

# End-of-life Decision-making Differs Between a Cancer and a Dementia Patient: Influences of the Physician's Background Factors

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**Abstract.** *Background/Aim:* Appropriate decision-making is essential for end-of-life (EOL) care without futile therapies. However, these decisions might vary in cases of cancer and other advanced diseases according to physicians' experience, education, and values. This study aimed to compare the decisions in EOL care of advanced cancer and dementia and the factors that influence them in medical students, general practitioners (GPs), and physicians with special competence in palliative medicine (cPM). *Patients and Methods:* A questionnaire presenting patient scenarios concerning different decisions and ethical aspects of EOL care with additional questions on attitudes and background factors was delivered to 500 Finnish GPs, all Finnish physicians with cPM (n=82), and all graduating medical students (n=639) in 2015-2016. Altogether 601 responses were obtained (53%). *Results:* Palliative care was chosen more often for a patient with advanced prostate cancer (83%) than for a patient with advanced dementia (41%) (both patients males, same age). A suspicion of iatrogenic bleeding in the prostate cancer patient decreased the willingness to choose palliative care, especially among the students. Patient benefit was regarded as an

important background factor in decision making by all respondent groups, but physicians' legal protection was not considered as important among the physicians with cPM as it was among the other respondent groups. *Conclusion:* Finnish doctors and students were more likely to choose palliative care options for an advanced prostate cancer patient than for an advanced dementia patient. Decision-making was influenced by respondents' background factors and attitudes. Education on EOL care for different types of advanced and incurable diseases is highly needed.

Identifying patients in need of palliative care and timely end-of-life (EOL) decisions are challenging. Considering the strong historical ties between palliative care and care of cancer patients, cancer patients are still more likely to be referred to specialists in palliative care, and palliative care is initiated earlier for cancer patients than for patients with terminal noncancer illnesses (1-3).

Even though palliative care has gradually been integrated into the care of incurable non-malignant diseases, such as dementia, patients with advanced dementia are often exposed to recurrent emergency unit visits and hospitalizations during the last months of their lives, and EOL decisions occur in acute care settings without knowledge of the patient's medical history or wishes concerning EOL care (4, 5). Less than 40% of patients with dementia undertake advance care planning (ACP), and hospital deaths are still common among individuals with dementia (6-10). EOL decision making is often complex and multidimensional and varies a lot between similar clinical situations (11, 12). There is increasing evidence showing that physician-related factors like personal and professional experience, values and avoidance of criticism have strong influence on EOL decision making (13-15). This may lead to inequality in EOL care and should be widely acknowledged

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**Key Words:** Decision-making, end-of-life care, advanced prostate cancer, advanced dementia, physicians, medical students, special competence in palliative medicine.



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(12). Considering our ageing population and growing number of frail patients with many incurable chronic diseases, the need for better understanding and skills in EOL care is essential. The aims of this study were to explore how decision making is affected by the illness of the patient (cancer vs. dementia) and how decisions differ among general practitioners (GPs), graduating medical students and physicians with and without special competency in palliative medicine (cPM) in two hypothetical patient scenarios and whether there are some identifiable factors that influence their decision making. The findings are relevant in planning education concerning the EOL care of the ageing population with different illness trajectories.

## Patients and Methods

**Participants.** This survey was mailed to 1,100 Finnish physicians who were randomly selected from the registry of Finnish Medical Association (500 GPs, 300 internists, 300 surgeons and all clinical oncologists) and to Finnish physicians with a cPM (n=82) in 2015 (16). In addition, the same survey was shared with all medical students in their last study year (N=639 autumn 2015 or spring 2016) at all five Universities with Medical Faculties in Finland. Two reminders were sent. For this study, responses from physicians with cPM, experienced GPs (GPs that had graduated less than five years ago were excluded, n=23), and students were included. Valid responses were obtained from 402 (63%), 67 (82%) and 245 (49%) of the students, physicians with cPM and GPs, respectively.

