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Physical and Psychological Distress Are Related to Dying Peacefully in Residents with Dementia in Long-Term Care Facilities

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ABSTRACT

Context: Although dying peacefully is considered an important outcome of high-quality palliative care, large-scale quantitative research on dying peacefully and the factors associated with a peaceful death is lacking.

Objectives: To gain insight into how many residents with dementia in long-term care facilities die peacefully, according to their relatives, and whether that assessment is correlated with observed physical and psychological distress.

Methods: This was a retrospective cross-sectional study of deceased nursing home residents in a representative sample of long-term care facilities in Flanders, Belgium (2010). Structured post-mortem questionnaires were completed by relatives of the resident, who were asked to what extent they agreed that the resident “appeared to be at peace” during the dying process. Spearman correlation coefficients gave the correlations between physical and psychological distress (as measured using the Symptom Management at the End of Life with Dementia and Comfort Assessment in Dying at the End of Life with Dementia scales) and dying peacefully (as measured using the Quality of Dying in Long Term Care instrument).

Results: The sample comprised 92 relatives of deceased residents with dementia. In 54% of cases, relatives indicated that the resident died peacefully. Weak to moderate correlations (0.2-0.57) were found between dying peacefully and physical distress in the last week of life. Regarding psychological distress, weak to moderate correlations were found for both the last week (0.33-0.44) and last month of life (0.28-0.47).

Conclusion: Only half of the residents with dementia died peacefully as perceived by their relatives. Relatives’ assessment of whether death was peaceful is related to both physical and psychological distress. Further qualitative research is recommended to gain more in-depth insights into the aspects on which relatives base their judgment of dying peacefully.

INTRODUCTION

It is a widely accepted assumption that people wish to die peacefully. In addition, dying peacefully is considered an important outcome of high-quality palliative care¹. However, large-scale quantitative research about how peacefully people die or what factors are associated with a peaceful death is lacking. The little research there has been up to now has focused predominantly on terminally ill patients who were not cognitively impaired. Research by Steihauser et al., for instance, showed that terminally ill patients with cancer or AIDS, recently bereaved family members, and health care professionals considered “having come to peace” or “being at peace” attributes of a “good death”^{2 and 3}. In addition, Steihauser et al. found that being at peace was strongly positively correlated with emotional and spiritual well-being^{3 and 4}. Ray et al. demonstrated that patients with advanced cancer who felt at peace had less psychological distress and had a higher overall quality of death as reported by their caretakers⁵. Peacefulness was found to be significantly associated with spirituality, but much of the variance remained unexplained⁵.

In aging societies, the number of people suffering from dementia is increasing, as is the number of people dying with dementia⁶. Because people with dementia very often reside and die in long-term care facilities^{7 and 8}, it is important to get a more in-depth understanding of what factors contribute to a peaceful death in people with dementia in these facilities. There is only one recent study on this subject, which revealed that only half of the residents (56%) with dementia in long-term care facilities in The Netherlands ($N=233$) died peacefully according to their relatives⁹. Residents were not only more likely to die peacefully if they had an optimistic attitude, but also if relatives found that there were enough nurses available and if residents died in facilities with a moderate perceived influence of religious affiliation on end-of-life decision-making policies (as opposed to no influence)⁹.

Dying peacefully as perceived by relatives is a highly subjective outcome¹; still, relatives can be considered as an appropriate “proxy” for patients and hence taking their perspective into account is essential. Moreover, if relatives perceive death as not peaceful, this can hamper their bereavement process and can affect their health and well-being⁵. Therefore, gaining insights into how relatives perceive whether the death was peaceful is crucial. More specifically, we are interested in whether the physical and psychological suffering of the resident is associated with dying peacefully as perceived by relatives. We expect that residents are perceived to die less peacefully when their physical and psychological distress is higher. This study aims to explore: 1) how many residents with dementia in long-term care facilities in Flanders, Belgium, die peacefully according to their relatives; and 2) whether the judgment of a peaceful death relates to physical and psychological distress in residents with dementia in long-term care facilities in Flanders, Belgium.

