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## Original Study

## A Family Booklet About Comfort Care in Advanced Dementia: Three-Country Evaluation

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## A B S T R A C T

## Keywords:

Decision aid  
decision making  
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palliative care  
nursing homes  
dementia

**Objectives:** To evaluate a booklet on comfort care in dementia from the perspective of family with relevant experience, and assess nursing home resident and family factors associated with evaluations.

**Design:** Retrospective study.

**Setting:** Long term care facilities in French-speaking Canada, and the Netherlands and Italy.

**Participants:** Bereaved family (n = 138).

**Measurements:** An 8-item scale assessed the booklet's acceptability. Usefulness was rated on a 0 to 10 scale, and perceived usefulness referred to usefulness if family had had the booklet during the resident's stay. Families indicated preferred ways of obtaining, and the most appropriate time to get the booklet. **Results:** Almost all families (94%) perceived the booklet as useful. Canadian and Dutch families evaluated the booklet's contents and format favorably, whereas Italian families' evaluations were less favorable. Almost all families endorsed roles for physicians or nurses and about half additionally accepted availability through own initiative, in print or through the Internet. Preference of timing was highly variable. Better acceptability, usefulness, and availability through own initiative were independently associated with non-Italian nationality, presence of more physical signs discussed in the booklet, feeling ill-prepared, and higher satisfaction with care. A preference of receiving the booklet early was more likely in Italian families, those without university education, and those involved with older residents.

**Conclusion:** The booklet is suitable to inform Dutch and Canadian families on comfort care in dementia, but implementation in Italy requires further consideration. The booklet may be integrated in advance care planning in long term care, and made available outside long term care settings to serve families who wish to be informed early.

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In western countries, most patients with dementia eventually die in long term care facilities.<sup>1,2</sup> When medical complications occur, difficult clinical and ethical decisions need to be made most commonly in relation to eating difficulties, treatment of infections, symptom management, and hospital transfer.<sup>3,4</sup> A consensus should ideally be reached between the health care team and family acting as substitute decision maker. However, decision making is complex owing to lack of evidence for effectiveness of treatment, difficult prognostication, and assessment of patients' (previous) wishes.<sup>5</sup> Family members may need support and guidance in this potentially stressful period.<sup>6–13</sup>

To educate families of nursing home residents with dementia on comfort (palliative) care, a booklet has been developed for use in Canada.<sup>14</sup> The booklet informs on the course of the dementia, expected complications, decision making (eg, regarding antibiotics and feeding tubes), dying, and grief (Box 1). It was based on qualitative study of decision making in dementia in Canada,<sup>8,9</sup> literature, and expert opinion.

Originally published in French and English, it has been translated into Italian, Dutch, and Japanese. Although upholding core issues about comfort care, it required adaptation to local cultural, ethical, and legal standards. Before providing it to families of dementia patients in countries other than where it has been developed, we felt evaluation by practitioners and bereaved family was necessary. Therefore, a practitioner survey study was performed in several countries and preliminary results showed a good acceptability level.<sup>18</sup> We included bereaved families' evaluations because they have experienced the course of the disease including the dying phase, addressing a quality criterion for decision aids, which is evaluation by those who have experienced the decisions,<sup>15</sup> and some families may avoid information.<sup>8,9,19,20</sup>

The objective of the study was to evaluate content and format, and to describe acceptability, usefulness, preferred way of obtaining the booklet, and best timing of the booklet from the perspective of bereaved family in 3 countries: the Netherlands and Italy in reference to the country of original development (Canada). We further assessed resident and family factors associated with the 4 outcomes.

## Methods

An international research team has been involved in translating, adapting, and evaluating the booklet.<sup>18</sup> Mainstays and aims of all versions were the same (Box 1), and all were structured according to questions and answers. The Dutch version copied the layout of the original Canadian version. Photographs and colors in the Italian version were modified using pictures of Italian settings.

### Setting and Sampling

Families participated after death of their loved one in a long-term care setting. A letter invited families about 2 months after death of their loved one, and upon written (Canada and Netherlands) or oral (Italy) informed consent, families received the booklet and the evaluation instrument (postal questionnaire survey, and face-to-face interviews in some Canadian families). Reminders were not used. The protocol was approved by the local institutional review boards.

Dutch and Italian families were recruited from other studies on dementia at the end of life<sup>5,21,22</sup> with participating long term care facilities geographically distributed across the Netherlands (29 facilities of 23 organizations employing 23 separate physician teams; 23 nursing homes and 6 residential homes) and Lombardia region (Italy; 4 nursing homes). Canadian families were from the

Box 1. Mainstays, guidance, and contents of original and translated versions of the booklet "Comfort care at the end of life for persons with Alzheimer's disease or other degenerative diseases of the brain"<sup>14</sup>

### Mainstays and aims

- To inform decision makers so that they can better understand the risks and benefits of care options and actively participate in decision making;
- To reassure family members who opt for comfort care that this is an acceptable option and probably the most appropriate one in advanced dementia both from a clinical and an ethical perspective. Although respectful of other views and of people's values and beliefs, the booklet's premises are that providing comfort is our main duty in advanced dementia and that life-prolonging therapy may not only be futile but also prolong suffering.

