation. The starting point was that the main message of the original booklet, dementia as a terminal disease for which palliative or comfort care applies (concepts which originate from Western cultures), was retained. Our assumption was that palliative care is good for the patient, at least those with advanced dementia, which reflects a consensus among experts, which then allows for local adaptations on how palliative care is given shape. Further, the availability of a promising Canadian version was a reason not to develop new local booklets from the beginning. For different types of tools, there are different accepted best practices regarding when to translate precisely, to adapt or to start from the beginning. For example, measurement instruments and ethical standards need a precise translation, whereas prognostic tools are preferably adapted to other populations. Implementation strategies or complex interventions in dementia may be newly developed or else need substantial adaption to care that is organised differently in different countries. Regarding transportability of decision aids and information booklets, however, there is little guidance on when to translate precisely, to adapt or to start from the beginning. Our work, along with recent work in Germany, may provide empirical input to build such guidance.

A large number of adaptations was carried through in the Japanese version. Although the Italian version resembled the original text closest, critical adaptations were made to the Italian version as well. The versions employ different styles to convince the reader that palliative care in advanced dementia applies. The Canadian version has a reassuring style, whereas the adapted versions provide more information to convince readers, either on considerations underlying decisions (Dutch version, and Italian version to a lesser extent) or on the legal and professional standards, attempting to outline what is feasible (Japanese version). Apart from an obvious need for local applicability, this might also be understood as the Canadian version only being firmly rooted in an in-depth understanding of needs of local families through the qualitative work on which the booklet was based.

Our qualitative content analyses identified three themes that comprise the adaptations to the text. The first two, relationships among the patient, physician and other professional

Box 3 Text fragments from the four versions of the booklet on dehydration and intravenous fluids

Original Canadian and Italian versions: ‘Some families believe that the patient would be more comfortable with an intravenous. Our experience is the total opposite, as IV results in more secretions in the breathing passages, puts off the onset of the coma, and prolongs the duration of the discomfort.’

Dutch (first adapted) version: Revision: ‘As mentioned before, decreased fluid intake and the accompanying dehydration is part of the dying process. Sometimes, people believe that their loved one is more comfortable if the possible dehydration is treated with an intravenous. However, it is important to only start a treatment if there is a symptom or complaint, which we may consider burdensome for the patient. So far, there are a number of indications that suggest that the process of slowly progressive dehydration is not burdensome for the patient. That is why as yet there is no reason to start an infusion (intravenous, via the veins, or under the skin). By experience, we know an intravenous rarely has a positive effect. By contrast, there are slight indications suggesting a negative effect. It is possible a patient with an intravenous even gets too much fluids resulting in fluids in the patient’s lungs generating breathlessness.’

Japanese (first adapted) version: Addition to original text: ’Note. In Japan, tube feeding and drip infusion are often considered as ‘routine care’ and ‘food.’ Therefore, patients’ families might consider not providing a feeding tube and drip infusion as allowing the patients to starve. Thus, proper considerations and explanations for such families are necessary.’
caregivers, and patient rights and the position of the family members (surrogate decision maker), covered ethical and legal aspects. Other work has shown differences in positions: US ethics experts in contrast to Japanese experts, for example, first consult a grandson rather than a daughter-in-law as surro-
gate decision making for a dementia patient.20 Patient autonomy in general is not as firmly established in Japan as in other countries.21 In Italy, patient living wills in case of incompetent patients are not legally binding as they are in the Netherlands.22 The physician’s role in decision making was stronger in the adapted versions. This concurs with other cross-
cultural work on end-of-life decision making that demonstrates a stronger position for the physician. This is evident from, for example, comparisons between the US and other countries—Japan, the Netherlands,23 and European countries—more generally.9

The third theme, a typology of treatments and decisions at the end of life, additionally covered treatment decisions in which medical, ethical and legal aspects are closely interwoven. Across the new versions, the text on decisions on artificial hydration and nutrition, and on euthanasia was revised most heavily. These two issues and the use of opioids have been indi-
cated as a controversial legal issue in cross-national work com-
paring law on palliative care.24 Further, practice of sedation—
the only topic that was added to any of the versions—and of stopping artificial rehydration and nutrition were most fre-
quently misconstrued as euthanasia or ‘murder’ in a US study among palliative care physicians.24 Moreover, evaluation of a set of recommendations on palliative care in dementia by 64 experts from 25 countries revealed that agreement was the lowest on whether to treat with artificial hydration—euthana-
asia not being addressed in the recommendations.8

