

Educating families about end-of-life care in advanced dementia: acceptability of a Canadian family booklet to nurses from Canada, France, and Japan

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In advanced dementia, because of the severe cognitive decline, families generally have an important role in medical decision making. They may regard this as challenging, especially in the absence of written or verbal advance directives (Forbes et al, 2000; Givens et al, 2009). To help them participate in those decisions, families should receive timely information (Biola et al, 2007). For instance, they need to understand the course of dementia, possible complications, and therapeutic options. They may also want clarifications about their role in the decision-making process, especially if withholding or withdrawing life-prolonging measures are to be considered (Givens et al, 2009). Furthermore, being prepared for death and what to expect at the end of life can be important for families' own wellbeing (Hebert et al, 2006).

To educate the families of nursing home residents about end-of-life care for those with dementia, a Comfort Care booklet has been developed in Canada with French and English versions. It has also been translated into Dutch, Italian, and Japanese, and collaborations have been established between researchers from these different countries. The researchers first decided to verify the acceptability of the various versions of the booklet to practitioners. Acceptability of the contents of the booklet including its mainstay that comfort/palliative care can be beneficial for advanced dementia is important because professionals need to feel comfortable in providing information that is sometimes very sensitive. Moreover, information on acceptability is crucial to preparing for implementation in other settings, where the idea of dementia as a terminal disease and the relevance of comfort care may be less well accepted.

The acceptability of the Dutch and Italian versions of the booklet to physicians and nurses has previously been tested (van der Steen et al,

Abstract

Background: The families of people with late-stage dementia need to be informed about the course of the dementia and the comfort/palliative care option. A booklet was written for that purpose and can be provided to family members by physicians and nurses. **Methods:** The acceptability of the booklet for nurses was tested in Canada (French and English version), France (French Canadian version) and Japan (translated and adapted version). **Results:** Overall, 188 nurses completed a survey questionnaire. The booklet was accepted best in Canada and less so in France and Japan. Despite regional variation, the majority of the nurses perceived the booklet as useful for families. The French and Japanese nurses also reported a greater need for palliative care education in advanced dementia. **Conclusion:** The booklet may help nurses educate families about end-of-life issues in dementia palliative care, but local adaptation of the booklet content and physician engagement are necessary.

Key words: Dementia ● Family education ● Nurses ● Decision tool ● Decision-making process ● Palliative care

2011a). Acceptability was higher in the Netherlands, and in both countries it was higher for nurses. Surveying nurses is valuable as the booklet may empower them to address sensitive end-of-life issues in dementia. In long-term care settings, nurses are often the main professional contact for families (Forbes et al, 2000; de Veer et al, 2008).

Focussing on nurses working in long-term care (LTC) settings, the present paper reports on surveys carried out in French Canada (Quebec), where the booklet was developed, English Canada (Ontario), France, and Japan. The various Comfort Care booklet versions surveyed differ in language alone (French and English Canada), country alone (same French version for Quebec and France) or—the largest possible difference—language, country, adaptations, and non-Western culture (Japan).

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The hypothesis was that the booklet would be acceptable in Quebec, Ontario, and France but, owing to significant cultural differences, less acceptable in Japan (Ruhnke et al, 2000; Yaguchi et al, 2005). The study also looked at how nurses would implement the booklet in those different cultural contexts.

Methods

The booklet

The original Canadian booklet was developed in Quebec (English and French versions) (Arcand and Caron, 2005) after a qualitative study of decision making in dementia from the perspective of families (Caron et al, 2005). It informs on the course of the dementia, expected complications, the decision-making process, symptom management, dying, and grief. Potentially more controversial core statements of the booklet are presented in *Box 2*. These statements are based on current scientific literature (Givens et al, 2010; Gillick and Yurkofsky, 2012) and the booklet has been accepted by the World Health Organization (Hall et al, 2011) as an example of better practices in palliative care for older people.