METHODS

Study Design and Setting

The Dying Well with Dementia study^{10, 11, 12 and 13} is a retrospective cross-sectional study in a representative sample of long-term care facilities in Flanders. Flanders is the northern Dutch-speaking part of Belgium where the majority of the population live (60%). In Belgium, the majority of older people with dementia (65.9%) die in long-term care facilities⁸. The care of individual residents is managed by their own

general practitioner (GP). Nursing care is provided by skilled nurses who are available 24 hours a day.

A random sample was taken of 69 Flemish long-term care facilities, stratified for region, size, and ownership (public, private/non-profit, private/profit), as these factors have been found to be related to end-of-life care quality in long-term care facilities in previous research^{14 and 15}. A detailed description of the study design can be found elsewhere^{11, 12 and 13}.

The Medical Ethical Committee of the University Hospital of Brussels approved the study protocol. Patient anonymity and GPs' confidentiality were maintained throughout the study.

Study Population

The administrators of the long-term care facilities in the sample made a selection from all the residents who died with dementia between May and October 2010, selecting residents meeting the following criteria used by the Belgian health insurance system: either the person has a category C dementia, i.e., was "completely care dependent or in need of help for bathing, dressing, eating, toileting, continence, and transferring, plus showing signs of disorientation in time and space", or was "having a problem with orientation in time and space on an almost daily basis." This first broad selection minimized the risk of missing eligible residents with dementia but risked including residents who were not cognitively impaired. Therefore, GPs and nurses of residents fulfilling these criteria were sent questionnaires in which additional eligibility criteria were assessed. These additional eligibility criteria required an indication from the GP or nurse that the resident "had dementia" or "was diagnosed with dementia." One hundred ninety-eight deceased residents with dementia were identified¹¹. In the present study, we only included the residents in the analyses whose relative had completed the question concerning dying peacefully ($N=92$).

Data Collection

Different structured questionnaires were completed by the nurse most involved in care for the resident, a close relative (family member or friend) of the resident, and the administrator of the long-term care facility. The nurses and administrators received a questionnaire no later than three months after the resident's death. Non-respondents received a reminder after three weeks, mediated (in the case of the nurses) by the administrator of the long-term care facility to guarantee anonymity. Relatives received the questionnaire no earlier than two weeks and no later than three months after the resident's death; non-responding relatives also received a reminder.

Measurements

Dying peacefully was surveyed in the relatives' questionnaire using the following question, which was originally an item of the Quality of Dying in Long Term Care instrument (QOD-LTC) validated in Dutch^{16 and 17}: "I would like you to think back over the last month of [RESIDENT'S] life. Here are some statements that have been considered important during the dying process. Please tell me how true this statement is for [RESIDENT]: "[RESIDENT] appeared to be at peace". The response options included: "not at all", "a little bit", "a moderate amount", "quite a bit" and "completely."

The relatives' questionnaire also included the Symptom Management at the End of Life with Dementia scale (SM-EOLD) to explore the frequency of distressing

physical and psychological symptoms in the last month of life. The SM-EOLD comprises nine items (three physical and six psychological), with a response scale ranging from 0 to 5; higher scores indicate lower symptom frequency¹⁸. In addition, the relatives' questionnaire included the Comfort Assessment in Dying at the End of Life with Dementia scale (CAD-EOLD)¹⁸ comprising fourteen items that were scored on a scale ranging from 1 to 3, with higher scores indicating more comfort during the last week of life. The CAD-EOLD has four subscales: "physical distress", "dying symptoms", "emotional distress" and "well-being." Both the SM-EOLD and CAD-EOLD were validated in Dutch¹⁶.