### Level of guidance – decision aid

The booklet is similar to a decision aid in many respects, but it differs from it in that its main goals are neutral in terms of eliciting of individual preferences or presentation of treatment options.<sup>15</sup> It was based on consensus that, at least for end-stage dementia,<sup>16,17</sup> comfort care is best practice.

### Contents

- 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 palliative/Comfort care approach
- Decisions at the end of life
  - Role of the family and the physician
  - What to do if 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

Sherbrooke and Magog regions (Quebec), from 5 nursing homes, 2 of which were homes that had also participated in studies to develop the booklet.<sup>8,9</sup>

Data collection in the Canadian study was between May 2009 and October 2009. The response rate was 55% (54/99; 38 refused and 7 did not respond). A chart review identified residents who had died with dementia, excluding 16 sudden deaths. Face-to-face interviews at home were held with 29% (16/54) of respondents, mostly aged spouses and less educated family members unfamiliar with the questionnaire format, to help them complete parts that they were unsure of. In the Netherlands, data were collected between March 2009 and May 2010. The response rate to the postal

questionnaire survey was 69% (59/86; 1 to 5 per facility; 22 refused and 5 did not respond). In Italy, data collection was from October 2009 to April 2010. The response rate to the survey was 76% (25/33; 2 to 10 per facility; 8 did not respond).

### Evaluation Instrument

The survey questionnaire was developed in English by the research team. Local teams translated the survey and it was back-translated by a professional translator. Any relevant discrepancies were resolved through discussions. We evaluated the booklet's contents (eg, amount of information) and format (questions and answers, photographs). We also queried for any imbalance in sensitive issues<sup>23</sup> referring to hospital transfer, resuscitation, antibiotics for pneumonia, stop medications, intravenous use for dehydration, and feeding tubes.

We developed an 8-item acceptability scale selecting applicable items from a longer practitioner scale.<sup>18</sup> The scale was based on previous work in evaluation of decision aids<sup>23,24</sup> and included items such as: "This booklet will result in families making more informed decisions," and "The booklet will positively affect family-doctor relationships." Item scores were 1 to 5 with extremes labeled "strongly disagree" and "strongly agree."<sup>23,24</sup> Cronbach's alpha of the 8-item instrument in the family data was 0.92. Two-thirds (66%) of variance was explained by a single factor; item loadings were between 0.62 and 0.87. We regarded total scores of 24 and higher as "acceptable," and of 32 or higher as "highly acceptable" referring to a minimum average of 3 and 4 points on the 1 to 5 item scales, respectively. The 32-point cutoff is also close to the 75th percentile of the theoretical range, in accordance with means commonly reported for satisfaction with care scales that mostly report process items,<sup>22,25</sup> including for families of nursing home residents with dementia.<sup>26</sup>

We also used a 0 (not at all useful) to 10 (extremely useful) scale to assess how useful, overall, the booklet would have been to the respondent. We regarded a minimum mean of 8 as useful, anticipating bias toward higher overall scores. Perceived usefulness was assessed as a personal evaluation; whether the respondent would have "found the booklet useful at some point during the nursing home stay."

In those who perceived the booklet as useful, we assessed the preferred way of obtaining as the best preference "in your case specifically." We used 5 prestructured answering categories and an option "other." Two were before admission to long term care and combined as "early." Further, we asked for preferences (allowing for more than one) regarding way of obtaining, listing professions and options of obtaining through own initiative.

Finally, we assessed family and resident factors such as demographics and health problems. We used a grief item that referred to grief resulting in impairment in social, occupational, or other areas of functioning the past 6 weeks, as key part of criteria for, and outcome of complicated grief.<sup>27</sup> Higher scores at the 5-point scale represent more grief.

### Analyses

We tested differences in resident and family characteristics for pairs of countries, using *t* tests for continuous variables and chi-square tests for dichotomous variables. Difference in length of stay and influence of religious orientation on the evaluation was tested with the nonparametric Mann-Whitney test. We correlated scales using Pearson's coefficient.

We assessed independent associations with 2 continuous outcomes (acceptability and usefulness) and 2 dichotomous outcomes (any preference for availability not through practitioner,

and obtaining it early). We first calculated intraclass correlation coefficients (ICCs) for clustering of patients and families at the level of facilities. We defined a single facility as an institute with a physician team that was not shared by other facilities, except in Canada where one of the facilities consisted of 4 locations cared for by different teams, but which could not be identified as single facilities. Although 3 of 4 ICCs were negligible (<0.001), the ICC of the acceptability scale was not (0.04). We therefore adjusted for clustering at the level of facilities using generalized estimating equations<sup>28,29</sup> for all outcomes. We entered dummy variables for country with Canada as the reference, and patient and family factors potentially related to the outcome.

