Dissertation

END OF LIFE – CARE DEPENDENCY – OLD AGE

Concepts, Characteristics and Attitudes

submitted by

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Declaration

I hereby declare that this thesis is my own original work and that I have fully acknowledged by name all of those individuals and organisations that have contributed to the research for this thesis. Due acknowledgement has been made in the text to all other material used. Throughout this thesis and in all related publications I followed the “Guideline of the Medical University of Graz on Good Scientific Practice”

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Disclosures

The current dissertation has been published/accepted and submitted as the following articles:

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All co-authors have explicitly agreed to the use of their data in this thesis.

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Table of Contents

Abbreviations and Definitions

ADL	Activities of Daily Living
CDS	Care Dependency Scale
CREDES	Guidance on Conducting and Reporting Delphi Studies in palliative care
EAPC	European Palliative Care Organization
EoL	End of life
Eol-Care	End-of-life Care
EoLC	End-of-life Care
HPNA	Hospice and Palliative Nurses Association
IADL	Instrumental Activities of Daily Living
NICE	National Institute for Health and Care Excellence
ÖPG	Austrian Association of Palliative Care
PPS	Palliative Performance Scale
SPICT	Supportive and Palliative Care Indicator Tool
SQ	Surprise Question
STROBE	Strenghtening the Reporting of Observational studies in Epidemiology

Definition

Care dependency:

“a process in which the professional offers support to a patient whose self-care abilities have decreased and whose demands make him/her to a certain degree dependent, with the aim of restoring this patient´s independence in performing self-care” (Ate Dijkstra 1998)

Zusammenfassung

Lebensende (*end of life*) ist ein häufig verwendeter Begriff in Forschung und Praxis, jedoch unklar in seiner Bedeutung. Pflegeabhängigkeit ist ein eindeutig definiertes Konzept, das aber noch nicht für Menschen am Lebensende beschrieben wurde. Beides – das Lebensende und auch die Pflegeabhängigkeit - werden vorwiegend im hohen Alter erfahren. Dem Lebensende, insbesondere im hohen Alter, geht zumeist eine Pflegeabhängigkeit voraus.

Ziel dieser Dissertation war es, den Begriff des Lebensendes zu analysieren und zu definieren, die Pflegeabhängigkeit am Lebensende zu beschreiben und die Pflegeabhängigkeit sowie die Einstellungen in Bezug auf Hochaltrigkeit zu untersuchen.

Der Begriff *end of life* wurde mittels einer Konzeptanalyse beschrieben. Die Definition von *end of life* wurde mittels einer Delphi Studie ermittelt. Die Pflegeabhängigkeit am Lebensende (*end of life*) und bei hochaltrigen Personen wurde durch eine Sekundärdatenanalyse beschrieben. Die Einstellungen zu Hochaltrigkeit wurden mittels einer Querschnittstudie erhoben.

Dem Konzept *end of life* wurden die Attribute klinischer Status/physische Symptome, psychosoziale Symptome, Zeit und Würde zugeordnet. Der Übergang in die End-of-Life Phase sollte von den Gesundheitsprofessionen rechtzeitig erkannt werden, um eine adäquate Versorgung, nämlich End-of-Life Care, anbieten zu können. *End of life*, das Lebensende, ist als prozesshaftes Geschehen definiert, welches insbesondere einen holistischen Zugang erfordert und folglich auch physische, psychische und spirituelle Bedürfnisse der Betroffenen berücksichtigt. In End-of-Life Situationen ist eine hohe Pflegeabhängigkeit beobachtbar. Die Wahrscheinlichkeit für eine hohe Pflegeabhängigkeit erhöht sich in end-of-life Situationen auch durch verschiedene Krankheiten, wie etwa durch eine dementielle Erkrankung. Was die Einstellungen in Bezug auf Hochaltrigkeit betrifft, so werden über 80-jährige Personen vorwiegend als pflegeabhängig und krank gesehen, was sie aber nicht unbedingt sein müssen, sofern sie nicht von einer dementiellen Erkrankung oder von Hemiparese und/oder einem Schlaganfall betroffen sind.

Die Beschreibung des Konzeptes *end of life* sowie dessen Definition können unterschiedliche Gesundheitsprofessionen dabei unterstützen, dieses Lebensphase eindeutiger identifizieren zu können. Die Integration des holistischen Zuganges, sowohl in der Beschreibung des Konzepts wie auch in der erarbeiteten Definition, unterstreichen dessen Bedeutung für diese Lebensphase. Der Anstieg der Pflegebedürftigkeit kann ein Zeichen für den Übergang in die letzte Lebensphase sein. Die Ergebnisse zeigen aber, dass das Erkennen der letzten Lebensphase insbesondere bei dementiellen Erkrankungen durch den bereits bestehenden hohen Pflegebedarf erschwert werden kann. Die Pflegeabhängigkeit am Lebensende ist sehr ausgeprägt, auf Hochaltrigkeit ohne schwere Erkrankungen trifft dies jedoch nur bedingt zu.

Abstract

End of life is a frequently used term in research and practice but has been unclear in its meaning. Care dependency is a clearly defined concept, but has not been described for individuals at their end of life. Both – end of life and care dependency - are primarily experienced in old age. The end of life, in particular when experienced in old age, is often preceded by care dependency.

The overall aim of this thesis was to analyze and define the term *end of life*, to describe care dependency at the end of life and in old age as well as to investigate attitudes towards old age.

The term *end of life* was analyzed and described by conducting a concept analysis. The definition was created by means of a Delphi Study. Care dependency at the end of life and in old age was described by performing a secondary data analysis. The attitudes toward old age were investigated using a cross-sectional study.

For the concept of end of life, the attributes clinical status/physical symptoms, psychosocial symptoms time and dignity emerged. The transition into the end-of-life phase should be recognized appropriately and in a timely manner by health professionals in order to ensure the provision of adequate end-of-life care. The end of life is defined as a process which requires a holistic approach and, consequently, meets *physical, psychosocial and spiritual needs* of the respective individuals. A high degree of care dependency was observed at the end of life. The risk of high care dependency at the end of life is also increased by certain underlying diseases, for example dementia. With regard to attitudes toward old age, people aged 80 years and older are mainly attributed as care dependent and in poor health. However, this is not necessarily the case, if they are not affected by dementia or hemiparesis and/or stroke.

The description and the definition of the concept of end of life may support health professionals to better identify the end-of-life phase. The integration of the holistic aspect in the description of the concept as well as in the definition underlines the importance of this aspect during the last phase of life. The increase of care dependency can be an indicator for an individual’s transition into the end-of-life phase, but results show this transition might be more difficult to identify in individuals affected by dementia due to their already pre-existing high care dependency. Care dependency at the end of life is high, but this is not always true for old age, in particular in individuals without a severe disease.

Introduction

In 2019, the life expectancy of people born in the countries of the European Union was 84 years for females and 78.5 years for males (1). The number of persons in the age cohort of 65 years and older in the European countries is projected to grow by 2070 to 30 % of the whole population. The age group comprising persons 80 years and older is projected to double to 13 % by 2070 (2). The remaining life expectancy of people currently at the age of 65 is estimated to be 20.2 years (21.8 years for females and 18.3 years for males) (1).

When the health status of older people is discussed in health science, healthy life years might be a more meaningful indicator than life expectancy (3). Healthy life years are defined as *"…the number of years that a person is expected to continue to live in a healthy condition…a healthy condition is defined as the absence of limitations in functioning/disability…"* (4, 5). These years were estimated in 2019 to be 65.1 years for females and 64.2 years for males in the countries of the European Union. Actual predictions concerning correlations between the health status and the increasing life expectancy can hardly be made (6). Since there is a span of about 15 years between the average life expectancy and number of average healthy life years, these data indicate that most very old people will unavoidably experience illness and disability.

Nursing care basically requires a holistic understanding of human beings, and it is of significant importance to comprehensively understand the context of nursing care. Therefore, this doctoral thesis has been written to clarify the particular meaning of the last phase of life – also referred to as the end of life - and how this phase of life can be defined.

End of life is mostly accompanied by a functional decline, which leads to a dependency on others, in other words, care dependency. Care dependency as a major and important concept in nursing is the second focus of this thesis. Since the end of life and associated care dependency are mostly experienced in very old age, the phenomenon of very old age is also considered.

Theoretical Framework

The theoretical framework for this thesis is based on three aspects, namely, the terms end of life and old age and the concepts care dependency (Figure 1). As described above, these aspects partially overlap; the end of life, which is often correlated with old age, may go hand in hand with an increase in care dependency.

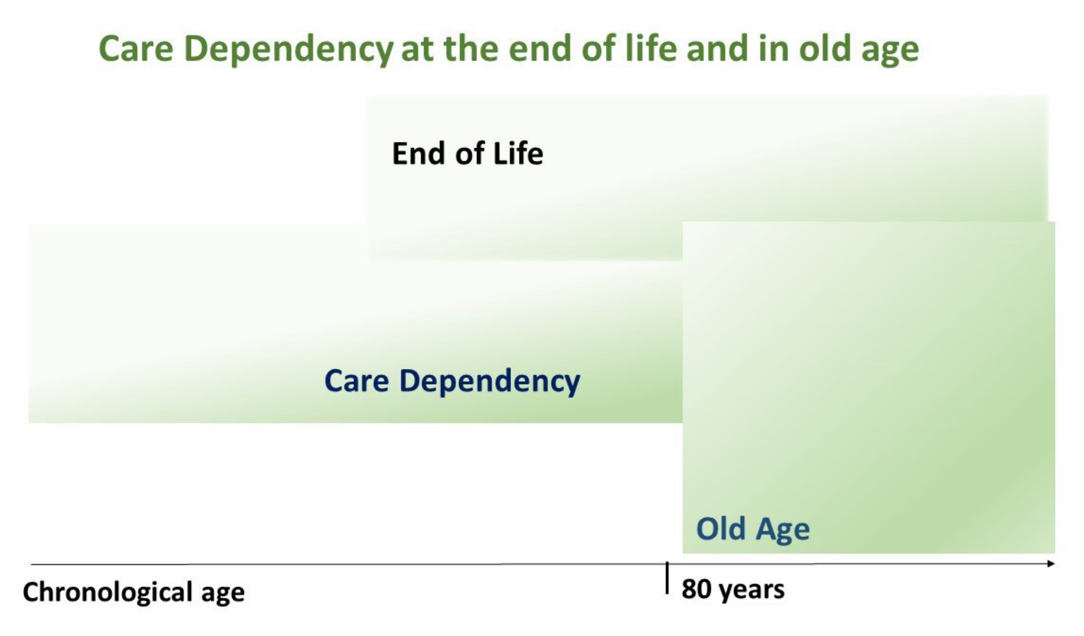

Figure 1: Theoretical background for the thesis

End of life

In the NICE Guidelines “End of life care for adults”, the authors defined end of life as *“final weeks and months of life, although for people with some conditions, this could be months or years”* (7). The timespan is often used as a characterization of the term end of life, but it is also most debatable, since it can vary from days to years. A systematic review was performed to synthesize the evidence on the end-of-life care needs of people with frailty, and the authors of this review described time frames ranging from the last day to the last two years (8). Cohen-Mansfield et al. described time frames ranging from 3 weeks to 25 years in their cross-sectional study, carried out to characterize the end-of-life period (9).

In addition to the time factor, physical and psychosocial symptoms and, therefore, the related functional decline are predominantly used to describe the end of life. Since end of life can be seen as a part of palliative care, and palliative care as a discipline was mainly developed with a focus on dying patients with cancer, symptoms for end-of-life conditions are often described on the basis of a cancer diagnosis (10). Research has shown that symptoms are similar at the end of life, regardless of the diagnosis (11). Pain, breathlessness, nausea, vomiting, cognitive impairment and fatigue are listed as common symptoms at the end of life, regardless of the underlying illness (10, 12-15). It is noteworthy that especially symptoms for patients with advanced dementia are depicted as aspiration, breathing difficulties, pain, breathlessness and include neuropsychiatric symptoms, such as insomnia (16, 17). Symptoms at the end life may not differ much from symptoms associated with the underlying illness, but the disease trajectories do. Lunney et al. described four distinct end-of-life trajectory groups of functional decline in the last year of life (18). Beside the possibility of a sudden death, which implies an independent function until death, the authors indicated different trajectories for terminal illness/ cancer, organ failure and frailty /dementia. Stolz et al. found similar trajectories, using cancer, organ failure and frailty/dementia as conditions leading to death (19). For cancer patients, a short time frame (about 6 months) has been defined, characterized by a gradual increase in disability followed by a steep decline until the terminal phase starts (18, 19). Lunney et al. described a continuous decline intersected by repeated short-term recovery cycles for patients with organ failure, and a gradual decline which worsens in the last three months of life for frailty/dementia patients (18). Stolz et al. cited organ failure, frailty, or dementia and described a gradual increase in disability, without defining a clear terminal phase (19). Morgan, Tieman described two main trajectories, one of which displayed a slow decline up until the last 14 days of life, followed by a more rapid functional decline, which was observed in patients with cancer, organ failure and cardiovascular diseases (20). The second trajectory comprises functional impairments 120 days before a rapid decline occurs in the last two weeks of life, observable in individuals with dementia and neurological conditions. The description of decline trajectories may support the timely identification of the starting point of the end-of-life phase.

Instruments also have been developed to support the identification of the end-of-life phase, such as the Supportive and Palliative Care Indicator Tool (SPICT) which can be used to identify patients with palliative care needs (21, 22). The Palliative Performance Scale (PPS) is used as a predictive tool for patients with cancer and other end-of-life diagnoses, such as heart diseases, pulmonary diseases, or dementia (23, 24). Another way to identify end of life is to ask the so-called Surprise Question (SQ), which is *“would I be surprised if this patient died in the next year?”* (25-27). The SQ is a simple and frequently used tool, but a meta-analysis showed that the surprise question is often imprecise, and further research is recommended (28). Recently, the SPICT was tested for the first time for an older hospitalized population (29). In a systematic review of the PPS, more studies about the prognostic value were recommended (23).

Despite descriptions of the end-of-life phase, typical functional decline trajectories and predictive tools, it is still challenging for health care professionals to identify patients approaching the end of life (16). In a study about differences in geriatric conditions, the authors concluded that particular patients with frailty and end-stage organ failure were not identified as approaching the end of life (30). The difficulty of early recognition of the end of life might also be explained by the confusion regarding terminology used to refer to the end of life and/or palliative care. Especially the lack of a common definition for end of life and the synonymous or interchangeable use of terms such as end of life, end-of-life care, terminal care and palliative care cause problems in clinical practice and research (31, 32). The interchangeable or synonymous use of these terms results in a reduced or non-use of special medical services, because palliative care or end-of-life care is not initiated until the patients are designated as end of life in some settings (33). Some researcher developments are currently underway to create a glossary of key palliative terms, which might facilitate communication by enabling the use of consistent language across care settings, but the term end of life is not a part of this glossary (34).

The timely identification of end of life is crucial for integrating appropriate care in the last phase of life early on; this means assessing and managing symptoms and performing advanced care planning, as well as ensuring person-centered care, continuity of care and collaboration among health care providers (17, 30).

To gain a deeper insight into the meaning of the term end of life, the aspect of old age has to be considered in particular, since the difficulty of making a timely identification of this phase preliminarily occurs in non-cancer patients with conditions like frailty and dementia.

Old age and care dependency

No single chronological age can be defined for the term old age. In recent decades, most individuals aged 65 or older were defined as old adults in scientific research papers and reports on ageing (35); however, especially people in their 60s or 70s no longer fit the traditional perception of old age. People of this age are no longer often viewed negatively as being ill and dependent, nor are they often viewed positively as being particularly serene or wise (36, 37). Furthermore, *“old people”* are not a homogenous group; they are diverse in many health aspects, such as their functional status or multimorbidity (38).

One attempt was made to address the diversity of older people in the description of the third age by Peter Laslett in 1989. He described the third age as an active, healthy and functionally fit phase of life. Even when the intention of this description was to address the heterogeneity of the *“group of people”* aged 65 years and older, the positivity of this description may lead to a negative view of the subsequent fourth age, connoted with biocultural incompleteness, vulnerability, unpredictability and lack of resources (39, 40). In a publication on the gerontology perspectives of the end of life in the literature, Kriebernegg described the so-called fourth age displayed in movies, television and literature as *“individuals who are reduced on their purely physical existence, which is placed on the edge of society”* (41). It is known that ageing stereotypes are transported by the literature and media (42). Stereotypes are shared beliefs about (older) people’s attributes, behavior, competences and desires (43).

Especially for the fourth age, the stereotypes of frailty and dependency are held by members of society, health care professionals and the oldest old themselves (39, 44). Stereotypes concerning age are just one aspect of ageism (45). Ageism is defined as *“stereotypes, prejudice and discrimination directed toward others or oneself based on age”* (46), and it poses a problem in health care, because it leads to negative health outcomes, such as poor quality of life or physical and mental illness (47).

Wahl and Ehni recommended not to use the distinction between the third and fourth age for scientific purposes, because it has disadvantages and eventually even incurs risks due to the negative view of the fourth age (39). For research purposes, it is recommended to use chronological age groups, for instance, 10-year cohorts instead of the imprecise term fourth age (48). In the scientific literature, it is noticeable that terms other than *“old-old”*, *“oldest old”*, or *“advanced old age”* are used as well (39). For example, the chronological age of 80 or 85 years and older is defined for the term oldest old and very old (38, 44, 49, 50).

Functional decline and care dependency

In a study carried out in 2011 in Newcastle to describe the capability and dependency of individuals age 85 years and older (N = 841), the authors found that 20 % of the participants had no difficulties performing activities of daily living (38).

In a longitudinal study (n = 19528) conducted in China, the authors observed that the onset of functional decline is postponed in lifetime, but decline seemed unavoidable in later life (50). In another study conducted in China, the authors showed rapid increase in functional decline between the ages of 80 and 100 years (51). In a German longitudinal study (n = 578, mean age at death: 76.59), the researchers demonstrated that the functional health significantly decreased over time, but this was more strongly related to being near death than to the chronological age (52). Summarizing the scientific data, functional decline in old age seems unavoidable. The phenomenon of functional decline is usually assessed using the well-known Barthel Index, the scale for Activities of Daily Living (ADL), and/or the scale for Instrumental Activities of Daily Living (IADL) (53).

The Barthel Index is used to measure functional independence in areas such as feeding, bathing, grooming, dressing, bowel control, bladder control, toilet use, transfer, mobility and stairs (54). It was originally developed for patients with neuromuscular disorders and later psychometrically tested in different settings and with stroke patients or older people in rehabilitation settings (55, 56). The ADL scale can in particular be used to quantitate the functional decline by measuring six basic ADL, such as dressing, bathing, eating, grooming, toileting, continence (53, 57) An additional instrument is Brody´s Scale for Instrumental Activities of Daily Living (IADL) which encompasses eight items, such as handling small objects, handling finances, using the telephone, shopping, going to distant places, preparing food, housekeeping and handling medication (58-61). All of these instruments place a focus on a dependency status that is mainly physical (56), but dependency is a multidimensional phenomenon (62), and the concept of dependency is fundamental in caring relationships (63). Therefore, dependency should be measured by applying a more holistic approach. This requirement is addressed by the Care Dependency Scale (CDS), and especially supported by splitting the scale into two factors: physical care dependency and psychosocial care dependency (64-67).

