

Palliative care needs and symptoms of nursing home residents with and without dementia: a cross-sectional study

Running title

Palliative care needs in nursing homes

Authors

1. Kirsten HERMANS, MSPsy,^a (Corresponding author)

Email address: Kirsten.Hermans@med.kuleuven.be

Phone: +32 16 37 34 07

Fax: +32 16 33 69 22

2. Joachim COHEN, MSSoc, PhD, Professor^b

3. Nele SPRUYTTE, MSPsy, PhD,^a

4. Chantal VAN AUDENHOVE, MSPsy, PhD, Professor^a

5. Anja DECLERCQ, MSSoc, MsEcon, PhD, Professor^a

^aKU Leuven – University of Leuven, LUCAS, Centre for Care Research and Consultancy,

Minderbroedersstraat 8 / 5310 B-3000 Leuven

^bEnd-of-Life Care Research Group, Vrije Universiteit Brussel (VUB) & Ghent University, Laarbeeklaan 103

B-1090 Brussels

Contribution of each author

All authors made substantial contributions to the conception and design, the acquisition of data and the interpretation of data. K Hermans drafted the article and conducted the analysis. J Cohen, N Spruytte, Ch Van Audenhove and A Declercq revised it critically. All authors gave their final approval of the version to be published.

Abstract

Aims: The aims of this study were: 1) to describe palliative care needs and symptoms of older adults anticipated to be in the last year of their life in Flemish nursing homes (Belgium) and 2) to evaluate whether these needs differ between residents with and without dementia.

Methods: A cross-sectional study was conducted in 2014. Nurses and nursing assistants in 15 Flemish nursing homes (Belgium) filled out the Palliative care Outcome Scale (POS) for 109 residents with palliative care needs.

Results: Pain as well as other physical symptoms were present in more than half of the nursing home residents according to caregivers. Most prominent needs occurred on psychosocial and spiritual domains like patient anxiety, support, finding life worth living and self-worth. Caregivers indicated that residents with dementia experienced less physical symptoms apart from pain than did residents without dementia (Coef: -.73; 95% CI: -1.18-.84; $P=0.001$). Furthermore, residents with dementia received higher scores on the items 'support' (Coef.: .75; 95% CI: .15-1.34; $P=0.015$), 'life worthwhile' (Coef.: .58; 95% CI: .090-1.07; $P=0.020$) and 'self-worth' (Coef.: .58; 95% CI: .13-1.03; $P=.012$).

Conclusions: According to caregivers, residents with dementia experienced fewer other physical symptoms (e.g. nausea) than residents without dementia. This, however, may be a result of an under-detection of other symptoms in nursing home residents with dementia. Furthermore, most challenges in nursing homes lie within the spiritual and psychosocial domains of palliative care, particularly in people with dementia. These aspects should be integrated in the professional education of caregivers. Assessment tools may be of help to improve the identification of needs and symptoms.

Key words: Palliative care, Nursing homes, Older adults, Needs assessment, Symptom assessment

Introduction

With the growth of the ageing population, the number of people living in long-term care settings is also increasing.^{1,2} The population residing in nursing homes is also increasingly composed of frail older people with chronic, progressive diseases, with dementia as a major cause for nursing home admission.³ In Western countries, 25 to 74% of the nursing home population has some form of dementia.⁴ Dementia has been described by the World Health Organization as “a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing.”⁵

One in five deaths in developed countries occurs in a nursing home.⁶ In Belgium, 26% of the total population dies in a nursing home.⁷ Therefore, nursing homes are important locations for palliative care.⁸ Palliative care has been defined by the WHO as “an approach that improves the quality of life of the patient and his or her family through an early detection of palliative care needs, an impeccable assessment and an impeccable treatment of physical, psychosocial and spiritual domains”.⁹

High quality palliative care in nursing homes requires a structured evaluation and treatment of physical, psychosocial, emotional, spiritual and information needs of the care receiver.¹⁰ Since palliative care in nursing homes is increasingly being provided for people with dementia, understanding the needs and symptoms of people with dementia who are potentially in need for palliative care is also essential.¹¹ However, research shows that complex palliative care needs of people with dementia are often poorly recognized and treated.¹¹ Most research on palliative care needs and symptoms in nursing homes concerns residents with cancer, and there is a lack of evidence regarding palliative care needs of nursing home residents with other chronic diseases.^{12,13} In 2005, one study in 16 nursing homes in the Netherlands has been conducted to map needs and symptoms of people with and without dementia in the last days of life. This study shows that psychosocial and spiritual aspects need to be better addressed.¹⁴ The study of Brandt et al. (2005) focused on nursing home residents in the last days of life and was conducted in a Dutch nursing home population. However, differences in needs and symptoms between residents with and without dementia who potentially require palliative care have not yet been examined. Furthermore, no studies have quantitatively evaluated the palliative care needs and symptoms of nursing home residents in the last months or year of their lives. Research shows that needs and symptoms in the last days of life may differ from needs and symptoms in the last months or the last years of life.¹⁵