The level of significance was .05. Missing values were at most 5%, and for regression when variables were used as independent factors associated with outcome, were imputed with the mode or mean when appropriate. Two missing items were allowed and imputed with family means when calculating the 8-item acceptability scale, resulting in 2% (3 of 138) missing summed scores. Usefulness and timing were missing in 2 cases (1%). All respondents selected at least one option regarding preferred ways of obtaining the booklet. Stata 11 was used to calculate ICCs for continuous outcomes, Stata 10.1 for ICCs for the dichotomous outcomes. The generalized estimating equation analyses were performed with SPSS 15.0.1 (SPSS Inc., Chicago, IL).

### Results

Table 1 shows that patients' demographics did not differ among decedents from Canada, the Netherlands, and Italy. Mean length of stay in the Netherlands, however, was less than half of length of stay in Italy (2.0 versus 4.2 years) and also shorter than in Canada (3.1 years). Shortness of breath was most commonly reported in Italian patients. Feeding difficulties were less common in Dutch residents. Table 2 shows that family caregivers' demographics did not differ among the 3 settings except for religion, which was more diverse in the Netherlands. Canadian families reported more grief, and were also more satisfied with care than Dutch families. Italian families were least likely to have had discussions about what to expect, or to feel prepared, and were more likely to report that death happened suddenly and unexpectedly.

Table 3 shows that the contents and format of the booklet was generally endorsed. Italian families more frequently wished for more information than the booklet provided (26% vs 2% to 4%), and rated the quality of the information high (mean 4.0 on the 1–5 scale), but significantly lower than Canadian (4.7) and Dutch families (4.6). Patterns were similar for ratings of the quality of the information of individual chapters (data not shown). Nevertheless, the Italian respondents were equally as likely as the Canadian and Dutch respondents to agree with the booklet (94%–100%) and to

**Table 1**  
Nursing Home Resident Characteristics

	Canada (n = 54)	Netherlands (n = 59)	Italy (n = 25)
Female gender, %	65	63	60
Age, mean (SD)	86.8 (6.7)	86.4 (5.4)	84.6 (8.0)
Mean length of stay, years (SD)	3.1 (3.0)*	2.0 (1.9)* <sup>†</sup>	4.2 (3.2) <sup>†</sup>
Presence of symptoms and problems discussed in the booklet, in last 2 weeks of life, %			
Pain	46	46	39
Shortness of breath	41*	37 <sup>†</sup>	74* <sup>†</sup>
Difficulty drinking enough fluids	65	49	70
Feeding difficulties	83*	63*	83
Fever	30	22	35

\*<sup>†</sup>*P* < .05 for difference between 2 countries.

**Table 2**  
Family Characteristics

	Canada (n = 54)	Netherlands (n = 59)	Italy (n = 25)
Female gender, %	72	66	78
Age, mean (SD)	61.1 (7.7)	59.9 (9.6)	58.7 (12)
Non-native, %	0	2	0
Religious background, %			
Catholic	93*	34* <sup>†</sup>	88 <sup>†</sup>
Protestant	0*	29* <sup>†</sup>	0 <sup>†</sup>
Other (eg, Humanist)	2*	12*	0
None	6*	25*	12
Believe that religious or spiritual orientation influenced evaluation of booklet, %			
Yes, strongly	11	8	0
Yes, a little	19	22	29
No	70	69	71
University education (completed Master's or Bachelor's), %	25	40	22
Relationship with the deceased, %			
Son or daughter	69	69	63
Spouse or partner	11	14	13
Other relative, or friend	20	17	25
Grief resulted in impairment in functioning, mean (SD)	2.0 (1.2)*	1.3 (0.7)*	1.5 (0.9)
Felt prepared of relative's death, %	91*	82 <sup>†</sup>	52* <sup>†</sup>
Reported death happened suddenly and unexpectedly	9*	7 <sup>†</sup>	33* <sup>†</sup>
Reported discussion about what to expect with nurse or physician, %	80* <sup>†</sup>	56 <sup>†</sup> <sup>‡</sup>	9* <sup>‡</sup>
Satisfaction with care, mean (SD) on 0 (not at all) -10 (extremely satisfied) scale	8.7 (1.5)*	8.1 (1.5)*	8.3 (2.0)
Time between assessment and death of relative, mean number of days (SD)	120 (25)	125 (65)	123 (35)

\*<sup>†</sup><sup>‡</sup>*p* < .05 for difference between 2 countries.

find the information on possible sensitive decisions balanced (84%–92%). Regarding format, Italian families more frequently preferred a system of fact sheets or did not find the (different, Italian) photographs appropriate.

