Physician visits and recognition of residents' terminal phase in long-term care facilities: findings from the PACE cross-sectional study in 6 EU countries

ABSTRACT

Objectives: To describe the relation between physician visits and physicians' recognition of a resident's terminal phase in long-term care facilities (LTCFs) in Belgium, England, Finland, Italy, the Netherlands, and Poland.

Design: In each country, a cross-sectional study was conducted across representative samples of LTCFs. Participating LTCFs reported all deaths of residents in the previous three months, and structured questionnaires were sent to several proxy respondents among which the treating physician.

Setting and Participants: 1094 residents in 239 LTCFs, about whom 505 physicians returned the questionnaire.

Measures: Number of physician visits, the resident's main treatment goal, whether physicians recognized the resident's terminal phase and expected the resident's death, resident and physician characteristics.

Results: The number of physician visits to residents varied widely between countries, ranging from a median of 15 visits in the last 3 months of life in Poland to 5 in England, and from 4 visits in the last week of life in The Netherlands to 1 in England. Among all countries, physicians from Poland and Italy were least inclined to recognize that the resident was in the terminal phase (63.0% in Poland compared to 80.3% in the Netherlands), and residents in these countries had palliation as main treatment goal the least (31.8% in Italy compared to 92.6% in the Netherlands). Overall however, there were positive associations between the number of physician visits and the recognition of the

resident's terminal phase and between the number of physician visits and the resident having palliation as main treatment goal in the last week of life.

Conclusions and Implications: This study suggests that LTCFs should be encouraged to work collaboratively with physicians to involve them as much as possible in caring for their residents. Joint working will facilitate the recognition of a resident's terminal phase and the timely provision of palliative care.

INTRODUCTION

Despite health policies in many Western countries aiming to enable people to live and die within their own home, many older people will require long-term institutional care at some point in their life. Consequently, the care and support that is provided in long-term care facilities (LTCFs) − such as nursing homes and residential care homes − has become increasingly complex.[1-3] Older people that move into LTCFs will go on to require palliative care within these facilities, supported by staff working within, and external to, the organization.[2]

Identifying the appropriate time to switch focus to comfort and palliation requires a multidisciplinary approach among the LTCF staff, often with an essential role for the treating physician.[4] Depending on the type of LTCF in which the resident resides, some residents continue to receive care from the same General Practitioner (GP) they had before admission, whereas for others a specialized physician employed within or linked to the LTCF may take over their care. However, it can be difficult to entice physicians to become or remain involved in providing care to residents of LTCFs.[5] In studies conducted in the United States[6], Canada[7], Norway and the Netherlands[8,9], many family members of deceased residents expressed their concern that physicians were 'missing in action': physicians were viewed as poorly available or absent in the nursing home. This absence has been quantified elsewhere; Teno et al. (2004) reported that 31% of family members of deceased nursing home residents in the United States wanted but did not have contact with a physician, and of those who did have contact, 18% reported concerns with communication.[10] Possible explanations for the 'missing in action' phenomenon may be that physicians consider nursing home practice a low priority compared with other aspects of their practices, the low reimbursement, frequent office interruptions, difficult

54 logistics and excessive paperwork, as well as perceptions of a loss of authority and a lack of time,
55 competence and interest.[5,9,11]
56
57 Poor physician presence in LTCFs has been linked to mistaken diagnoses, inadequate symptom
58 management, inappropriately high rates of hospitalizations, difficulties in communication and
59 decision-making, uncertainty of and dishonored family preferences, and a general dissatisfaction of
60 residents and family members.[6,12-15] In contrast, direct contact with and frequent visits of physicians
61 to residents appeared to be associated with increased detection of infections[16], more appropriate
62 drug-describing[17] and has been identified as a precondition for successful advance care planning. [18]
63
64 Research focusing on physician involvement in LTCFs in relation to the extent to which they recognize
65 the residents' last phase of life is however scarce. Recognizing that death is approaching is essential
66 to ensure the delivery of an appropriate standard of palliative care in LTCFs, including a discussion of
67 end-of-life wishes with both the resident and family.[4] Using data collected in six European countries
68 participating in the PACE (Palliative Care for Older People) study, this article addresses the following
69 research questions: (1) How many visits do residents living in LTCFs in six European countries receive
70 from their physician in the last three months and last week of life?; (2) To what extent do physicians
71 recognize the resident's terminal phase in the last week of life, and which proportion of residents had
72 a palliation as main treatment goal?; and (3) How are the number of physician visits and
73 characteristics of physicians associated with the extent to which physicians recognize the resident's
74 terminal phase?
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METHODS