The concept of care dependency was defined by Dijkstra as *“a process in which the professional offers support to a patient whose self-care abilities have decreased and whose demands make him/her to a certain degree dependent, with the aim of restoring this patient´s independence in performing self-care”* (68). Based on this concept and the care theory of Virginia Henderson, the CDS was developed (64). Henderson described 14 basic human needs which are identical for all human beings. For instance, basic human needs are breathing, eating and drinking, moving and maintaining desirable posture or working, playing and learning (69). Whilst the scientific literature provides some information about the influence of the functional decline at the end of life, such as evoking feelings of meaninglessness and existential loneliness and worrying about the future (70, 71), descriptions for the concept of care dependency at end of life are lacking. In a qualitative study, Piredda et al. showed that care dependency is experienced as having a strong influence over the meaning of life regarding the experience of care dependency in patients with advanced cancer (72). The factor of age itself is not the main causal mechanism for the occurrence of care dependency, but acts as a proxy variable (52).

Research Gaps

End of life is an unclear and undefined term, which is used synonymously and interchangeably with other terms, such as palliative care, end-of-life care, or the terminal phase or dying phase (31). This is a result of a lack of a common definition or even a common description of the end of life (31, 73, 74). A clear distinction between the term end of life and other terms, such as palliative care, is necessary, since the synonymous or interchangeable use causes problems in clinical practice and research (75-77). In clinical practice, it has been shown that palliative care should be started early on, when no curable treatment is possible. This implies that the onset of palliative care is not concurrent with the end of life, because if palliative care is offered early enough, then the end of life can be located at the end of this palliative pathway (75). The lack of a description/definition of the end of life prevents an accurate allocation to end of life care; this means, for instance, that offering specialized pain treatment, nursing care with a more holistic view (e.g. considering the spiritual needs or carefully considering whether a treatment in hospital would lead to improvement or would only be perceived as a stressful event by the individual) (78). This late or prevented allocation to the end of life is also hindered by the difficulty health care professionals have in recognizing the end of life phase in a timely manner (79). This might also be due to the lack of a clear definition and description of the term.

In order to conduct valid research, clear definitions of terms, concepts and phenomena are indispensable.

Functional decline, which occurs almost in every end-of-life situation except for sudden death situations, is always accompanied by dependency (19). To date, the concept of care dependency, which describes nursing care needs from a holistic perspective, has not been investigated in the end-of-life phase context. Care dependency and end of life occur mostly late in life; therefore, old age as phenomenon should be considered in concordance with care dependency and the end of life. In addition, since it is known that negative attitudes toward old age exist in society and that they influence health care outcomes, attitudes towards old age have to be considered in research on old age. Care dependency is a measurable concept, and it should be measured in relation to old age and in end-of-life situations. These data might help researchers to gain a deeper knowledge of how the last phase of life can be comprehensively described.

Aims and outline of the doctoral thesis

The lack of a common understanding of what the term end of life means supports the first aim of this doctoral thesis, i.e. to analyze the meaning and use of the term end of life. Based on this first aim, the second aim was developed to create a common definition of the term end of life in order to contribute to the already-existing attempts to clarify and distinguish between the variety of terms used for palliative and end-of-life situations. Since care dependency at the end of life had not yet been investigated, the third aim was to describe care dependency at the end life. In particular, the aspects of dependency that are affected and the extent to which they are affected were investigated, because these results contribute to a deeper knowledge about care needs at the end of life. End of life and care dependency mainly occur very late in life; negative stereotypes are typically observed during this life period. To gain a deeper insight into care dependency at the end of life and in old age, a comprehensive consideration of the phenomenon old age is required. The fourth and concluding aim of this thesis work was to correlate and examine the associations among the factors of old age, end of life and care dependency. Figure 2 depicts an outline based on the contextual framework of the (published) studies.

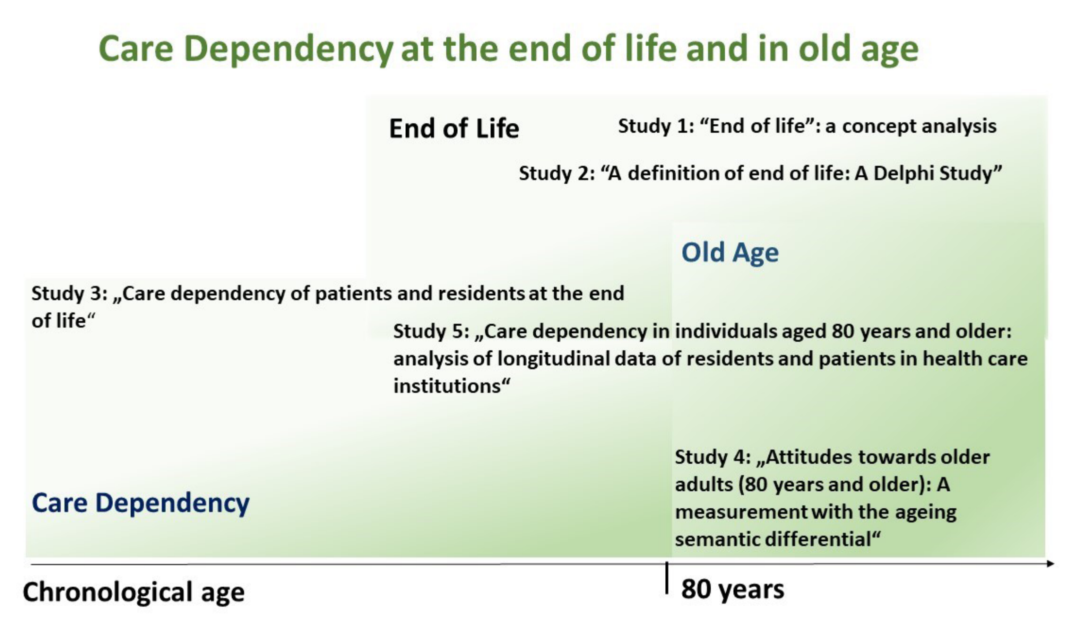

Figure 2: Outline of the doctoral thesis

The detailed aims of this thesis work

Study 1

The aim of the first study was to gain a deeper understanding of the term end of life (EOL) as used in a health care setting and to clarify the concept.

Study 2

The aim of the Delphi study was to find a commonly used, unambiguous, international and interdisciplinary definition of the end-of-life phase.

Study 3

The aim of the cross-sectional study was to measure and to characterize the main areas of care dependency in end-of-life situations.

Study 4

The fourth study was performed to obtain comprehensive and detailed knowledge about attitudes toward persons aged 80 year and older and to confirm the four-factor structure of the ageing semantic differential (ASD).

Study 5

The aim of this study was to provide a comprehensive description of persons aged 80 years and older, enabling us to get deeper knowledge about the phenomenon of care dependency in the oldest old.

Methods

This chapter gives an overview (Table 1, Table 2) about the methods used for the 5 conducted studies for this doctoral thesis. In Table 1 and Table 2 the aims, designs, setting & sample, data collection and data analysis strategies are summarized. Detailed information concerning the methods, can be found in the articles.

Table 1: Study 1-2 Methods

	Study 1	**Study 2**
Aim	To gain a deeper understanding of the term end of life (EOL) used in health care setting.	To find a commonly used, unambiguous, international and interdisciplinary definition for the end of life phase
Design	Concept analysis	Modified Delphi Study
Setting & sample	60 articles included	International & interdisciplinary panel of experts R 1 *n* = 34 R 2 *n* = 27 R 3 *n* = 21 R 4 *n* = 21
Data collection	Literature search in DB: Pubmed Cinahl Web of Science Cochrance Databased of Systematic Reviews PubPsych	4 Anonymous, Panel rounds via limey survey; standardized questionnaire based on the previously performed concept analysis

Table 2: Study 3-5 Methods

	Study 3	Study 4	Study 5
Aim	To measure and characterise the main areas of care dependency in EOL patients and residents.	To obtain a comprehensive and detailed knowledge about the attitudes toward people aged 80 years and older and to confirm the four-factor structure of the German version of the Ageing semantic differential (ASD).	To develop a comprehensive description of care dependency of individuals aged 80 years and older to get a deeper knowledge about possibly influencing factors (diseases, end-of-life phase, age and sex).
Design	Cross-sectional, multicentre study	Cross sectional study	Longitudinal multicentre study
Setting & sample	Patients and residents (*n* = 389) who were allocated to the pathway of end of life	Convenience sample (*n* = 255) students of nursing science, medicine and humanity	Patients and residents (*n* = 14509) aged 80 years and older
Data collection	Secondary data analysis of the data of the Nursing Quality Measurement 2017	Self-reported standardized questionnaire	Secondary data analysis of the data of the Nursing Quality Measurement between 2009 - 2021

Results

This section summarizes key findings of the five original articles.

- Gerhilde Schüttengruber, Ruud J.G. Halfens, Christa Lohrmann. “End of life”: A Concept Analysis. *International Journal of Palliative Nursing*. (accepted 08/21)
- Gerhilde Schüttengruber, Franziska Großschädl, Christa Lohrmann. “A consensus definition of end of life from an international and interdisciplinary perspective: A Delphi Panel Study”. *Journal of Palliative Medicine*. (accepted 04/22)
- Gerhilde Schüttengruber, Ruud J.G. Halfens, Christa Lohrmann. 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. *Journal of Clinical Nursing* Vol. 31, Issue 5-6, pp.:657-668.
- Gerhilde Schüttengruber, Erwin Stolz, Christa Lohrmann, Ulla Kriebernegg, Ruud Halfens, Franziska Großschädl. Attitudes towards older adults (80 years and older): A measurement with the ageing semantic differential – A cross-sectional study of Austrian students. *International Journal of Older People Nursing* Vol. 17, Issue 3.
- Gerhilde Schüttengruber, Franziska Großschädl, Christa Lohrmann. Care dependency in individuals aged 80 years and older: analysis of 2009–2021 data for residents and patients in long-term care facilities and hospitals in Austria. Submitted.

The overall aim of this doctoral work was to gain deeper knowledge about the use and definition of the concept end of life itself and how care dependency in this phase of life occurs.

The description of the term end of life in the field of health care was the first aim of this doctoral work and, therefore, a concept analysis was conducted by applying Rodger´s evolutionary method in the first study. This method requires taking clear stepwise approach by analysing the international literature for attributes and contexts of the concept.

As defining attributes, the clinical status with physical symptoms, psychosocial symptoms, time and dignity emerged. The clinical status is characterized by a physical decline which is often accompanied particularly by pain, breathing difficulties, mobility and eating and drinking difficulties. In addition, psychosocial symptoms such as anxiety, distress and fear of loss of autonomy were identified as attributes. The remaining timeframe until death remains a very important factor, but is difficult to define. In the literature, a wide range of specific timeframes for the end-of-life phase from hours to years is reported, and a central wish to preserve dignity is often described. The transition and the correct identification of the entry into the end-of-life phase is an antecedent for the end of life. End-of-life care and a good death (e.g. adequate symptom control and/or the presence of loved ones) at the end-of-life phase are described as consequences.

The second study was conducted to formulate a definition for the concept end of life; therefore, the Delphi technique was chosen for this study. The standardized questionnaire used for the modified Delphi study was developed on the basis of the results obtained from the concept analysis carried out in study 1. After four rounds, the Delphi study enabled the formulations of a comprehensive and holistic definition of end of life, which was agreed upon by 21 internationally and interdisciplinary experts. The definition comprises aspects of the overall functional decline and closely related physical symptoms. The need to consider the transition into the end-of-life phase well ahead of time and the requirement to offer a specific end of life care are also part of the definition. The definition also addresses the fact that health care professionals should consider the patient's individual needs and wishes. The importance of relationships and dignity and, in particular, the fear of a loss of dignity are also included in this definition. The definition ends by pointing out that, especially at the end of life, the individual's physical, psychosocial and spiritual (care) needs must be addressed.

The needs, and especially the care needs, as expressed as care dependency and measured with the Care Dependency Scale (CDS) were addressed in the third study.

A secondary data analysis of data from 389 individuals allocated to a pathway at the end of life was performed to determine their care dependency. The mean age of individuals in this sample was 78 years, 43 % suffered from dementia, and 65 % lived in a long-term care or geriatric institution. Of these, 60 % were completely or to a great extent care dependent. In particular, this sub-group was completely care dependent in the areas of learning ability, recreational activities, daily activities, sense of rules and values, contact with others, hygiene, continence and avoidance of danger. Individuals who were diagnosed with dementia were significantly more care dependent in all areas of care dependency than the ones who had not been diagnosed with dementia. The high mean age (78 years) of the individuals at the end of life led to the fourth study. Since the review of the current scientific literature revealed the tendency that individuals with a high age are especially strongly affected by negative stereotypes and attitudes, we investigated attitudes toward people aged 80 years and older. This precise chronological age cohort (80 years and older) was chosen, because the related scientific literature recommends the use of specific age groups to consider the diversity among the groups. Attitudes were measured by applying the Ageing Semantic Differential (ASD) scale, a scale that comprises 32 adjective pairs and has a four-factor structure. The ASD scale was developed to measure stereotypes about age. A convenience sample of 255 Austrian nursing, humanity and medical students participated in the study. The four-factor structure (instrumentality, autonomy, acceptability, integrity) of the ASD was confirmed by performing a factor analysis. The mean age of the sample was 23.6 years, and 79 % of the participants were female. Of this sample, 82 % had experience in caring for or assisting individuals aged 80 years and older. Overall, a slight general tendency toward negative attitudes, and especially negative attitudes concerning dependency and health, was observed. People aged 80 years and older were seen mainly as dependent and unhealthy. A stratification by study programme revealed small differences between the groups; however, the medical students held more negative attitudes than nursing or humanity students. The regression analysis results show that having the possibility to talk about personal affairs with an older person and having knowledge about the meaning of ageism positively influenced people's attitudes toward older people.

The level of care dependency and the areas in which individuals aged 80 years and older are care dependent were assessed in the fifth study.

For this purpose, data derived from Austrian Nursing Quality measurement performed between 2009 and 2021 were collected. These 14,509 datapoints were analyzed to identify care dependency and potential predicting factors, such as diseases like dementia.

The stratification into three age groups showed that 46 % were between 80 and 85 years old, 35 % were between 86 and 90 years old, and 19 % were 91 years or older. Of the individuals aged 80 years and older, 66 % were affected by cardiovascular diseases, 40 % by musculoskeletal diseases, and 31 % by dementia. The care dependency measured with the CDS was highest in the age cohort of 91 years and older for all areas of care dependency. The stratification also showed that almost 50 % of the individuals aged between 80 and 85 were completely or to a great extent independent regarding all areas of care dependency. The descriptive analysis results show that individuals affected by dementia or allocated to a pathway for end of life were highly care dependent. The binominal logistic regression analysis results reveal that all areas of care dependency were related to a higher odds ratio for being care dependent if the individuals were affected by dementia or hemiparesis/stroke.

Discussion

End of life

The results of the concept analysis show that a wide range of symptoms occur at the end of life, but it was not possible to determine specific symptoms for the definition. Some symptoms were often described as specific end-of-life symptoms, such as pain, breathlessness, eating and drinking problems, nausea and vomiting, agitation and apathy and fatigue (12, 17, 80). Suggested symptoms included in the standardized questionnaire for the Delphi panel, such as cognitive decline, pain, dyspnea, or restriction of movement, did not receive an agreement in the first round or the following rounds. The experts argued that every symptom can occur in situations that are not end-of-life as well. Symptoms have often been described in relation to a defined underlying disease, such as cancer, dementia, or heart failure (81-83). For cancer patients at the end of life, pain, loss of appetite and shortness of breath have been described (84). For individuals with dementia, studies have described high risks for pressure sores, pain, difficulty in swallowing (16). In other publications, symptoms have only been differentiated between cancer and non-cancer conditions or specifically for an older patient cohort. Non-cancer patients, for instance, often display shortness of breath, pain or fatigue, or, for older patients (70 years and older), urinary incontinence, anxiety, or memory problems (14, 85).

In the Delphi study, the experts finally agreed to include the term overall physical decline and physical symptoms, citing dyspnea as an example. In addition, the term functional status was integrated into the definition, since both terms (physical decline and functional decline) are often used in the scientific literature and clinical practice (18). The occurrence of a functional decline at the end of life is also described in the literature for almost every end-of-life situation, unless it is a sudden-death situation (18-20).

Another aspect which was pointed out as being quite difficult to define was the timeframe. The concept analysis results show that a wide range of timeframes can be applied to the end of life have, ranging from hours to years, and that no specific timeframe for end of life could be found (8, 26, 86, 87).

Accordingly, the Delphi panel experts refused to define a specific timeframe for the end of life. They agreed on the statement that time is an important point, but did not agree to define a specific timeframe. Timeframes have been defined in the literature; for instance, in the ESMO Clinical practices guidelines for the care of adult cancer patients at the end of life, the last weeks and days are defined as the end of life (88). In the NICE guidelines for end of life care, a 12-month timeframe for end of life is used (7). The “Surprise Question”, a frequently used prognostication tool, also uses a 12-month timeframe (89). Even though patients, their families and clinicians desire an estimate of the remaining timeframe until death, it seems impossible to set a specific timeframe (90, 91).

Maybe even more crucial than exactly defining the timeframe for the end of life is the timely recognition of when the end-of-life phase begins. The concept analysis results reveal the timely recognition of the end of life as well as the transition into the end of life phase as antecedents. Experts on the Delphi panel also agreed that the needs to recognize the end of life and the transition into the end-of-life phase in a timely manner needed to be elements of the definition. Recognizing (accurately) the end of life well ahead of time has been described by several authors as crucially for providing appropriate care at the end of life (17, 90, 92). End-of-life care can support the fulfilment of the often-expressed wish of people to die with dignity (71, 93). Dignity emerged clearly as a defining attribute of the end of life in the concept analysis and achieved a high level of agreement in the first round of the Delphi study. It was, therefore, indicated as part of the definition of the end of life. The strong wish to preserve dignity and the fear of losing dignity can be explained by the expected and almost inevitable dependency that occurs at the end of life (18-20). The loss of autonomy or the fear of a loss of autonomy, which also imply dependency, might be the main reasons for the fear of losing dignity (94-95).

Care dependency at end of life and in old age

The characteristic of care dependency at the end of life was addressed in the third study.

As an overall result, a high level of care dependency at the end of life emerged. Individuals were highly care dependent regarding almost all aspects of care dependency, such as continence, mobility, getting dressed and undressed, hygiene, avoidance of danger, sense of rules and values, daily activities, recreational activities and learning abilities. The specific areas of the CDS showed that physical and psychosocial aspects of dependency are affected. These results confirm the results of the concept analysis (Study 1) and of the Delphi Study (Study 2), which showed that physical, psychosocial and spiritual aspects matter at the end of life.

The data used for the regression analysis revealed that dementia is a significant predictor for high care dependency at the end of life. Other diseases, such as cardiovascular diseases or musculoskeletal diseases, were not significant factors for being care dependent. Previous studies in this area have shown that dementia highly influences the level of care dependency and leads to high care dependency, particularly in areas of dependency such as incontinence or a sense of rules and values, for instance (96, 97). Dementia also considerably influences the level and area of care dependency in the end-of-life phase. Studies that tracked the trajectory of functional decline at the end of life show that dementia impacts this trajectory (18, 20). In study 3, we showed that patients and residents at the end of life who are not affected by dementia were significantly less care dependent than those with dementia. In this context, we must mention that the dementia stages (mild, moderate, severe) were not observed. The stage of dementia can be assumed to impact ADL, functional abilities and care dependency, even if the literature has rarely cited this (98).