In the present study, the original French language version was used for both French Canada and France. The original English version was tested in English Canada. For the Japanese survey, a version adapted by local experts in medicine and ethics was used. Most of the adaptations were made to conform with Japanese law and cultural context, such as referring to opioid availability, and commentaries were added to soften some of the core statements. However, the mainstay of comfort care as beneficial for patients with advanced dementia was retained in all versions. The term 'comfort care' was used as equivalent to 'palliative care'. In the booklet the

term comfort care was preferred as probably more readily understood by family members.

Design of the evaluation study

The unit of analysis was the nurse, and the inclusion criterion was: nurse working in an LTC setting looking after residents with advanced dementia. Surveys were distributed on a convenience basis in LTC settings known to the researchers. All of the nurses in each facility were invited to take part. There are national differences in the way LTC is organised in different countries, but all of the settings cared for people with advanced dementia. There was a mix of private and public institutions, but all were not-for-profit and only one (in English Canada) had a religious affiliation (Catholic).

The settings chosen in Canada were two LTC facilities in Sherbrooke, Quebec, and three in Hamilton, Ontario. In France, four facilities in the area of Bayeux (Normandy) were selected and, in Japan, three facilities from the Saitama and Fuluoka regions (near Tokyo). The nursing homes varied in size but were typical for their country. The unit of analysis, however, was the nurses who provided an individual evaluation on the acceptability and usefulness of the booklet. Participants were also invited with open questions to explain their answers or give general comments on the booklet.

Instrument for evaluation

The survey instrument has been described in more detail in a previous publication (van der Steen et al, 2011a). Briefly, it was developed in English by the research team, translated into French and Japanese, and then back-translated to English for checking by a professional translator. The French Canadian survey instrument was used basically unchanged in France. The instrument asks participants to rate the quality of the booklet overall and of its five chapters individually (natural evolution of those illnesses, decisions about the end of life, relief of symptoms, the final moments, and after the death) on a scale from 1 to 5 where 1 corresponds to 'poor' and 5 to 'excellent'.

The main outcome measure, acceptability, refers more specifically to acceptability for informing families and supporting decision making, two main goals of the booklet. For this, a 15-item scale summing rating of agreement with statements was developed. It includes statements such as 'This booklet will result in my patients' families making more informed decisions', along with statements relevant to practical implementation such as 'I would decide to adopt

Box 2. Core statements in the original booklet

Advanced dementia as a terminal illness

1. Advanced dementia should be considered a terminal illness with the majority of patients dying from nutrition/hydration or infectious problems, especially pneumonia.

Hydration and nutrition issues

2. In case of malnutrition, feeding tube is not recommended for the sole purpose of prolonging life at this stage of dementia.
3. Use of parenteral hydration (IV or hypodermoclysis) may be helpful in selected cases but can also contribute to discomfort (e.g. increase in bronchial secretions, delay of pain-free coma state) and prolong the dying process.
4. Withholding or withdrawing artificial nutrition/hydration is an acceptable option in the context of advanced dementia associated with an irreversible swallowing difficulty.
5. Withholding or withdrawing of artificial nutrition/hydration is generally not associated with manifestations of discomfort if there is adequate mouth care.

Antibiotics for end-stage pneumonia

6. When 'comfort care without life prolongation' is the goal of care, antibiotics can be withheld and treatment will then aim at symptom control
7. Even when pneumonia is treated with antibiotics, clinicians should pay attention to symptom control (e.g. prescription of opioids despite risk of respiratory depression) because pneumonia usually causes significant discomfort.

Use of opioids and sedation

8. Prescription of opioids may be necessary to control pain or breathing difficulties and is acceptable if the intention is to relieve the patient and not to hasten death and if the dosage is increased gradually.
9. Sedation is useful in some patients because these patients can become very anxious and the advantages of less sedation are not as relevant in a severely demented individual as in a lucid cancer patient.

Cardiopulmonary resuscitation

10. Cardiopulmonary resuscitation is not recommended in advanced dementia because it can harm the patient and has very little chance of success.

Hospital transfer

11. Hospital transfer of the patient with advanced dementia should be exceptional e.g. only to provide comfort by technical means not available in the nursing home (such as hip fracture surgery).