**Questionnaire.** Seven hypothetical patient scenarios, most of them cancer cases, were presented in the questionnaire as described in our previous publications (16-25). Following the patient scenarios, attitudes regarding several moral and ethical aspects were assessed with a 100 mm visual analogue scale (VAS; “definitely agree”=0 mm to “definitely disagree”=100 mm). The details of these are presented in our previous publications (16-19). The overall results concerning these attitudes among experienced GPs and students have been previously reported (23, 24). There were also questions concerning respondents’ background and personal features. This international questionnaire has been validated by our group and previously used in our studies with Finnish physicians (16-25).

**Patient scenarios.** The patient scenarios have been separately presented in previous studies (16-25). In this comparative study, we included two patient scenarios: one advanced cancer and one advanced dementia patient. Shortly, scenario 1 presented an 82-year-old retired forest worker, who received a diagnosis of prostatic cancer three years ago. In the past year, he has been treated for bone metastases, and is currently hospitalized for a month, almost totally bedridden, and needs help with all daily activities. Mental condition is good, but now he is totally bedridden due to a weakening and is receiving large doses of pain medication. Today he became comatose with low blood pressure and anaemia (haemoglobin count 68 g/l now, a week before, 118 g/l). No verbal or written advance directive was found and his wife previously announced that she expects the doctors to make all treatment decisions. After the case, several treatment options were presented. The treatment options were explained as: 1) palliative care: good nursing, sufficient medications for pain and other symptoms and intravenous hydration only when it is considered to

relieve the patient’s symptoms; 2) active care: the use of antibiotics, intravenous hydration or blood transfusions aimed at saving the patient’s life in a life-threatening condition; and 3) intensive care: moving the patient to the intensive care unit (ICU). After that the following four additional alternatives were presented and for each were prefaced by the same treatment options; 1) It has been discovered that the patient’s faeces are black. You remember that you started pain medication with ketoprofen a week ago. 2) The patient’s son is coming from America the day after tomorrow to see his father while he is still alive. 3) The patient is having spiritual anxiety, and he has an appointment with a minister and the Lord’s Supper tomorrow. 4) The patient’s written advance directive was found; the patient has expressed that all active interventions should be withheld if there is no hope for recovery. After the treatment decisions, a Likert-type scale was presented to evaluate the influence of different factors (patient benefit, family benefit, patient legal protection, physician legal protection, ethical values, patient age, cost of care, and patient social status) on the decisions (from 1 – very little influence to 5 – very much influence) (16, 19, 21, 24).

The scenario 2 (shortly) described an 82-year-old man, who was diagnosed with Alzheimer’s disease three years ago and due to the progressive dementia, was living in a nursing home. He has urinary and faecal incontinence and needs help in washing and dressing and cannot identify his daughter (25). He is brought to an emergency department at 2 am with life-threatening gastrointestinal bleeding, low blood pressure (70/40 mmHg), and heart rate 120 beats/min. The patient is unable to communicate, his family or physician cannot be reached, and the accompanying nurse’s aide is not familiar with the patient. There is no information available as to his or his family’s wishes in this type of situation. The decisions asked were 1) palliative care, 2) active care or 3) intensive care (these treatment options explained as in the cancer patient case). After asking for the decisions, a same Likert-type scale (1 to 5) was presented to evaluate the influence of the same factors as in the case of cancer on their decisions (25).

**Statistical analysis.** The answers were recategorized dichotomously for the statistical analysis for both of the scenarios presented in this study. The conversion was conducted as follows (responses shown in brackets): “choosing palliative care” (1) or “not choosing palliative care” (2 and 3) and “not having much influence” (Likert 1-3) or “having much influence” (Likert 4-5). A comparison of the students, physicians with cPM and GPs was performed using the Pearson Chi-Square test for the dichotomous variables. *p*-Values of less than 0.05 were accepted as statistically significant.