Euthanasia formally does not belong to palliative care and is
globally known as a controversial topic, but it was included in the booklet because qualitative work identified families’ inform-
ation needs regarding euthanasia or shortening of the termi-
nal phase,9 consistent with clinical experience in Canada of the developer and colleague physicians. We believe that address-
sing requests and decisions regarding intake and euthanasia may be particularly sensitive, the text most strongly reflecting local ethical principles and legal and professional standards. By contrast, use of antibiotics or withdrawing medication may involve stronger medical indications, and may therefore be less culturally dependent.

Regarding attitudes towards artificial nutrition and hydration in patients with cancer or severe stroke, Japanese reports reflect controversy; some physicians and nurses considered it dispens-
sible or a minimum standard of care.25 26 and Japanese pallia-
tive care practitioners being more positive on withholding it than oncologists.27 In general, in Japan, there are multiple bar-
riers towards palliative caregiving and many of these are related to practitioners, families’ or patients’ perceptions on palliative care and terminal disease.27 Empirical research in the ICU has shown that Japanese physicians have more of a ‘do everything’ end-of-life attitude than Canada, Northern and Southern European countries.21 The current debate is also reflected in a new law in Italy, which says that ‘artificial hydration and nutrition can be withdrawn only ‘in terminally ill patients in whom they are no longer effective’, in addition to ‘any form of euthanasia and assisted suicide is forbidden’.20 Even though the Netherlands has a law on euthanasia, its application to dementia patients is heavily debated,25 and it was felt that the text on artificial rehydration needed more explanation to convince readers of it being less useful in dementia.

Having carried through the adaptations, physicians, nurses and families mostly found the information provided on treatment decisions balanced, including on intake problems, although overall a perception of the information being slanted towards comfort care was more likely for Italian than for Dutch profes-
sional caregivers.15 Although the booklet comprises all important clinical domains of palliative care in dementia (nine of 11 domains accepted by an international expert panel),6 further work is needed to validate effectiveness of the adapted booklets.

Of note, Japanese language is more indirect and open to interpretation than English, and back translation into English for analyses may not have fully captured the nuances.30 Our work was further limited to adaptations made by small local teams, who were, however, knowledgeable about local requirements, practice, and sensitivities and all covered relevant expertise. Adaptations needed also depended on the specificity of the original version that, for example, did not detail on Canadian (federal) regulations on surrogate decision making. We identified particularly sensitive issues, and we are not aware of other such cross-national work directly comparing a diversity of aspects on palliative care in dementia. We did not perform a systematic review and analytic comparison of ethical approaches in the four countries, and our interpretation of differences in end-of-life care is based on a non-systematic literature search for comparative empirical studies. We also acknowledge as a limitation that places that needed revision do not necessarily address sensitive topics, but may address more practical or neutral cultural issues. Our interpretation of sensi-
tivity of the main adaptations was based on the literature and the experiences of and discussions between our teams and with others in international settings.

We may conclude that professional caregivers practicing in nursing homes across very distant cultures may be convinced of the applicability of palliative care to dementia if local sensi-
tivities, mostly medical end-of-life decisions with strong ethical and legal components, are addressed. Acceptability studies have confirmed that the core issue of palliative care in dementia, including the progressive and ultimately terminal evolution of the disease and the necessity to provide comfort, can be retained. Our work provides a cross-national perspective on end-of-life care in dementia and particular sensitivities on addressing euthanasia requests and decisions around intake prob-
lems that are useful for an ongoing debate on how to give shape to palliative care in dementia.

Contributors All authors were involved in the design of the study, the interpretation of the study data and read and contributed to the paper for important intellectual content.

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Author note All versions of the booklets described in this manuscript are publicly available, either online (Canadian, Dutch and Italian version) or upon request (Japanese version).

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