In the current study, we use the three physical symptoms of the SM-EOLD scale, and the "physical distress" and "dying symptoms" subscales of the CAD-EOLD instrument to evaluate physical distress. For psychological distress, we use the six SM-EOLD items concerning psychological symptoms in the last month of life, and the "emotional distress" and "well-being" subscales of the CAD-EOLD instrument. Besides rating these scales, relatives also were asked to state their gender, age, and relationship to the resident.

The nurses' questionnaire surveyed the functional and cognitive status one month before death with the help of the following validated instruments: the Global Deterioration Scale (GDS)¹⁹, classifying dementia into seven stages based on deficits in cognition and function⁷, and the Cognitive Performance Scale (CPS)^{7 and 20}. Advanced dementia was defined as GDS stage 7 and a CPS score of 5 or 6⁷.

The administrators' questionnaire included questions about the resident's gender, age and date of admission to the long-term care facility.

Statistical Analysis

Statistical analyses were performed using IBM SPSS v. 20.0 (IBM Corp., Armonk, NY). Frequencies and descriptive statistics were calculated for the deceased residents with dementia and the relatives who rated the symptoms. On all the EOLD scales, item scores were reversed if the items reflected negative conditions in order to enhance the interpretability: higher scores indicate better symptom control in the last month of life and more comfort in the last week of life. Missing items, with a maximum of one of three or four items, were imputed with patient means to calculate a total subscale score.

We used Spearman correlation coefficients to explore whether the validated subscales^{16 and 21} concerning the residents' physical and psychological distress were related to dying peacefully in this sample. Correlation coefficients between 0.7 and 0.9 are considered to indicate strong correlation, coefficients between 0.4 and 0.6 to indicate moderate correlation, and coefficients between 0.1 and 0.3 to indicate weak correlation²². Because we presumed that the psychological subscale of the SM-EOLD scale containing the item "calm" would have high correlations with dying peacefully, we performed the analysis both with and without the "calm" item.

RESULTS

Description of the Sample

As shown in Table 1, 65% ($N=57$) of the relatives who filled out the questionnaire were female; the mean age was 60.5 years. Of these relatives, 69% ($N=63$) were the resident's offspring, 8% ($N=7$) the spouse.

[TABLE 1]

Our study sample comprised 92 residents with dementia, of whom 59% ($N=51$) were female; the mean age was 87.5 years and half of them (49%, $N=45$) had advanced dementia. The median length of stay in a long-term care facility was two years (Table 1).

Regarding physical distress, the lowest symptom control and comfort levels were reported for pain in the last month of life (mean SM-EOLD score 1.8) and difficulty in swallowing in the last week of life (mean CAD-EOLD score 1.8). The highest comfort levels were reported for skin breakdown in the last month of life (mean SM-EOLD score 3.9) and shortness of breath in the last week of life (mean CAD-EOLD score 2.2). As regards psychological distress, the lowest comfort levels were observed for anxiety in the last month of life (mean SM-EOLD score 2.4) and calm in the last week of life (mean CAD-EOLD score 1.9), and the highest comfort levels for calm in the last month of life (mean SM-EOLD score 3.9) and crying in the last week of life (mean CAD-EOLD score 2.6).

Dying Peacefully

As Fig. 1 shows, 54% ($N=50$) of the residents died peacefully according to their relatives. Nonetheless, 11% ($N=10$) of relatives indicated that the resident did not die peacefully at all.

[FIGURE 1]

Correlations Between Dying Peacefully and Physical and Psychological Distress

Table 2 presents an overview of the correlations between dying peacefully and physical and psychological distress. With regard to the physical distress, there was a weak to moderate positive correlation between dying peacefully and the total subscale score of CAD-EOLD physical distress ($r=0.37$) and no to weak correlations between dying peacefully and physical symptoms in the last month of life and dying symptoms in the last week of life. As higher scores indicate better symptom control and more comfort, this means that less physical distress in the last week of life was associated with dying more peacefully. Looking at the individual items in these scales concerning physical distress, moderate positive correlations were found between dying peacefully and lower levels of discomfort in the last week of life ($r=0.57$) and less restlessness in the last week of life ($r=0.41$); and a weak positive correlation between dying peacefully and less choking in the last week of life ($r=0.22$). This implies that dying peacefully is associated with less discomfort, less restlessness, and less choking in the last week of life. None of the three symptoms in the SM-EOLD in the last month of life (pain, shortness of breath and skin breakdown) was significantly related to dying peacefully as perceived by the relatives.