The large majority of families (96%–100%) in the 3 countries believed there is a need for such a brochure and more specifically, they perceived the booklet useful should they have had it earlier (93%–96%; Table 4). The booklet was found useful (0–10 scale) and “highly acceptable” by Canadian and Dutch families but Italian families scored lower (“acceptable”) and below the cutoff of 8 on the usefulness scale. Seven Canadian families (11%) had already seen the booklet when their loved one was in the nursing home. Their evaluations were largely similar regarding acceptability (mean score 35.3 SD 4.1 versus 36.0 SD 5.2), usefulness (8.7 SD 0.8 versus 9.0 SD 1.5), and preference for available on own initiative (4 of 6 who responded versus 59%), but none of the 6 wished to have the booklet early (versus 26% of

Canadian families who had not seen the booklet during the resident's stay).

The 9 respondents (7%) who would not have found the booklet useful stated that (more answers possible) the specific circumstances were not discussed (3 cases), that they preferred talking over reading (3), that reading it would have increased anxiety (1), created conflicts with other family (1), or otherwise that they knew about the topic through their profession (2). Possible reasons not checked by any of the respondents were that they did not agree with the contents, that the style of writing was too difficult, or that it would have created conflicts with staff. Further, many families used the open-ended questions to comment on what they liked and disliked about the booklet (comments in Box 2). They frequently cited clarity and simplicity, and also that they wished they had had the booklet earlier.

Of those who would have found the booklet useful, almost all (96%–100%) accepted any of the practitioners to have a role in

**Table 3**  
Evaluation of Contents and Format of the Booklet

	Canada (n = 54)	Netherlands (n = 59)	Italy (n = 25)
The amount of information, %			
Too much	11	5	4
Too little	4*	2 <sup>†</sup>	26* <sup>†</sup>
Just right	85	93	70
Quality of the information of the booklet, mean on 1–5 scale (SD)	4.7 (0.6)*	4.6 (0.6) <sup>†</sup>	4.0 (0.8)* <sup>†</sup>
Any parts of booklet respondent did not understand, %	0	3	0
Any part of booklet respondent did not agree with, %	6	5	0
Information on possibly sensitive decisions			
Too much slanted toward comfort care	0	7	4
Too much slanted toward life-prolonging care	8	9	4
Balanced	92	84	92
Preferred format, %			
A booklet (current)	96	97	80
A system of fact sheets	2*	3 <sup>†</sup>	20* <sup>†</sup>
Other	2	0	0
Photographs appropriate, %	85*	88 <sup>†</sup>	63* <sup>†</sup> <sup>‡</sup>

\*<sup>†</sup>*p* < .05 for difference between 2 countries.

<sup>‡</sup>Photographs in the Italian booklet differed (see Methods section).

**Table 4**  
Need, Usefulness, and Acceptability of the Booklet

	Canada (n = 54)	Netherlands (n = 59)	Italy (n = 25)
Believe general need for information brochure with the topic, in the country of residence, %	96	100	100
Would have found booklet useful at some point during the nursing home stay (perceived usefulness), %	93	93	96
Usefulness to respondent on 0–10 scale, mean (SD)	9.0 (1.4)* <sup>†</sup>	8.3 (1.4)*	7.7 (2.2) <sup>†</sup>
Acceptability scale with range 8–40, mean (SD)	35.9 (5.0)*	34.6 (5.6) <sup>†</sup>	30.0 (6.6)* <sup>†</sup>

The usefulness and acceptability scales correlated significantly and positively (0.63;  $P < .001$ ).

\*<sup>†</sup> $P < .05$  for difference between 2 countries.

providing the booklet (Table 5). Additionally, in each country about half (42%–58%) endorsed availability not through practitioners. More Canadian families selected the nurse to provide the booklet over the physician, whereas this was the reverse for Italian families, and Dutch families selected either profession in equal amounts.

There was large variation across individuals and settings in preference of when to obtain the booklet, but the last, dying phase was rarely preferred (Table 5). One-third or more of Italian families would have preferred to receive the booklet upon diagnosis, of

Canadian families upon admission, and of Dutch families shortly after admission. Of Canadian families, 23% wished to have had the booklet early (at diagnosis or before admission), and this was 25% for Dutch, and 38% for Italian families. A preference to receive the booklet early, or availability not through practitioner was unrelated to acceptability or usefulness.

In unadjusted multilevel analyses, Italian respondents found the booklet less acceptable than Canadian respondents (beta  $-5.9$ , confidence interval [CI]  $-9.5$ ;  $-2.2$ ) and there was no difference between Dutch and Canadian respondents. The Italian–Canadian difference remained after adjustment (beta  $-7.8$ , CI  $-11$ ;  $-4.8$ ; Table 6). Usefulness was lower according to Italian and Dutch respondents compared to Canadians, both in unadjusted (beta  $-1.3$ , CI  $-2.0$ ;  $-0.6$  and  $-0.7$ , CI  $-1.0$ ;  $-0.4$  respectively) and in adjusted analyses (beta  $-2.0$ , CI  $-2.6$ ;  $-1.4$  and  $-0.8$ , CI  $-1.2$ ;  $-0.4$ ). Italian respondents were less likely to prefer availability on own initiative in adjusted analyses only (OR 0.27, CI 0.13–0.57), but more likely to prefer receiving the booklet early both in unadjusted (OR 2.1, CI 1.1–4.1) and in adjusted analyses (OR 7.9, CI 1.9–33.0; Tables 5 and 6).