The assumption that the end of life is mainly experienced by people at a high age, based on the high life expectancy, could be confirmed in study 3 as well (1, 99). The mean age of the individuals at the end of life in this study was 78 years. This implies that caring for individuals at the end of life means mainly caring for individuals who are very old. It is important to note that the attitudes toward age and ageing in society are often negative; therefore, the effects of ageism should be considered as well (100). To address this topic, study 4 was conducted. The findings revealed slightly negative attitudes towards individuals aged 80 years and older. The literature on attitudes toward age and ageing indicates that all forms of attitudes (positive, negative and neutral) are observable within health care professionals (101-103). Since attitudes might affect the health status of older adults, this aspect should be addressed (37, 47, 104). Negative attitudes of health care professionals toward age and ageing lead to negative patient health outcomes, such as a low quality of life or even reduced longevity (47). In their systematic review on suicides in late life, Gramaglia et al. noted that ageism prevalent in society and from the perspective of physicians affects the decision to commit suicide in later life (105). The measurement of the attitudes with the ASD showed that the areas of healthy – unhealthy, self-reliant – dependent and independent – dependent were especially classified as tendentially negative by nursing, humanity and medical students (values between 5 and 7 on the 7-point Likert scale). This finding agrees with those cited in the literature, which describe the predominant stereotype about people in the 4th age as frail and dependent (106). Interestingly, a similar study (sample, questionnaire) conducted in Sweden showed more positive attitudes overall and in particular in the areas of dependency and health status (107). The reason for this difference is unclear, but the authors assumed cultural differences. For instance, young Swedish adults cited having more experience with older adults who were in good health and actively participating in life, since more older adults are economically active after retirement in Sweden than in Austria (107).The regression analysis results show that the knowledge of the meaning of the term ageism is a predicting factor for more positive attitudes. We assume that knowledge about ageism is based on educational measures, since some participants of the convenience sample attended lectures and classes about geriatric care at the time of the measurement. Our results agree with those of other studies, where more knowledge and educational measures were associated with more positive attitudes (108, 109).

The topic of age, and especially old age, was also addressed in study 5 by investigating the care dependency of individuals aged 80 years and older. The relation between care dependency and age has also been addressed in other studies. Some authors have already shown that age has an influence on the risk of being care dependent (110-112). The particular age group of 80 years and older in relation to care dependency had not been previously investigated. The portion of the sample who was 91 years and older showed the highest levels of care dependency. Age also emerged as predicting factor for care dependency in the regression analysis, but with lower odds than the diseases of dementia and/or hemiparesis/stroke. The medical diagnoses dementia and hemiparesis/stroke are significant predictors for being care dependent in the age group of 80 years and older. The high care dependency of stroke patients, mainly in the initial phase when the diseases occurs, was shown by a smaller and younger sample (mean age 60,33) in Indonesia but not for a specific older sample, as in this study (113). Even in older individuals (i.e. 80 years and older), the underlying disease seems to be the strongest predictor for being care dependent. This is strongly confirmed by the result that individuals without dementia showed significant lower levels of care dependency in all areas.

Conclusion

End of life as a concept is described as a situation that is mainly determined by physical and psychosocial symptoms and functional decline and partially determined by the small amount of time remaining until death. Dignity emerged as a main wish in this phase of life. The fear of losing dignity is based on the assumption that autonomy will be lost, which is related to the expected or already manifested functional decline. The experts in the Delphi study also confirmed the importance of symptoms, functional decline, time and dignity. Beside the physical aspects of the end of life, these experts focused on the importance of taking a holistic view of end of life and end of life care by considering psychosocial needs as relationships or spiritual needs.

These results indicate that care dependency is a prominent phenomenon at the end of life and in individuals aged 80 years and older. Care dependency is determined by the underlying diseases, and in particular by dementia. We conclude that dementia predicts care dependency even long before individuals are allocated to their end-of-life phase.

In addition, we conclude from the results of our studies that age is a proxy variable for care dependency rather than a predicting factor for the end of life.

Negative attitudes that are held toward age and ageing by members of society and health care professionals – even if they are slight – are considerable because attitudes influence health care outcomes. The end-of-life phase might be affected two-fold by negative attitudes, since these attitudes mostly affect people of very old age who often have high levels of care dependency.

Methodological reflection

In this chapter, methods used for this dissertation work are reflected upon critically.

Study 1

To describe the concept end of life effectively, Rodger´s evolutionary method was chosen. Concept analyses overall are developed to create knowledge and support the theory development in the discipline (114-117). Conceptual work in particular is considered as meaningful when it contributes to a solution to a specific problem in the discipline (118). Since several authors have identified the lack of a description of the end of life, this specific problem was addressed by performing a concept analysis in the first study (119-121).

Rodger´s evolutionary method was chosen, because the authors of the method based it on the philosophical perspective of evolutionary views. These can be summarized by noting that concepts can be viewed as abstractions of words that change over time and in different situations. This seems to be particularly appropriate for the concept of the end of life, since it is used in the interdisciplinary field of palliative care. In addition, the philosophical background is supported by a so-called cycle of concept development, which is described by the *significance, use and application* of the concept. Thus, these factors must be considered within the context of time (122). Furthermore, the six steps that are the crucial elements for the method itself are clearly described and distinct. This was assumed as an advantage for performing the analysis (122). One method paper also recommended defining quality criteria for the inclusion of the material to strengthen the method (114). This was addressed by using mainly scientific databases and search engines in this study and, namely, PubMed, the Cumulative Index of Nursing and Allied Health Literature (CINAHL) and PubPsych, in the systematic literature review.

One critical point of using the evolutionary method is that no detailed description for identifying the concept attributes is provided (115). Therefore, the data analyses were performed by applying the principle of thematic analyses. Major themes and subthemes for each category were identified, including attributes, contextual factors and related concepts.

Study 2

The second study was carried out to create a definition of end of life. For this purpose, the method of a Delphi technique was chosen. The study followed Guidance on Conducting and REporting DElphi Studies (CREDES) (123).

The Delphi technique is applied by gathering opinions from a broad range of experts who finally reach a consensus on a specific topic (124, 125). Over the years, different variants of the Delphi technique have emerged (126). The method of a modified Delphi study, which was used for study 2, omits the first round with open-ended questions and begins with the use of a structured questionnaire instead (127). This was possible, since the concept analysis previously conducted provided information that enabled the creation of a structured questionnaire. This procedure had the advantage that the time-consuming first round could be left out. For the analysis of the quantitative data, the cut of point of was set at 70 %. This means that, if 70 % of the panel agreed on a statement, then it was considered for the final definition. Leaving out the first round also meant reducing the number of rounds overall, which was thought to results in a more stable panel size regarding the number of experts included. It is known that the panel size decreases from round to round (128).

Another point of consideration was that the online process used ensured the anonymity of the experts, which enabled us to ensure that an opinion or reaction of each panel member was not influenced by other experts (129-131). In addition, it was possible to assume that the experts did not interact with each other, thereby reducing the effect of influence from dominant individuals or social pressure on the result (131).

The validity of the method was determined by examining the qualifications of the experts and the number of experts; however, no gold standard for both factors exists (126, 132). Concerning the sample size, the literature indicates that valid results can be gained with 60 participants as well as and fewer than 15 participants (133). 60 participants were invited, and between 34 (first round) and 21 (fourth round) took part in the panel, which implies that we achieve a large enough sample size to obtain valid results.

The strength of the conducted Delphi study rests on the interdisciplinary and international nature of the sample. The experts were invited based on their areas of expertise and, namely, on the basis of their scientific publications if they worked as a researcher and on the basis of personal contacts if they were experts in clinical practice. Some experts worked in both clinical practice and research, which might have greatly contributed to our ability to obtain valid results (126). The experts represented 11 countries and most of them had more than 10 years of experience in the field of palliative or hospice care. The panel also represented ten different professions with individuals working in both research and clinical practice.

Since the standardized questionnaire also included open-ended questions, much qualitative data were generated and could be analysed with the content analysis. Content analysis is a common technique used to analyse qualitative data in Delphi studies (133). The process of content analysis was supported by the MAXQDA Software 2020 (134). The qualitative data complemented and confirmed the quantitative data, adding to the rigor of the study.

Study 3

For study 3, data from the annually conducted Austrian Nursing Quality Measurement, which is designed as a cross-sectional multicentre study, were analysed. A cross sectional design is basically appropriate if the prevalence of diseases, for instance, should be observed (135).

The study was carried out to describe the extent to which and patients and residents are at their end of life are care dependent, to identify the aspects of this dependency, and to determine which factors might influence the care dependency of this specific target group. Therefore, a secondary data analysis of data collected in the cross-sectional study was performed. The data analysis was conducted following the STROBE guideline for cohort, case-control and cross-sectional studies (136).

Secondary data analyses are often criticized because data are analysed which are not collected to address a particular research question (137). However, some advantages to performing secondary data analyses exist. This method allows researchers to answer research questions, saving time and personal resources, and represents a low risk for participants (138). The method was particularly appropriate for the research aim of study 3, in that the data collected the Austrian Nursing Quality Measurement could be used for several reasons (139). End of life, which was basically an unclear and undefined concept at the measurement time, was defined by the research team for the purpose of the measurement. The definition was provided in the user manual for the participants (140). The definition was also comprehensively explained in a specific training session held at the participating institutions by the research team. This measure supports the correct allocation for patients and residents as in their end-of-life phase. The process of allocation to a pathway for end of life also requires an interdisciplinary team consensus. This is another aspect which strengthens the data. Even when the allocation I based on the subjective estimation of health care professionals, the allocation is always based on a team decision.

Another strength of this method was that the concept of care dependency could be measured with a valid and reliable instrument: the care dependency scale (CDS). At the time of the study, the CDS had not been previously tested for the specific end-of-life situation. Individuals at the end-of-life can be a vulnerable group, and a secondary data analysis was considered as a preferable research method for answering research questions about this vulnerable group.

To determine the influencing factors, the method of a logistic regression analysis was chosen, which is a good method to control confounding factors (135). The dependent variable of care dependency was dichotomized. This was due to the fact that the sample size was small, because an analysis with more than two groups could lead to very small sample within the analytic groups. The interpretation of the results is easier if the dependent variable is dichotomous.

As possible influencing variables (confounder), age, sex and diseases were considered and included in the univariate logistic regression analysis. All of the variables which were identified as statistically significant in the univariate analysis were considered in the bivariate model.

Even with the small sample size, significant results could be obtained. A clear limitation of the study design is that no statements about causal relationships can be made.

Study 4

For study 4, a cross-sectional design was also chosen. The cross-sectional design was appropriate for this study, since the goal was to measure attitudes about adults aged 80 years and older using a single measurement point. One strength of the study is the instrument used, which is a valid instrument for measuring attitudes (141). In particular, the ASD has a main advantage in that requires little time to perform; this is an especially important factor for health professionals (142). Currently, no other short-duration instrument based on the semantic approach is available. Some adjective pairs of the ASD should be reconsidered to determine whether they are still appropriate, since the original instrument was developed in the late 1960s (143).

In this study, the method of regression analysis was also used to identify factors that potentially influenced attitudes toward adults aged 80 years and older. As mentioned above, the regression analysis can be used to control for confounding effects. Clear limitations of the study are the convenience sample and the small sample size. Despite these limitations, the ASD could be tested for the first time in Austria in this study, and the four-factor structure could be confirmed. The study provided the first insights into attitudes that are held by students of nursing science, humanities and medicine. Therefore, the results might provide a foundation for further research.

Study 5

In order to describe care dependency and to identify predicting factors in the specific cohort of individuals aged 80 years and older, a secondary data analysis was again conducted. The Austrian Quality Measurement, which was annually conducted between 2009 and 2021, provided a large dataset that enabled us to achieve this research aim (139). Since the necessary variables for achieving this aim did not change over the years, it was possible to cumulate data over a period of 10 years. These procedures led to a large sample size, and the multicentre approach taken in the study provided data from 91 different hospitals and 49 different nursing homes throughout Austria. These aspects contributed to our success in gaining a comprehensive dataset for this specific age cohort (80 years and older) (139). The CDS was used to measure the care dependency; this is a valid and reliable instrument, and the German version in particular has been tested with an older age cohort in hospitals and geriatric institutions as well (110, 144). Furthermore, the overall questionnaire has been revised and adapted several times by an international research team, supporting the validity of the questionnaire (139).

Recommendation for clinical practice

The description of the concept end of life might be helpful in clinical practice to identify the end-of-life phase of persons well ahead of time. The end of life normally does not start suddenly; instead, the transition into the end-of-life represents an antecedent. Recognition of this transition might raise awareness among health care professionals that the functional decline or physical symptoms might increase before a person enters the end-of-life phase. End-of-life care, described in the concept analysis as well as in the Delphi study, is a clear task for health care professionals. The experts on the Delphi panel agreed on some highly specific recommendations for health care professionals. One recommendation was to use prediction tools (e.g. the surprise question) so that the time remaining until death could be more precisely determined.

Individual needs and wishes should be addressed at the end of life. Physical, psychosocial and spiritual needs should be considered, which requires the health care professionals to take holistic perspective on care. The Delhi panel agreed to include the main wish to receive dignified care, which was already described in the concept analysis, in the definition as a considerable aspect of care offered at the end of life. The experts mentioned that dignity is a multifaceted and individual concept. Health care professionals should be aware of this and consider asking about specific wishes for a dignified care.

The results of the third study might underline the need to identify special care needs in the end-of-life phase. Patients and residents might be affected by high care dependency at the end of life in the areas of learning ability, daily activity, avoiding of danger, hygiene, getting (un-) dressed and continence. This should be considered during care assessment and when creating care plans.

The health care professionals should be aware that the underlying disease of dementia might influence the care needs of individuals, even at the end of life. That means that patients and residents who are affected by dementia might have more care needs at the end of life than patients who do not have dementia.

The results of the fourth study imply that some educational interventions at the undergraduate and postgraduate education levels might be helpful, improving awareness of ageism and the consequences of holding negative attitudes or stereotypes about old individuals. The fifth study may also support the awareness that age itself does not necessarily lead to dependency and poor health. Age might be a proxy variable and underlying diseases, especially dementia and hemiparesis/stroke in old age, are main predictors for being care dependent. This knowledge might again influence the attitudes toward ageing. If individuals are affected by dementia or stroke/hemiparesis, they have many care needs. This knowledge might also be helpful for nurse managers, enabling them to predict staff needs more efficiently (number and educational level) on institutions/wards that have many patients or residents with dementia or stroke/hemiparesis.

Recommendation for future research

The results of the concept analysis as well the definition of end of life might serve as a basis for further theory development in this particular field. For instance, other concepts related to end of life, such as the terminal phase or dying phase, could be clarified to clearly distinguish them from end of life.

The experts in the Delphi round did not agree on common symptoms at the end of life, but a discussion about these emerged via the open-ended question. This and information from the scientific literature, i.e. that the symptoms may not differ between the underlying diseases, indicate that a systematic literature review may help health care professionals more precisely recognize common symptoms at the end of life.

The experts in the Delphi study also discussed a specific timeframe for end of life, leading them to recommend the use of so-called prediction tools. The validity and practicability of prediction tools (e.g. surprise question) should be further investigated.

The high level of care dependency in the end-of-life phase implies that care dependency or the increase in care dependency might be a predictor for the transition into or presence in the end-of-life phase, but this assumption requires further investigation. In particular, a retrospective study design might address this issue and help to estimate the significant starting point of the increase in care dependency.

Dementia was identified as a main predicting factor for care dependency in end-of-life situations and in dementia. Due the fact that dementia was not observed considering its specific stages (mild, moderate, severe), it is highly recommended that investigations on the influence of the specific states of dementia on care dependency are carried out.

Concerning the attitudes toward individuals aged 80 years and older, the investigation of a larger sample in different settings and, in particular, with different health care professionals can be recommended.

Bibliography

(1) EUROSTAT. Mortality and life expectancy statistics 2021 [updated 05 2021. Available from: https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Mortality_and_life_expectancy_statistics#Life_expectancy_at_age_65.

(2) European Commission. European Commission Report on the Impact of Demographic Change. 2020.

(3) Stiefel MC, Perla RJ, Zell BL. A healthy bottom line: healthy life expectancy as an outcome measure for health improvement efforts. The Milbank quarterly. 2010;88(1):30-53.

(4) European Commission. Measuring progress towards a more sustainable Europe: Sustainable development indicators for the European Union DATA 1990-2005. European Commission; 2005.

(5) EUROSTAT. Healthy life years statistics 2019 [updated 03 2021. Available from: https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Healthy_life_years_statistics.

(6) European Commission. The 2021 Ageing Reoprt: Economic & Budgetary Projections for the EU Member States (2019 -2070). European Commission 2021.

(7) NICE. End of life care for adults: service derlivery: National Institute for Health and Care Excellence; 2019 [Available from: https://www.eolc.co.uk/uploads/end-of-life-care-for-adults-service-delivery-pdf-66141776457925.pdf.

(8) Stow D, Spiers G, Matthews FE, Hanratty B. What is the evidence that people with frailty have needs for palliative care at the end of life? A systematic review and narrative synthesis. Palliative Medicine. 2019;33(4):399-414.

(9) Cohen-Mansfield J, Cohen R, Skornick-Bouchbinder M, Brill S. What Is the End of Life Period? Trajectories and Characterization Based on Primary Caregiver Reports. J Gerontol A Biol Sci Med Sci. 2018;73(5):695-701.

(10) Brennan F. 'To die with dignity': an update on Palliative Care. Intern Med J. 2017;47(8):865-71.

(11) Boyd M, Frey R, Balmer D, Robinson J, McLeod H, Foster S, et al. End of life care for long-term care residents with dementia, chronic illness and cancer: prospective staff survey. BMC Geriatr. 2019;19(1):137.

(12) Henson LA, Maddocks M, Evans C, Davidson M, Hicks S, Higginson IJ. Palliative Care and the Management of Common Distressing Symptoms in Advanced Cancer: Pain, Breathlessness, Nausea and Vomiting, and Fatigue. J Clin Oncol. 2020;38(9):905-14.

(13) Suh SY, Won SH, Hiratsuka Y, Choi SE, Cheng SY, Mori M, et al. Assessment of Changes in Symptoms Is Feasible and Prognostic in the Last Weeks of Life: An International Multicenter Cohort Study. J Palliat Med. 2021.

(14) Conen K, Guthrie DM, Stevens T, Winemaker S, Seow H. Symptom trajectories of non-cancer patients in the last six months of life: Identifying needs in a population-based home care cohort. PloS one. 2021;16(6):e0252814.

(15) Moens K, Higginson IJ, Harding R. Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review. J Pain Symptom Manage. 2014;48(4):660-77.

(16) Sampson EL, Candy B, Davis S, Gola AB, Harrington J, King M, et al. Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. Palliat Med. 2018;32(3):668-81.

(17) Eisenmann Y, Golla H, Schmidt H, Voltz R, Perrar KM. Palliative Care in Advanced Dementia. Front Psychiatry. 2020;11:699.

(18) Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at the end of life. JAMA. 2003;289(18):2387-92.