Medical decision process

12. In decisions regarding whether or not to use life-prolonging therapy in advanced dementia, the ideal decision-making process is to reach a consensus between the physician, the substitute decision maker and other significant relatives or friends of the patient.
13. In the decision-making process, the substitute decision maker does not actually make decisions but his role is rather to give consent to the medical option that is most suited to the patient's best interests (e.g. according to patient values and written or verbal advanced directives) and refuse options that would not presumably be acceptable to the patient.
14. The doctor does not have the power to impose a solution to the family. If the substitute decision maker and the physician disagree about the appropriate course of action, they should compromise.

Euthanasia

15. Active life termination (hastening death) is not an acceptable option for advanced dementia.

the booklet even before experimenting with it'. Item scores ranged from 1 'strongly disagree' to 5 'strongly agree'. Higher total scores therefore represent better acceptability. Scores of 45 and higher are regarded as 'acceptable', and scores of 60 and higher as 'highly acceptable'.

Perceived usefulness to families was assessed as the proportion of families for which the booklet would be useful. Each participant was also asked whether they would be likely to provide the booklet to families within the next 3 months. For more controversial issues, the

participants were asked to make a judgment about the neutrality of the information provided (whether it was balanced, slanted too much towards low-technology comfort care, or slanted too much towards life-prolonging care). Preferences as to who should provide the booklet to families were assessed, as well as preferences for when it should be presented. Respondent characteristics that may have affected evaluations were also assessed, such as age, experience (Forbes et al, 2000), ethnicity (van der Steen et al, 2011a), and religion.

Table 1. Characteristics of nurses (n=188)

	French Canada (n=39)	English Canada (n=71)	France (n=18)	Japan (n=60)	P-value
Female	79%	96%*	88%	68%	<0.001
Mean age in years (SD)	49.1 (12.7)	46.2 (11.2)	36.8 (10.8)*	37.2 (11.2)*	<0.001
Mean years experience in dementia care (SD)	18.1 (10.6)	11.6 (10.0)*	7.6 (9.7)*	8.1 (5.5) *	<0.001
Not a native of that region	5%	49%*	6%	0%	<0.001
Personal experience with family or friend suffering from advanced dementia at the end of their life	44%	38%	11%*	25%	0.037
Religious background was Catholic	85%	30%*	63%	0%*	Any versus none: <0.001
... Protestant	5%	32%	6%	0%	Catholic versus not Catholic: <0.001
... Buddhist	0%	1%	0%	44%	
... Jewish	0%	1%	0%	0%	
... Muslim	0%	1%	0%	0%	
... other (e.g. Hindu, 'believer')	5%	23%	0%	0%	
... none	55	10%	31%*	56%*	
Believed religious or spiritual orientation strongly influenced how they evaluated the booklet	11%	21%*	6%	2%	<0.001
... had little influence on how they evaluated the booklet	16%	29%	12%	18%	<0.001
... had no influence on how they evaluated the booklet	74%	50%	82%	81%	<0.001
Had educational needs concerning the comfort care approach for end-of life care of dementia patients	57%	56%	76%	93%*	<0.001

*Significant difference ($P<0.05$) with French Canada. SD, standard deviation.

Analyses

Analyses were performed with PASW 18.0.0. Each group was compared with the French Canadian group and across the four regions. T-tests and ANOVA were used for continuous data, and Chi-square tests for proportions were used to compare respondent characteristics and outcomes by region. To compare perceived usefulness (ordinal categorical outcome) by region, gamma correlation tests were used. Linear regression was used in unadjusted analyses with acceptability as the outcome, and in analyses adjusted for the nurses' characteristics (gender, age, native of the region, religion (Catholic, none, other), professional and personal experience, perceived influence of religious or spiritual orientation on evaluation, and educational needs).