Better acceptability, usefulness, and availability through own initiative were consistently and independently associated with non-Italian nationality, presence of more physical signs discussed in the booklet, feeling ill-prepared, and higher satisfaction with care (Table 6). Acceptability was also better with longer length of stay and in nonspousal respondents. Acceptability or usefulness were better with no mainstream religion, or no (influence of) religion, respectively. A sudden and unexpected death was related to preferred availability through own initiative. Those who preferred to receive the booklet early were more likely to be Italian, have no university education, and cared for older residents.

## Discussion

We evaluated a booklet on comfort care in dementia from the perspective of families who have experienced death of their loved one in a long term care setting. Need for and perceived usefulness of the booklet was almost universally acknowledged. There was great support for its contents in the development setting (French-speaking Canada) and in the 2 European countries in the study. The results suggest that the booklet has the potential to help many families who face common challenges in late-stage dementia. This is consistent with studies in long term care settings in the United States and other countries that have identified strong educational needs regarding end-of-life issues among families of dementia patients<sup>4,6,7,11–13,30</sup>

However, the booklet was found highly acceptable and useful by Canadian and Dutch families, but less so by Italian families. Similar to Italian families, Italian practitioners also rated the booklet less favorably than did Dutch practitioners.<sup>18</sup> Possible explanations for lower acceptance among Italian families relate to the adapted booklet and to the setting. The Italian booklet was only slightly adapted; possibly more adaptation was needed to better suit an Italian taste way of presenting data. However, families' comments

### Box 2. Selected comments on usefulness of the booklet

#### Positive comments

- “I liked the format, the simplicity and clarity of the writing, the possibility of taking time to reread it and to share it with other family members” (Canadian daughter)
- “It is direct and efficacious, easy to understand, suitable for everybody and written entirely in Italian” (Italian daughter)
- “It helped me better understand the actions that were taken and my role” (Canadian son)
- “The last phase of life of a person with dementia has been described very well. I wish I had had the booklet before my mother died” (Dutch son)
- “If I had read it before the events, I could have advocated for less aggressive treatments and would now feel less guilty about what happened” (Canadian spouse)
- “It helps me deal with my feelings of guilt” (Dutch daughter)
- “I liked its straight forwardness/honesty” (Dutch widow)
- “I like the fact that the booklet is there!” (Italian daughter)

#### Negative comments

- “It focuses too much on Alzheimer disease. It is less useful for other scenarios. My husband had fronto-temporal dementia and the part about natural evolution of disease was not relevant to his case. However, I appreciated the sections on decision making and symptom control” (Canadian wife)
- “It may make you even more anxious, but you will need to face that” (Dutch daughter)
- “It addresses what to expect as a family member, nevertheless, every death is different” (Dutch daughter)
- “I dislike to have received it only after my mother's death/that I did not have it when my mother was in the nursing home” (Italian and Dutch daughters)

**Table 5**  
Preferences for Providing the Booklet: Profession and Timing

(n = 138 – 9 = 129 whom found useful)	Canada (n = 50)	Netherlands (n = 55)	Italy (n = 24)
Profession, %			
Physician (includes nursing home physician, general practitioner, and other [specialist])	45* <sup>†</sup>	73* <sup>‡</sup>	96 <sup>†,‡</sup>
Nurse practitioner	12	11	0
Nurse (includes head nurse, nurse trained in explaining the booklet, nurse assistant or aid, and other [nurse who knows resident])	78*	71 <sup>†</sup>	33* <sup>†</sup>
Social worker	26*	4* <sup>†</sup>	25 <sup>†</sup>
Profession - any	96	100	96
Preferences with regard to being made available, %			
Should be made available with other free printed documents for families in nursing homes (brochure cabinet)	46	38	25
Available through Internet	42	31	25
Available not through practitioner - total	58	51	42
Preferred time to get booklet, %			
When diagnosed with dementia or shortly afterwards	23	18	33
Before admission to the nursing home	0	7	4
At the time of admission to the nursing home	35* <sup>†</sup>	16*	13 <sup>†</sup>
When general goals of care are discussed initially / advanced care planning shortly after admission	10*	40*	25
When there were discussions about a medical problem (eg, eating, drinking, fever, hospital transfer)	27	16	21
When it became clear that my relative was about to die	4	0	4
Other ("upon request; indicate availability upon admission")	0	2	0

\*<sup>†,‡</sup>P < .05 for difference between 2 countries.

to the text, if provided, showed appreciation of the Italian language, but the Italian photographs were frequently not appreciated, and format of decision aids matter.<sup>31</sup> Families including Italian families did not perceive the booklet as slanted toward comfort care, even

though Italian practitioners did,<sup>18</sup> and Italian physicians perceive withholding of treatment as less acceptable than in the Netherlands.<sup>32,33</sup> Nevertheless, the booklet may have been less well adapted to needs in Italy; more information and a fact sheet