(19) Stolz E, Gill TM, Mayerl H, Rásky É, Freidl W. Trajectories of Late-Life Disability Vary by the Condition Leading to Death. J Gerontol A Biol Sci Med Sci. 2021;76(7):1260-4.

(20) Morgan DD, Tieman JJ, Allingham SF, Ekström MP, Connolly A, Currow DC. The trajectory of functional decline over the last 4 months of life in a palliative care population: A prospective, consecutive cohort study. Palliat Med. 2019;33(6):693-703.

(21) Highet G, Crawford D, Murray SA, Boyd K. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. BMJ Support Palliat Care. 2014;4(3):285-90.

(22) Boyd K, Murray SA. Recognising and managing key transitions in end of life care. Bmj. 2010;341:c4863.

(23) Baik D, Russell D, Jordan L, Dooley F, Bowles KH, Masterson Creber RM. Using the Palliative Performance Scale to Estimate Survival for Patients at the End of Life: A Systematic Review of the Literature. J Palliat Med. 2018;21(11):1651-61.

(24) Jansen WJ, Buma S, Gootjes JR, Zuurmond WW, Perez RS, Loer SA. The palliative performance scale applied in high-care residential hospice: a retrospective study. J Palliat Med. 2015;18(1):67-70.

(25) White N, Kupeli N, Vickerstaff V, Stone P. How accurate is the ‘Surprise Question’ at identifying patients at the end of life? A systematic review and meta-analysis. BMC Medicine [Internet]. 2017; 15(1):[1-14 pp.].

(26) Flierman I, Nugteren IC, van Seben R, Buurman BM, Willems DL. How do hospital-based nurses and physicians identify the palliative phase in their patients and what difficulties exist? A qualitative interview study. BMC Palliative Care. 2019;18(1):54.

(27) Flierman I, van Rijn M, Willems DL, Buurman BM. Usability of the surprise question by nurses to identify 12-month mortality in hospitalized older patients: A prospective cohort study. Int J Nurs Stud. 2020;109:103609.

(28) White N, Kupeli N, Vickerstaff V, Stone P. How accurate is the ‘Surprise Question’ at identifying patients at the end of life? A systematic review and meta-analysis. BMC Med. 2017;15(1):139.

(29) Piers R, De Brauwer I, Baeyens H, Velghe A, Hens L, Deschepper E, et al. Supportive and Palliative Care Indicators Tool prognostic value in older hospitalised patients: a prospective multicentre study. BMJ Support Palliat Care. 2021.

(30) Huijberts S, Buurman BM, de Rooij SE. End-of-life care during and after an acute hospitalization in older patients with cancer, end-stage organ failure, or frailty: A sub-analysis of a prospective cohort study. Palliative Medicine. 2016;30(1):75-82.

(31) Hui D, Nooruddin Z, Didwaniya N, Dev R, De La Cruz M, Kim SH, et al. Concepts and definitions for “actively dying,” “end of life,” “terminally ill,” “terminal care,” and “transition of care”: a systematic review. Journal of Pain & Symptom Management. 2014;47(1):77-89.

(32) Hill E, Savundranayagam MY, Zecevic A, Kloseck M. Staff Perspectives of Barriers to Access and Delivery of Palliative Care for Persons With Dementia in Long-Term Care. American journal of Alzheimer’s disease and other dementias. 2018;33(5):284-91.

(33) Chu C-P, Huang C-Y, Kuo C-J, Chen Y-Y, Chen C-T, Yang T-W, et al. Palliative care for nursing home patients with dementia: service evaluation and risk factors of mortality. BMC Palliative Care. 2020;19(1):122.

(34) Xiao J, Brenneis C, Ibrahim N, Bryan A, Fassbender K. Definitions of Palliative Care Terms: A Consensus-Oriented Decision-Making Process. J Palliat Med. 2021;24(9):1342-50.

(35) United Nations, Departement of Economic and Social Affairs, Division P. World Population Prospects 2019: Highlights. Departement of Economic and Social Affairs; 2019.

(36) Hansen S, Kaspar R, Wagner M, Woopen C, Zank S. The NRW80+ study: conceptual background and study groups. Zeitschrift für Gerontologie und Geriatrie. 2021;54(2):76-84.

(37) Dionigi RA. Stereotypes of Aging: Their Effects on the Health of Older Adults. Journal of Geriatrics. 2015;2015:954027.

(38) Jagger C, Collerton JC, Davies K, Kingston A, Robinson LA, Eccles MP, et al. Capability and dependency in the Newcastle 85+ cohort study. Projections of future care needs. BMC Geriatrics. 2011;11(1):21.

(39) Wahl H-W, Ehni H-J. Advanced old age as a developmental dilemma: An in-depth comparison of established fourth age conceptualizations. Journal of Aging Studies. 2020;55:100896.

(40) Baltes PB, Smith J. New Frontiers in the Future of Aging: From Successful Aging of the Young Old to the Dilemmas of the Fourth Age. Gerontology. 2003;49(2):123-35.

(41) Kriebernegg U. Graue Zellen in total tollen Institutionen? Zur Verortung des Alters im Pflegeheimroman: Literaturgerontologische Perspektiven auf das Lebensende. In: Gastager J, Niedrist V-M, editors. Lebensende in Institutionen. Räume und Identitäten. Österreich: Jan Sramek Verlag KG; 2020.

(42) Ng R. Societal Age Stereotypes in the U.S. and U.K. from a Media Database of 1.1 Billion Words. International journal of environmental research and public health. 2021;18(16).

(43) Popham L, Hess T. Theories of Age Stereotyping and Views of Aging Encyclopedia of Geropsychology 2015.

(44) Reissmann M, Geithner L, Storms A, Woopen C. Stereotypes about very old people and perceived societal appreciation in very old age. Zeitschrift für Gerontologie und Geriatrie. 2021;54(2):93-100.

(45) WHO. Global Report on Ageism. World Health Organization United Nations Departement of Economic and Social Affaiers; 2021.

(46) WHO. Ageism: WHO; 2021 [updated 18 March 2021. Available from: https://www.who.int/news-room/questions-and-answers/item/ageing-ageism.

(47) Chang ES, Kannoth S, Levy S, Wang SY, Lee JE, Levy BR. Global reach of ageism on older persons' health: A systematic review. PloS one. 2020;15(1):e0220857.

(48) Kydd A, Fleming A, Paoletti I, Hvalič Touzery S. Exploring Terms Used for the Oldest Old in the Gerontological Literature (Published in The Journal of Aging and Social Change). 2020;10:53-73.

(49) Cresswell-Smith J, Amaddeo F, Donisi V, Forsman AK, Kalseth J, Martin-Maria N, et al. Determinants of multidimensional mental wellbeing in the oldest old: a rapid review. Social Psychiatry and Psychiatric Epidemiology. 2019;54(2):135-44.

(50) Zeng Y, Feng Q, Hesketh T, Christensen K, Vaupel JW. Survival, disabilities in activities of daily living, and physical and cognitive functioning among the oldest-old in China: a cohort study. Lancet. 2017;389(10079):1619-29.

(51) Zhang PD, Lv YB, Li ZH, Yin ZX, Li FR, Wang JN, et al. Age, Period, and Cohort Effects on Activities of Daily Living, Physical Performance, and Cognitive Functioning Impairment Among the Oldest-Old in China. J Gerontol A Biol Sci Med Sci. 2020;75(6):1214-21.

(52) Wettstein M, Spuling SM, Cengia A. Trajectories of functional health and its associations with information processing speed and subjective well-being: The role of age versus time to death. Psychol Aging. 2020;35(2):190-203.

(53) Pearson VI. Assessment of Function in Older Adults. In: Kane RL, Kane R, A. , editors. Assessing Older Persons: Measures, Meaning and Practical Applications. Oxford: Oxford University Press; 2000.

(54) Yi Y, Ding L, Wen H, Wu J, Makimoto K, Liao X. Is Barthel Index Suitable for Assessing Activities of Daily Living in Patients With Dementia? Front Psychiatry. 2020;11:282.

(55) Yang H, Chen Y, Wang J, Wei H, Chen Y, Jin J. Activities of daily living measurement after ischemic stroke: Rasch analysis of the modified Barthel Index. Medicine (Baltimore). 2021;100(9):e24926.

(56) Kaambwa B, Bulamu NB, Mpundu-Kaambwa C, Oppong R. Convergent and Discriminant Validity of the Barthel Index and the EQ-5D-3L When Used on Older People in a Rehabilitation Setting. International journal of environmental research and public health. 2021;18(19).

(57) Buurman B, van Munster BC, Korevaar JC, de Haan RJ, de Rooij SE. Variability in measuring (instrumental) activities of daily living functioning and functional decline in hospitalized older medical patients: a systematic review. Journal of clinical epidemiology. 2011;64 6:619-27.

(58) Brijoux T, Woopen C, Zank S. Multimorbidity in old age and its impact on life results. Zeitschrift für Gerontologie und Geriatrie. 2021;54(2):108-13.

(59) Meucci RD, Aguiar de Oliveira ASL, Araújo GC, Gonzalez TN, Pagliaro G, Hoffmann T, et al. Functional dependence among older adults: a cross-sectional study with a rural population of southern Brazil. Rural Remote Health. 2020;20(4):5985.

(60) Menezes K, Auger C, Barbosa JFS, Gomes CS, Menezes WRS, Guerra RO. Trajectories and Predictors of Functional Capacity Decline in Older Adults From a Brazilian Northeastern Hospital. J Geriatr Phys Ther. 2021;44(2):82-7.

(61) Hsu AT, Manuel DG, Spruin S, Bennett C, Taljaard M, Beach S, et al. Predicting death in home care users: derivation and validation of the Risk Evaluation for Support: Predictions for Elder-Life in the Community Tool (RESPECT). CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne. 2021;193(26):E997-e1005.

(62) Baltes M. The Many Faces of Dependency in Old Age USA: Cambridge University Press; 1996.

(63) van der Weele S, Bredewold F, Leget C, Tonkens E. What is the problem of dependency? Dependency work reconsidered. Nursing philosophy : an international journal for healthcare professionals. 2021;22(2):e12327.

(64) Dijkstra A, Buist G, Moorer P, Dassen T. Construct validity of the Nursing Care Dependency Scale. J Clin Nurs. 1999;8(4):380-8.

(65) Piredda M, Bambi S, Biagioli V, Marchetti A, Ianni A, Lusignani M, et al. Cross-validation of the Care Dependency Scale in intensive care unit (ICU-CDS). Intensive Crit Care Nurs. 2020;57:102787.

(66) Piredda M, Biagioli V, Gambale G, Porcelli E, Barbaranelli C, Palese A, et al. Psychometric testing of the modified Care Dependency Scale (Neuro-CDS). NeuroRehabilitation. 2016;38(2):211-9.

(67) Piredda M, Candela ML, Marchetti A, Biagioli V, De Maria M, Facchinetti G, et al. The Care Dependency Scale: A cross validation study in inpatients with cancer. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2021;56:102087.

(68) Dijkstra A, Buist G, Dassen T. Operationalization of the concept of ´nursing care dependency`for use in long-term care facilities. Australian and New Zealand Journal of Mental Health Nursing. 1998;7:142-51.

(69) Henderson V. THE NATURE OF NURSING. The American journal of nursing. 1964;64:62-8.

(70) Staats K, Grov EK, Husebø BS, Tranvåg O. Dignity of older home-dwelling women nearing end-of-life: Informal caregivers' perception. Nurs Ethics. 2020:969733020956372.

(71) Bolt SR, van der Steen JT, Khemai C, Schols J, Zwakhalen SMG, Meijers JMM. The perspectives of people with dementia on their future, end of life and on being cared for by others: A qualitative study. J Clin Nurs. 2021.

(72) Piredda M, Bartiromo C, Capuzzo MT, Matarese M, De Marinis MG. Nursing care dependence in the experiences of advanced cancer inpatients. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2016;20:125-32.

(73) Hui DMDMMF, Mori MMD, Parsons HAMD, Kim SHMDP, Li ZMS, Damani SM, et al. The Lack of Standard Definitions in the Supportive and Palliative Oncology Literature. Journal of Pain and Symptom Management. 2012;43(3):582-92.

(74) Nauck F, Jaspers B. Is palliative care synonymous with end-of-life care? EUROPEAN JOURNAL OF PALLIATIVE CARE. 2003;10(Part 6):223-4.

(75) Hawley PH. The bow tie model of 21st century palliative care. J Pain Symptom Manage. 2014;47(1):e2-5.

(76) Radbruch L. White Paper on standards and norms for hospice and palliative care in Europe: part 1: Recommendations from the European Association for Pallliative Care. European Journal of Palliative Care. 2009;16(3).

(77) Radbruch L, De Lima L, Knaul F, Wenk R, Ali Z, Bhatnaghar S, et al. Redefining Palliative Care-A New Consensus-Based Definition. J Pain Symptom Manage. 2020.

(78) Guo Q, Jacelon C, Marquard J. An Evolutionary Concept Analysis of Palliative Care. Journal of Palliative Care Medicine. 2012;2(7).

(79) Stiel S, Krause O, Berndt CS, Ewertowski H, Müller-Mundt G, Schneider N. Caring for frail older patients in the last phase of life. Zeitschrift für Gerontologie und Geriatrie. 2020;53(8):763-9.

(80) Albert RH. End-of-Life Care: Managing Common Symptoms. American Family Physician. 2017;95(6):356-61.

(81) Saphire ML, Prsic EH, Canavan ME, Wang SJ, Presley CJ, Davidoff AJ. Patterns of Symptom Management Medication Receipt at End-of-Life Among Medicare Beneficiaries With Lung Cancer. J Pain Symptom Manage. 2020;59(4):767-77.e1.

(82) Årestedt K, Brännström M, Evangelista LS, Strömberg A, Alvariza A. Palliative key aspects are of importance for symptom relief during the last week of life in patients with heart failure. ESC Heart Fail. 2021;8(3):2202-9.

(83) Browne B, Kupeli N, Moore KJ, Sampson EL, Davies N. Defining end of life in dementia: A systematic review. Palliat Med. 2021:2692163211025457.

(84) Seow H, Guthrie DM, Stevens T, Barbera LC, Burge F, McGrail K, et al. Trajectory of End-of-Life Pain and Other Physical Symptoms among Cancer Patients Receiving Home Care. Curr Oncol. 2021;28(3):1641-51.

(85) Gill TM, Gahbauer EA, Leo-Summers L, Murphy TE. Trends in Restricting Symptoms at the End of Life from 1998 to 2019: A Cohort Study of Older Persons. J Am Geriatr Soc. 2021;69(2):450-8.

(86) Leitlinienprogramm Onkologie: Palliativmedizin für Patienten mit einer nicht heilbaren Krebserkrankung, Langversion 1.1, 128/001OL (2015).

(87) NICE NIfHaCE. End of life care for adults: service delivery. NICE guideline2019.

(88) Crawford GB, Dzierżanowski T, Hauser K, Larkin P, Luque-Blanco AI, Murphy I, et al. Care of the adult cancer patient at the end of life: ESMO Clinical Practice Guidelines. ESMO Open. 2021;6(4):100225.

(89) Downar J, Goldman R, Pinto R, Englesakis M, Adhikari NK. The “surprise question” for predicting death in seriously ill patients: a systematic review and meta-analysis. CMAJ: Canadian Medical Association journal = journal de l’Association medicale canadienne. 2017;189(13):E484-e93.

(90) Carlini J, Bahudin D, Michaleff ZA, Plunkett E, Shé É N, Clark J, et al. Discordance and concordance on perception of quality care at end of life between older patients, caregivers and clinicians: a scoping review. Eur Geriatr Med. 2021:1-13.

(91) Chu C, White N, Stone P. Prognostication in palliative care. Clin Med (Lond). 2019;19(4):306-10.

(92) Cardona-Morrell M, Lewis E, Suman S, Haywood C, Williams M, Brousseau AA, et al. Recognising older frail patients near the end of life: What next? Eur J Intern Med. 2017;45:84-90.

(93) Gesell D, Lehmann E, Gauder S, Wallner M, Simon S, Bausewein C. National and international non-therapeutic recommendations for adult palliative and end-of-life care in times of pandemics: A scoping review. Palliative and Supportive Care. 2021:1-13.

(94) Kadivar M, Mardani-Hamooleh M, Kouhnavard M. Concept analysis of human dignity in patient care: Rodgers’ evolutionary approach. Journal of medical ethics and history of medicine. 2018;11:4.

(95) Rodriguez-Prat A, Monforte-Royo C, Porta-Sales J, Escribano X, Balaguer A. Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. PloS one. 2016;11(3):e0151435.

(96) Schussler S, Dassen T, Lohrmann C. Care dependency and nursing care problems in nursing home residents with and without dementia: a cross-sectional study. Aging clinical and experimental research. 2016;28(5):973-82.

(97) Schussler S, Lohrmann C. Change in Care Dependency and Nursing Care Problems in Nursing Home Residents with and without Dementia: A 2-Year Panel Study. PloS one. 2015;10(10):e0141653.

(98) Giebel CM, Sutcliffe C, Challis D. Activities of daily living and quality of life across different stages of dementia: a UK study. Aging Ment Health. 2015;19(1):63-71.

(99) Leeson GW. Increasing Longevity and the New Demography of Death. International Journal of Population Research. 2014;2014:521523.

(100) Berger R. Aging in America: Ageism and General Attitudes toward Growing Old and the Elderly. Open Journal of Social Sciences. 2017;05:183-98.

(101) Ben-Harush A, Shiovitz-Ezra S, Doron I, Alon S, Leibovitz A, Golander H, et al. Ageism among physicians, nurses, and social workers: findings from a qualitative study. European journal of ageing. 2017;14(1):39-48.

(102) Ridgway V, Mason-Whitehead E, McIntosh-Scott A. Visual perceptions of ageing; A longitudinal mixed methods study of UK undergraduate student nurses' attitudes and perceptions towards older people. Nurse Education in Practice. 2018;33:63-9.

(103) Mansouri Arani M, Aazami S, Azami M, Borji M. Assessing attitudes toward elderly among nurses working in the city of Ilam. Int J Nurs Sci. 2017;4(3):311-3.

(104) Chrisler JC, Barney A, Palatino B. Ageism can be Hazardous to Women's Health: Ageism, Sexism, and Stereotypes of Older Women in the Healthcare System. Journal of Social Issues. 2016;72(1):86-104.

(105) Gramaglia C, Calati R, Zeppegno P. Rational Suicide in Late Life: A Systematic Review of the Literature. Medicina (Kaunas). 2019;55(10).

(106) Enßle F, Helbrecht I. Understanding diversity in later life through images of old age. Ageing and Society. 2020:1-20.

(107) Heckemann B, Schüttengruber G, Grosschädel F, Holmberg C, Wolf A. Nursing students' attitudes towards the oldest old. A survey study and international comparison. 2020.

(108) Donizzetti AR. Ageism in an Aging Society: The Role of Knowledge, Anxiety about Aging, and Stereotypes in Young People and Adults. International journal of environmental research and public health. 2019;16(8).

(109) Rush KL, Hickey S, Epp S, Janke R. Nurses' attitudes towards older people care: An integrative review. J Clin Nurs. 2017;26(23-24):4105-16.

(110) Lohrmann C, Dijkstra A, Dassen T. The Care Dependency Scale: an assessment instrument for elderly patients in German hospitals. Geriatric nursing (New York, NY). 2003;24(1):40-3.