The aims of this study are: 1) to describe palliative care needs and symptoms of older adults anticipated to be in the last year life in Flemish nursing homes (Belgium) and 2) to evaluate whether these palliative care needs differ between residents with and without dementia.

Methods

Study design

A cross-sectional study was conducted in 2014 in 15 Flemish nursing homes (Belgium). The study was designed with the help of the checklist for cross-sectional studies of the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE).¹⁶

Setting and participants

Calls for participation to the study were sent out by four umbrella organizations of 717 Flemish nursing homes (Belgium). An announcement was also made during a national conference for nursing home staff. Fifteen nursing homes volunteered to participate in the study. These nursing homes varied concerning ownership, facility size and geographical region.

In order to obtain a view on the current state of palliative care in the 15 participating nursing homes, nurses and nursing assistants filled out the Palliative care Outcome Scale (POS, see further) for all nursing home residents aged 65 and over, anticipated to be in the final year of life. The latter identification was based on the 'surprise question', i.e. those with a positive answer on the question 'would you be surprised if this person was to die within 6 to 12 months?' were included.¹⁷ Research has shown the 'surprise question' to be a feasible, effective and simple screening tool to identify people with greatly increased risk of mortality in the next year.¹⁸ Furthermore, when general practitioners used the 'surprise' question for their patients with advanced cancer, the prognostic accuracy was very high.¹⁹ When applied by specialists, the 'surprise question' has also been shown to be a reliable and valid tool to identify patients who had an increased risk of mortality in the coming year.²⁰ In the UK, the surprise question has been included in palliative care guidance with the aim of supporting the identification and care planning of those nearing the end of life.²¹ For this study, the answers on the surprise question were discussed during multidisciplinary team meetings (MDT). Depending on the conventions of the nursing homes, the MDT respectively consisted of nurses, certified nursing assistants, psychologists, physiotherapists, quality coordinators, directors, and/or medical directors.

Data collection

Palliative care needs and symptoms were measured with the Palliative care Outcome Scale (POS). The POS is a ten-item multidimensional scale that covers physical, psychological, emotional and spiritual domains of life.²² It is a suitable instrument for evaluating palliative care needs and symptoms of people with and without dementia.¹⁴ Based on a validation study in specialist palliative care settings throughout the UK,

the POS was found to be internally consistent (patient-version $\alpha=.70$, staff-version $\alpha=.65$). Furthermore, the POS shows moderate to good construct validity (Spearman $\rho=.43$ to $.80$), and good test-retest reliability for 7 of 10 items.²³

The first eight items of the POS are scored on a five-point Likert scale ranging from 0 (no problem) to 4 (overwhelming problem). Items 9 (wasted time) and 10 (personal affairs) are scored on a three-point scale: 0 (good), 2 (moderate) and 4 (bad). Individual POS item scores of 0 or 1 require less clinical attention than items that score two, three or four.²² A mean score equal and above 2 was interpreted as clinically unfavorable in this study. The POS also contains one open question for indicating important problems.

There are two versions of the POS: the POS-patient version is to be filled out by the patient and the POS-staff version is to be filled out by the staff. Agreement between both versions was found to be acceptable for eight out of ten items.²³ It is not possible to obtain the POS-patient version for all nursing home residents. Especially for people with dementia, filling out a structured questionnaire is not always feasible. Since this study includes residents with and without dementia, the POS-staff version was used for all residents for reasons of comparability. Nurses and nursing assistants received a POS-manual. Depending on the degree of cognitive impairment of the nursing home resident, the POS-staff version was completed individually by nurses and nursing assistants who knew the resident well or in consultation with the nursing home resident or a relative.