**Logistic regression analysis.** A forward stepwise logistic regression was used to create models that explain the decision to choose active/intensive care over the palliative care approach in patient scenarios 1 a) and 2. Background factors, life values, and attitudes were all included in the model. The *p*-value limit for significance was set at 0.10 to enter and 0.15 to remove from the model.

The data analysis was performed using IBM SPSS Statistics for Windows, version 27.0, IBM Corp. Armonk, NY, USA.

**Ethical considerations.** An introduction to the study and an assurance of anonymity and voluntariness were included in a cover letter attached to the questionnaire. This study was approved by the Regional Ethics Committee of Tampere University Hospital, Tampere, Finland (R15101).

Table I. Characteristics of the participants.

	cPMs	GPs	Students	Total
Number (% of total)	67 (10)	222 (32)	402 (58)	691 (100)
Response rate, %	82	49	63	53
Female, n (%)	57 (85)	157 (71)	248 (62)	462 (67)
Median age (IQR)	55 (48-58)	51 (41-57)	26 (25-28)	41 (27-54)
Age distribution, n (%)				
<25	0 (0)	0 (0)	40 (10)	40 (6)
25-34	0 (0)	26 (12)	347 (86)	373 (54)
35-49	20 (30)	80 (36)	15 (4)	115 (17)
≥50	47 (70)	116 (52)	0 (0)	163 (24)
Years from graduation, median (IQR)*	27 (21-32)	23 (12-31)	0 (0)	25 (15-31)

cPM: Special competence in palliative medicine; GP: general practitioner; IQR: interquartile range. \*For one participant, year of graduation was not available.

## Results

The respondents' background factors are presented in Table I. The median ages of the GPs and the physicians with cPM were over 50 years, whereas most of the students were under the age of 30 years. Two-thirds of the participants were women. The respondents' decisions in the patient scenarios are presented in Table II.

In the original scenario of advanced prostate cancer patient (scenario 1), 83% of the respondents chose the palliative care approach without significant differences among the respondent groups ( $p=0.865$ ), while in scenario 2, (advanced dementia patient) 57% of the physicians with cPM, 39% of the GPs and 42% of the students chose the palliative care approach ( $p=0.050$  across the groups), giving a total of 41% of the respondents. In scenario 1a (with a possible influence of the ketoprofen prescription), the students chose the palliative care approach less often (55%) than physicians with cPM (70%) and GPs (60%) ( $p=0.036$  across the groups). In contrast, there were no significant differences among the groups in scenario 1b, with the patient's son coming to visit the day after tomorrow, or 1c, with the patient having an appointment with a minister tomorrow. However, almost all respondents selected a palliative care approach (93-96%), when the patient's advance directive expressing a wish to withhold unhelpful curative interventions was found. The factors that influenced the EOL decisions are presented in Table III.

All agreed that the patient benefit is important, but the family benefit was less important for the students and for the GPs than for the physicians with cPM in both scenarios. 28% of the students and 27% of the GPs chose the family benefit to be influential compared to 49% of the physicians with cPM in scenario 1 with the cancer patient ( $p=0.002$ ). In scenario 2 with the dementia patient, the family benefit was regarded as an influential factor by 23% of the students, 19% of the GPs and 36% of the physicians with cPM ( $p=0.022$ ).

The physicians with cPM did not consider physicians legal protection as important as the students and GPs (49% vs. 74% and 75%, respectively, in scenario 1 and 51% vs. 77% and 72%, respectively, in scenario 2 ( $p<0.001$  for both)). In the case of advanced cancer (scenario 1) over 90% of the respondents in all groups reported ethical values as an influential factor in their decision making, while in scenario 2 (advanced dementia), a slightly lower proportion of the GPs (87%) and the students (84%) regarded ethical values as influential in their decisions compared to the physicians with cPM (97%,  $p=0.014$ ). A significantly higher proportion of the students considered the patient age as an influential factor in their decision making compared to the GPs and the physicians with cPM in both scenarios. The costs of care or patient social status had almost no effect on the participants' decisions inside the study groups in either of the scenarios.