(111) Doroszkiewicz H, Sierakowska M, Muszalik M. Utility of the Care Dependency Scale in predicting care needs and health risks of elderly patients admitted to a geriatric unit: a cross-sectional study of 200 consecutive patients. Clinical interventions in aging. 2018;13:887-94.

(112) Puto G, Sowińska I, Ścisło L, Walewska E, Kamińska A, Muszalik M. Sociodemographic Factors Affecting Older People's Care Dependency in Their Daily Living Environment According to Care Dependency Scale (CDS). Healthcare (Basel, Switzerland). 2021;9(2).

(113) Nursiswati N, Halfens RJG, Lohrmann C. Change in Care Dependency of Stroke Patients: A Longitudinal and Multicenter Study. Asian nursing research. 2017;11(2):113-8.

(114) Tofthagen R, Fagerstrøm LM. Rodgers' evolutionary concept analysis - a valid method for developing knowledge in nursing science. Scandinavian Journal of Caring Sciences. 2010;24:21-31.

(115) Beecher C, Devane D, White M, Greene R, Dowling M. Concept development in Nursing and Midwifery: An overview of methodological approaches. International journal of nursing practice. 2019;25(1):e12702.

(116) Rodgers BL, Jacelon CS, Knafl KA. Concept Analysis and the Advance of Nursing Knowledge: State of the Science. Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing. 2018;50(4):451-9.

(117) Cronin P, Ryan F, Coughlan M. Concept analysis in healthcare research. International Journal of Therapy and Rehabilitation. 2010;17(2):62-8.

(118) Rodgers BL, Jacelon CS, Knafl KA. Concept Analysis and the Advance of Nursing Knowledge: State of the Science. Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau. 2018;50(4):451-9.

(119) Hui D, Mori M, Parsons HA, Kim SH, Li Z, Damani S, et al. The lack of standard definitions in the supportive and palliative oncology literature. J Pain Symptom Manage. 2012;43(3):582-92.

(120) Jünger SDrm, Payne SBARNDPC, Brearley SP, Ploenes VMD, Radbruch LMD. Consensus Building in Palliative Care: A Europe-Wide Delphi Study on Common Understandings and Conceptual Differences. Journal of Pain and Symptom Management. 2012;44(2):192-205.

(121) Izumi S, Nagae H, Sakurai C, Imamura E. Defining end-of-life care from perspectives of nursing ethics. Nurs Ethics. 2012;19(5):608-18.

(122) Rodgers BL, Knafl KA. Concept Development in Nursing: Foundations, Techniques, and Applications. 2 ed. Philadelphia, Pennsylvania: Saunders Company; 2000.

(123) Jünger S, Payne SA, Brine J, Radbruch L, Brearley SG. Guidance on Conducting and REporting DElphi Studies (CREDES) in palliative care: Recommendations based on a methodological systematic review. Palliat Med. 2017;31(8):684-706.

(124) Chia-Chien H, Brian S. The Delphi Technique: Making Sense of Consensus. Pracitcal Asessement, Research & Evaluation. 2007;12(10).

(125) Dalkey N, Helmer O. An Experimental Application of the Delphi Method to the Use of Experts. Management Science. 1963;9(3):458-67.

(126) Niederberger M, Spranger J. Delphi Technique in Health Sciences: A Map. Front Public Health. 2020;8:457-.

(127) McKenna HP. The Delphi technique: a worthwhile research approach for nursing? J Adv Nurs. 1994;19(6):1221-5.

(128) Keeney S, Hasson F, McKenna H. The Delphi Technique in Nursing and Health Research. United Kingdom: Wiley-Blackwell; 2011.

(129) Keeney S, Hasson F, McKenna H. A critical review of the Delphi technique as a research metholodogy for nursing. International Journal of Nursing Studies. 2001;38:195-200.

(130) Keeney S, Hasson F, McKenna H. Consulting the oracle: ten lessons from using the Delphi technique in nursing research. Journal of Advanced Nursing. 2006;53(2):205-12.

(131) Chia-Chien H, Sandford B. The Delphi Technique: Making Sense of Consensus. Pracitcal Asesscement, Research & Evaluation. 2007;12(10).

(132) Powell C. The Delphi technique: myths and realities. Journal of Advanced Nursing. 2003;41(4):376-82.

(133) Hasson F, Keeney S, McKenna H. Research guidelines for the Delphi survey technique. Journal of Advanced Nursing. 2000;32(4):1008-15.

(134) Software V. MAXQDA 2020. Berlin, Germany2019.

(135) Wang X, Cheng Z. Cross-Sectional Studies: Strengths, Weaknesses, and Recommendations. Chest. 2020;158(1s):S65-s71.

(136) STROBE. STROBE Checklists 2020 [Available from: https://www.strobe-statement.org/checklists/.

(137) Cheng HG, Phillips MR. Secondary analysis of existing data: opportunities and implementation. Shanghai Arch Psychiatry. 2014;26(6):371-5.

(138) Dunn SL, Arslanian-Engoren C, DeKoekkoek T, Jadack R, Scott LD. Secondary Data Analysis as an Efficient and Effective Approach to Nursing Research. Western Journal of Nursing Research. 2015;37(10):1295-307.

(139) Eglseer D, Osmancevic S, Hoedl M, Lohrmann C, Bauer S. Improving the quality of nursing care in Austria: 10 years of success. J Nurs Manag. 2021;29(2):186-93.

(140) Hödl M, Eglseer D. LPZ Pflegequalitätserhebung 2.0 Anleitung zum Fragebogen [User Manual]. In press 2017.

(141) Gluth S, Ebner NC, Schmiedek F. Attitudes toward Younger and Older Adults: The German Aging Semantic Differential. International Journal of Behavioral Development. 2010;34(2):147-58.

(142) Gonzales E, Tan J, Morrow-Howell N. Assessment of the Refined Aging Semantic Differential: Recommendations for Enhancing Validity. Journal of Gerontological Social Work. 2010;53(4):304-18.

(143) Rosencranz HA, McNevin TE. A factor analysis of attitudes toward the aged. The Gerontologist. 1969;9(1):55-9.

(144) Lohrmann C, Dijkstra A, Dassen T. Care dependency: testing the German version of the Care Dependency Scale in nursing homes and on geriatric wards. Scand J Caring Sci. 2003;17(1):51-6.

Appendix

The following publications are appended (in order of appearance):

- Gerhilde Schüttengruber, Ruud J.G. Halfens, Christa Lohrmann. “End of life”: A Concept Analysis. *International Journal of Palliative Nursing*. (accepted 08/21)

- Gerhilde Schüttengruber, Franziska Großschädl, Christa Lohrmann. “A consensus definition of end of life from an international and interdisciplinary perspective: A Delphi Panel Study”. *Journal of Palliative Medicine*. (accepted 04/22)

- Gerhilde Schüttengruber, Ruud J.G. Halfens, Christa Lohrmann. 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. *Journal of Clinical Nursing* Vol. 31, Issue 5-6, pp.:657-668.

- Gerhilde Schüttengruber, Erwin Stolz, Christa Lohrmann, Ulla Kriebernegg, Ruud Halfens, Franziska Großschädl. Attitudes towards older adults (80 years and older): A measurement with the ageing semantic differential – A cross-sectional study of Austrian students. *International Journal of Older People Nursing* Vol. 17, Issue 3.

- Gerhilde Schüttengruber, Franziska Großschädl, Christa Lohrmann. Care dependency in individuals aged 80 years and older: analysis of 2009–2021 data for residents and patients in long-term care facilities and hospitals in Austria. Submitted.

„End of life“: A Concept Analysis

Gerhilde Schüttengruber, Ruud J.G. Halfens, Christa Lohrmann

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Abstract

Background: The concept of end of life (EOL), as in the term end-of-life care, is used synonymously with others such as palliative or terminal care. Practitioners and researchers both require a clearer specification of the end-of-life concept to be able to provide appropriate care in this phase of life and to conduct robust research on a well-described theoretical basis.

Aims: The aim of this study was to critically analyze the end-of-life concept and terminology.

Method: The concept analysis was performed by applying Rodgers' evolutionary concept analysis method.

Findings: Time, clinical status/physical symptoms, psychosocial symptoms, and dignity were identified as main attributes of the concept. Transition into the end-of-life phase and its recognition were identified as antecedents. End-of-life care emerged as a consequence of the application of the end-of-life concept.

Conclusion: An early recognition of the end-of-life phase seems to be crucial to dignified death of an individual's dignified death with well-managed symptoms.

Keywords: concept analysis, end of life, end-of-life care

Background

The term palliative care was first mentioned by Balfour Mount in 1975 (1, 2). Prior to this date, terminology such as terminal illness, terminal care, care for the dying, and hospice was used to describe the last phase of life and the care for people nearing death (1). In 2020, the term palliative care was defined by the WHO as *“an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness…”* (3). Palliative Care is a well-established concept, but other terms are frequently used, including end-of-life care, hospice care, terminal care, supportive care, and care for the dying (4-7). Due to a lack of definition, these terms are used interchangeably and synonymously both in palliative care settings and in research (4, 6-9).

In the literature on the last phase of life, the term end of life is often used to describe the very last phase of life (i.e., the last days) and is, as used adjectivally in the term end-of-life care, used interchangeably with the terms hospice care and terminal care (10). The terms end of life (EOL), end-of-life care (EOLC), hospice care, and terminal care can be placed at the end of the palliative care spectrum, if palliative care is viewed as a pathway starting with the diagnosis of an incurable disease (11). Izumi et al. (10) tried to define end-of-life care from the perspective of nursing ethics and pointed out the lack of a clear definition. Flierman et al. (8) also stated that the range of interchangeable definitions of the palliative phase creates difficulties for its identification.

The existing definition of EOLC provided by the European Association for Palliative Care (EAPC) defines the end of life as an “extended period of one to two years during which the patient/family and health professionals become aware of the life-limiting nature of the illness.” The EAPC white paper on standards and norms for hospice and palliative care in Europe also mentions the synonymous use of the term end-of-life care with palliative care (12). In the NICE guideline “End of life care for adults: service delivery,” EOLC is defined as care provided in the last year of life or in the last months or years (13). These examples illustrate the ambiguity regarding the use of the concept, especially with end of life as in end-of-life care being used synonymously with other terms or end of life being incorporated in descriptions or definitions about end-of-life care. In this context it should be clarified that the end of life is the last phase of life and end-of-life care is the care which is provided during this phase, which requires clear distinction between these two terms because they refer to different concepts. To describe the underlying concept, the method of concept analysis was used in this study. Concept analyses are considered crucial for the development of nursing research and theory development in nursing and an essential element of advancing nursing practice (14, 15). Therefore, since conceptual work is essential for progress within a discipline, such efforts lay the foundation for clinical research; without a clear concept, efforts to conduct research or develop theories are weakened (16-18). The aim of conducting this study was to gain a deeper understanding of the term end of life (EOL) used in health care settings and to clarify the concept of EOL by applying a concept analysis approach.

Method

For this study, we chose Rodgers' evolutionary method of concept analysis because it can be applied to resolve a gap or inconsistency in disciplinary knowledge (16, 19). This method is based on the interpretative paradigm of research of concepts which implies that concepts are understood across particular contexts and over time. The steps of this method are displayed in Table 1. The six main activities represent a process guideline but do not necessarily have to be used in this sequence (15).

Table 1: Evolutionary method of concept analysis: activities (19)

Step	Activity	
1	Identify the concept of interest and associated expressions (including surrogate terms)	
2	Identify and select an appropriate realm (setting and sample) for data collection	
3	Collect relevant data to identify the:	a. Attributes of the concept b. Contextual basis of the concept, including interdisciplinary, sociocultural and temporal (antecedents and consequential occurrences) variations.
4	Analyze data regarding the above mentioned characteristics of the concept	
5	Identify an example of the concept, if appropriate	
6	Identify implications, hypotheses and implications for further development of the concept	

Search strategy

We conducted a systematic literature search from May to September 2019 (Table 2). In order to understand the concept of end of life across disciplines, we used various databases and performed a comprehensive hand search (Figure 1). Since the aim of the concept analysis was to discover how the term is used in various contexts, several types of literature were included, such as original articles, literature reviews, guidelines, nursing books, and information provided on websites of palliative care organizations. No time limit was set because Rodgers' evolutionary method especially requires an over-time analysis of the use of the concept. As the term end of life emerged in various contexts in our search, literature describing end-of-life care was also considered for analysis due to its proximity to our topic.

Table 2: Search strategy

Search strategy	Source	
Systematic literature search with keywords:		
"end of life" AND (concept OR definition)	Search engine	Pubmed
Mesh terms were used		PubPsych
	Electronic database	CINAHL
		Web of Science
		Cochrane Library
Manual search		
	Search engine	Google
		Google Scholar
	Reference list of relevant articles	
	Guidelines in the field of palliative care/hospice care/end-of-life care	
	Websites of expert associations and organizations for palliative care/hospice care/end-of-life care	

All relevant literature in German or English was included which describes the concept of end of life and/or contributes to describing its attributes, antecedents, consequences and related concepts. As a first step, the titles were examined for their eligibility for abstract screening, i.e., whether the title included sufficient hints regarding attributes for end of life and possibly related concepts like end-of-life care. The abstract screening focused more on the description of the concept – whether the article describes attributes, antecedents, consequences or possibly related concepts. During the following full-text screening, the texts were studied carefully to contribute to the analysis of the concept (Figure 1).

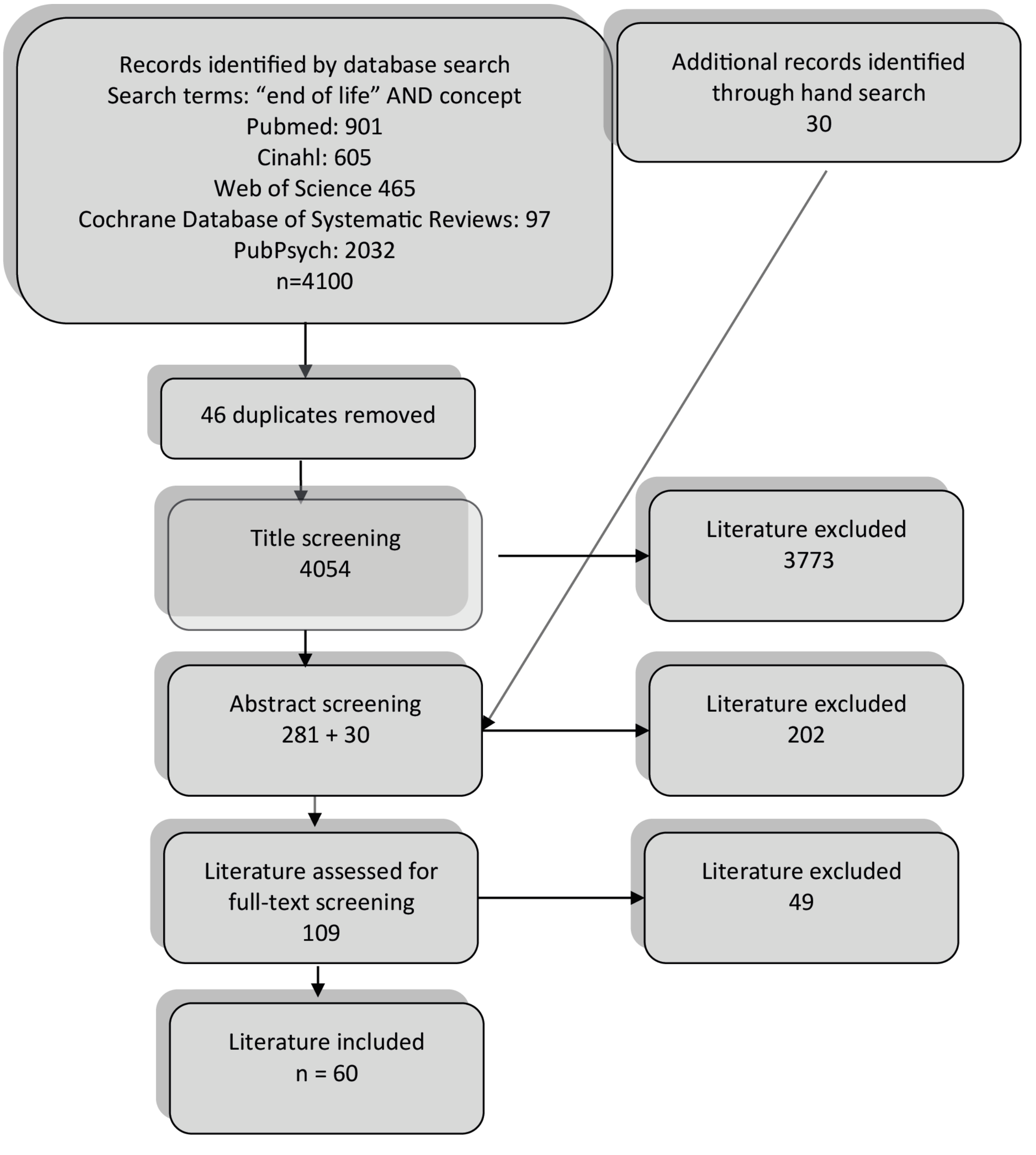

Figure 1: Flow chart - search strategy

Results

Additional surrogate terms

The online dictionaries Merriam-Webster and Lexico (former Oxford Online Dictionary) did not include the term “end of life” (20, 21). The Cambridge Online Dictionary defines “end of life” as follows: *“End-of-life issues relate to someone’s death and the time just before it, when it is known that they are likely to die soon from an illness or condition“* (22). Lorenz et al. (23) stated in their systematic review that “active dying” or “patient readiness” were used as terms for EOL.

Attributes

According to the definition of attributes by Rodgers and Knafl (19), characteristics of the analyzed concept such as clinical status/physical symptoms, psychosocial symptoms, time, and dignity were identified. Clinical status and physical symptoms are central factors for defining end of life (24). A wide range of prevalent physical symptoms in the end-of-life phase was found in the literature, with pain and breathing difficulties occurring very often (23-36). Eating and drinking difficulties, mobility difficulties, and cognitive decline were also described as typical symptoms in the last phase of life (28, 30, 37-39). Some authors mentioned a general physical decline, diagnoses like renal failure, and clinical symptoms like malaise, loss of body function, fatigue, and weight loss occuring in the last phase of life (27, 34, 37-41).

Apart from these physical symptoms, psychosocial symptoms were described as well, for instance anxiety, distress, (fear of) loss of control, (fear of) loss of autonomy, fear of dependency, and fear of being a burden (34, 38, 42-46). Related to these psychosocial aspects, the wish for dignity or the fear of loss of dignity in the last phase of life emerged as a prevailing attribute. (45-47). Loss of dignity seems to be related to a loss of autonomy, which in turn coincides with the fear of being a burden (45, 48-53). In addition, the ability to consciously anticipate when the transition to active dying will occur is regarded as a main aspect of autonomy (54). Time as an attribute of end of life, i.e., relating to a timeframe until death is expected, is described with a large variance showing a lack of consensus regarding this central aspect. Specified timeframes range between hours and years, with vaguer terms like “final” and “last” also being used for describing this attribute. Descriptions like “final hours” or “final days”, or “last days of life” are also commonly used (27, 36, 55). To describe timeframes more precisely, weeks, years or the admission to a care home as a starting point for the end of life were identified (8, 26). Other sources, however, are more precise by using timeframes like seven days, 90 days, two to six months, three months, six months, one year, or even two years (23, 24, 28, 30, 37, 56-59). Time was also identified as an attribute on an individual level, being described as an important but very limited resource. Individuals have great concern about the little time remaining (60-62).