The recording of the diagnosis of dementia in the medical record was based on a consultation with the general practitioner, in combination with a score < 15 on the Mini Mental State Examination (MMSE).²⁴

Statistical analysis

Statistical analysis was conducted using the IBM SPSS Version 22. Frequencies were calculated in order to identify the prevalence of palliative care needs and symptoms in nursing home residents with a life expectancy of one year or less. Furthermore, mean and median POS-scores were calculated.

Since several POS items were not normally distributed, non-parametric Mann-Whitney U tests were used to evaluate the differences between mean POS scores of people with and without dementia. Differences based on age and gender were also tested using non-parametric Mann-Whitney U tests. Furthermore, Generalized Linear Mixed Models (GLMM) were used to adjust for clustering by nursing home. Two tests were performed: a Linear Model to test for fixed-, between-, and random-effects adjusted for the cluster and a Generalized Linear Mixed Effect Regression. Analysis were conducted using STATA 11.2. Both tests yielded the same results.

Power analysis

Each year, on average 18 percent of the residents in a nursing home in Flanders (Belgium) die. Based on these data, this study aimed at including at least 74 nursing home residents anticipated to be in the last year of life, in order to evaluate the needs and symptoms of Flemish nursing home residents anticipated to be in the last year of their life, using the POS. Calculations were based on a medium effect size of 0.50, a two-sided significance level of 0.05 and a power of 0.95 (using G*Power 3.1.5 software). In order to achieve this objective, we aimed at including 15 nursing homes in this study.

Ethical statement

Approval to conduct this research was granted by the Belgian Commission for the Protection of Privacy (BCPP) and by the UZ Leuven Medical Ethics Committee (file number B322201421986).

Results

Participants

Care professionals of fifteen nursing homes that were deemed to be representative of all Flemish nursing homes that have been acknowledged by the Belgian government (based on region, ownership and size), were included in the study. The number of beds in these nursing homes ranges from 40 to 150. Profit nursing homes, non-profit nursing homes as well as Public Centers for Social Welfare were incorporated in the study. Care professionals of the participating nursing homes answered the surprise question for a total of 1635 nursing home residents. The answer on the surprise question was 'no' for 111 nursing home residents. After excluding residents younger than 65 years of age, the sample consisted of 109 (7%) nursing home residents anticipated to be in the last year of life. For this sample, the POS-staff version was completed by the care professionals of the multidisciplinary nursing home staff.

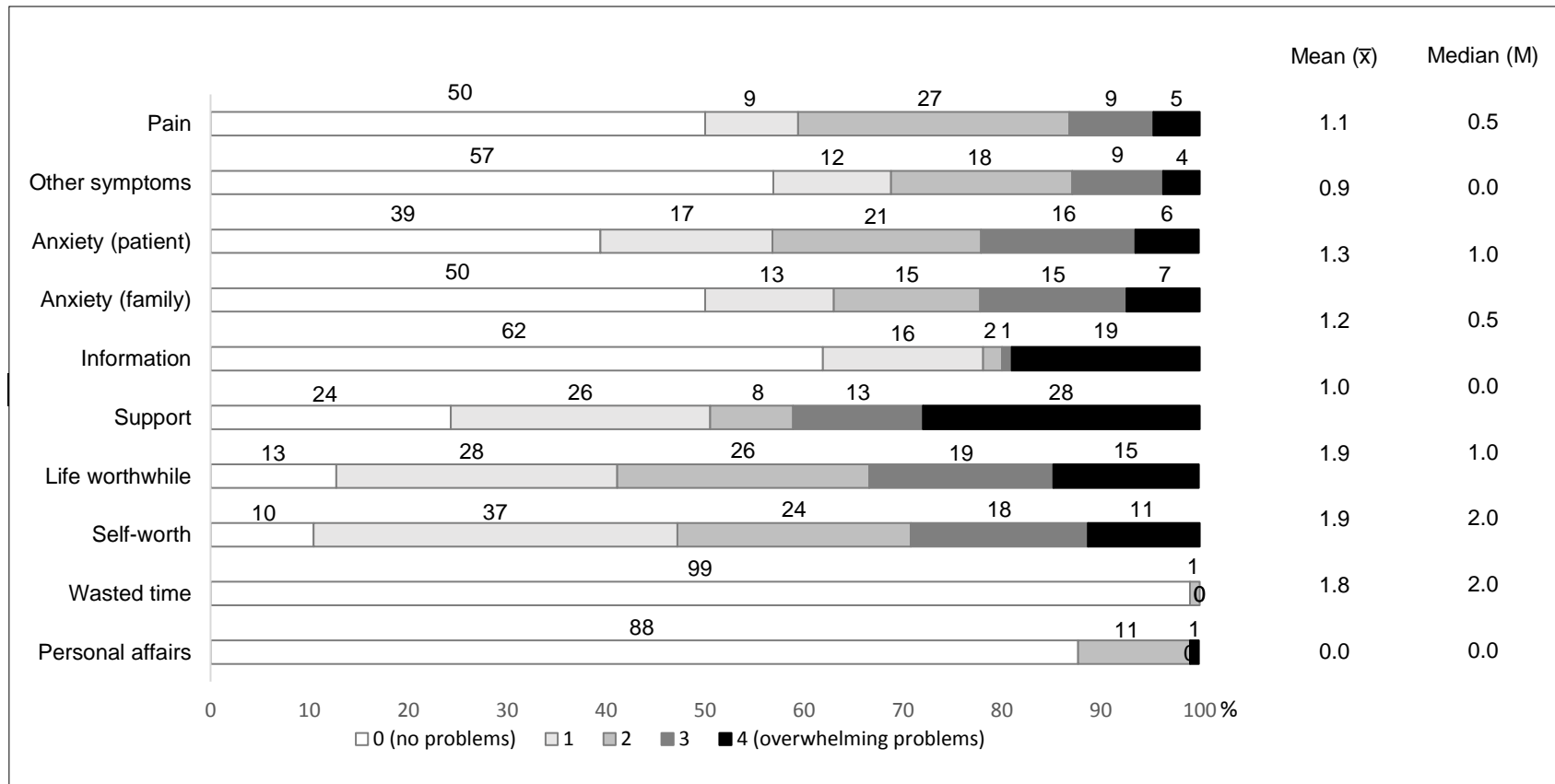
The average age of the nursing home residents anticipated to be in the last year of their life was 87 years. 29% (32) of the residents were male and 60% (66) of the residents were female. In total, 55% (60) of the residents were diagnosed with dementia.