[TABLE 2]

As regards psychological distress, a moderate positive correlation was found between dying peacefully and the three total subscale scores: psychological symptoms in the last month of life ($r=0.39$), emotional distress in the last week of life ($r=0.46$), and well-being in the last week of life ($r=0.44$) (Table 2). Hence, dying peacefully is related to less psychological distress in the last month of life, and less emotional distress and more well-being in the last week of life. All individual items had weak

to moderate positive correlations with dying peacefully, except for the following: “calm” and “resistiveness to care” in the last month of life, and “crying” in the last week of life. We found no differences regarding the significance or size of the correlation coefficient when the item “calm” was excluded from the analysis; hence, the results in Table 2 include “calm” in the SM-EOLD scale.

When comparing the correlation coefficients of subscales and items scored in the last month and last week of life, physical distress in the last week of life ($r=0.37$) was found to have a stronger correlation with dying peacefully than physical distress in the last month of life ($r=0.06$) and the dying symptoms in the last week of life ($r=0.18$). For psychological distress, psychological distress in the last month of life, and emotional distress and well-being in the last week of life have comparable correlation coefficients ($r=0.39$, $r=0.46$ and $r=0.44$, respectively) (Table 2).

DISCUSSION

Only half of the residents (54%, 50 of 92) died peacefully in the sample of residents in long-term care facilities in Flanders, Belgium, according to their relatives, and 11% (10 of 92) did not die peacefully at all. Both less physical distress in the last week, and less psychological distress in the last week and last month of life were correlated with dying peacefully, however, the correlations were only weak to moderate. This implies that when residents’ physical and psychological distress is higher, residents are perceived to die less peacefully.

Dying Peacefully

Little research has been done regarding the percentage of residents with dementia who die peacefully in long-term care facilities. We can only compare our results to one similar study in The Netherlands, where 56% of residents with dementia died peacefully according to their relatives and 11% did not die peacefully at all⁹, percentages that are comparable to the ones found in our study.

Dying Peacefully Correlated with Physical and Psychological Distress

Our study indicates that relatives base their judgment of dying peacefully both on physical and psychological distress. Less physical distress in the last week of life and less psychological distress in the last week and month of life were associated with dying peacefully. Correlations with psychological distress were stronger than correlations with physical distress, both in the last month and last week of life. Psychological items that had significant correlations covered both the last week and last month of life, whereas the physical symptoms with significant correlations came from the last week of life only. This shows that the last week of life is important in the perception of dying peacefully. It may be that the last week has more influence on this perception, especially when looking at the physical symptoms, which might worsen in the final days of life, whereas psychological symptoms may be more constant over time, so that a correlation can be observed for the last month as well. A lower correlation with physical distress also could be explained by the fact that the three physical symptoms in the SM-EOLD in the last month of life, namely pain, shortness of breath and skin breakdown, are quite disparate symptoms. Some authors argue that these three items should not be considered as a subscale¹⁸. We did calculate the correlation of the sum of these three items with dying peacefully, but there was no significant correlation.

