




ORIGINAL ARTICLE

Care dependency of patients and residents at the end of life: A secondary data analysis of data from a cross-sectional study in hospitals and geriatric institutions

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Abstract

Aims and objectives: The holistic care dependency concept can be applied to gain comprehensive insights into individuals' care needs in the end-of-life (EoL) phase. This study was carried out to measure and characterise the "care dependency" phenomenon in this phase and to obtain deeper knowledge about this phenomenon.

Background: The end of a human life is often characterised by a physical decline, often implying that a high amount of care is needed. Non-malignant diseases can develop unpredictably; therefore, it is difficult to detect the onset of the EoL phase.

Design: Data were collected in a cross-sectional multicentre study, using the Austrian Nursing Quality Measurement 2.0.

Methods: Descriptive and multivariate statistical methods were used. Care dependency was measured with the Care Dependency Scale (CDS). The study follows the STROBE guideline.

Results: Ten per cent ($n = 389$) of the sample ($N = 3589$) were allocated to "a pathway for management of patients at the end of life." The patients and residents in the EoL phase are significantly older and more often diagnosed with dementia, and circulatory system and musculoskeletal system diseases. Of these patients, 60% were care dependent completely or to a great extent. Dementia and age represent main influencing factors that affect the degree of care dependency at the end of life.

Conclusion: Our results show that the "typical" EoL patient or resident is female, old and affected by dementia and/or circulatory system diseases. Dementia and age were identified as main factors that contribute to very high care dependency.

Relevance to clinical practice: The measurement of care dependency may support the identification of special care needs in the EoL phase. Gaining deeper knowledge about the care dependency phenomenon can also help healthcare staff better understand the needs of patients with non-malignant conditions in their last phase of life.

KEYWORDS

care dependency, Care Dependency Scale, end of life, EoL care, geriatric palliative care, palliative, palliative care

1 | INTRODUCTION

In Austria, almost 70% of people die in institutions, hospitals, or long-term care facilities (Statistics Austria, 2020). These facts indicate that these individuals experience their last phase of life in institutions. Every institution where people die must provide end-of-life (EoL) care. In 2011, the WHO estimated that over 19 million people were in need of palliative care in the EoL phase (WHO 2014 Global Atlas of Palliative Care at the End of Life). The NICE (National Institute for Health and Care Excellence) Guideline “End of life care for adults: service delivery” formulated certain key recommendations that could be followed to initially review the services provided and to then refer patients to additional palliative care services. These services are especially helpful for patients with non-cancer diagnoses, supporting the assessment of their holistic needs and advanced care planning. The scientific literature contains discussions on issues related to EoL care, highlighting significant stumbling blocks, such as inadequate policies and guidelines, a lack of advanced care planning, poor staff experience, knowledge and training, and uncertainties in terms of the prognosis (Omar Daw Hussin et al., 2018; Threapleton et al., 2017). Another frequently discussed key factor that affects the provision of EoL care is the recognition of the EoL phase (Bamford et al., 2018).

Care needs in the last phase of life are the focus of the current study. By obtaining deeper and more detailed knowledge about the care needs of individuals in the EoL phase, researchers and practitioners can better understand the end of life and the care which should be provided in this phase.

2 | BACKGROUND

Physical decline is a highly prominent phenomenon in the last phase of life (Stow et al., 2019). Geriatric patients with chronic diseases are especially affected by a physical decline, which often leads to a high number of care needs (Finucane et al., 2017). Care needs in the last phase of life include symptom management such as pain management, and social needs such as care for family members (Santivasi et al., 2020). To meet these care needs, it is important to detect patients who are in their last phase of life early on. Whilst hospice and palliative care programmes have historically placed a focus on meeting the needs of people with cancer, most healthcare providers now recognise that the majority of people who require palliative care are geriatric patients who have been diagnosed with non-malignant conditions (WPCA, 2014). The palliative care needs of these patients are especially difficult to identify, because the course of non-malignant diseases is generally less predictable. The unclear distinction made

What does this paper contribute to the wider global clinical community?