**Table 6**  
Multivariable Associations of Resident and Family Factors with Outcomes Adjusted for Clustering of Resident-family Pairs within Facilities

	Acceptability (Scale)	Usefulness (Scale)	Preference for Available Not Through Practitioner (Own Initiative)	Timing: Before Admission
Country				
Canada (reference)				
Netherlands		↓		
Italy	↓	↓	↓	↑
Female gender resident				
Age of resident				↑
Length of stay	↑			
Number of symptoms and signs*	↑	↑	↑	
Female gender family				
Age of family				
Religious background				
Catholic (reference)				
Protestant				
Other (eg, Humanist)	↑			
None		↑		
Believe that religious or spiritual orientation influenced evaluation of booklet, 3-point scale		↓		
University education family				↓
Relationship with the deceased				
Son or daughter (reference)				
Spouse or partner	↓			
Other relative, or friend				
Impairment through grief, 5-point scale				
Felt prepared of relative's death	↓	↓	↓	
Death happened suddenly and unexpected			↑	
Reported discussion with nurse or physician about what to expect				
Mean time since death of relative, per day				
Higher overall satisfaction with care	↑	↑	↑	
r <sup>2</sup> model <sup>†</sup>	0.30	0.29	0.20	0.15

↑ positive association, P < .05; ↓ negative association, P < .05; Blank cell, no significant independent association.

\*Number of symptoms and physical signs discussed in the booklet, out of 5 (pain, shortness of breath, difficulty drinking enough fluids, feeding difficulties, fever). Of note, multivariable associations were only slightly different when the 7 families who had already seen the booklet were excluded. This referred to small shifts in some variables with significant levels between .01 and .08, except for number of symptoms and signs discussed in the booklet where shifts were larger and only the association with usefulness remained (so exposure to the booklet may have increased associations of importance of symptoms and signs with outcomes).

<sup>†</sup>Measures for explained variance. Note: r is the correlation between predicted and observed values. The r<sup>2</sup> for the models with continuous outcomes (2nd and 3rd columns) cannot be directly compared with those for the dichotomous outcomes (last 2 columns).

providing pieces of information was preferred more frequently in Italy. Further, in spite of lower acceptability, usefulness was not different for Italian families. In addition to the booklet itself, a need for more information may be key to the lower acceptance, related to an overall weaker tradition of discussing end-of-life decisions and patient preferences, in comparison with Canada and the Netherlands for which we found evidence in our study. Other work has indicated that palliative care services are less progressed in Italy compared with the Netherlands,<sup>34</sup> and that information needs in cancer patients, including on noncurative care may be more similar between the Netherlands and Canada compared with Italy.<sup>35</sup>

To prepare for implementation, we have also examined preferences as to who should provide the booklet, the best timing, and factors associated with preferences as well as acceptability and usefulness. Almost all families endorsed roles for practitioners in providing the booklet, with the specific professions varying across settings, and about half favored availability through their own initiative. Preferences for who should provide the booklet among families were similar to those preferred by European practitioners.<sup>18</sup> In a community study, most families wished information by a practitioner, backed up by written material.<sup>36</sup>

Preference of timing was highly variable across both individuals and countries. Only a few factors were associated with a preference of receiving the booklet early. These were families of older residents, with no university education, and Italian nationality—the last 2 of which might be related to lower access to information. Better acceptability, usefulness, and availability through own initiative (even though the latter was not associated with the first 2 outcomes) were consistently and independently associated with non-Italian nationality, more symptoms and physical signs discussed in the booklet, feeling ill-prepared, and higher satisfaction with care. Additional accepting of availability without practitioner encounters was unrelated to dissatisfaction with care, and therefore probably does not reflect distrust.

Preference of timing may reflect comfort in thinking about death and dying and to plan end-of-life care in advance, and also to unfavorable experiences with care. Readiness to plan ahead has been shown to be highly individual and difficult to predict in other work.<sup>37–40</sup> Moreover, some family members do not wish to be involved, may give full responsibility to the physician, may avoid information, or accept information only in the actual situation.<sup>8,9,19,20</sup> Information also does not always reduce uncertainty or anxiety.<sup>19,20</sup> A comparable Australian booklet was provided early, and half of families stated it increased anxiety.<sup>13</sup>

Palliative care may consider individual information needs prudently. Patient- and family-centered care implies practitioners' skill in identifying the right moment and amount of information. However, it makes sense to prepare "for the worst" because the number and nature of future health problems, one of the factors associated with usefulness of the booklet, cannot be predicted accurately. Our findings support integrating use of the booklet in advanced care planning with health care providers, providing information in a step-wise fashion,<sup>36,40</sup> in addition to making the booklet freely available. It may help these families initiate discussions with practitioners if needed, or to better formulate questions. It may also help distant relatives who may be more dissatisfied with information received,<sup>41</sup> a factor we have not studied.