Several background factors (Table IV and Table V) explained the choice of active/intensive care ( $n=249$  and  $n=245$ , respectively) over the palliative care approach ( $n=350$  and  $342$ , respectively) in the scenarios.

In the case of the advanced prostate cancer patient, both the idea that a physician cannot estimate cancer pain and religion as an influential factor in ethical decision making were associated with a decreased likelihood of choosing an active/intensive care approach. In the case of the patient with advanced dementia, the respondents' view that it is a waste of resources to treat patients over 80 years of age in ICUs was associated with choosing an active/intensive care approach. The participation in a family member's EOL care was associated with a decreased likelihood of choosing active/intensive care in both cases.

## Discussion

In this study, Finnish physicians and medical students chose a palliative care approach more often for an advanced cancer

Table II. Number and proportion (%) of respondents choosing palliative care approach for the cancer and dementia patients.

	cPMs	GPs	Students	Total	p-Value*
Scenario 1	57 (85%)	181 (82%)	334 (83%)	572 (83%)	0.865
Scenario 1a	47 (71%)	139 (60%)	219 (55%)	405 (59%)	0.036
Scenario 1b	38 (58%)	131 (60%)	253 (63%)	422 (61%)	0.570
Scenario 1c	45 (67%)	154 (71%)	292 (73%)	491 (71%)	0.622
Scenario 1d	63 (94%)	205 (93%)	383 (96%)	651 (94%)	0.350
Scenario 2	33 (57%)	82 (39%)	168 (42%)	283 (41%)	0.050

Scenario 1: Prostate cancer patient (original scenario). Scenario 1a: Prostate cancer patient with black feces after ketoprofen prescription. Scenario 1b: Prostate cancer patient waiting to meet his son the day after tomorrow. Scenario 1c: Prostate cancer is suffering spiritual anxiety and is going to and he has an appointment with a minister and the Lord's Supper tomorrow. Scenario 1d: Prostate cancer patient with the advance. Scenario 2: Dementia patient. \*Pearson Chi-Square (global p-value across all groups). cPM: Special competence in palliative medicine: GP: general practitioner.

Table III. Factors influencing the decisions concerning the level of care of the prostate cancer and dementia patients.

Having influence	Prostate cancer patient					Dementia patient				
	cPMs	GPs	Students	Total	p-Value*	cPMs	GPs	Students	Total	p-Value*
Patient benefit	66 (99%)	218 (99%)	399 (99%)	683 (99%)	0.705	65 (97%)	201 (92%)	362 (91%)	628 (92%)	0.226
Family benefit	32 (49%)	57 (27%)	112 (28%)	201 (30%)	0.002	23 (36%)	42 (19%)	92 (23%)	157 (23%)	0.022
Patient legal protection	57 (86%)	193 (88%)	356 (89%)	606 (88%)	0.861	56 (84%)	175 (81%)	323 (81%)	554 (81%)	0.850
Physician legal protection	32 (49%)	164 (75%)	296 (74%)	492 (72%)	<0.001	34 (51%)	157 (72%)	307 (77%)	498 (73%)	<0.001
Ethical values	65 (97%)	205 (93%)	368 (92%)	638 (93%)	0.295	65 (97%)	190 (87%)	336 (84%)	591 (86%)	0.014
Patient age	19 (29%)	84 (38%)	206 (51%)	309 (45%)	<0.001	22 (33%)	70 (32%)	176 (44%)	268 (39%)	0.010
Costs of care	4 (6%)	27 (12%)	52 (13%)	83 (12%)	0.278	4 (6%)	20 (9%)	50 (13%)	74 (11%)	0.181
Patient social status	1 (2%)	2 (1%)	10 (3%)	13 (2%)	0.377	2 (3%)	4 (2%)	11 (3%)	17 (3%)	0.755

cPM: Special competence in palliative medicine; GP: general practitioner. \*Global p-value across all groups (Pearson Chi-Square).

patient than for a patient with advanced dementia, both the same age (82 years). The suspicion of iatrogenic bleeding of the cancer patient increased the willingness to choose active care, especially among the students. Consistently, most of the students and GPs considered physicians legal protection to be an influential factor in EOL decision making, while this was true for only approximately half of the physicians with cPM.