- Age and dementia are main influencing factors that affect care dependency at the end of life.
- Individuals in their last phase of life are highly care-dependent in the aspects of learning ability, recreational activities, sense of rules and values, avoiding of danger, hygiene, mobility and continence.

between palliative care and EoL care also presents problems in practice (Amblàs-Novellas et al., 2016; Dalkin et al., 2016). Whilst palliative care has been defined by the WHO (WHO, 2020) as an approach “to improve the quality of life of patients and their families who are facing problems associated with life-threatening illness,” no universal definition for end of life has yet been established. This makes it difficult to clearly define patients as EoL patients. This, in turn, can lead to the provision of inadequate EoL care, such as an inadequate treatment of pain (Dalkin et al., 2016; Hill et al., 2018; Hui et al., 2014). Patients with dementia represent an especially highly vulnerable group, and the EoL care needs of individuals in this group often go undetected (Hill et al., 2018). Signs of functional and physical decline primarily occur in the last phase of life, supporting the assumption that care dependency is high at this time (Amblàs-Novellas et al., 2016; Stabenau et al., 2015), since both age and diseases strongly influence individual care needs (Caljouw et al., 2014; Edjolo et al., 2016). Different concepts have been developed to describe these care needs, such as concepts of frailty, functional decline, disability and care dependency. Care dependency is a specific nursing concept that was developed and defined by Dijkstra (1998) as a “process in which the professional offers support to a patient whose self-care abilities have decreased and whose care demands make him/her to a certain degree dependent, with the aim of restoring this patient’s independence in performing self-care” (Dijkstra et al., 1996). The operationalisation of the care dependency concept is based on the nursing theory of Virginia Henderson (Dijkstra et al., 1998; Henderson, 1966). This theory addresses the 14 basic human needs, including physical, psychosocial and spiritual aspects (Henderson, 1966). Care dependency is measured with the Care Dependency Scale (CDS). The CDS is a multidimensional assessment tool which is applied to measure physical and psychosocial needs and allows the use of a holistic care approach (Piredda et al., 2020; Piredda, Bartiromo, et al., 2016; Piredda, Biagioli, et al., 2016). Up until now, researchers have not applied the concept of care dependency in investigations to describe care needs at the end of life.

Care dependency, however, is especially suitable for the description of such needs, because a holistic approach is taken in its measurement. In addition to the holistic approach of the 14 human needs, Henderson (1966) especially mentioned terminal care as nursing task by describing the concept of nursing. This implies that those basic human needs, which the CDS is based on, might be especially suitable to describe the caring needs of individuals in their last phase of life.

Overall, the experience of dependency influences people very strongly (Piredda, Bartiromo, et al., 2016; Piredda, Biagioli, et al., 2016). Care dependency can affect their interpretation of the meaning of life, their awareness as a person who receives care, and some patients even begin to view their lives differently than before. In Piredda, Bartiromo, et al. (2016) and Piredda, Biagioli, et al. (2016), where the experience of care dependency of advanced cancer patients is described, and changes in their views on time and a change of the perception of really important things in life are mentioned. Regarding the view on time, for instance, the awareness of the lack of time can be mentioned. Concerning the really important things in life, for example, emotions such as love are recognised as most important things. Most people wish to be independent, even in the last phase of their life (Delgado-Guay et al., 2016; Horne et al., 2012). It is well known that functional decline increases, and many different care needs arise in the last phase of life (Schmidt et al., 2018; Stabenau et al., 2015). By gaining deeper and more detailed knowledge about the nature of care dependency in EoL situations, healthcare providers can provide more effective care using a holistic approach and improve the patient's quality of life, which is the main focus of EoL care.

The aim of this study was to measure and characterise the main areas of "care dependency" in EoL patients and residents. The following research questions were formulated:

- To which extent and in which aspects of care dependency are patients and residents mainly dependent at their end of life?
- Which factors influence the care dependency of patients and residents at the end of life?

3 | METHOD

As a study design, data were analysed that were collected in 2017 as part of the Austrian Nursing Quality Measurement 2.0, a cross-sectional multicentre study. This study is conducted annually in several European countries (e.g. Netherlands, UK and Switzerland) using a standardised questionnaire (Nie-Visser et al., 2013). The data collection is performed on 1 day each year; in 2017, the study was carried out in hospitals, geriatric hospitals and nursing homes in Austria. The participation of the institutions in this study is voluntary.

The measurement was conducted in cooperation with Maastricht University. The data collection procedure focussed on quality indicators regarding the care problems of continence, malnutrition, falls, restraints, pain and care dependency (Eglseer et al., 2018; Institute of

Nursing Science, 2020). The study is following the *Strengthening the reporting of observational studies in epidemiology* (STROBE) guideline for cohort, case-control and cross-sectional studies (Supplementary File S1).