Distribution of POS scores

Figure 1 shows the distribution of POS scores in 109 nursing home residents in the last year of their life. For 50% of these residents, caregivers filled out a score of 0 on the item 'pain'. Fifty percent experienced some form of pain according to caregivers. On the item 'physical symptoms other than pain', 57% of the residents received a score of 0 and 2% received a score of 4. Caregivers indicated that information needs were met for 62% of the residents. Nineteen percent received a score of 4, which means that these residents or their relatives did not receive any information. Caregivers indicated that 28% had overwhelming problems (score 4) sharing their feelings. Furthermore, per proxies, only 13% of the residents anticipated to be in the last year of life found life is worth living (score 0). For only 10% of the residents, caregivers indicated no problems for self-worth.

All mean POS scores were lower than 2. However, for the items life worthwhile and self-worth, the median was 2.

Figure 1. Distribution (%) of POS scores of 109 nursing home residents anticipated to be in the last year of life



Pain, Has the patient been affected by pain?; Other symptoms, Have other symptoms (coughing, constipation, etc.) been affecting how the patient felt?; Patient anxiety, Has the patient been feeling anxious or worried about his/her illness or treatment?; Family anxiety, Have any of the family or friends been feeling anxious or worried about the patient?; Information, How much information has been given to the patient and his/her family? ; Support, Has the patient been able to share his/her feelings with family or friends?; Life worthwhile, Has the patient felt life was worth living?; Self-worth, Did the patient feel good about himself/herself as a person?; Wasted time, How much time do you think was wasted on appointments related to the healthcare of the patient?; Personal affairs, Have any practical matters resulting from the illness of the patient, either financial or personal, been addressed?

POS scores for people with and without dementia

Table 1 shows that people with dementia scored lower than 2 on all POS items, except for the items 'support', 'life worthwhile' and 'self-worth'. People without dementia also scored lower than 2 on all POS items, except for the items patient anxiety and life worthwhile. Compared to nursing home residents without dementia symptoms, residents with dementia had significantly lower scores on the item 'other symptoms' after adjusting for the cluster (Coef: -.73; 95% CI: -1.18-.84; P=0.001). Additionally, residents with dementia scored higher on the items 'support' (Coef.: .75; 95% CI: .15-1.34; P=0.015), 'life worthwhile' (Coef.: .58; 95% CI: .090-1.07; P=0.020) and 'self-worth' (Coef.: .58; 95% CI: .13-1.03; P=.012). No significant differences were found between men and women. Finally, no significant differences were found between residents aged 65 to 89 years and residents aged 90 and over. Wilcoxon Mann-Whitney U test results were consistent with the results that were retrieved from the GLMM analyses.