Study design

A cross-sectional study of deceased residents of LTCFs was conducted in Belgium, England, Finland, Italy, the Netherlands and Poland.[19] To obtain representative samples, a proportional stratified random sampling procedure was used within each country. Based on available national or regional lists of all LTCFs, LTCFs were randomly and proportionally selected from several strata (based on at least region/province and facility size by beds). The exception was Italy, where a convenience sample covering the three macro-regional areas in Italy was used since no public list of all LTCF was available. Three types of facilities were identified within the six countries: type 1 includes LTCFs with 24/7 on-site physicians, nurses and care assistants, type 2 are facilities with 24/7 on-site nurses and care assistants and off-site physicians and type 3 consists of facilities with 24/7 on-site care assistants and off-site nurses and physicians.[2] In each country, LTCFs provided data on all residents who died in the preceding three-month period. The study protocol was approved by the relevant ethics committee in each country and has been published elsewhere.[19]

Data collection and study population

For each identified resident, structured questionnaires were sent to the facility manager/administrator, the staff member most involved in care (preferably a nurse), the treating physician and the contact relative. The manager, or administrator, also completed a questionnaire about facility characteristics.

This analysis uses the answers that were provided by the physician and the facility manager. Of the 1707 deceased residents included in the study, we selected those for whom both the manager and a

physician had returned the questionnaire (N=1094; mean response 64.1%; Belgium 63.5%, England 23.2%; Finland 78.1%; Italy 72.9%; the Netherlands 55.0%; Poland 75.6%).

Measurements

The questionnaire for the manager included questions about the resident's age, sex, length of stay, cause of death, place of death and the type of LTCF. The treating physicians answered questions regarding his/her own characteristics (sex, age, years working as physician, number of terminally ill patients cared for in the preceding year, education in palliative care) as well as regarding elements of the care provided to the resident. The following care elements were analyzed: number of visits paid to the resident in the last three months and last week of life, whether the physician had the impression in the last week of life that the resident was in the terminal phase, the treatment goal that was given priority in the last week of life, and to what extent the physician expected the resident's death.

Statistical analysis

Descriptive statistics were applied to the characteristics of the residents and their treating physicians by country. To control for clustering of observations within countries and LTCFs, differences in characteristics were assessed using generalized linear mixed models reporting significance (p values) for countries as a fixed effect. Then, we analyzed whether and how these characteristics were associated with the number of physician visits to residents. We excluded 50 residents from the analysis who had missing or incorrect answers on the questions regarding number of physician visits in the last three months and last week of life. Again, multilevel analyses were performed, additionally controlling for clustering of residents within physicians. Subsequently, we examined which combination of variables regarding visits in the last three months of life and physician characteristics

related to a physician recognizing a resident's terminal phase in the last week of life and the resident having palliation as main treatment goal. Because of the non-normal distribution, we dichotomized the number of visits in the last three months of life (below or above median value, <10 and ≥10). Then, because many variables were candidates to remain in the model, we entered them all into a backward multivariable logistic regression model using generalized linear mixed models. We removed the independent variables stepwise until all p-values were below 0.05, and we calculated odds ratios. Last, analyses for the comparison of number of physician visits and recognition of a resident's terminal phase between LTCFs types within countries were conducted in similar multilevel models except that data was first selected per country for each analysis and LTCF type was used as a fixed effect. These analyses were only conducted for countries that had both type 1 and 2 LTCFs, i.e. Italy, Poland and The Netherlands. All analyses were performed with SPSS version 22.[20]

RESULTS

Characteristics of study population

The analysis included 1094 deceased residents, 217 from Belgium, 39 from England, 221 from Finland, 167 from Italy, 181 from the Netherlands and 269 from Poland (Table 1). They resided in 239 different LTCFs. Most residents lived in a LTCF with physicians working off-site, except for the Netherlands and Poland where the majority of the residents stayed in LTCFs with on-site care from physicians. About two thirds of the residents were female with no significant differences in sex distribution across countries. Mean age of the residents at time of death was over 85 years with the exception of residents in Poland (mean age 81 years). Cause of death varied substantially between countries with cardiovascular diseases as the main cause of death in Belgium, Italy and Poland, and dementia in Finland, the Netherlands and England.