3.1 | Questionnaire

The questionnaire used was initially developed by Maastricht University and is regularly updated by an international research team. The questionnaire, which is based on Donabedian's Model of Quality (structure, process and outcome), includes questions about institutions, the hospital wards, and the patients or residents. The questions posed about the patients or the residents allow the collection of demographic data, medical diagnoses and specific nursing care problems, such as the occurrence of pain, pressure ulcers, falls or malnutrition. Since 2017, the German version of the questionnaire has included the question "Is the client on a pathway for management of patients at the EoL?" In the manual that accompanies the questionnaire, the end of life is describe as a state that extends from several days to 1 year, leading up to the point that the individual is expected to die. A consensus in the interdisciplinary team is needed that the patient or resident is at the end of life indicating by the question that the patient is expected to die within 1 year.

In the current study, care dependency was measured with the German version of the CDS, which is a valid and reliable instrument used to measure care dependency (Dijkstra et al., 1996; Lohrmann et al., 2003b). To date, the scale has been translated into different languages, adapted and tested for reliability, validity and utility in different settings and with different patient groups, such as neurology or rehabilitation patients (Dijkstra et al., 1999, 2000, 2002; Kottner et al., 2010; Lohrmann et al., 2003b; Piredda, Bartiromo, et al., 2016; Piredda, Biagioli, et al., 2016; Tork et al., 2008). The CDS was also tested for a two-factor structure which comprises physical care dependency and psychosocial care dependency (Boggatz et al., 2009; Piredda et al., 2020; Piredda, Bartiromo, et al., 2016; Piredda, Biagioli, et al., 2016). As psychosocial items, the day and night patterns, communication, contact with others, and an understanding of rules and values have been defined by several authors (Piredda et al., 2020; Piredda, Bartiromo, et al., 2016; Piredda, Biagioli, et al., 2016).

The CDS covers 15 items, and each item can be rated with a score from 1 to 5 (completely dependent, to a great extent dependent, partially dependent, to a great extent independent, completely independent). By adding the scores on the item level, a sum score across the whole scale is obtained, and the assessed patients can then be divided into five groups as well. The five groups are named the same as the five groups for each item. Patients with a sum score of 0–24 are defined as completely dependent, those with a sum score of 25–44 are dependent to a great extent, those with a sum score of 44–59 are partially dependent, and those with a sum score of 60–69 are assessed as independent to a great extent. Patients with a sum score higher than 69 are regarded as independent (Dijkstra et al., 2006; Doroszkiewicz et al., 2018).

3.2 | Data collection

All nurses at the participating institutions were trained and received written information material prior to the data collection. The data collection was conducted on a single scheduled date. The data collection team consisted of two nurses: one nurse from the ward where the data collection was conducted, and the second nurse from another ward. They conducted the questionnaire for each patient together, reaching a consensus whilst completing the questionnaire. The consensus was gained through discussion. If a consensus was not reached, the answer provided by the “independent” nurse from the second ward was chosen. If the consensus finding was difficult cause of ambiguity of the question, this might be cleared by using the manual for the questionnaire. Additionally, the data collection team has the possibility to contact a hotline, which is provided scientist from the Austrian Nursing Quality Measurement team.

3.3 | Sample

All Austrian inpatient healthcare institutions with more than 50 beds were invited by letter in June 2017 to participate in the Nursing Quality Measurement 2.0. Forty-three institutions—37 hospitals, 2 geriatric hospitals and four nursing homes—took part in the measurement in 14 November 2017. To participate in the study, 3589 patients and residents gave their informed consent. 389 participants, consisting of patients or residents in the EoL phase, were defined through a positive answer to the question “Is the client on a pathway for management of patients at the EoL?” As outlined in the manual for the questionnaire, the decision if the patient or resident is at the end of life must be made by the interdisciplinary team before the Nursing Quality Measurement is performed.

3.4 | Data analysis

Data were analysed with IBM SPSS Statistics (Version 26; IBM Corp., 2019). To describe the sample, a descriptive analysis of the data was performed. The differences in the sample descriptions for patients and residents on the pathway at the end of life, and those who were not, were calculated by conducting chi-square tests.

Descriptive analyses were also performed to analyse the care dependency of EoL patients and residents by using the score of the whole CDS and analysis for each item of the 15 items of the CDS. For the analysis on item level, the median was used. Statistical significance levels were calculated by performing chi-square tests for nominal scaled data, as diagnoses or sex and for parametric data, as age Mann–Whitney *U* test was used. Correlation coefficients were calculated between the CDS items and possible influencing factors of care dependency to show possible statistically significant correlation.

3.5 | Binominal logistic regression

A binominal logistic regression analysis was performed for each item of the CDS. It was necessary to create a dependent dichotomous variable based on the five dependency groups of the CDS. The characteristics for those who were completely dependent or dependent to a great extent were combined, and this group was defined as “highly dependent.” The characteristics for those who were partially dependent, independent to a great extent or completely independent were combined, and this group was defined as “partially or not care dependent.” For each item of the CDS, a separate model for the logistic regression analysis was built. Based on the literature and the results of the descriptive analysis with the possible independent variables, a univariate logistic regression analysis was performed. All those were considered independent variables which showed statistically significances between EoL and non EoL patients and residents. To create a model for the logistic regression, a univariate regression analysis was performed and variables showing significant values were included in the multivariate model ($p < .05$).