Table 1.

Mean POS scores of 109 nursing home residents anticipated to be in the last year of life

Items	Dementia (n=60)	No dementia ^a (n=49)	Cluster-adjusted ^b	
	Mean (SD)	Mean (SD)	P	Coef. [95% CI]
Over the past three days:				
Has the patient been affected by pain? (Pain)	1.2 (1.3)	1.0 (1.1)	.200	.33 [-.18;-.84]
Have other symptoms (coughing, constipation, etc.) been affecting how the patient felt? (Other symptoms)	0.6 (1.1)	1.1 (1.2)	.001*	-.73 [-1.18;-.28]
Has the patient been feeling anxious or worried about his/her illness or treatment? (Patient anxiety)	1.1 (1.3)	1.5 (1.3)	.084	-.46 [-.97;-.06]
Have any of the family or friends been feeling anxious or worried about the patient? (Family anxiety)	1.2 (1.4)	1.0 (1.3)	.536	.61 [-.35;-.67]
How much information has been given to the patient and his/her family? (Information)	1.1 (1.5)	0.9 (1.6)	.779	.09 [-.52;-.70]
Has the patient been able to share his/her feelings with family or friends? (Support)	2.2 (1.6)	1.5 (1.5)	.015*	.75 [.15;-1.34]
Has the patient felt life was worth living? (Life worthwhile)	2.2 (1.3)	1.7 (1.1)	.020*	.58 [.09;-1.07]
Did the patient feel good about himself/herself as a person? (Self-worth)	2.0 (1.2)	1.7 (1.0)	.012*	.58 [.13;-1.03]
How much time do you think was wasted on appointments related to the healthcare of the patient? (Wasted time)	0.0 (0.1)	0.0 (0.0)	.367	.02 [-.02;-.06]
Have any practical matters, either financial or personal, been addressed? (Personal affairs)	0.3 (0.8)	0.2 (0.8)	.834	.03 [-.27;-.34]

^aReferent Group^bBy Generalized Linear Mixed Model to adjust for confounding by cluster

*Significance level = 0.05

Discussion

In this study, we evaluated physical symptoms and psychological, emotional, spiritual, information and support needs of nursing home residents anticipated to be in the last year of life, in 15 Flemish nursing homes (Belgium).

Pain as well as other physical symptoms were present in more than half of the residents who were anticipated to be in the final year of life. Pain can lead to a reduced quality of life and to limitations in activities of daily living.²⁷ Therefore, an impeccable assessment and treatment of pain is essential.²⁶ Pain should be managed systematically, taking into account pharmacological and non-pharmacological pain treatment methods. Pain treatment guidelines could help health care professionals to improve the quality of their daily services.²⁸

In this study, according to the care providers, residents with dementia experienced fewer problems with physical symptoms other than pain (nausea, coughing, etc.) than did those without dementia.¹⁴ This may be a result of an under-detection of other symptoms in nursing home residents with dementia anticipated to be in the last year of their life. A more accurate screening and observation of symptoms in people with dementia in nursing homes is thus also required. Adequate recognition of symptoms in people with dementia and communication skills to enable this need to be incorporated into the regular education programs of professional caregivers. Furthermore, education on assessment tools to identify symptoms in people with dementia (e.g. The Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale (MOBID), The PAINAD scale, etc.) could be of help.

When evaluating psychosocial and spiritual needs, most overwhelming problems occurred on support, finding life worth living and self-worth. More than one third of the residents were rarely or never able to share their feelings with their friends or family. Furthermore, caregivers indicated that many residents did not feel life is worth living anymore. These findings are consistent with research on Dutch nursing home residents in the last days of their lives, showing that most shortcomings occurred in subjective domains such support, sharing feelings and self-worth.¹⁴ Residents with dementia had less favorable scores than people without dementia on the ability to share their feelings with family and/or friends, on having the feeling that life is worth living and on self-worth. The fact that there are more problems in the area of sharing feelings, might be attributed to an under-recognition of care providers to detect the need to share feelings in people with dementia.²⁷ Furthermore, it might also be due to the difficulty or inability of people with dementia to express what they feel.²⁷ Additionally, studies using the POS to evaluate needs and symptoms of terminal elderly show that care professionals tend to overestimate some symptoms, especially in psychological domains such as finding life worth living and sharing feelings. This could also explain the higher dementia