Another interesting result is that we did not find any differences between the correlations with and without the item “calm” from the psychological subscale of the SM-EOLD scale. We had assumed that this item would have a high correlation with dying peacefully. However, we found only a weak correlation between “calm” in the last month of life and dying peacefully, which also was rated over the last month of life^{16 and 17}. This illustrates that physical and psychological distress often co-exist and, therefore, it is hard to determine how relatives interpret calmness. Some relatives might consider calmness as a solely physical aspect, whereas other relatives might include a psychological component in the item as well. Particularly in persons with dementia, aspects of physical and psychological or emotional distress interfere. For example, symptoms like crying and moaning (items of the CAD-EOLD emotional subscale) also may be seen as non-verbal pain indicators. This is also the case for dying peacefully itself: some relatives might see this as having reached a state of peace with oneself, looking back at the life one has had, independent of the symptoms the resident is confronted with in the actual dying process, whereas for other relatives dying peacefully might be seen as being without burdensome symptoms and being physically at rest, rather than involving psychological or existential issues.

Additionally, one could argue that the relatives who were able to say goodbye to a resident undergoing a gradual decline, for instance in the case of advanced dementia or another life-limiting and chronic disease, perceived the dying process as less stressful and, therefore, rated it as more peaceful, even though distressing physical or psychological symptoms might be present.

In our study, we had no information concerning the spiritual well-being of the residents with dementia and, therefore, could not correlate dying peacefully with spirituality, although being at peace has been correlated positively with spiritual well-being in other studies^{3, 4 and 5}. Nevertheless, it can be questioned to what extent spiritual well-being can be assessed in a population with dementia, and advanced dementia in particular. Research concerning spirituality in dementia mainly focused on people with dementia whose communicative skills were unimpaired or only mildly impaired^{23, 24 and 25}; this research found that the important themes in spirituality were comparable to those of other populations of older people.

Future Research and Implications for Practice

We can presume that the items that were uncorrelated with dying peacefully in our study do not influence relatives’ judgment of whether a death was peaceful. This study is only a first step in finding out which aspects matter most in this judgment, and we found that both psychological and physical items are correlated. To explore further how dying peacefully is perceived by relatives and what factors they consider important in their judgment, more in-depth qualitative research is needed using in-depth-interviews. This research is necessary first of all, because perception that death was not peaceful can have a negative influence on the bereavement process, for instance, and supporting family members in their bereavement process is a component of palliative care, too²⁶. Second, achieving a better understanding through future qualitative research of family members’ actual perception of the characteristics of a peaceful death can provide information on how we can improve palliative care for both the dying patient and the family. So far, we do not have a complete picture of what makes a death peaceful. Nevertheless, “the percentage of relatives who indicate that the patient has died peacefully” has been proposed as a

quality indicator for palliative care¹. A quality indicator has to provide an indication of the quality of care provided. The question that remains is whether dying peacefully can be considered as a separate outcome of the quality of care provided, or whether it is more or less an indication of adequate symptom relief. To draw conclusions about whether “the percentage of relatives who indicate that the patient has died peacefully” is a useful quality indicator, more insight is needed both into the aspects of care that could influence dying peacefully and into the characteristics of a peaceful death, according to relatives.

Strengths and Limitations

As far as we know, this is one of the first studies describing the extent to which residents with dementia in long-term care facilities die peacefully. It is the first study exploring whether physical and psychological distress in the last week and month of life as perceived by relatives are correlated to their judgment of whether a death was peaceful. Furthermore, it is a strength that this study is taking into account all residents with dementia in long-term care facilities in Flanders, regardless of the stage of dementia, as most research on dementia focuses on either the early stages or advanced dementia.

This study also has some limitations. We made use of ratings by proxies, which have been shown to not always be valid. However, communication with the patient might be impaired when they are in a moderate to advanced stage of dementia, leaving proxy rating as the only solution. Also, only the relatives who remain behind can assess the final outcome: the peacefulness or otherwise of the resident’s death.

CONCLUSION

This study revealed that only half the residents in Flemish long-term care facilities died peacefully according to their relatives. This judgment of relatives of whether the resident died peacefully is related to both physical and psychological distress. Further qualitative research is needed to gain more in-depth insights into the aspects on which relatives base their judgment of dying peacefully. This way, we could gain a deeper understanding of this potentially important indicator of the quality of palliative care and discover what aspects of care can be improved.