3.6 | Ethical considerations

The ethical committee of the Medical University of Graz approved the study (EK-Number: 20-192 ex 08/09). A written informed consent form was signed by all participants. In the participating hospitals, possible participants were informed a day before data collection; in long-term-care facilities, possible participants were informed a couple of weeks before the data collection. This procedure ensured that possibly needed proxies have enough time to be informed and can think about giving a written informed consent for patients or residents who are not able to give an informed consent by themselves.

4 | RESULTS

4.1 | Participants

Of the patients and residents in the whole sample ($N = 3589$), 389 (10.8%) were on a pathway for the EoL. Most of the patients and residents who were allocated to the pathway to end of life lived in geriatric institutions (geriatric hospitals and nursing homes). Of these EoL patients and residents, 43% suffered from dementia. Musculoskeletal system diseases, circulatory system diseases and dementia were the most common diagnoses out of the 27 queried diagnoses (Table 1). The number of patients and residents who were diagnosed with cancer was also considered, since cancer might imply a high degree of care dependency, especially at the end of life. The patients and residents on the pathway to end of life significantly differ ($p < .05$) in sex, age, diseases of the circulatory system diseases of the musculoskeletal system, dementia, cancer and regarding the institution where they were at the point of data collection from non-EoL patients or residents (Table 1).

TABLE 1 Descriptive statistic of EoL versus non-EoL patients and residents

	EoL (n = 389)	Non EoL: (n = 3200)	p-value
Sex	65% female	53% female	<.001
Age	Mean (SD) 78 (16)	Mean (SD) 68 (17)	<.001
Hospital	34.5%	93%	<.001
Long-term care (LTC)/Geriatric institution	65.5%	7%	<.001
Diseases of the circulatory system	68.6% (267)	47.8% (1528)	<.001
Diseases of the musculoskeletal system	43.2% (168)	25% (802)	<.001
Dementia	43.2% (168)	7.5% (239)	<.001
Cancer/neoplasm	20.3% (79)	16% (523)	.048

Care dependency in EoL patients and residents



FIGURE 1 Care Dependency in EoL Patients and Residents on an Item Level

4.2 | Care dependency of EoL patients and residents—descriptive analysis

Care dependency was analysed by examining the CDS results with the scoring system for the whole scale as well as on item level. The analysis of EoL patients' and residents' data for the five categories of care dependency across the whole scale (completely dependent, to a great extent dependent, partially dependent, to a great extent

independent, completely independent) revealed that 60% of the patients and residents who were described as EoL were care dependent completely or to a great extent. In contrast, 12% of the non-EoL patients and residents were care dependent completely or to a great extent.

The item-level (median) analysis of the CDS results shows that EoL patients and residents were dependent to a great extent with regard to the items learning ability, recreational activities, daily

activities, sense of rules and values, contact with others, hygiene, continence and avoidance of danger. These analyses' results overall show that the EoL patients and residents had a high level of care dependency (Figure 1).

For the further descriptive analysis, the dichotomous variable for care dependency was used: highly care dependent versus partially or not care dependent. Patients and residents diagnosed with dementia or a circulatory system disease had high levels of care dependency for all CDS items significantly more often ($p < .05$). Patients and residents diagnosed with a musculoskeletal disease had high care dependency levels significantly more often ($p < .05$) for all items except incontinence, communication, contact with others and recreational activities. Patients and residents who were diagnosed with cancer also differed significantly ($p < .05$) in all items except mobility. No significant differences were identified between these two groups regarding the sex of the patient or resident.

The results of the correlation analysis on the CDS item level with regard to sex, age, dementia, cardiovascular diseases, musculoskeletal diseases and cancer show that weak to moderate correlations exist. The following correlation coefficients were calculated with the CDS sum score: age, -0.480 ($p < .000$); sex, -0.444 ($p < .383$); dementia, -0.515 ($p < .000$); cardiovascular diseases, -0.262 ($p < .000$); musculoskeletal diseases, -0.151 ($p < .003$); and cancer, -0.156 ($p < .000$).