Table 1 furthermore shows the characteristics of the 505 physicians who treated these residents. Significant differences in physician characteristics between the countries were found with regard to sex, mean number of years working as a physician, median number of terminally ill patients cared for in last year and proportion of physicians with a specific education in palliative care.

Number of physician visits in the resident's last three months and last week of life

The number of physician visits varied widely across countries. In the last three months of life, residents from Poland were visited most often (median 15 times) and residents from England least often (5 times) (Table 2). In the last week of life, the number of physician visits ranged from a median of 4 visits in the Netherlands to 1 visit in England. Compared to residents from Belgium, residents from Finland, the Netherlands and Poland were more likely to receive 10 or more visits from their physician in the last three months of life (OR 5.48, 2.18 and 3.78 respectively). In contrast, residents

158 from England were less likely to receive 3 or more visits in the last week of their life, as compared to
159 Belgian residents (OR 0.16). Two resident characteristics were significantly associated with the
160 number of physician visits in the last phase of life: residents dying from cardiovascular disease or
161 dying outside the LTCF were visited less often. With regard to physician characteristics, working on-
162 site the LTCF, having cared for more than 10 terminally ill patients in the preceding year and having a
163 specific education in palliative care were positively associated with number of physician visits (Table
164 2). Comparing the number of physician visits within countries with both type 1 and 2 facilities showed
165 no significant differences between LTCF types in the Netherlands and Italy (see Appendix). For Poland
166 however, the analysis revealed that residents living in type 1 LTCFs receive significantly more visits
167 from their physician than residents in type 2 facilities.
168
169 **Recognition of the resident's terminal phase**
170 Table 3 shows there is large variation between countries with regard to physicians recognizing the
171 resident's terminal phase. Physicians from Poland and Italy least often had the impression that
172 residents were in a terminal phase in the last week of life (63.0% and 69.1% respectively), in contrast
173 to physicians in The Netherlands who reported to have recognized the terminal phase in 80.3% of
174 cases. Almost all Dutch residents had palliation as main treatment goal in the last week of life
175 (92.6%), whereas this was the case for 60.2% of the residents in Poland and for only 31.8% of the
176 residents in Italy. In the latter country, 30.4% of the residents still had a curative treatment goal, and
177 for 8.1% of the residents there were no treatment goals set. Significant differences between
178 countries also existed with regard to the level of expectation of a resident's death; the percentage of
179 residents whose death was expected by the physician was highest in Finland (71.0%) and lowest in
180 Poland (50.6%) (Table 3). Comparing the level to which physicians recognize the terminal phase and
181 the proportion of residents with palliation as main treatment goal in the last week of life in countries

with both type 1 and 2 facilities showed no significant differences between LTCF types (see Appendix).

Factors associated with recognizing the terminal phase

The proportion of residents whose terminal phase was recognized by the physician was higher among residents who were visited at least 10 times in their last three months of life (78.1% against 65.5% for residents who received less than 10 visits) (Table 4). A similar pattern was seen with regard to the outcome variable 'palliation as main treatment goal in the last week of life'.

Accordingly, in a multivariate model, the factor 'receiving at least 10 visits in the last three months of life' was positively associated with both the physician recognizing the resident's terminal phase (OR 2.20) and the resident having palliation as main treatment goal (OR 2.15). In addition, physicians who had cared for more than 10 terminally ill patients in the preceding year were more likely to recognize the terminal phase (OR 1.51) and residents in Italy had a significantly lower odds to be treated with a palliative goal as compared to Belgian residents (OR 0.05).