Results

Participant demographics

Response rates were 41% (Japan), 50% (France), 60% (French Canada), and 61% (English Canada), giving a total sample of 188 nurses. Respondent nurses were significantly older in French Canada than in France or Japan and had been exposed to dementia end-of-life care for a longer period than in the three other regions (Table 1). There was also variability in personal

experience with family or friends suffering from advanced dementia at the end of life. Religious or spiritual orientation varied between settings but, except in English Canada, most respondents did not feel that it influenced how they evaluated the booklet. Perceived need for palliative care education was variable and significantly greater in Japan than in French Canada.

Booklet quality

The mean overall rating for the quality of the booklet was 4.24 (standard deviation (SD) 0.79) on the 1–5 scale. The quality rating differed little between chapters: the lowest mean rating was for 'after death' (4.09, SD 0.92) and the highest was for 'final moments' (4.26, SD 0.82). The mean ratings of the quality of the five chapters differed significantly across the regions ($P<0.001$) for all chapters, with consistently higher ratings for French Canada and lower ratings for Japan.

Acceptability and perceived usefulness

The booklet was better accepted in French Canada than in the other regions (Table 2). It was also 'highly acceptable' in English Canada, and still 'acceptable' to the French and Japanese nurses. Acceptability seemed to vary the most in Japan (highest SD and largest range). Better

Table 2. Acceptability and perceived usefulness of the booklet

	French Canada (n=39)	English Canada (n=71)	France (n=18)	Japan (n=60)	P-value
Mean total acceptability score on 15-item scale [†] (SD, range)	67.5 (7.8, 49–75)	62.2* (9.8, 32–75)	55.7* (8.9, 37–69)	49.2* (10.9, 24–72)	<0.001
Booklet useful for all families of dementia patients	41%	51%	24%*	12%*	<0.001
... the majority of families	59%	40%	41%	38%	
... about half of families	0%	6%	29%	29%	
... a minority of families	0%	3%	6%	21%	
... not any family	0%	0%	0%	0%	
Think likely to provide the booklet to families within the next 3 months	85%	93%	83%	52%*	<0.001

*Significant difference ($P<0.05$) with French Canada. [†]Theoretical range of total score on acceptability scale is 15–75, with higher scores representing better acceptability. SD, standard deviation.

Table 3. Evaluation of information on more sensitive issues—per cent who thought it was slanted too much towards low-technology comfort care, slanted too much towards life-prolonging care, or thought it was balanced, respectively

	French Canada (n=39)	English Canada (n=71)	France (n=18)	Japan (n=60)	P-value[†]
Hospital transfer	3%, 8%, 90%	4%, 3%, 93%	11%, 0%, 89%	22%, 7%, 72%*	0.005
Resuscitation	3%, 8%, 90%	4%, 4%, 92%	17%, 6%, 78%	17%, 13%, 70%*	0.006
Antibiotics for pneumonia	0%, 3%, 97%	3%, 0%, 97%	11%, 11%, 78%*	24%, 8%, 68%*	<0.001
Stop medications	0%, 0%, 100%	0%, 1%, 99%	11%, 6%, 83%*	19%, 7%, 75%*	<0.001
IV use for dehydration	3%, 5%, 92%	3%, 6%, 92%	12%, 6%, 82%	27%, 5%, 68%*	0.002
Feeding tube	5%, 8%, 87%	7%, 6%, 87%	24%, 12%, 65%	20%, 3%, 77%	0.096

*Significant difference ($P<0.05$) with French Canada. [†]Chi² for proportion balanced. IV, intravenous

acceptability in French Canada was not explained by 64% of respondents having prior access to the booklet, as there was no difference from those in this region with no previous access.

In all regions, the nurses felt the booklet could be useful for at least a minority of families (Table 2). Even in Japan, no one answered that it would not be useful to any family. The majority of nurses in Canada (85–93%) and France (83%) thought that they would be likely to provide the booklet to families within the next 3 months (Table 2). In Japan, half (52%) of the respondents would do so. The most frequent reasons Japanese nurses gave for not providing the booklet were that they feared it could increase family anxiety and that they preferred talking to families. Some Japanese respondents also thought the literacy level of the booklet was too high for families.