4.3 | Binary regression analysis of EoL patient and resident data

The results of the previous analysis regarding the high level of care dependency of EoL patients and residents encouraged us to perform a regression analysis to identify factors that might predict the probability of a high grade of care dependency. The dichotomised variable highly care dependent versus partially or not care dependent was the dependent variable. For each item of the CDS, a separate model for the logistic regression analysis was created. Age, sex and the medical diagnoses of cancer, dementia, circulatory system diseases, or diseases of the musculoskeletal system and connective tissue were included as independent variables in a univariate regression analysis.

Those independent variables which show significant relationships in the univariate logistic regression were added to the models.

Age and dementia predict significantly likelihood to be ($p < .05$) highly care dependent, for every item of the CDS (Table 2). Especially dementia increases the likelihood to be highly care dependent. Only in the model for the item daily activities, diseases of the circulatory system increase the likelihood to be highly care dependent. Cancer and diseases of the musculoskeletal system and connective tissue do not show significant likelihoods to be highly care dependent (Table 2).

Due to the fact that the regression analysis results show that the factors age and dementia increase the likelihood of being dependent for every item in the Care Dependency Scale, a stratification

by age and dementia was performed. The group of EoL patients who were diagnosed with dementia ($n = 168$) was significantly more ($p < .001$) care dependent regarding all items than EoL patients who had not been diagnosed with dementia ($n = 221$). EoL patients and residents diagnosed with dementia were completely care dependent concerning the items learning ability, recreational activities, daily activities, sense of rules and values, avoidance of danger, hygiene, getting dressed and undressed, and continence (Figure 2). Regarding the two-factor structure of the CDS, these items were allocated as physical care dependency items.

Statistically significant differences ($p < .001$) were identified when the care dependency levels of EoL and non-EoL patients and residents who were 80 years of age or older were compared. Whilst patients and residents who were 80 years of age or older and not allocated as EoL patients were mostly, to a great extent or completely independent, EoL patients and residents who were 80 years of age or older were dependent mainly, completely or to a great extent (Figure 3).

5 | DISCUSSION

In the sample, the patients and residents allocated to a pathway for management at the end of life differed considerably from those who were not allocated to an EoL pathway regarding their ages, sex and medical diagnoses. EoL patients were significantly older and suffered significantly more often from dementia and circulatory system diseases. The level of care dependency in EoL patients and residents seems to be mainly influenced by age and dementia. A comparison between EoL and non-EoL patients and residents who were 80 years of age or older showed that most non-EoL patients and residents who were over 80 years old were independent. The influence of age on care dependency has already been shown by Lohrmann et al. (2003a) and Dijkstra et al. (2012), where an age over 80 proved to be an influencing factor on care dependency. Schüssler et al. (2015) showed that dementia is a strong influencing factor on the level of care dependency. In their study sample, 72% of the residents with dementia were care dependent completely or to a great extent. In our analysis of EoL patients and residents, we observed that every CDS item was affected by dementia, and most of the items were affected by the residents or patients age. In the descriptive comparison of the level of care dependency, it becomes clearer that dementia and being in the last phase of life mainly define the level of care dependency.

Nevertheless, EoL patients without dementia are more independent than those affected by dementia. Our finding that care needs may be affected by the diagnosis of dementia, especially in the last phase of life, agrees with other research findings (Finucane et al., 2017; van der Steen et al., 2017). Care needs of geriatric patients suffering from chronic diseases differ from those of young patients diagnosed, for example with incurable cancer (Boyd et al., 2019; Finucane et al., 2017; Hall et al., 2011; Smets et al., 2018; van Der Steen et al., 2009). One crucial but very difficult point