DISCUSSION

This international cross-sectional study of deceased residents in LTCFs revealed large variations between countries with regard to the number of physician visits and the extent to which physicians recognize the residents' terminal phase. Although the number of physician visits was highest in Poland and Italy, physicians in these countries least often recognized the terminal phase in the last week of life and their residents least often had palliation as main treatment goal. This implies that the majority of visits to Polish and Italian residents were for curative purposes, reflecting a culture of 'treating as long as possible'. This is a striking result, as residents from Poland and Italy had the shortest length of stay among all countries, caused by a lower amount of LTCF resources, long waiting lists and strict admission criteria. Upon admission, residents in these countries are very severely ill and disabled, making that one would expect it to be obvious that a palliative approach is warranted. In both countries, families play an important role in providing long term care for older people as they are often the main caregiver.[21,22] This might contribute to this 'treating culture'; in a scoping exercise in seven European countries on culture and end- of-life care, family members from Italy were frequently characterized as barriers to full disclosure and to limitation of futile treatments.[23] In addition, other studies in Italy found a low awareness of and misconceptions around palliative care among the general public[24] and uncertainty of GPs regarding theoretical issues on palliative care.[25] This uncertainty might be due to the limited specific education on palliative care that Italian, and also Polish, physicians receive and report in our study. In contrast, almost all Dutch physicians reported that they had received specific education in palliative care. Also taking into account the Dutch cultural context, characterized by an open attitude towards end-of-life decisions and a long research tradition in palliative care[23], it is not surprising that Dutch physicians most often recognized the resident's terminal phase and that Dutch residents most often had palliation as main treatment goal.

Notwithstanding the large variation across countries, positive associations were found between the number of physician visits in the last three months of life and the recognition of the resident's terminal phase, and between the number of physician visits and the resident having palliation as main treatment goal in the last week of life. Although caution should be applied in interpreting the direction of causality, it seems that physician visits over a longer period of time contribute to a better and earlier recognition of imminent death. As more physician visits allow for more opportunity to interact with the resident, staff and family, it is likely that a higher amount of physician visits results in a more complete picture of the resident's condition. A second explanation could be that physicians who are not as present in the LCTF likely have duties elsewhere, including in the hospital, which could make them feel more comfortable with a hospital-oriented approach to care. Because the other way around (i.e. a physician pays more visits to a resident once he/she has recognized the resident's terminal phase) probably also plays a role, information about the reasons for the physician to visit the resident is needed to unravel this association. It is therefore recommended that future studies more closely examine how physicians use their time when they visit a resident, in order to better understand the importance of their presence.

In this paper, we focused on the number of visits the physician paid to a resident. Visits to a resident are only one part of physician involvement in resident's care. Physician involvement also includes participating in multidisciplinary meetings and being accessible to care home staff. Several palliative care programs, such as the PACE 'Steps to Success' palliative care programme[26], focus on improving the involvement of physicians in residents' care by teaching and stimulating staff to organize regular multidisciplinary meetings. The aim of these meetings is not only to help to build good coordinated care and improve relationships within the LTCF and with those professionals external to the LTCF, but

also to facilitate an earlier recognition of the resident's last phase of life, and hence an earlier initiation of palliative care. It is indeed an early initiation of palliative care that has been found to lead to favorable outcomes such as fewer transfers between care settings, fewer hospitalizations and lower hospital mortality.[27,28] Moreover, physician involvement has been designated as an important element in bereaved relatives' evaluation of the palliative care trajectory.[29]

Strengths and limitations

This is the first large-scale study to describe and compare the number of physician visits and their recognition of the last phase of life of deceased LTCF residents across six European countries. Although the response rate among participants from England was low - limiting the generalizability of findings in this country, the use of different proxy respondents allowed for data collection on multiple characteristics of the same group of deceased residents. A limitation of the study is the retrospective nature of data collection, which may have led to recall bias. Although this was minimized by including only deaths from the three previous months, it is possible that physicians were inclined to overestimate the extent to which they recognized the terminal phase, given that they knew the resident had ultimately died. Furthermore, the answers were provided by the physicians themselves. When a physician answered that he/she did not recognize the terminal phase of the resident, it does not necessarily mean that no one else expected the resident's death and enacted upon this by providing elements of palliative care. Although the physician is ultimately responsible for the care given to a resident, the quality of care provided is dependent on more factors than only physician visits. For example, the presence of nurse practitioners in LTCFs in some countries allow the physician to be less present while still having a trained geriatric clinician on site and providing good quality care. Further research that combines different perspectives or observes the dynamics between LTCFs teams may provide a more detailed understanding of this.

CONCLUSIONS

As the number of physician visits were associated with a better recognition of the residents' terminal phase in the last week of life, LTCFs should be encouraged to work with and involve physicians as much as possible in caring for their residents. More research into the dynamics of recognizing the terminal phase and starting palliative treatment is needed.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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