scores in the population of elderly with dementia symptoms.²⁹ Care professionals also suggested a low self-worth, especially in people with dementia. The study of Brandt et al. (2005) on residents in the last days of their lives shows unfavorable scores on self-worth for both people with dementia and without dementia in the final days. This may reflect the fact that disability in diseases other than dementia increases more steadily as people progress to the terminal phase of their illness.¹⁴ Previous research in cancer patients with palliative care needs shows that people who are functionally active and not dependent on others feel more worthy and have a higher self-esteem compared to people who are disabled.³⁰ Since dementia is one of the major causes of disability, this might explain why scores on self-worth are particularly low for people with dementia in a phase before the terminal stage.³¹

Care providers indicated that information needs were met for most of the residents in the last year of life. However, still 19% did not receive any information. Concerning the item 'wasted time', caregivers indicated that little time was wasted on appointments related to the healthcare of the patients. This finding is consistent with research on nursing home residents in the last days of their lives.¹⁴ Additionally, in almost every case, there were no practical matters (personal, financial, etc.) to be taken care of, or practical matters had already been addressed.

To our knowledge, this is the first study that provides a general overview of palliative care needs and symptoms of older adults anticipated to be in the final year of life in Flemish nursing homes (Belgium). Furthermore, this is the first study to evaluate differences in palliative care needs for residents with and without dementia in Flanders (Belgium) with the Palliative care Outcome Scale (POS). The POS is a valid and reliable instrument for evaluating physical symptoms and psychological, spiritual, information and support needs of people with and without dementia.

Limitations of the study should also be acknowledged. Even though 15 Flemish nursing homes in Belgium agreed to participate in the study, some participation bias cannot be excluded. Furthermore, this study provides a general overview of needs and symptoms of nursing home residents requiring palliative care measured at one time point. Additionally, future studies could take into account 'time between assessment and death' as a confounder. For this study, the POS-staff version was used instead of the POS-patient version. Even though agreement between both versions was found to be acceptable²³, it is possible that caregivers underrated or overrated certain items. Future research should look into the needs and symptoms of nursing home residents without dementia and who may be in the last year of their lives by means of the POS-patient version. Finally, the POS contains items on the presence and the severity of pain. However, information on pain medication use and other pain treatments is not taken into account.

This study -evaluating needs and symptoms of nursing home residents anticipated to be in the last year of their life in Flanders (Belgium)- underscores the fact that physical needs require attention as pain and/or other physical symptoms are present in more than half of the nursing home residents. Pain assessment and treatment guidelines could help health care professionals to improve this situation. Furthermore, challenges for Flemish nursing homes lie within spiritual and psychosocial domains of palliative care, such as support, finding life worth living and self-worth. Therefore, special attention is required for the detection of psychosocial and spiritual needs in the professional education of caregivers. Observation tools may be needed to improve the identification of needs and symptoms, especially in people with cognitive impairment. The lower physical problems other than pain (e.g. coughing, nausea) and the higher psychosocial and spiritual problems in residents with dementia may be a consequence of underestimation and overestimation by the care providers and the inability of people with dementia to express themselves. In Belgium, educational programs on palliative care for healthcare providers mainly address physical and medical aspects of care.³² In order to provide high quality palliative care, psychosocial and spiritual care aspects should also be taken into account.^{10,32} These aspects should be integrated in the professional education of caregivers.^{10,33} Observation tools may be of help to improve the identification of these symptoms.

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Disclosure statement

The authors declare no conflict of interest.

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Figure legends

Figure 1.

Distribution (%) of POS scores of 109 nursing home residents anticipated to be in the final year of life.

Pain, Has the patient been affected by pain?; Other symptoms, Have other symptoms (coughing, constipation, etc.) been affecting how the patient felt?; Patient anxiety, Has the patient been feeling anxious or worried about his/her illness or treatment?; Family anxiety, Have any of the family or friends been feeling anxious or worried about the patient?; Information, How much information has been given to the patient and his/her family? ; Support, Has the patient been able to share his/her feelings with family or friends?; Life worthwhile, Has the patient felt life was worth living?; Self-worth, Did the patient feel good about himself/herself as a person?; Wasted time, How much time do you think was wasted on appointments related to the healthcare of the patient?; Personal affairs, Have any practical matters resulting from the illness of the patient, either financial or personal, been addressed?