TABLE 2 Care Dependency in EoL Patients and Residents on an Item Level

	B	SE B	Wald X ²	p	Exp (B)	95% CI for Exp (B)	
Eating and drinking							
Age	.04	.01	16.11	.00	1.04	1.02	1.06
Cancer	-.36	.29	1.51	.22	0.70	0.40	1.24
Dementia	1.21	.24	24.62	.00	3.36	2.08	5.42
D. o. Circulatory S.	-.46	.30	2.38	.12	0.63	0.35	1.13
D. o. Musculoskeletal S.	-.13	.24	.30	.58	0.88	0.54	1.41
Incontinence							
Age	.04	.01	15.49	.00	1.04	1.02	1.06
Cancer	1.18	.26	2.69	.00	3.25	1.96	5.40
Dementia	-.02	.29	.01	.94	0.98	0.55	1.74
D. o. Circulatory S.	-.36	.28	1.60	.21	0.70	0.40	1.22
Body position							
Age	.03	.01	8.50	.00	1.03	1.01	1.05
Cancer	-.17	.28	.38	.54	0.84	0.49	1.46
Dementia	1.01	.24	17.97	.00	2.75	1.72	4.39
D. o. Circulatory S.	-.06	.28	.05	.83	0.94	0.54	1.63
D. o. Musculoskeletal S.	.06	.23	.06	.81	1.06	0.67	1.67
Mobility							
Age	.04	.01	13.29	.00	1.04	1.02	1.06
Dementia	.87	.24	13.31	.00	2.38	1.49	3.78
D. o. Circulatory S.	.02	.28	.01	.94	1.02	0.59	1.77
D. o. Musculoskeletal S.	.01	.23	.00	.96	1.01	0.64	1.60
Day and night patterns							
Age	.02	.01	5.25	.02	1.02	1.00	1.05
Cancer	-.63	.33	3.76	.05	0.53	0.28	1.01
Dementia	1.17	.25	22.53	.00	3.21	1.98	5.20
D. o. Circulatory S.	-.04	.30	.01	.91	0.97	0.54	1.74
D. o. Musculoskeletal S.	.35	.24	2.12	.15	1.42	0.89	2.27
Getting dressed and undressed							
Age	.04	.01	17.28	.00	1.04	1.02	1.06
Cancer	-.38	.29	1.73	.19	0.69	0.39	1.20
Dementia	1.27	.27	21.70	.00	3.57	2.09	6.09
D. o. Circulatory S.	-.15	.31	.23	.63	0.86	0.47	1.58
D. o. Musculoskeletal S.	.11	.26	.17	.68	1.11	0.67	1.84
Body temperature							
Age	.03	.01	8.75	.00	1.03	1.01	1.05
Cancer	-.55	.31	3.25	.07	0.58	0.32	1.05
Dementia	1.40	.25	32.65	.00	4.05	2.51	6.55
D. o. Circulatory S.	-.26	.30	.75	.39	0.77	0.43	1.39
D. o. Musculoskeletal S.	.10	.24	.18	.67	1.11	0.69	1.78
Hygiene							
Age	.05	.01	19.37	.00	1.05	1.03	1.07
Cancer	-.26	.29	.80	.37	0.77	0.43	1.36
Dementia	1.40	.29	22.77	.00	4.06	2.28	7.21
D. o. Circulatory S.	-.17	.32	.30	.58	0.84	0.45	1.56
D. o. Musculoskeletal S.	.19	.27	.51	.48	1.21	0.72	2.05

(Continues)

TABLE 2 (Continued)

	B	SE B	Wald X ²	p	Exp (B)	95% CI for Exp (B)	
Avoidance of danger							
Age	.05	.01	18.40	.00	1.05	1.03	1.07
Cancer	-.21	.30	.50	.48	0.81	0.45	1.46
Dementia	1.89	.29	43.19	.00	6.59	3.75	11.56
D. o. Circulatory S.	-.11	.32	.13	.72	0.89	0.48	1.67
D. o. Musculoskeletal S.	-.09	.27	.10	.75	0.92	0.54	1.55
Communication							
Age	.02	.01	2.49	.11	1.02	1.00	1.04
Cancer	-.92	.36	6.57	.01	0.40	0.20	0.80
Dementia	1.12	.26	19.37	.00	3.08	1.87	5.08
D. o. Circulatory S.	.04	.30	.01	.91	1.04	0.57	1.88
Contact with others							
Age	.03	.01	7.92	.00	1.03	1.01	1.05
Cancer	-.52	.32	2.63	.10	0.60	0.32	1.11
Dementia	1.59	.25	4.78	.00	4.90	3.01	7.98
D. o. Circulatory S.	.00	.30	.00	1.00	1.00	0.55	1.81
Sense of rules and values							
Age	.03	.01	6.32	.01	1.03	1.01	1.05
Cancer	-.35	.31	1.32	.25	0.70	0.38	1.28
Dementia	1.92	.26	54.07	.00	6.81	4.08	11.35
D. o. Circulatory S.	.31	.31	1.03	.31	1.37	0.75	2.49
D. o. Musculoskeletal S.	-.13	.26	.25	.61	0.88	0.53	1.46
Daily activities							
Age	.03	.01	1.16	.00	1.03	1.01	1.06
Cancer	-.09	.31	.09	.77	0.91	0.50	1.67
Dementia	2.17	.29	54.91	.00	8.77	4.94	15.58
D. o. Circulatory S.	.53	.31	2.85	.09	1.69	0.92	3.12
D. o. Musculoskeletal S.	-.49	.28	3.15	.08	0.61	0.36	1.05
Recreational activity							
Age	.02	.01	4.87	.03	1.02	1.00	1.04
Cancer	-.14	.30	.23	.63	0.87	0.48	1.56
Dementia	1.93	.26	53.49	.00	6.88	4.10	11.53
D. o. Circulatory S.	.38	.30	1.62	.20	1.47	0.81	2.64
Learning ability							
Age	.03	.01	6.66	.01	1.03	1.01	1.05
Cancer	-.13	.32	.16	.69	0.88	0.48	1.64
Dementia	2.47	.31	64.86	.00	11.76	6.46	21.42
D. o. Circulatory S.	.72	.32	4.91	.03	2.04	1.09	3.85
D. o. Musculoskeletal S.	-.34	.28	1.42	.23	0.71	0.41	1.24