Balance of the information

In general, the booklet information was considered balanced. However, more nurses from Japan thought that the discussion about decisions

such as hospital transfer was slanted too much towards low-technology comfort care (Table 3). The proportions of French nurses who rated the information as balanced were consistently lower than in Canada, and the differences between France and French Canada were significant for antibiotics in pneumonia and stopping medications. Only views on information on feeding tubes did not vary significantly between regions; this information was considered the least balanced by the French Canadian nurses.

Implementing the booklet

In French and English Canada, 85% of the nurses thought they could use the booklet themselves, but the proportion was lower in Japan (63%) and even more so in France (50%). About three quarters or more (73–91%) of the nurses indicated that the best moment to provide the booklet was when there are discussions about a medical problem (eating, drinking, fever or possible need for hospital transfer) for which comfort care is an option (Table 4). The proportion of nurses who thought the booklet could be

Table 4. Occasions on which to use the booklet (only those participants who indicated that they were likely to provide the booklet to families within the next 3 months)

	French Canada (n=33)	English Canada (n=66)	France (n=15)	Japan (n=31)	Overall P-value (Chi²)
When diagnosed with dementia or shortly afterwards	9%	36%*	20%	42%*	0.012
Before admission to a nursing home	9%	24%	13%	29%*	0.17
Timing: before admission, total (any of two rows above) [†]	12%	42%*	27%	55%*	0.002
At the time of admission to a nursing home	27%	33%	27%	48%	0.28
When general goals of care are discussed initially / advanced care planning shortly after admission	33%	56%*	47%	48%	0.21
When there are discussions about a medical problem (e.g. eating, drinking, fever, hospital transfer) for which comfort care is an option	91%	73%*	80%	87%	0.13
When it becomes clear that a patient is about to die	61%	71%	53%	42%	0.047
In case of family pressure to treat with inappropriate life-prolonging treatments	64%	71%	60%	29%*	0.001

*Significant difference ($P < 0.05$) with French Canada. [†]Some respondents indicated both 'when diagnosed' and 'before admission to a nursing home'.

provided earlier (at the time of diagnosis or before nursing home admission) was higher in Japan and English Canada than in French Canada.

Discussion

The acceptability and perceived usefulness of the booklet were high in French and English Canada, with mean acceptability scores of 67 and 62 respectively. These scores are similar to the mean score of 60 obtained from Dutch nurses reported previously (van der Steen et al, 2011a). It is interesting to note that in French Canada, where the booklet was developed and where it has been available since 2005, the acceptability scores were the highest, and this was not due to prior access. It may be because the booklet was originally designed for this context, with input only from families and physicians from this particular area (Caron et al, 2005).

Acceptability and perceived usefulness were lower among the French nurses. This could be because the booklet was not adapted for France's cultural and legal context. Some French nurses also mentioned that they did not like certain expressions used in the French Canadian version, such as 'gavage' for tube feeding. One nurse said that the booklet does not represent reality, which may indicate that withholding antibiotics or fluids is rarely if ever considered in the context of her practice. The situation in France may be similar to in Italy, where artificial hydration and nutrition are more of an issue than in the Netherlands or Canada (Yaguchi et al, 2005) and where the acceptability of the

booklet among nurses was also lower (mean score 55 in Italy, 56 in France) (van der Steen et al, 2011a).

Acceptability was lowest in Japan despite multiple adaptations, probably because of important cultural differences. Artificial hydration and antibiotics are considered minimum standards of care by the Japanese medical profession (Miyashita et al, 2007; Aita and Kai, 2010), and advanced dementia is not currently thought of as a terminal illness. For example, morphine is not usually prescribed for breathing difficulties even in probable end-stage pneumonia. However, there was more variability in the acceptability and perceived usefulness of the booklet in this country than in the other regions. Furthermore, 52% of the Japanese nurses answered that they would be likely to provide the booklet to families within the next 3 months.

A final consideration with respect to the booklet's acceptability is that a large proportion of the nurses from France (76%) and Japan (93%) believed that they had educational needs concerning the comfort/palliative care approach for people with dementia who are at the end of life. This perceived need was lower, although still high, in Canada (57%).