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TABLES AND FIGURES

Table 1. Characteristics of the Residents with Dementia in Long-Term Care Facilities in Flanders, Belgium and Their Relatives (*N*=92)

CHARACTERISTICS ^a	<i>N</i> (%)
RELATIVE	
Female sex	57 (64.8)
Age, yrs, mean (SD)	60.5 (11.0)
Relation to resident	
Spouse	7 (7.6)
Child	63 (68.5)
Other	22 (23.9)
RESIDENT	
Female sex	51 (58.6)
Age, yrs, at death, mean (SD)	87.5 (6.9)
Advanced dementia ^b	45 (48.9)
Median length of stay in long-term care facility in yrs (interquartile range)	2.1 (1.1-4.3)
Physical distress (mean (SD))	
SM-EOLD physical subscale last month of life (range 0-15)	9.0 (4.0)
Pain (range 0-5)	1.8 (2.1)
Shortness of breath (range 0-5)	3.0 (2.2)
Skin breakdown (range 0-5)	3.9 (1.9)
CAD-EOLD physical distress last week of life (range 4-12)	8.2 (2.3)

CHARACTERISTICS ^a	N (%)
Discomfort (range 1-3)	2.2 (0.7)
Pain (range 1-3)	2.0 (0.8)
Restlessness (range 1-3)	1.9 (0.8)
Shortness of breath ^c (range 1-3)	2.2 (0.9)
CAD-EOLD dying symptoms last week of life (range 4-12)	8.2 (2.6)
Shortness of breath ^c (range 1-3)	2.2 (0.9)
Choking (range 1-3)	2.1 (0.8)
Gurgling (range 1-3)	2.1 (0.9)
Difficulty swallowing (range 1-3)	1.8 (0.8)
Psychological distress (mean (SD))	
SM-EOLD psychological subscale last month of life (range 0-30)	18.3 (8.9)
Calm (range 0-5)	3.9 (1.9)
Depression (range 0-5)	3.2 (2.1)
Fear (range 0-5)	2.7 (2.2)
Anxiety (range 0-5)	2.4 (2.1)
Agitation (range 0-5)	2.9 (2.1)
Resistiveness to care (range 0-5)	3.4 (2.1)
CAD-EOLD emotional distress last week of life (range 4-12)	9.1 (2.3)
Fear (range 1-3)	2.2 (0.8)
Anxiety (range 1-3)	2.1 (0.8)
Crying (range 1-3)	2.6 (0.6)
Moaning (range 1-3)	2.3 (0.8)
CAD-EOLD well-being last week of life (range 3-9)	5.9 (1.9)
Serenity (range 1-3)	2.0 (0.7)
Peace (range 1-3)	2.0 (0.7)
Calm (range 1-3)	1.9 (0.7)

SM-EOLD: Symptom Management at the End of Life with Dementia; CAD-EOLD: Comfort Assessment in Dying at the End of Life with Dementia.

Item scores were reversed if the items reflected negative conditions in order to increase the interpretability: higher scores indicate better symptom control in the last month of life and more comfort in the last week of life.

- a. Missing values: Gender resident: $N=5$, Age resident: $N=7$, Advanced dementia: $N=0$, Length of stay in long-term care facility: $N=4$, Physical distress: $N=6-15$, Psychological distress: $N=5-17$, Gender relative: $N=4$, Age relative $N=11$, Relation to resident: $N=0$
- b. Advanced dementia was defined as Global Deterioration Scale stage 7 and a Cognitive Performance Scale of 5 or 6⁷.

- c. The item shortness of breath is part of both the CAD-EOLD physical distress subscale and the dying symptoms subscale.