Contextual basis

Passages where the concept occurs are defined as the contextual basis. The term antecedents describes those situations or facts which precede the identification of the end-of-life phase. Consequences relate to the results of the end-of-life phase (19).

Antecedents

Transition to the EOL phase and the correct identification of an individual's entry into the end-of-life phase were identified as main antecedents (59, 63). This phase is of critical importance for the affected individuals, representing an existential turning point (43). Other authors have described the transition to the end-of-life phase as a period in which final decisions can be made and the past can be evaluated. During this phase, admission to healthcare institutions like nursing homes or hospice care units may occur. Transitioning from assuming to be cured to recognizing the end-of-life phase is an existential phenomenon and is described as "living transiently within the shadow of death" (44, 62, 64).

The early recognition of entry into the EOL phase is crucial for affected individuals because as soon as the EOL phase begins, special measures like advance care planning or symptom control should be offered (58, 59, 63). Thus, the discontinuation of active disease management with its change of treatment goals can be defined as a critical turning point (40). Lamont (30) stated that in order to offer optimal care, the EOL phase should be identified at least three months before a patient's death.

Consequences

As mentioned above, the transition into the EOL phase should be accompanied by a change of treatment goals and the initiation of specific and adapted care – end-of-life care (EOLC).

EOLC is described very broadly and with a multitude of interventions. Griffith (65) defined EOLC as the support offered by nurses to help patients and families prepare for a patient's impending death. The NHS end-of-life strategy specifies EOLC as care provided in the last phase of life with a special focus on pain and symptom management and support of psychological, social, spiritual, and practical needs (66). The following defining factors were reported for end-of-life care: timely discussions to ensure end-of-life planning, recognizing the end-of-life phase, providing supportive care to ensure effective management of key symptoms, co-ordination and continuity of care, effective assurance of primary care, managing hospitalization, continued care after death, and valuing healthcare staff (25). The main tasks of EOLC are symptom management and pain control (35, 66, 67). EOLC should be attentive to personal, cultural, and spiritual values, and should also offer support to the people around the affected individual (68). Supporting the relationship of the affected individual with others, meaningful and effective communication, and especially conversations about death are also part of EOLC (33, 45, 64, 69-72). In practice, ideal EOLC, for example for people with dementia, guarantees comfort, maintains satisfactory physical appearance, promotes family involvement, upholds independence, provides a sense of religious support, provides basic physical needs, reduces pain, provides respectful treatment, and preserves dignity (35).

Additionally, a "good death" can also be identified as a consequence, for if the end-of-life phase is seen as pathway, then a "good death" might constitute a consequence or, as described by Kehl et al. (73), as a primary outcome of end-of-life care. A "good death" has been described by several authors with the following associated attributes: freedom from pain, symptom control, advance care planning, effective communication, and the presence of loved ones (29, 33, 47, 63).

Related concepts

Rodgers & Knafl (19) classified those concepts as related ones which are very similar to the concept of interest but do not share the same set of attributes. With regard to the concept of EOL, the dying phase, terminal phase, a good death, and death preparedness were identified as related concepts. The dying phase is very close to the end of life, often described using either a timeframe or a reference to physical and mental decline (27, 36, 37). However, our analysis showed that the timeframe for the dying phase is much shorter than for EOL, ranging from the last hours to days in most of the studies (36, 37, 40). The description of the terminal phase shows a relevant overlap with the dying phase. Therefore, we conclude that the terminal phase is synonymous with the dying phase, since both span a narrow timeframe and physical decline (40, 74).

The “activity of dying” is described in the nursing textbook *Applying the Roper, Logan, Tierney Model in Practice*. Factors with an identified impact on this process are biological, psychological, sociocultural, environmental as well as spiritual factors. To assess the activity of dying, it is recommended to consider the expected remaining lifespan and the level of dependency (75).

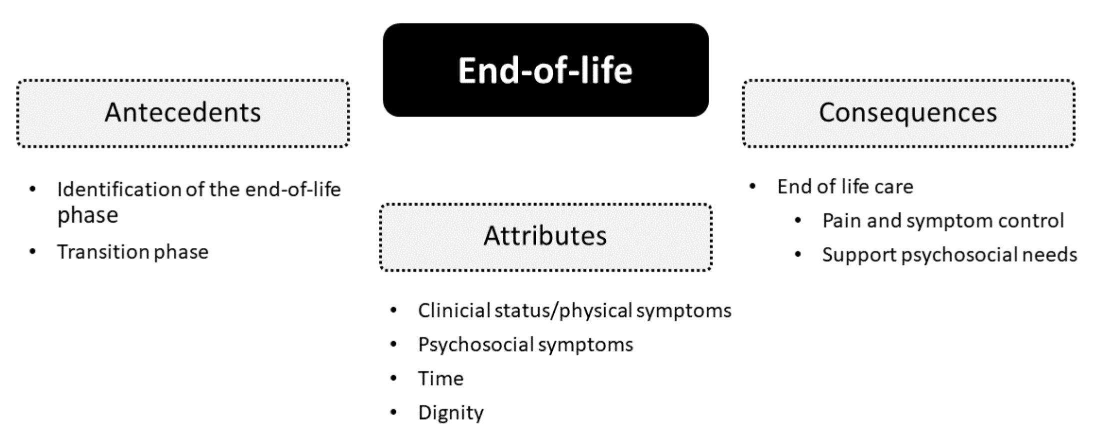

Figure 2: Schematic description of the concept of EOL

Discussion

This analysis of the concept of EOL identified clinical status/physical symptoms, psychosocial symptoms, time, and dignity as attributes to describe this concept. The identification of the start of the EOL phase and the transition phase were identified as antecedents. The main consequence is end-of-life care, which means treatment adapted to this special phase of life.

Clinical status is described quite clearly as decline in physical function and includes some frequently observed symptoms such as pain and breathing difficulties. In contrast, time and timeframes of EOL show a broad variety ranging between hours and years, impeding a common understanding of the concept that is generalizable over different care settings. We assume that these broad ranges of timeframes are related to the various settings where patients experience the end-of-life phase. For instance, the timeframe of EOL might be considerably shorter in a specialized palliative care institution than in a long-term care facility (76). One of the analyzed records stated that the end-of-life phase starts with the admission to a care home, showing how differently this phase can be perceived depending on the context of the setting (26). An analysis about the end-of-life period showed a median length of timeframe of 3.25 years (77).

Nevertheless, our analysis shows that the timeframe could mainly be located between the last days of life and one year (24). One year seems to be the most commonly used timeframe for the end of life, since the Surprise Question, a predictive tool for death, also uses a timeframe of 12 months. However, it must be considered that the Surprise Question is not a valid tool for predicting death, even though it is often used due to a lack of alternative predicting instruments (78, 79). Timeframe, or knowledge about the length of time remaining until the end, appears as crucial in the discourse about the end of life. But this knowledge or information about remaining time is a difficult subject because it may, in instances, cause confusion or distress. Therefore, an early EOL phase recognition seems to be of greater consequence (80). This is in line with our results, where the requirement of a correct, clear, and timely identification of the end-of-life phase emerged as an antecedent. The distinct starting point of the end of life is mainly defined as when active disease management is ended (40, 58). This point may be defined more easily in an acute care setting with a clear diagnosis and a clearly identifiable clinical decline. In contrast, it is known that in frail geriatric patients, the initiation of the end-of-life phase is very difficult to assess (8, 81).

In patients with severe chronic illness it is particularly difficult to define when the last phase of life has started due to fluctuating and long disease trajectories (82, 83). Recognition of the EOL phase by nurses and family members and its distinction from other phases such as the dying phase are of critical importance because they are a prerequisite for adequate treatment and interventions (28, 82). Adequate interventions are summarized as EOLC finally ensuring a “good death” in dignity. Loss of dignity is related to a loss of control and autonomy (43). Preserving dignity, autonomy, and control over the dying process emerged as main wishes in end of life (34, 49, 84). These needs and wishes for the last phase of life underscore the importance of awareness for the end-of-life phase and of professionals who are highly skilled in EOLC. (77)

Implications for Nursing

Timely recognition of the transition to the EOL phase is indispensable for appropriate end-of-life care. Timeframes may vary, but we recommend that the EOL phase be considered distinct from other phases like the dying phase. It is impossible to set an exact time frame, but a recognized physical or psychosocial decline as well as cessation of curative therapy may indicate its start. A main aim of providing EOLC is to help people prepare for a “good death” and, to reach this goal, patients and care professionals need sufficient time. Dignity was identified as a very important concept in the last phase of life – therefore, enough time should be dedicated to it in both EOLC and the education of care professionals.

Conclusion

The end of life is described by the attributes of clinical status/physical status, psychosocial symptoms, time, and dignity. A physical decline is recognizable and often accompanied by psychosocial symptoms. Affected individuals are faced with a limited lifetime and have considerable concerns about dignity and freedom of pain in their last phase of life. Caregivers should therefore be able to recognize the beginning of the end-of-life phase and provide adequate end-of-life care focusing on symptom control and patients' dignity. A "good death," described as pain and symptom free and in the presence of loved ones is the result of this process. Therefore, an adequate understanding of EOL is crucial to ensure it. For a common international definition of EOL, the following attributes emerged from our concept analysis: time, clinical status/physical symptoms, psychosocial symptoms, dignity, End-of-life care and relationships should be considered for inclusion into the definition.

Limitations

It has to be noted that Rodgers' methodology, which was applied in this study, does not have clear criteria for the analysis process, which means that this process is author-specific and may be subject to certain limitations.

References

(1) Mount BM. The problem of caring for the dying in a general hospital; the palliative care unit as a possible solution. Can Med Assoc J. 1976;115 (2):119-21.

(2) Mount B. The father of palliative care in Canada, physician Balfour Mount on the legacy of Cicely Saunders, the start of palliative care, and the true meaning of medical aid in dying. In: Phillips D, editor. Palliative Care McGill/Portraits. www.mcgill.ca: McGil University; 2019.

(3) WHO. Palliative Care 2020 [Available from: https://www.who.int/news-room/fact-sheets/detail/palliative-care.

(4) Nauck F, Jaspers B. Is palliative care synonymous with end-of-life care? EUROPEAN JOURNAL OF PALLIATIVE CARE. 2003;10 (Part 6):223-4.

(5) Guo Q, Jacelon C, Marquard J. An Evolutionary Concept Analysis of Palliative Care. Journal of Palliative Care Medicine. 2012;2 (7).

(6) Hui D, De La Cruz M, Mori M, Parsons HA, Kwon JH, Torres-Vigil I, et al. Concepts and definitions for “supportive care,” “best supportive care,” “palliative care,” and “hospice care” in the published literature, dictionaries, and textbooks. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2013;21 (3):659-85.

(7) Hui DMDMMF, Mori MMD, Parsons HAMD, Kim SHMDP, Li ZMS, Damani SM, et al. The Lack of Standard Definitions in the Supportive and Palliative Oncology Literature. Journal of Pain and Symptom Management. 2012;43 (3):582-92.

(8) Flierman I, Nugteren IC, van Seben R, Buurman BM, Willems DL. How do hospital-based nurses and physicians identify the palliative phase in their patients and what difficulties exist? A qualitative interview study. BMC Palliative Care. 2019;18 (1):54.

(9) Hui D, Nooruddin Z, Didwaniya N, Dev R, De La Cruz M, Kim SH, et al. Concepts and definitions for “actively dying,” “end of life,” “terminally ill,” “terminal care,” and “transition of care”: a systematic review. Journal of Pain & Symptom Management. 2014;47 (1):77-89.

(10) Izumi S, Nagae H, Sakurai C, Imamura E. Defining end-of-life care from perspectives of nursing ethics. Nurs Ethics. 2012;19 (5):608-18.

(11) Hawley PH. The bow tie model of 21st century palliative care. J Pain Symptom Manage. 2014;47 (1):e2-5.

(12) Radbruch L. White Paper on standards and norms for hospice and palliative care in Europe: part 1: Recommendations from the European Association for Pallliative Care. European Journal of Palliative Care. 2009;16 (3).

(13) NICE NIfHaCE. End of life care for adults: service delivery. NICE guideline2019.

(14) Lee SM, Coakley E. Geropalliative Care: A Concept Synthesis. Journal of Hospice & Palliative Nursing July/August. 2011;13 (4):242-8.

(15) Foley AS, Davis AH. A Guide to Concept Analysis. Clinical nurse specialist CNS. 2017;31 (2):70-3.

(16) Weaver K, Mitcham C. Nursing concept analysis in North America: state of the art. Nursing philosophy : an international journal for healthcare professionals. 2008;9 (3):180-94.

(17) Rodgers BL, Jacelon CS, Knafl KA. Concept Analysis and the Advance of Nursing Knowledge: State of the Science. Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing. 2018;50 (4):451-9.

(18) Holland MM, Prost SG. The End of Life Within Social Work Literature: A Conceptual Review. Omega. 2019:30222819835650-.

(19) Rodgers BL, Knafl KA. Concept Development in Nursing: Foundations, Techniques, and Applications. 2 ed. Philadelphia, Pennsylvania: Saunders Company; 2000.

(20) Meriam-Webster Online Dictonary. 2019. “end of life”

(21) 2019. “end of life”.

(22) Cambridge online dictionary. 2019. “end-of-life”.

(23) Lorenz KA, Lynn J, Dy SM, Shugarman LR, Wilkinson A, Mularski RA, et al. Evidence for improving palliative care at the end of life: a systematic review. Ann Intern Med. 2008;148 (2):147-59.

(24) Stow D, Spiers G, Matthews FE, Hanratty B. What is the evidence that people with frailty have needs for palliative care at the end of life? A systematic review and narrative synthesis. Palliative Medicine. 2019;33 (4):399-414.

(25) Boyd M, Frey R, Balmer D, Robinson J, McLeod H, Foster S, et al. End of life care for long-term care residents with dementia, chronic illness and cancer: prospective staff survey. BMC Geriatr. 2019;19 (1):137.

(26) Goddard C, Stewart F, Thompson G, Hall S. Providing End-of-Life Care in Care Homes for Older People: A Qualitative Study of the Views of Care Home Staff and Community Nurses. Journal of Applied Gerontology. 2013;32 (1):76-95.

(27) Kennedy C, Brooks-Young P, Brunton Gray C, Larkin P, Connolly M, Wilde-Larsson B, et al. Diagnosing dying: an integrative literature review. BMJ Support Palliat Care. 2014;4 (3):263-70.

(28) Koppitz A, Bosshard G, Schuster DH, Hediger H, Imhof L. Type and course of symptoms demonstrated in the terminal and dying phases by people with dementia in nursing homes. Z Gerontol Geriatr. 2015;48 (2):176-83.

(29) Krishnan P. Concept analysis of good death in long term care residents. Int J Palliat Nurs. 2017;23 (1):29-34.

(30) Lamont EB. A demographic and prognostic approach to defining the end of life. J Palliat Med. 2005;8 Suppl 1:S12-21.

(31) NHS DoH. End of Life Care Strategy: Promoting high quality care for all adults at the end of life. 2008.

(32) Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. Jama. 1999;281 (2):163-8.

(33) Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. Ann Intern Med. 2000;132 (10):825-32.

(34) Stewart AL, Teno J, Patrick DL, Lynn J. The concept of quality of life of dying persons in the context of health care. J Pain Symptom Manage. 1999;17 (2):93-108.

(35) Stewart-Archer LA, Afghani A, Toye CM, Gomez FA. Dialogue on Ideal End-of-Life Care for Those With Dementia. Am J Hosp Palliat Care. 2015;32 (6):620-30.

(36) Leitlinienprogramm Onkologie: Palliativmedizin für Patienten mit einer nicht heilbaren Krebserkrankung, Langversion 1.1, 128/001OL (2015).

(37) Domeisen Benedetti F, Ostgathe C, Clark J, Costantini M, Daud ML, Grossenbacher-Gschwend B, et al. International palliative care experts' view on phenomena indicating the last hours and days of life. Support Care Cancer. 2013;21 (6):1509-17.

(38) Amblàs-Novellas J, Murray SA, Espaulella J, Martori JC, Oller R, Martinez-Muñoz M, et al. Identifying patients with advanced chronic conditions for a progressive palliative care approach: a cross-sectional study of prognostic indicators related to end-of-life trajectories. BMJ Open. 2016;6 (9):e012340.

(39) Cohen-Mansfield J, Skornick-Bouchbinder M, Brill S. Trajectories of End of Life: A Systematic Review. The journals of gerontology Series B, Psychological sciences and social sciences. 2018;73 (4):564-72.

(40) Sercu M, Beyens I, Cosyns M, Mertens F, Deveugele M, Pype P. Rethinking End-of-Life Care and Palliative Care: Learning From the Illness Trajectories and Lived Experiences of Terminally Ill Patients and Their Family Carers. Qualitative Health Research. 2018;28 (14):2220-38.

(41) GSF TGSF. The Gold Standrads Framework Proactive Identification Guidance (PIG) 2016 [Available from: https://www.goldstandardsframework.org.uk/cd-content/uploads/files/PIG/NEW %20PIG %20- %20 %20 %2020.1.17 %20KT %20vs17.pdf.

(42) Paal P, Buekki J. "If I had stayed back home, I would not be alive any more..." - Exploring end-of-life preferences in patients with migration background. PloS one. 2017;12 (4).

(43) Tarbi EC, Meghani SH. Existential experience in adults with advanced cancer: A concept analysis. Nursing outlook. 2019.

(44) Haley W, Kasl-Godley J, Larson D, Neimeyer R. Roles for Psychologists in End-of-Life Care: Emerging Models of Practice. Professional Psychology: Research and Practice 2003;34 (6):626-33.

(45) Lloyd L, White K, Sutton E. Researching the end-of-life in old age: cultural, ethical and methodological issues. Ageing & Society. 2011;31 (3):386-407.

(46) Witten TM. End of Life, Chronic Illness, and Trans-Identities. Journal of Social Work in End-of-Life & Palliative Care. 2014;10 (1):34-58.

(47) Wakunami M, Kawabata H, Murakami M, Maezawa M. Families' acceptance of near death: a qualitative study of the process for introducing end-of-life care. Geriatrics & Gerontology International. 2009;9 (2):140-7.

(48) Davies N, Rait G, Maio L, Iliffe S. Family caregivers' conceptualisation of quality end-of-life care for people with dementia: A qualitative study. Palliat Med. 2017;31 (8):726-33.

(49) Rodriguez-Prat A, Monforte-Royo C, Porta-Sales J, Escribano X, Balaguer A. Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. PloS one. 2016;11 (3):e0151435.

(50) Guo Q, Jacelon CS. An integrative review of dignity in end-of-life care. Palliative Medicine. 2014;28 (7):931-40.

(51) Fernandez-Sola C, Diaz Cortes MM, Hernandez-Padilla JM, Aranda Torres CJ, Munoz Terron JM, Granero-Molina J. Defining dignity in end-of-life care in the emergency department. Nursing Ethics. 2017;24 (1):20-32.

(52) Nolan MT, Mock V. A conceptual framework for end-of-life care: a reconsideration of factors influencing the integrity of the human person. Journal of professional nursing : official journal of the American Association of Colleges of Nursing. 2004;20 (6):351-60.