Some other limitations of our study should be noted. Retrospective evaluation may have introduced bias especially regarding receptiveness to information when the respondent's loved one was still alive. The study is not necessarily representative of the 3 countries, and a smaller number of Italian families participated. There were some methodological differences in sampling methods, exclusion criteria, and the possibility for help to complete the

survey. However, the exclusion of sudden deaths may have had limited effects on the Canadian sample, because presence of feeding difficulties (mostly in later stages) was unrelated to outcome, and in regression analyses, we adjusted for unexpected death, which Canadian families still reported. Further, the methodology, after-death questionnaire, or telephone interviews did not affect families' satisfaction with care in a Dutch study.<sup>21</sup>

## Conclusion

The booklet is suitable to inform Dutch and Canadian families on comfort care in dementia. Implementation in Italy requires further consideration and possible adaptation. We recommend integrating the booklet in advance care planning if families are receptive, and because preferences vary and depend on the later course of the disease, to also make it available before nursing home admission.

## References

- Houttekier D, Cohen J, Bilsen J, et al. Place of death of older persons with dementia. A study in five European countries. *J Am Geriatr Soc* 2010;58:751–756.
- Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. *J Am Geriatr Soc* 2005;53:299–305.
- Olson E. Dementia and neurodegenerative diseases. In: Morrison R, editor. *Geriatric Palliative Care*. New York: Oxford University Press; 2003. p. 160–172.
- Givens JL, Kiely DK, Carey K, Mitchell SL. Healthcare proxies of nursing home residents with advanced dementia: Decisions they confront and their satisfaction with decision-making. *J Am Geriatr Soc* 2009;57:1149–1155.
- van der Steen JT. Dying with dementia: What we know after more than a decade of research. *J Alzheimer Dis* 2010;22:37–55.
- Forbes S, Bern-Klug M, Gessert C. End-of-life decision making for nursing home residents with dementia. *J Nurs Scholarsh* 2000;32:251–258.
- Gessert CE, Forbes S, Bern-Klug M. Planning end-of-life care for patients with dementia: roles of families and health professionals. *Omega (Westport)* 2000;42:273–291.
- Caron C, Arcand M, Griffith J. Creating a partnership with families in decision making for end-of-life care in Alzheimer disease: The perspective of family caregivers. *Dementia* 2005;4:113–136.
- Caron C, Griffith J, Arcand M. Decision making at the end of life in dementia: How family caregivers perceive their interactions with health care providers in long-term care settings. *J Appl Gerontol* 2005;24:231–247.
- Bern-Klug M. The emotional context facing nursing home residents' families: A call for role reinforcement strategies from nursing homes and the community. *J Am Med Dir Assoc* 2008;9:36–44.
- Biola H, Sloane PD, Williams CS, et al. Physician communication with family caregivers of long-term care residents at the end of life. *J Am Geriatr Soc* 2007;55:846–856.
- Hennings J, Froggatt K, Keady J. Approaching the end of life and dying with dementia in care homes: The accounts of family carers. *Rev Clin Gerontol* 2010;20:114–127.
- Chang E, Easterbrook S, Hancock K, et al. Evaluation of an information booklet for caregivers of people with dementia: An Australian perspective. *Nurs Health Sci* 2010;12:45–51.
- Arcand M, Caron C. *Comfort Care at the End of Life for Persons with Alzheimer's Disease or Other Degenerative Diseases of the Brain*. Sherbrooke, Canada: Centre de Sante et de Services Sociaux – Institut Universitaire de Geriatrie de Sherbrooke, 2005. Available at: <http://www.vumc.nl/afdelingen-themas/4851287/27785/5214110/HandreikingDementie.pdf>. Accessed March 10, 2011. The Italian text is available at Associazione Italiana Malattia di Alzheimer (AIMA): [www.alzheimer-aima.it/libri.htm](http://www.alzheimer-aima.it/libri.htm). Accessed January 8, 2011. The Dutch version is available from: <http://www.vumc.nl/afdelingen-themas/4851287/27785/5214110/HandreikingDementie.pdf>. Accessed March 10, 2011.
- Elwyn G, O'Connor A, Stacey D, et al. International Patient Decision Aids Standards (IPDAS) Collaboration. Developing a quality criteria framework for patient decision aids: Online international Delphi consensus process. *BMJ* 2006;333:417.
- Gove D, Sparr S, Dos Santos Bernardo AM, et al. Recommendations on end-of-life care for people with dementia. *J Nutr Health Aging* 2010;14:136–139.
- Hewitt M, Simone JV, eds. *Ensuring Quality Cancer Care*. Washington DC: National Academies Press, 1999. In: Davies E and Higginson IJ, eds. *Better Palliative Care for Older People*. Geneva: World Health Organization (WHO), 2004.
- van der Steen JT, Toscani F, de Graas T, et al. Physicians' and nurses' perceived usefulness and acceptability of a family information booklet about comfort care in advanced dementia. *J Pall Med*; 2011. Accepted for publication.
- Case DO, Andrews JE, Johnson JD, Allard SL. Avoiding versus seeking: The relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. *J Med Libr Assoc* 2005;93:353–362.