often occurs during the care of geriatric patients: the onset of the EoL phase (Bamford et al., 2018; Dwyer et al., 2008; Smets et al., 2018). Flierman et al. (2019) showed that practitioners face difficulties when attempting to define a palliative phase in non-cancer patients. Patients with dementia are especially difficult to define as palliative care patients, as they experience gradual decline (Finucane et al., 2017; Mataqi & Aslanpour, 2019). Bern-Klug (2004) referred to this phenomenon as the "ambiguous dying syndrome," which keeps many older people from accessing the kind of

emotional and spiritual comfort and care that might be available if their dying status were more clearly established (Lloyd et al., 2011). It is well known that patients with dementia have special needs in their last phase of life. McCleary et al. (2018) described some unique aspects of the EoL care for persons with dementia, such as, for example, adequate time. More time is needed to care for someone with dementia, because he/she cannot express their needs clearly or (often) verbally. Behavioural symptoms are extremely challenging to interpret. Touch is an important means of

Care dependency of EoL patients and residents with and without dementia



FIGURE 2 Care dependency of EoL patients and residents with and without dementia

communication, especially for people with dementia (McCleary et al., 2018). In our analysis, communication was one of the items for which patients and residents were partially dependent or to a limited extent independent. It might be helpful to have more knowledge about the trajectories of palliative care to solve the problem of how to accurately identify the onset of the EoL phase in older demented patients. Trajectories with a rapid, steady progress and a clear terminal phase are allocated to cancer patients. In contrast, a prolonged gradual decline as an EoL trajectory has been described for frail older people or people with dementia (Finucane et al., 2017; Murray et al., 2005). Recently, Boyd et al. (2019) highlighted the differences in illness trajectories, investigating the experiences patients with cancer have, also referring to chronic illnesses and dementia and examining their EoL trajectories. Cancer patients display fewer physical symptoms in the last month of life than patients with dementia or chronic diseases. The authors recommend that a complex and integrated palliative care is offered in the months and even years leading to death in long-term care facilities (Boyd et al., 2019). Our data show that patients and residents in the EoL phase are especially highly care dependent

regarding physical care dependency items such as continence, learning ability, recreational ability, daily activities, avoidance of danger and hygiene.

Another crucial aspect of providing care for patients in the EoL phase is to meet special care needs where they are identified. The analysis results on an item level show that almost all the same items are affected throughout the EoL sample, that is in the EoL sample with dementia as well as in the EoL sample of people over 80 years of age. These items include learning ability, recreational ability, daily activities, a sense of rules and values, avoidance of danger, hygiene, getting dressed and undressed, and continence. Koppitz et al. (2015) conducted a retrospective study on the type and development of symptoms in people with dementia in the final terminal and dying phase in nursing homes in Switzerland. They described ten of the most frequent symptoms that occur in the last 90 days of life: mobility problems (81%), pain (71%), sleep disturbances (63%), unusual behaviour (62%), feeding problems (62%), agitation (39%), breathing abnormalities (29%), apathy (25%), anxiety (22%) and depressive episodes (14%). Some of these symptoms are also reflected in our findings on the item level, such as mobility, eating and drinking, and a sense of rules and values.