A relatively high proportion of nurses in France, English Canada, and Japan (27–55% versus only 12% in French Canada) thought the booklet could be provided before nursing home admission. This probably reflects a perceived need for more advance information about end-of-life care.

Nurse provision of information about comfort care

Ideally, both physicians and nurses should be knowledgeable in the palliative care of advanced dementia and capable of providing information in a coordinated way. Physician–nurse coordination is needed so that families do not become confused owing to opposing opinions or statements. Physicians usually focus on decision making and nurses on the end-of-life experience (Kaasalainen et al, 2007). However, physicians are not always readily available for discussions with the family (Shield et al, 2005; Helton et al, 2011), and so nurses are often the main professional contact. It is often the nurses who help family members manage their feelings of guilt and helplessness and who may be providing information about palliative care issues, such as on the trajectory of disease, which decisions might impede a natural death, and comfort options.

However, nursing practices, positions, and educational levels vary from country to country, and this should feed into appropriate strategies for advance care planning and provision of the booklet. For instance, in Japanese nursing homes, nurses presently do not have sufficient autonomy to provide the booklet to families and discuss it with family members.

In France, the physician is required to disclose information to the family about any life-threatening condition and specific treatment options. Nurses are not normally involved in these discussions and they are not trained to take such a role. It would be appropriate for the physician to provide the booklet to the family, whereas the nurse could be available later to answer any questions from the family and explain the content of the booklet if needed.

In the Canadian context, nurses may have a little more autonomy and families also tend to trust them. Indeed, in a study into the acceptability of the booklet for families (van der Steen et al, 2011b), 78% of family members thought that a nurse could have provided the booklet when their relative was dying. Therefore, empowerment of nurses appears to be possible in Canada but probably less so in Japan and France. It may be that the doctor is more of an authority in those cultures (Yaguchi et al, 2005).

Some authors (Froggatt and Houlton, 2002; Philpot et al, 2011) suggest that the addition of an advanced practice nurse such as a nurse practitioner could facilitate and improve palliative care processes. She or he could be positioned to supervise care delivery by other nurses and act as a consultant for staff and families. French,

Japanese, and Canadian physicians would probably be willing to share this task with a palliative care nurse specialist.


Limitations

Caution is needed when extrapolating the findings in each region because the study was conducted in a limited number of settings, the sampling procedures were not necessarily representative, and sample sizes were small. The response rate was lower than 60% in France and Japan. Because this coincides with lower acceptability in these countries, the findings might even be an underestimate of differences between the regions if the response rate was biased to more favourable evaluations. However, the finding of higher acceptability in the region of development is consistent with findings in Canadian, Dutch, and Italian families, and the Dutch study was conducted nationwide (van der Steen et al, 2011b).

Conclusion

Palliative care is increasingly considered a relevant option in advanced dementia. The Comfort Care booklet can play a part in informing families about this option and its alternatives, especially when people develop complications related to their advanced dementia. In this study, evaluation of the booklet varied in different areas. Cultural adaptations (van der Steen et al, 2012) probably improve acceptability but to a limited extent, as shown in a previous study in the Netherlands, in which the English Canadian version was evaluated similarly to an adapted Dutch version (van der Steen et al, 2011a), and in Japan, where the booklet had lower acceptability despite multiple adaptations (Nakanishi et al, 2012). The data also suggest that educating staff about a palliative approach for advanced dementia could make a difference.

Overall, the booklet is well accepted by nurses in very different settings. If physicians recognise that advanced dementia is a terminal illness and that a palliative care approach is relevant, it is possible that the booklet could help nurses play a more active part in informing families about comfort care, supporting them, and contributing to better quality of end-of-life care.

Further studies should test the booklet as part of an advance care planning package. It can also be used as a complementary educational tool for staff. Those interventions should demonstrate a positive change in clinically significant outcomes such as patient comfort at the end of life and family satisfaction with care. 

‘The Comfort Care booklet can play a part in informing families about this option and its alternatives, especially when people develop complications related to their advanced dementia.’

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