(53) Mistry B, Bainbridge D, Bryant D, Tan Toyofuku S, Seow H. What matters most for end-of-life care? Perspectives from community-based palliative care providers and administrators. BMJ Open. 2015;5 (6):e007492.

(54) Houska A, Loučka M. Patients' Autonomy at the End of Life: A Critical Review. Journal of Pain & Symptom Management. 2019;57 (4):835-45.

(55) Froggatt K, Payne S. A survey of end-of-life care in care homes: issues of definition and practice. Health Soc Care Community. 2006;14 (4):341-8.

(56) Morin L, Johnell K, Van Den Block L, Aubry R. Discussing end-of-life issues in nursing homes: a nationwide study in France. Age & Ageing. 2016;45 (3):395-402.

(57) NICE. NICE Quality Standard for End of Life Care. 2011.

(58) NICE. End of life care for adults: service derlivery: National Institute for Health and Care Excellence; 2019 [Available from: https://www.eolc.co.uk/uploads/end-of-life-care-for-adults-service-delivery-pdf-66141776457925.pdf.

(59) Improving Care at the End of Life: Our Roles and Responsibilities, (2016).

(60) Gysels M, Evans N, Menaca A, Higginson IJ, Harding R, Pool R. Diversity in defining end of life care: an obstacle or the way forward? PloS one. 2013;8 (7):e68002.

(61) Bruce A. Time (lessness): Buddhist perspectives and end-of-life. Nursing philosophy : an international journal for healthcare professionals. 2007;8 (3):151-7.

(62) Larkin PJ, Dierckx de Casterle B, Schotsmans P. Transition towards end of life in palliative care: an exploration of its meaning for advanced cancer patients in Europe. J Palliat Care. 2007;23 (2):69-79.

(63) Granda-Cameron C, Houldin A. Concept Analysis of Good Death in Terminally Ill Patients. American Journal of Hospice and Palliative Medicine®. 2012;29 (8):632-9.

(64) Wallace CL, Adorno G, Stewart DB. End-of-Life Care in Nursing Homes: A Qualitative Interpretive Meta-Synthesis. Journal of Palliative Medicine. 2018;21 (4):503-12.

(65) Griffith S. Prepared for end-of-life care: a concept analysis. Int J Palliat Nurs. 2018;24 (8):399-410.

(66) NHS DoH. End of Life Care Strategy: Promoting high quality care for all adults at the end of life 2008.

(67) NICE. NICE Quality Standard for End of Life Care 2011.

(68) A guide to the end-of-life care for seniors. , (2000).

(69) Singer PA, Martin DK, Kelner M. Quality end-of-life care - Patients' perspectives. Jama-Journal of the American Medical Association. 1999;281 (2):163-8.

(70) Sinuff T, Dodek P, You JJ, Barwich D, Tayler C, Downar J, et al. Improving End-of-Life Communication and Decision Making: The Development of a Conceptual Framework and Quality Indicators. Journal of Pain & Symptom Management. 2015;49 (6):1070-80.

(71) Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, Grambow S, Parker J, et al. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. Journal of pain and symptom management. 2001;22 (3):727-37.

(72) Larkin PJ, De Casterle BD, Schotsmans P. Transition towards end of life in palliative care: An exploration of its meaning for advanced cancer patients in Europe. Journal of Palliative Care. 2007;23 (2):69-79.

(73) Kehl KA. Moving toward peace: an analysis of the concept of a good death. Am J Hosp Palliat Care. 2006;23 (4):277-86.

(74) van der Steen JT, Lemos Dekker N, Gijsberts MHE, Vermeulen LH, Mahler MM, The BA. Palliative care for people with dementia in the terminal phase: a mixed-methods qualitative study to inform service development. BMC Palliat Care. 2017;16 (1):28.

(75) Holland K, Jenkins J, Solomon J, Whittam S. Applying the Roger, Logan, Tierney Model in Pracitess. . 2 ed2008.

(76) Pivodic L, Smets T, Van den Noortgate N, Onwuteaka-Philipsen BD, Engels Y, Szczerbińska K, et al. Quality of dying and quality of end-of-life care of nursing home residents in six countries: An epidemiological study. Palliat Med. 2018;32 (10):1584-95.

(77) Cohen-Mansfield J, Cohen R, Skornick-Bouchbinder M, Brill S. What Is the End of Life Period? Trajectories and Characterization Based on Primary Caregiver Reports. J Gerontol A Biol Sci Med Sci. 2018;73 (5):695-701.

(78) Downar J, Goldman R, Pinto R, Englesakis M, Adhikari NK. The “surprise question” for predicting death in seriously ill patients: a systematic review and meta-analysis. CMAJ : Canadian Medical Association journal = journal de l’Association medicale canadienne. 2017;189 (13):E484-e93.

(79) Flierman I, van Rijn M, Willems DL, Buurman BM. Usability of the surprise question by nurses to identify 12-month mortality in hospitalized older patients: A prospective cohort study. International journal of nursing studies. 2020;109:103609.

(80) Horne G, Seymour J, Payne S. Maintaining integrity in the face of death: a grounded theory to explain the perspectives of people affected by lung cancer about the expression of wishes for end of life care. International journal of nursing studies. 2012;49 (6):718-26.

(81) Cardona-Morrell M, Lewis E, Suman S, Haywood C, Williams M, Brousseau AA, et al. Recognising older frail patients near the end of life: What next? Eur J Intern Med. 2017;45:84-90.

(82) Stiel S, Krause O, Berndt CS, Ewertowski H, Müller-Mundt G, Schneider N. Caring for frail older patients in the last phase of life. Zeitschrift für Gerontologie und Geriatrie. 2020;53 (8):763-9.

(83) Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. Bmj. 2005;330 (7498):1007-11.

(84) Hattori K, McCubbin MA, Ishida DN. Concept analysis of good death in the Japanese community. Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau. 2006;38 (2):165-70.

Attachment:

Table 3: Analysis process

Analysis process step	Main theme	Subthemes	Source
Attribute	Clinical status/ physical symptoms	Pain	Boyd et al. 2019; Goddard et al. 2013; Kennedy et al. 2014; Koppitz et al. 2015; Krishnan 2017; Lamont 2005; Lorenz et al. 2008; NHS 2008; Singer et al. 1999; Steinhauser et al. 2000; Stewart et al. 1999; Stewart-Archer 2015; Stow et al. 2019;
		Breathing difficulties: shortness of breath, death rattle, change of breathing rhythm, changes in breathing patterns; dyspnoe; choking; gurgling	Boyd et al. 2019; Deutsche Krebsgesellschaft 2015; Domeisen Benedetti 2013; Kennedy et al. 2014; Koppitz et al. 2015; Lamont 2005; Lorenz et al. 2008; Stewart et al. 1999; Steinhauser et al. 2000;
		Eating and drinking difficulties: difficulty swallowing, refusal of fluid or food	Domeisen Benedetti 2013; Koppitz et al. 2015; Amblàs-Novellas et al. 2016;
		Mobility difficulties	Domeisen Benedetti 2013; Koppitz et al. 2015;
		Cognitive decline	Cohen-Mansfield et al. 2018; Lamont 2005
		General decline	Sercu et al. 2018; Gold Standard Framework 2016; Amblàs-Novellas et al. 2016;
		Other symptoms/clinical diagnoses: renal failure, malaise; loss of body functions; fatigue; loss of weight	Cohen-Mansfield et al. 2018; Domeisen Benedetti 2013; Kennedy et al. 2014; Stewart et al. 1999
	Psychosocial symptoms	Anxiety; crying, peace, calm, fear of suffering, fear about dignity and increased dependency, anxieties regarding possible symptoms and about being a burden; depressive episodes; sense of dignity or self-esteem, sense of control; anxiety, fear and worry is prevalent in patients who are dying, emotional well-being and life satisfaction decline	Boyd et al. 2019; Cohen-Mansfield et al. 2018; Haley et al. 2003; Lloyd et al. 2011; Paal & Bükki 2017; Koppitz et al. 2015; Stewart et al. 1999; Steinhauser et al. 2000; Tarbi & Meghani 2019; Witten 2014; Amblàs-Novellas et al. 2016;

	Time	90 days	Koppitz al. 2015;
		7 days	Domeisen Benedetti et al. 2013; Lorenz et al. 2008; Stow et al. 2019;
		3 months	Lamont 2005; Morin et al. 2016;
		2-6 months	Lorenz et al. 2008
		6 months	Stow et al. 2019;
		1 year	Stow et al. 2019; NICE 2011;NICE 2019; Royal Australasia College of Physician 2016;
		2 years	Stow et al. 2019;
		Last days of life	Deutsche Krebsgesellschaft et al. 2015; Frogatt & Payne 2006
		Week to years	Flierman et al. 2019;
		Admission to care home	Goddard et al. 2013
		Final hours/final days	Kennedy et al. 2014
		Time as a significant aspect in end-of-life care in terms of spirituality (end of life from a Buddhist view)	Bruce 2007
		Time as an "critical descriptor" of patient experience in the transition toward palliative care	Larkin et al. 2007
	Dignity	Dying with dignity as a fundamental objective in end-of-life care	Fernández-Sola et al. 2017
		Dignity as a goal of high-quality end-of-life care: a human right, autonomy and independence, relieved symptom distress, respect, being human and being self, meaningful relationships, dignified treatment and care, existential satisfaction, privacy, and calm environment	Guo & Jacelon 2014
		Dignity diminished due a loss of functionality	Rodríguez-Prat et al. 2016
		Dignity in terms of identity	Rodríguez-Prat et al. 2016

		"Patients´perceived dignity at EOL is related to their sense of autonomy and ability to control physical functions and their immediate surroundings."	Rodríguez-Prat et al. 2016
		Autonomy as a determining factor of perceived dignity: desire for control over dying process and desire for autonomy in terms of self-determination	Rodríguez-Prat et al. 2016
		Consideration of dignity as a main priority especially at final stages of dementia patients	Davies et al. 2017
		Dignity	Steinhauser et al. 2000
		Autonomy not only a concern of choices and decisions about treatment and care but also in terms of emphasis on supporting patients' engagement in daily activities, in contributing to others, and in active preparation for dying	Houska & Loucka et al. 2019
		As most important topics in EOL care: addressing non-physical needs, healthcare teams´ way of palliative care delivery, Consideration of patients' wishes, adressing physical needs, preparing for and accepting death, communication and relationship development, involving and supporting relatives and other loved ones, understanding the patient and family experience, society and the health system have a culture of supporting palliative care;	Mistry et al. 2014
		Communication and decision making as high priorities in EOL phase	Sinuff et al. 2015
		Three over-arching themes were derived from the interviewers discourse including maintaining the person within, fostering respect and dignity and showing compassion and kindness	Davies et al. 2017
		Dignity, ordered financial affairs, sharing time with close friends, presence of family	Steinhauser et al. 2000
Antecedents	Identification of risk of dying	Correct identification of risk of dying	Granda-Cameron & Houldin 2012; NICE 2019; Royal Australasia College of Physician 2016;

		Active disease management has been stopped and treatment goals have been changed	Sercu et al. 2018;
	Transition phase	Transition phase	Haley et al. 2003
		End of active disesase management	Sercu et al. 2018
		Transition described as a phase prior to end of life	Haley et al. 2003; Larkin et al. 2007; Wallace et al. 2018
Consequences	End-of-life care (EOLC)	Reduce pain	Stewart-Archer 2015; NHS 2008; Fisher et al. 200
		Ensure dignity	Stewart-Archer 2015;
		Patients concerned about the economic burden they may be causing their families	Stewart et al. 1999
		Management of physical symptoms and ensuring comfort in the final days, pain relief; constant care and attention for care home residents nearing the end of life	Goddard et al. 2013
		Advance care planning	Lorenz et al. 2008; NICE 2011; NICE 2019; Royal Australasian College of Physicians 2016
		Symptom management	NICE 2011
		EOLC - no agreed definition, holistic approach, quality of life, specific timeframe	Gysels et al. 2013
		Importance of relationships	Larkin et al. 2007
		Transition and relationships	Wallace et al. 2018
		Recognizing imminent death, managing physical symptoms, dealing with holistic approach	Griffith 2018
		Symptom management, support of psychological, social, spiritual and practical needs	NHS 2008
		EOLC: symptom management, mainly pain management; strengthening of relationship with loved ones	Singer et al. 1999

Related Concepts	Dying phase	Dying phase	Deutsche Krebsgesellschaft et al. 2015; Domeisen Benedetti et al. 2013;
		Dying phase as a period of some hours to 1 week	Sercu et al. 2018
		Last days of life, with a progressing decline in physical and cognitive function, e.g. frailty, immobility, no eating and drinking, changes in breathing; guideline providing criteria for diagnosis of dying phase	Deutsche Krebsgesellschaft et al. 2015;
	Terminal phase	Terminal phase varying from 3 weeks to 3 months before death	Sercu et al. 2018
	Good death	Relief from suffering, being aware of dying, accepting the timing of one´s death, acceptance and autonomy, keeping hope alive, preparing for departure, making decision about where to die; distinct: good death is multi-faceted and more external factors are recognized or necessary;	Granda-Cameron & Houldin 2012
		Krishnan 2017: "good death" attributes: freedom from pain and other symptoms; presence of loved ones	Krishnan 2017
		Introducing EOL care is crucial to accomplishing a "good death"	Wakunami et al. 2009
		Good death consists of: pain and symptom management, clear decision making, preparation for death, contributing to others and affirmation of the whole person,	Steinhauser et al. 2000
		Highly individual and dynamic; being in control as the most important and most common attribute	Kehl 2006
		Good death attributes in the Japanese community: related to sociocultural norms, personal experience and continuous process	Hattorie et al. 2006

	Death preparedness	6 key attributes: interaction between patient and the health team in terms of facilitated communication delivering prognosis and exploring attitudes toward EOL decisions; acceptance; awareness; transition in death attitudes, acknowledging participation in EOL decisions; EOL planning	McLeod-Sordjan 2013
		Four phases: advanced illness phase, EOL phase, terminal phase, and dying phase	Sercu et al. 2018

A consensus definition of end of life from an international and interdisciplinary perspective: A Delphi Panel Study

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Abstract

Background: Those working in the field of palliative care have recognized that many terms are being used synonymously and that clear definitions (or any definitions) for many of these terms are lacking. The synonymous use of the terms *palliative* and *end of life* can especially lead to conflicts in clinical practice, such as a tardy referral to palliative care. Such conflicts may then result in poorer treatment of patients, for instance, pain management. In research, the lack of clear definitions or even of any established definition for central concepts, such as *end of life*, weakens study validity and research outcomes.

Objective: The aim of this study was to establish a concise definition for the end-of-life phase.

Design: A modified Delphi study design was chosen. A structured questionnaire based on a previously conducted concept analysis about the end of life was used.

Setting: A panel of international and interdisciplinary experts was established. Between 34 (1st round) and 21 (4th round) individuals participated in the anonymous online expert panel.

Results: After four (4) panel rounds, we were able to provide a definition which covers physical and psychosocial aspects that should be considered at the beginning of the end-of-life phase and possible predictions about the remaining time. The definition also covers aspects of end-of-life care, such as considerations related to the individual’s dignity, spirituality and maintenance of relationships.

Conclusion: *End of life* is a term which is defined by considering multiple aspects that affect the process of identifying the end-of-life phase, the end-of-life phase itself and the resulting care options.

Introduction

In the field of palliative care, a discussion about unclear terms, the synonymous use of terms and the lack of definitions for terms has arisen (1). The term *palliative care* has been subject to continuous redefinition and adaption due to the development of the discipline (2, 3). In the health care practice, the use of the term *palliative* is recognized as synonymous with *end of life*; therefore, health care professionals perceive this term as a barrier and tend to avoid using it at an early care stage (2, 4, 5). However, practitioners highly recommend initiating palliative care early on in the disease trajectory and, based on evidence that shows better outcomes, to improve quality of life (6, 7). Most practitioners recognize that drawing a distinction between the terms *palliative* and *end of life* might help prevent health care providers from explicitly locating palliative care at the very end of life or near death.

Because clear definitions for these and related terms are lacking, the synonymous use of several terms, such as *end-of-life care*, *palliative care*, *terminal care*, or *actively dying* has been recognized (8).

In clinical practice, practitioners have recognized that it is often very difficult to identify the starting point of the end of life, despite the fact that these carers need to provide appropriate and timely end-of-life care (e.g. in the form of special pain management) (5, 9-11). In some health care systems, individuals must be identified as entering their end-of-life phase in an appropriate and timely manner in order to receive access to special care services (12).

Brown and colleagues recently conducted a systematic review to find a definition for *end of life* in dementia patients and to gather methods used to identify the end-of-life phase. The main outcome of this review was a recognition of the difficulty associated with identifying the starting point of the end-of-life phase (13). Thus, identifying the beginning of the end-of-life phase and determining how much time remains until death seem to be crucial points (14, 15). In the literature, the timespans described vary from the last days to the last two years until death (16). In fact, the timespan of the end-of-life phase can be assumed as a highly individual and rarely predictable factor, which can be influenced by multiple factors such as disease or disease trajectory (5, 9).

Overall, evidence based palliative care requires a common understanding of terms, key concepts and definitions (17, 18). To generate valid data in research, researchers must have access to clear definitions and precise concepts (19-21).

Because a clear, generally accepted definition of the term *end of life* is currently lacking, we designed a Delphi study to find a commonly used, unambiguous, international and interdisciplinary definition for the end-of-life phase.

Method

McKenna (22) stated that carrying out a Delphi study makes sense if the research problem can be solved by collecting subjective judgments, which applies to our research question. The aim of conducting a Delphi study is to find a consensus among a board of experts, referred to as a Delphi panel (23). We conducted a so-called modified Delphi study, which is characterized by leaving out the initial round and including only open-ended questions. We started our first round instead by providing a structured questionnaire (22). This Delphi study was carried out by following the guidance on Conducting and Reporting Delphi Studies (CREDES) in palliative care (24).

Design of panel and rounds

The general aim for our panel was interdisciplinarity and internationality. As overall criterion for being an expert, experience in research or clinical practice in palliative care or similar fields like hospice care was required. The main approach to find experts for the panel consisted of contacting authors of specific publications for this topic. Additionally, the platform ResearchGate was used (keyword `end of life` for additional publications and contact data). For interdisciplinary practitioners, we mainly used authors' or third party (e.g. supervisors, colleagues) professional networks. We also used LinkedIn to specifically search for Palliative and Hospice Care Organizations in Western European and North American countries and Australia. Regarding those organizations, for instance the Hospice and Palliative Nurses Association (HPNA), or personally known national organizations like the Austrian Association of Palliative Care (ÖPG), we searched their webpages for organization leaders or other key parties from the field, e.g. speakers for professional/scientific conferences or podcast for palliative and hospice care. If potential experts were identified via social media, we also conducted an internet search to determine their special expertise (practice/research/both).

All persons identified as potential experts were invited by e-mail to join the panel. This e-mail included a cover letter with all information about the study procedure (e.g. study aim, number of rounds and ethical information), the voluntary nature of the participation, proof of the ethical nature of the researcher and an assurance of anonymity, as well as a link to the online survey. We decided to pre-define a maximum of four rounds, running between 3 and 4 weeks, to indicate how long the whole process would last. The time frames between the rounds varied from three to four weeks.