Even though patients with advanced dementia have a high mortality rate, advanced dementia is often unrecognized as a terminal illness, and patients undergo burdensome interventions and hospitalizations during the last months of their lives (6, 26-28). Although dementia is characterized by progressive and prolonged disability and patients often suffer from multimorbidity, identifying the end-stage of the illness can be very challenging (29-31). Due to the lack of reliable dementia prognostic markers that can be applied in clinical settings, the persons with dementia are often neglected concerning EOL discussions and advanced care planning. Unfortunately, also patients with advanced cancer are often referred to palliative care too late, and aggressive treatments may be continued near EOL (32, 33). A Finnish study showed that the palliative care decision was made <30 days prior to

death or not at all for 44% of patients with advanced pancreatic cancer and 68% of these patients used hospital service in the last month of life compared to 32% of patients with an earlier palliative care decision (p<0.001) (34). The findings of this study also support the need of education in palliative care.

In our study, the patient with dementia was living in a nursing home, was dependent on others, and had severe cognitive impairment; thus, he could be regarded as suffering from frailty and late-stage dementia (35, 36). Our patient with advanced prostate cancer had also a late-stage disease and both patients were over 80 years old. Thus, although we did not preselect strictly correct or incorrect answers to our questionnaire, we suggest that both patients could have benefitted more from a palliative care approach than life-prolonging care. However, modern mini-invasive diagnostic and therapeutic strategies for gastrointestinal bleeding may also be a reasonable option in our patient cases; thus, withholding a possibly life-sustaining treatment may be ethically difficult. Judging whether a clinical procedure is futile for a patient is complex, especially in acute care settings, and often it is easier to postpone EOL decision

Table IV. Different background factors and attitudes explaining the decision to choose active/intensive care (n=249) over palliative care approach (n=350) concerning the prostate cancer patient with probably iatrogenic GI-bleeding (scenario 1a) in forward logistic regression analysis.

	n	OR	(95%CI)	p-Value
Physicians can't estimate cancer pain (VAS)	599	0.91	(0.85-0.98)	0.011
Religion has influence when I make ethical decisions (VAS)	599	0.94	(0.89-0.99)	0.022
I feel burn out, tired to work (VAS)	599	0.94	(0.87-1.00)	0.058
It is waste of resources to treat patients over 80 years of age in intensive care units (VAS)	599	1.07	(1.00-1.15)	0.061
I have done own advance directive				0.077
No	557	ref.		
Yes	42	0.51	(0.25-1.08)	
Taking care of a family member in end-of-life				0.014
No	357	ref.		
Yes	242	0.64	(0.45-0.91)	
Having children				0.011
No	337	ref.		
Yes	262	0.63	(0.45-0.90)	
Length of life				0.004
Important	510	ref.		
Not important	89	0.46	(0.28-0.78)	

VAS: Visual analogue scale (0 definitely agree, 10 definitely disagree). One unit is equivalent to 10 mm on a 100-mm VAS (19).