Care dependency of patients and residents over 80 EoL vs non-EoL

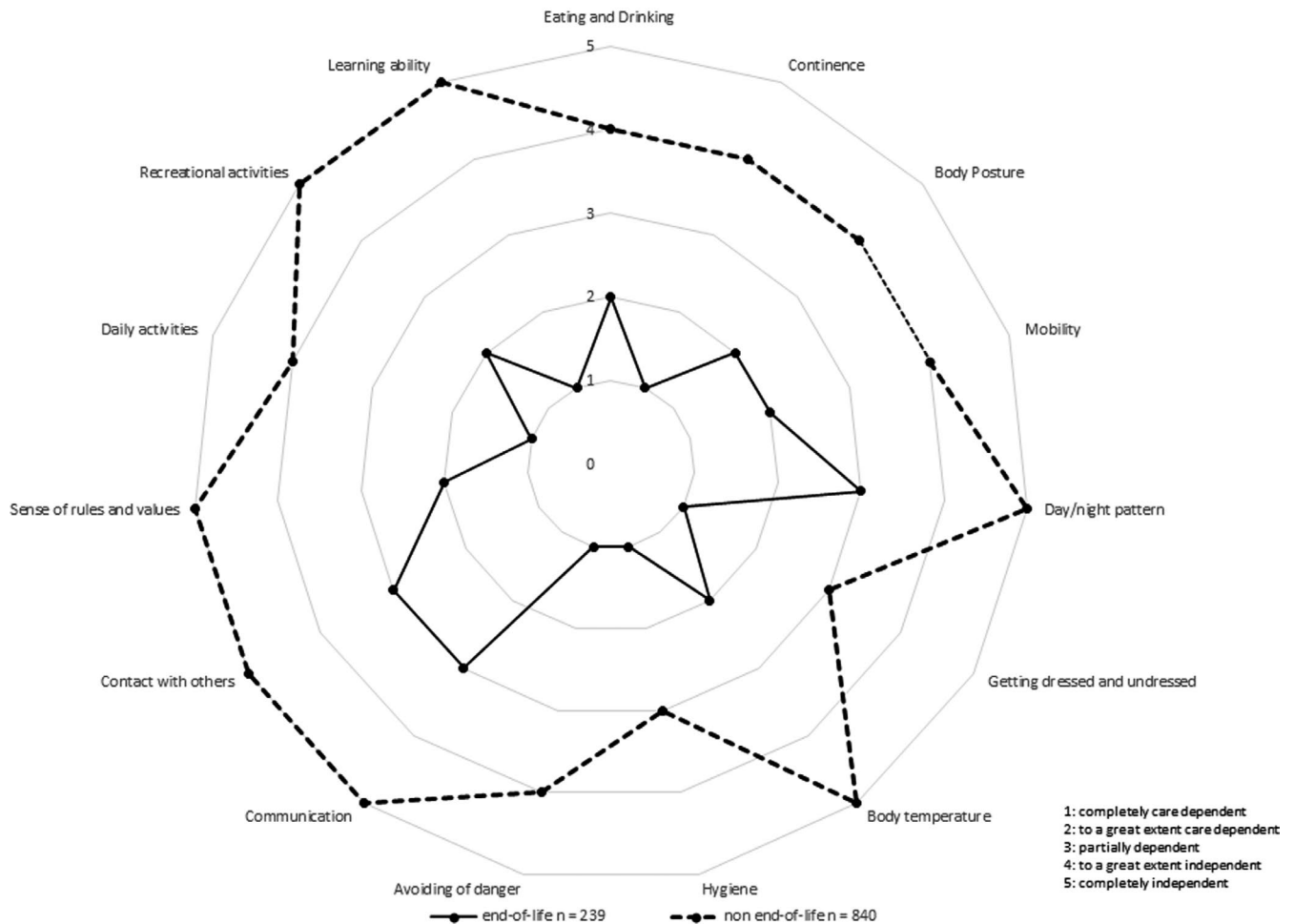


FIGURE 3 Care dependency of EoL and non-EoL patients and residents who were 80 years of age and older

6 | CONCLUSION

Our results lead us to conclude that a “typical” geriatric EoL patient or resident is female, old, affected by dementia and/or a circulatory system disease which results in a very high level of care dependency in terms of their physical and psychosocial needs. An increase in care dependency can be a sign that the patient is entering the EoL phase.

If the last phase of life can be described in great detail, this can be helpful for nurses in clinical practice, increasing their awareness of the last phase of life and enabling them to provide specific care, that is EoL care.

6.1 | Limitations

The main limitation of our study is that the study participants were identified as EoL patients on the basis of a subjective evaluation performed by healthcare professionals. Furthermore, the overall sample of EoL patients and residents is small.

6.2 | Recommendations

Further research is necessary to gather detailed information that will enable healthcare professionals to accurately define geriatric patients as needing palliative care and, respectively, as EoL patients. This will allow them to receive optimal care in their last phase of life. It is necessary to define the (onset of the) EoL phase (Schüttengruber et al. paper submitted).

6.3 | Relevance to clinical practice

The results of these data analyses may help clinical practitioners to more effectively identify patients and residents in the EoL phase. Furthermore, these results may help them to more efficiently identify the special care needs of these patients and residents, such as their physical needs in the EoL phase, and support efforts to apply a holistic approach in EoL care.

CONFLICT OF INTEREST

The author has no conflict of interest to disclose.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

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