20. Polk DM. Communication and family caregiving for Alzheimer's dementia: Linking attributions and problematic integration. *Health Commun* 2005;18: 257–273.
21. van der Steen JT, van Soest-Poortvliet M, Achterberg W, Ribbe M, de Vet R, Zimmerman S, Cohen LW. End-of-life in long-term care in the Netherlands: new findings and measurement issues. *Gerontologist* 2009;49(52, Oct):57.
22. van Soest-Poortvliet M, van der Steen JT, Zimmerman S, Cohen LW, Munn J, Achterberg WP, Ribbe MW, de Vet HCW. Measuring the quality of dying and quality of care when dying in long-term care settings: a qualitative content analysis of available instruments. *J Pain Symptom Manage* 2011. Accepted for publication.
23. O'Connor AM, Cranney A. Patient Decision Aids – Evaluation Measures. User manual for acceptability. Ottawa, Canada: University of Ottawa, Ottawa Hospital Research Institute, 2002. Available at: [http://decisionaid.ohri.ca/docs/develop/User\\_Manuals/UM\\_Acceptability.pdf](http://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Acceptability.pdf). Accessed January 8, 2011.
24. Graham ID, Logan J, Bennett CL, et al. Physicians' intentions and use of three patient decision aids. *BMC Med Inform Decis Mak* 2007;7:20.
25. Salisbury C, Wallace M, Montgomery AA. Patients' experience and satisfaction in primary care: Secondary analysis using multilevel modelling. *BMJ* 2010;341: c5004.
26. van der Steen JT, Gijsberts MJ, Muller MT, et al. Evaluations of end of life with dementia by families in Dutch and U.S. nursing homes. *Int Psychogeriatr* 2009; 21:321–329.
27. El-Jawahri AR, Prigerson HG. Bereavement care. In: Berger AM, Hushter Jr JL, Von Roenn JH, editors. *Principles and Practice of Palliative Care and Supportive Oncology*. 3rd ed. Philadelphia: Lippincott Williams & Wilkins; 2007. p. 645–653.
28. Hardin JW, Hilbe JM. *Generalized Estimating Equations*. Boca Raton FL: Chapman & Hall/CRC; 2003.
29. Agresti A. *Categorical Data Analysis*. 2nd ed. New York: Wiley; 2002.
30. Wolf-Klein G, Pekmezaris R, Chin L, Weiner J. Conceptualizing Alzheimer's disease as a terminal medical illness. *Am J Hosp Palliat Care* 2007;24:77–82.
31. Feldman-Stewart D, Brundage MD. Challenges for designing and implementing decision aids. *Patient Educ Couns* 2004;54:265–273.
32. Miccinesi G, Fischer S, Paci E, et al. EURELD consortium. Physicians' attitudes towards end-of-life decisions: A comparison between seven countries. *Soc Sci Med* 2005;60:1961–1974.
33. Löfmark R, Nilstun T, Cartwright C, et al. EURELD Consortium. Physicians' experiences with end-of-life decision-making: Survey in 6 European countries and Australia. *BMC Med* 2008;6:4.
34. Centeno C, Clark D, Rocafort J, et al. Task force on the development of palliative care in Europe. Ranking of palliative care development in the European Union. Presented at the EAPC, Vienna, 2009. Available at: <http://www.eapc-taskforce-development.eu/documents/taskforce/madrid0508.pdf>. Accessed January 8, 2011.
35. Feldman-Stewart D, Capirci C, Brennenstuhl S, et al. Information needs of early-stage prostate cancer patients: A comparison of nine countries. *Radiother Oncol* 2010;94:328–333.
36. Wald C, Fahy M, Walker Z, Livingston G. What to tell dementia caregivers—the rule of threes. *Int J Geriatr Psychiatry* 2003;18:313–317.
37. Pfeifer MP, Mitchell CK, Chamberlain L. The value of disease severity in predicting patient readiness to address end-of-life issues. *Arch Intern Med* 2003; 163:609–612.
38. Mattimore TJ, Wenger NS, Desbiens NA, et al. Surrogate and physician understanding of patients' preferences for living permanently in a nursing home. *J Am Geriatr Soc* 1997;45:818–824.
39. Fried TR, Bullock K, Iannone L, O'Leary JR. Understanding advance care planning as a process of health behavior change. *J Am Geriatr Soc* 2009;57: 1547–1555.
40. Fried TR, Redding CA, Robbins ML, et al. Stages of change for the component behaviors of advance care planning. *J Am Geriatr Soc* 2010;58:2329–2336.
41. Thompsell A, Lovestone S. Out of sight out of mind? Support and information given to distant and near relatives of those with dementia. *Int J Geriatr Psychiatry* 2002;17:804–807.