Table 2. Correlations Between Dying Peacefully and Physical and Psychological Distress Rated by Relatives

Subscales and Items	Dying Peacefully Spearman Correlation Coefficient Relatives (N=92) ^a
PHYSICAL DISTRESS	
SM-EOLD physical subscale last month of life	0.06
Pain	0.07
Shortness of breath	-0.04
Skin breakdown	-0.06
CAD-EOLD physical distress last week of life	0.37 ^e
Discomfort	0.57 ^e
Pain	0.05
Restlessness	0.41 ^e
Shortness of breath ^b	0.14
CAD-EOLD dying symptoms last week of life	0.18
Shortness of breath ^b	0.14
Choking	0.22 ^c
Gurgling	0.04
Difficulty swallowing	0.13
PSYCHOLOGICAL DISTRESS	
SM-EOLD psychological subscale last month of life	0.39 ^e
Calm	0.09
Depression	0.44 ^e
Fear	0.35 ^d
Anxiety	0.38 ^d
Agitation	0.33 ^d
Resistiveness to care	0.17
CAD-EOLD emotional distress last week of life	0.46 ^e
Fear	0.45 ^e
Anxiety	0.43 ^e
Crying	0.20
Moaning	0.27 ^c
CAD-EOLD well-being last week of life	0.44 ^e

Subscales and Items	Dying Peacefully Spearman Correlation Coefficient Relatives (N=92) ^a
PHYSICAL DISTRESS	
Serenity	0.42 ^e
Peace	0.47 ^e
Calm	0.28 ^c

SM-EOLD: Symptom Management at the End of Life with Dementia; CAD-EOLD: Comfort Assessment in Dying at the End of Life with Dementia

Item scores were reversed if the items reflected negative conditions in order to increase the interpretability: higher scores indicate better symptom control in the last month of life and more comfort in the last week of life.

^a Missing values between 5.4% and 18.5% (N=5-17). Missing items, with a maximum of 1 of 3 or 4 items, were imputed with patient means to calculate a total subscale score.

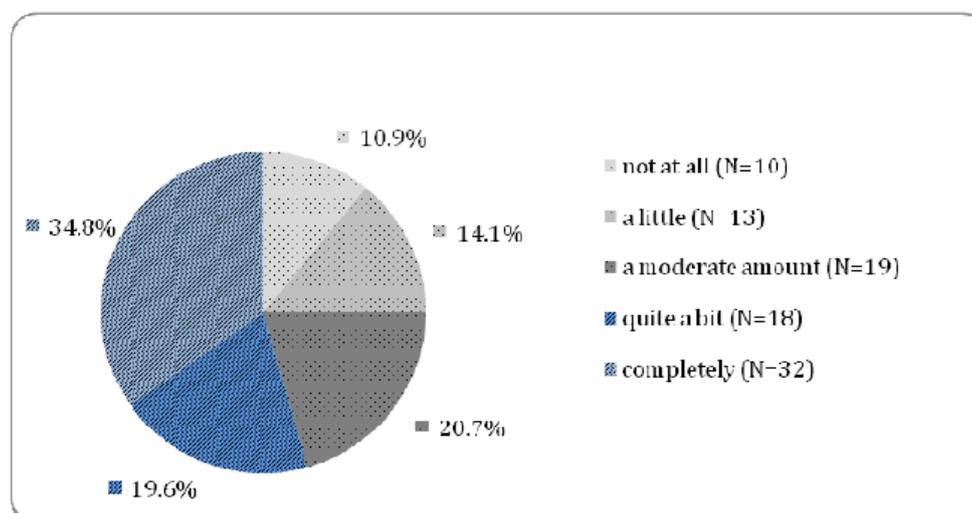
^b The item shortness of breath is part of both the CAD-EOLD physical distress subscale and the dying symptoms subscale.

^c Significant at $P < 0.05$.

^d Significant at $P < 0.01$.

^e Significant at $P < 0.001$.

Fig. 1. Frequency of residents with dementia dying peacefully in long-term care facilities (N=92)



"Not at all," "a little" and "a moderate amount" were seen as not dying peacefully. "Quite a bit" and "completely" were seen as dying peacefully.