Table V. Different background factors and attitudes explaining the decision to choose active/intensive care (n=342) over palliative care approach (n=245) concerning the dementia patient (scenario 2) in forward logistic regression analysis.

	n	OR	(95%CI)	p-Value
Withdrawal of life-sustaining treatments is reprehensible (VAS)	587	0.94	(0.88-1.01)	0.096
It is waste of resources to treat patients over 80 years of age in intensive care units (VAS)	587	1.08	(1.01-1.15)	0.032
Taking care of a family member in end-of-life				0.010
No	354	ref.		
Yes	233	0.64	(0.46-0.90)	

VAS: Visual analogue scale (0 definitely agree, 10 definitely disagree). One unit is equivalent to 10 mm on a 100-mm VAS (19).

making until all treatment options have been exhausted also in the cases of advanced cancer (37, 38).

Our study reveals the importance of education in palliative care and in EOL decision making in all advanced, incurable diseases. Only 41% of all respondents chose palliative care for the dementia patient, while palliative care was chosen by 83% of the respondents in the case of the cancer patient. We suggest that this may reflect multidimensional and more difficult aspects in EOL decision making for non-cancer patients also in real life settings.

The presence of possible iatrogenic complications has been shown to affect physicians' decision making and, for instance, to lead to overriding the patient's do-not-resuscitate (DNR) order (39). The same phenomenon was seen in our study, where the respondents were less willing to choose palliative care after finding out that the deterioration of a patient with the prostate cancer was due to probable iatrogenic bleeding. The change towards active care in this situation was greatest

among the students, whereas the physicians with cPM were least affected by this information. Errors in health care are usually very distressing for health care professionals, but it is possible that physicians with more experience are more able to accept a possible iatrogenic complication if the patient's prognosis is already poor.

EOL decisions entail not only medical but also legal and ethical dimensions. According to Finnish law (the Act on the Status and Rights of Patients, 1992), a patient has to be cared for by considering a mutual understanding with him or her, and in the case of his or her incompetency, a representative of the patient has to be heard, if possible, to assess what type of care and treatment would be in accordance with the patient's will (40). Sadly, EOL decisions for older patients often take place in acute care settings, without the possibility of discussing treatment options with the patient or his or her family.

If physicians perceive legal risk, then treatment choices at EOL can be more aggressive (41). In our study, the students



and GPs regarded physician's legal protection as more important for their decision making than the physicians with cPM. This may reveal that physicians with cPM are more familiar with EOL decisions, including the legal aspects related to them.

Nearly all of our respondents regarded patient benefit as an influential factor in decision making (Table III). Family benefit was not considered influential in either case but seemed to affect the physicians with cPM more than the others. We suggest that physicians with cPM are more familiar with the holistic approach of palliative care and give more attention to the needs and wishes of the family than other physicians.

The patients in our scenarios represented an older population and less than half of all the respondents reported that patient age influenced their decision making. However, the students regarded patient age as an influential factor more often than the other studied groups. The physicians with cPM were least affected by patient age when making EOL decisions for the patient with advanced cancer. We suggest that more experienced physicians are more confident in EOL decision making on the basis of the patient's overall health, frailty, and functional status rather than on the basis of the chronologic age of the patient.

Our study has several limitations. Although our study population was a large and representative sample of Finnish physicians, a response rate of 53% is a limitation, and possible nonresponse bias cannot be excluded (42). In addition, we must admit that the decisions could have been different in real-life situations. However, we assume that the answers sufficiently reflect real-life decision making and physicians' real attitudes.

## Conclusion

The novel finding of our study is that there is variability in physicians' EOL decision making between different disease trajectories, and physician-related factors affect the decisions. The decision making for a patient with an advanced cancer seems to be less complex than the decision making in the case of advanced dementia. Regarding the growing number of patients with cancer and dementia, post- and undergraduate education in palliative care in both diseases is still highly needed.

## Conflicts of Interest

The Authors declare that they have no competing interests in relation to this study.

## Authors' Contributions

PLKL, RP, and JL designed the study outline and the questionnaire. RP, JL, and PLKL collected the data. SH, RP, JL, PLKL and RM

analysed the data. SH, RP, and RM did the final statistical analysis. All the Authors contributed to the writing and reviewing of the manuscript, read and approved the final manuscript.

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