Following the CREDES recommendations, we used their recommended four-point Likert scale (24). Based on their recommendations for the content validity index (CVI), we pre-defined the consensus agreement level (25) as having a cutoff point of 70 %.

Questionnaire

The authors developed the structured questionnaire based on a previously performed concept analysis of *end of life (*26). The concept analysis identified the attributes *clinical status/physical symptoms, psychosocial symptoms, time* and *dignity*. The transition into the end-of-life phase emerged as antecedent and end-of-life care as its consequence, respectively. Those terms were used as main criteria. Additionally, the term *relationship* was added as a main criterion because it emerged as a pertinent aspect for describing *end of life* during a literature search. All of the main criteria included subgroups which were formulated as statements or single terms that could be rated by panel experts using a four-point Likert scale. In addition, the participating experts could add additional suggestions for all criteria by answering open-ended questions. The questionnaire was also used to collect demographic data on the experts, including their age, working position (e.g. ward nurse, researcher), workplace (e.g. hospital, research lab) and years of experience in palliative care/end-of-life care or hospice care. The questionnaire was tested for face validity by the two co-authors of this manuscript and subsequently proofread by a translator with expertise in the field of palliative and hospice care. Based on the results of each round, the questionnaire was adapted by the authors and the translator. The adapted questionnaires (round 2-4) also included a summary of the results of the former round.

Data analysis

Analysis of the quantitative data collected via the questionnaire was conducted with IBM® SPSS® Statistics 26 (27).

Quantitative analysis

As in other Delphi studies conducted in the field of palliative care, the answer categories of “totally agree” and “agree” were subsumed into “agreement” and the answer categories “disagree” and “totally disagree” were subsumed into “disagreement” for data analysis purposes (12). Statements that were collectively rated at the 70 % agreement level were included in the definition. Accordingly, statements which were collectively rated at the 70 % disagreement level were excluded. Answers which were not collectively rated as achieving a 70 % agreement or disagreement level were asked again in the second round. Questions with answers that could not be collectively rated as either achieving agreement or disagreement in the second round were excluded from the definition. The decision to exclude or include the questions was always based on the results of the open-ended questions.

Qualitative analysis

The answers to the open-ended questions were analyzed by conducting a content analysis with MAXQDA version 2020 (28), applying a combination of a concept-driven strategy and a data-driven coding frame. Since the questionnaire included open-ended questions in each main category, the seven main criteria emerged as main categories (time, clinical status/physical symptoms, psychosocial symptoms, dignity, transition into the end-of-life phase, end-of-life care/specialized treatment and relationships) and therefore built the coding frame.

The subcategories were subsequently created by applying a data-driven strategy, which was based on subsumption of the data (29).

Ethical approval

The study was approved by the local ethics committee (EK-Nr. 33-372). The questionnaire was sent out via the free, open-source online statistical survey web application Lime Survey, which ensures anonymous participation. The decision to participate in the study was interpreted as an informed consent, an aspect which was also explained in Lime Survey before the individual began filling out the questionnaire.

Results

Panel characteristics

In total, 61 persons were personally invited by e-mail to participate in the Delphi panel. Four invited persons declined the invitation due to time constraints. The e-mail address of one person was not correct, and the correct one could not be found. Persons who did not decline the invitation received additional invitations by e-mail to participate in every round. The panel members were based in 11 countries, and most of them were between 51 and 60 years old. These members worked in ten different professions, with a high proportion of them having more than 10 years of working experience (Table 1 and Table 2).

Table 1: Panel characteristics: demographic data

	round 1 (*n* = 34)	**round 2 (*n* = 27)**	**round 3 (*n* = 21)**	**round 4 (*n* = 21)**
Country				
Australia	2	2	2	2
Austria	5	6	3	3
Belgium	1	1	1	1
Canada/Ontario	1	1	1	1
Germany	3	2	3	3
USA	3	2	2	2
Italy	1	2	2	1
The Netherlands	4	2	1	2
Spain	1	0	0	0
Switzerland	7	2	3	4
UK	4	4	3	3
Age groups				
20–30	1	1	1	1
31–40	3	2	2	2
41–50	6	3	1	1
51–60	18	14	13	14
61–70	5	5	4	2
71 and older	1	2	1	3

Table 2: Panel characteristics - professional data

	round 1 (*n* = 34)	round 2 (*n* = 27)	round 3 (*n* = 21)	round 4 (*n* = 21)
Profession				
Nurse	15	11	11	10
Physician	5	3	3	3
Gerontologist	1	1	0	0
Researcher	2	6	3	2
Humanist	1	0	0	0
Ethicist	3	1	1	1
Administrator	1	1	1	1
Psychologist	3	1	1	1
Social scientist	1	1	0	1
Social worker	1	1	1	1
not specified	1	1	1	1
Working area				
Hospice care	2	2	2	2
Hospital/University hospital	11	9	9	7
Joint positions in research (university) and clinical practice	6	2	2	3
University	14	14	10	8
Working position				
Academic teacher/lecturer/ senior lecturer	2	2	2	2
Advanced practice nurse	3	3	3	3
Associate professor	1	0	2	0
Assistant professor	1	0	1	1
Full professor	1	4	0	2
Chair of ethics committee	1	1	1	1
Clinic academician	1	1	0	1
Clinician in leadership position	1	1	0	0
Leader/manager	2	2	2	3
Ward nurse	2	1	2	1
Director	2	0	1	2
Head of palliative care department	1	0	0	0
Researcher	15	10	6	9
Senior physician	1	0	0	0
Senior research fellow	1	0	0	0

Senior researcher as full professor	1	0	0	0
Working experience in years				
Practical experience				
1–5 years	2	7	2	3
6–10 years	4	1	2	1
11 and more years	26	17	18	18
Research experience				
1–5 years	5	1	3	4
6–10 years	8	7	4	3
11 and more years	21	19	14	15

1st round

The analysis of data collected in the first round was based on 34 records and represented a response rate of 55 %.

Data provided in each category of the structured questionnaire were analyzed quantitatively by calculating the consensus level agreement of the statements provided (Table 3). The answers to the open-ended questions were analyzed by performing content analysis (Table 4).

Quantitative analysis

The quantitative analysis was performed by strictly adhering to the cutoff point of an agreement or disagreement of > 70 %. Consequently, the statement “death is expected within the next years” was excluded after the first round, because of a disagreement level above 70 %. The statements “death is expected within the next days”, “overall physical decline”, “difficulties with eating and drinking”, ”dignity is a main wish at the end of life”, “fear of loss of dignity”, “keeping relationships with close relatives and friends”, “building relationships with health care providers” and “building relationships with carers” achieved an agreement level of more than 70 %; therefore, these statements were excluded from the second round and considered for inclusion in the final definition, supporting the results of the qualitative analysis. Statements with an agreement level below 70 % were considered for inclusion in the 2nd round, if the statement seemed still appropriate after considering the results of the qualitative analysis.

Table 3: 1st round – agreements

Main criterion	Subgroups and further statements regarding the main criterion	Agreement/ Disagreement > 70 %
Time		
	Death is expected within the next years	79.4 % disagreement
	Death is expected within the next 12 months	no agreement/disagreement
	Death is expected within the next 6 months	no agreement/disagreement
	Death is expected within the next months	no agreement/disagreement
	Death is expected within the next weeks	no agreement/disagreement
	Death is expected within the next days	73.5 % agreement
	Time should be included in the definition, but without a specific time frame	no agreement/disagreement
Clinical status/physical symptoms		
	Overall physical decline	94 % agreement
	Cognitive decline	no agreement/disagreement
	Pain	no agreement/disagreement
	Dyspnea	no agreement/disagreement
	Difficulties with eating and drinking	73.5 % agreement
	Restriction of movement	no agreement/disagreement
Psychosocial symptoms		
	Anxiety	no agreement/disagreement
	Fear	no agreement/disagreement
	Fear of loss of control	no agreement/disagreement
	Fear of loss of autonomy	no agreement/disagreement
	Fear of dependency	no agreement/disagreement
	Fear of being a burden	no agreement/disagreement
Dignity		
	Main wish for end of life	85.3 % agreement
	Fear of loss of dignity is central at the end of life	76.5 % agreement
Transition into the end-of-life (EOL) phase		
	The transition into the EOL phase can be recognized by health care professionals	no agreement/disagreement
	The transition into the EOL phase can be recognized by the patient	no agreement/disagreement
	The transition into the EOL-phase can be recognized by the patient and the health care professionals	no agreement/disagreement

EOL care/ specialized treatment		
	EOL care/specialized treatment begins	no agreement/disagreement
	EOL care/specialized treatment should begin	no agreement/disagreement
Relationships		
	Maintaining relationships with close relatives and friends	73.5 % agreement
	Building relationships with health care provider	79.4 % agreement
	Building relationships with carers (formal/ informal)	73.5 % agreement

Qualitative analysis and synthesis

Concerning the criterion of time, 16 out of the 34 panel members made additional suggestions that identified time as a crucial factor and strongly recommended that the time frame should not be overly specific. These findings were used to adapt the questionnaire for the second round. The statements with precise time frames were omitted, and a broader statement was generated instead. This broader statement included time in the definition but did not include a time frame, indicating that death is expected between the next few days and one year. Based on suggestions from the experts, the use of predicting tools (e.g. surprise question) was also included in this adapted questionnaire. With reference to the criterion clinical status/physical symptoms, the content analysis results show that the symptoms were overly specific. For example, to broaden the statement “difficulties with eating and drinking”, the statements “functional status” and “physical symptoms” were added to incorporate these suggestions.

Regarding the criterion psychosocial symptoms, the content analysis showed that the suggested specific symptoms (anxiety and fear) were not suitable for describing the end of life. The experts argued that these symptoms are not specific to end-of-life situations. Therefore, we broadened the statement and asked if the statement “a broad variance of psychosocial symptoms might occur (e.g. anxiety or fear of loss of autonomy)” might be appropriate for inclusion in a universal definition of end of life. In response to the experts’ suggestions, a statement indicating that” spiritual needs should be considered” was added.

The content analysis results reveal the suggestion that dignity is an individual and multifactorial concept. To integrate this suggestion in the definition, we added the statement that “dignity is influenced by many individual factors”.

The suggestions related to the transition into the end-of-life phase mainly concerned the persons who should recognize this transition and to whether it is recognizable in every instance. We adapted the questionnaire by adding text messages to clarify that the transition might be recognized by patients and persons close to the patients and that it must be recognized by health care professionals.

The experts stated that the meaning of the term *specialized care*, which was used in the questionnaire, is unclear. This term was deleted, and the term *end-of-life care* was used exclusively in subsequent adaptations of the questionnaire.

13 experts gave suggestions concerning the criterion relationship; therefore, experts were asked in the second round if “maintaining existing relationships” and “building relationships as a part of end-of-life care” should be included in the definition.

Table 4: Content analysis - categories

Main category	Subcategory
Time	specific time frame
	without time frame
	predicting tool
Clinical status/physical symptoms	should be included
	should not be included
	are too specific
Psychosocial symptoms	should not be included
	are too specific
	fears
Dignity	is individual
	spirituality should be a part of definition
Transition into the end-of-life phase	transition is not recognized by the patient
	transition might be important
	transition is important
End-of-life care/specialized treatment	end-of-life care cannot be included in the definition
	specialized treatment should be renamed
	end-of-life care must begin
	end-of-life care should be included in normal care
	end-of-life care should not be included in the definition

Relationships	relationships should not be included
	relationship is very important
	relationship and communication
	wording unclear
	maintain relationships which already exists

2nd round

In the second round, 27 experts took part.

Quantitative analysis

As in the first round, the cutoff point mentioned above was applied in the second round to consider the statements for inclusion in the definition of the term end of life. The statements “death is expected between the next days and one year”, “restricted mobility” and “end-of-life care is recommended”, “building relationships is part of end-of-life care” did not achieve an acceptable level of agreement; therefore, these were not considered for inclusion in the third round.

The statements “time should be included in the definition, but without a specific time frame”, “predicting tools (e.g. surprise question) can be used to specify the time frame”, “cognitive decline”, “pain”, “dyspnea”, “functional status”, “physical symptoms”, “a broad variance of psychosocial symptoms might occur, e.g. anxiety or fear of loss of autonomy”, “spiritual needs should be considered”, “dignity is influenced by many individual factors”, “transition into the end-of-life phase may be recognized by the patient and/or persons who are close to the patient”, “transition into the end-of-life phase should be recognized by health care professionals”, “end-of-life care should be provided”, “end-of-life care (integrated in regular care or as special palliative care) should be mainly patient-centered to meet patients´ needs” and “maintaining existing relationships” all achieved an acceptable level of agreement. Therefore, these were considered for inclusion in the definition, if they were supported by the results from the analysis of the answers to the open-ended questions (Table 5).

Table 5: 2nd round – agreements

Main criterion	Subgroups and further statements regarding the main criterion	Agreement/Disagreement >70 %
Time		
	Time should be included in the definition, but without a specific time frame	81 % agreement
	Death is expected between the next few days and one year	no agreement/disagreement
	Predicting tools (e.g. Surprise question) can be used to specify the time frame	81 % agreement
Clinical status/ physical symptoms		
	Cognitive decline	70 % agreement
	Pain	70 % agreement
	Dyspnea	70 % agreement
	Restricted mobility	no agreement/disagreement
	Functional status	77 % agreement
	Physical symptoms	88 % agreement
Psychosocial symptoms		
	A broad variance of psychosocial symptoms might occur (e.g. anxiety or fear of loss of autonomy)	81 % agreement
	Spiritual needs should be considered	81 % agreement
Dignity		
	Dignity is influenced by many individual factors	70 % agreement
Transition into the end-of-life phase		
	Transition into the EOL phase may be recognized by the patient and/or persons who are close to the patient	77 % agreement
	Transition into the end-of-life phase should be recognized by health care professionals	77 % agreement
EOL care		
	End-of-life care is recommended	no agreement/disagreement
	End-of-life care should be provided	70 % agreement
	End-of-life care can be integrated in regular care	no agreement/disagreement
	End-of-life care (integrated in regular care or as special palliative care) should be mainly patient-centered to meet the patients' needs	77 % agreement
Relationships		
	Maintaining existing relationships	81 % agreement
	Building relationships is part of end-of-life care	no agreement/disagreement

Qualitative analysis and synthesis

Experts made eight additional suggestions regarding the main criterion of time. These comprised three suggestions to include a specific time frame and five suggestions to not include a specific time frame. The results of the first and second rounds led us to conclude that time is important but that setting a time frame is very difficult. Concerning the main criterion of clinical status/physical symptoms, seven panelists suggested to not use specific symptoms.

Regarding the psychosocial symptoms, panel members made five suggestions which mainly concerned the wording; specifically, they indicated that it was important not to confuse psychosocial symptoms with needs and spirituality. With regard to the criterion dignity, nine panel members advised us to consider cultural values and made recommendations about the wording and the use of the term dignity, especially at the end of life. In answers to the open-ended questions with reference to the criterion transition into the end-of-life phase, seven experts stated that it might be very difficult to recognize this transition in every individual.

In the open-ended questions about end-of-life care, six panel members suggested that end-of-life care should be defined, that it is essential, that it should only be provided if the individual wants it and that it is necessary for end-of-life care to be patient-centered. Regarding relationships, the answers to the open-ended questions concerned the definition and use of the term. Furthermore, four panel members indicated that the end-of-life phase is not a time to build new relationships but to strengthen existing relationships.

On the basis of the agreements/disagreements detected in the second round and the results of qualitative analysis, statements were formulated for the 3rd round as text (Table 6).

3rd round

In the third round, 21 panel members completed the questionnaire. An agreement level that exceeded the cutoff point of > 70 % was achieved for all statements (Table 6).

Table 6: 3rd round - results

Main criterion	Text passages regarding the main criterion	Agreement/ Disagreement > 70 %
Time		
	“Time is a crucial aspect, but it is not possible to set (define) a specific time frame; considerations of the overall physical decline and/ or the occurrence of physical symptoms, such as pain or dyspnea, might indicate that the time until death is limited. The use of specific prediction tools might help health care personnel to estimate a time frame, if this is desired.”	90 %
Clinical status/physical symptoms		
	“On the whole, an overall physical decline can be observed, which is also described as a decline in functional status. Additional physical symptoms (e.g. dyspnea, pain, cognitive decline) may often occur.”	85 %
Psychosocial symptoms		
	“In this phase (process) of life, a broad variety of psychosocial symptoms might occur (e.g. confusion, existential anxiety, or fear of loss of autonomy). In addition, the individual nearing death might also perceive that they have individual, spiritual needs. This should be considered by both formal and informal carers to ensure that the possible psychosocial and spiritual needs of the person in their care are recognized and fulfilled."	80 %
Dignity		
	“Health professionals need to be aware and take into consideration the fact that dignity is a highly individual and multifactorial concept that is influenced by personal experiences and/ or cultural aspects, as well as other factors. As the last phase of life is often accompanied by a fear of loss of dignity, the aspect of dignity or the wish for dignity, respectively, may take on particular significance during this time.”	100 %

Transition into the end-of-life phase		
	“For health professionals, a recognition of the transition into the end-of-life phase is an important prerequisite to initiate and provide appropriate care and person-centered treatment in a timely manner. This may prove to be a difficult task for every individual, including for health professionals. Nevertheless, it may be possible for the patient or for persons who are close to the patient to recognize their transition into the end-of life phase.”	71 %
EOL care		
	“End-of-life care (i.e., appropriate care or treatment for this particular phase of life), should be provided if the patient wishes for it or agrees to it. End-of-life care (integrated in regular care or as special palliative care) should be particularly patient-centered and consider the individual needs and wishes of patient as well as of the persons who are close to the patient.”	80 %
Relationships		
	“The wish to maintain the existing relationships may be crucial or of particular importance in the last phase of life. The wish to mend previously broken or difficult relationships may also increase in significance or deserve consideration during this time."	90 %

Analysis and synthesis of the answers to open-ended questions

In the third round, a content analysis was not performed due the low number of suggestions received. Nevertheless, the suggestions in the answers to the open-ended questions, and especially those on topics where disagreement was recognized, were considered for the formulation of the draft of the definition. In particular, some statements for the topic end-of-life care suggested that it should be patient-tailored or stressed the importance of spiritual needs. This draft definition was presented to the panel members in the 4th round.

4th round

In the 4th and last round, a draft definition was presented and panel members were asked to rate this definition. 20 experts agreed/strongly agreed with the definition, and one expert disagreed. In addition, 13 experts provided comments about the definition. These included six comments indicating that the definition was too long, five comments about language or sentence formulation, and five comments about the definition content. Even if the level of agreement was high, we also considered the received additional comments. On this basis, we provide the following definition of the term *end of life*:

"The end of life is a phase or process of life where an overall physical decline or a decline of functional status is observable. Time is a crucial aspect, even if it is rarely possible to set a specific time frame. Consideration of the overall physical decline or an acutely progressing symptom burden may indicate to health care professionals, the individuals nearing death themselves, or persons close to them that time until death is limited. Additional physical symptoms (e.g. dyspnea) or cognitive decline may often be present. A timely recognition of the transition into the end-of-life phase by health care professionals is an imperative prerequisite, which enables them to initiate and ensure appropriate care (end-of-life care). The use of specific prediction tools may assist in setting an approximate time frame. End-of-life care should be offered to all persons nearing death, address the individual needs and wishes of the persons nearing death, and consider the support needs of the persons close to the patient. A person's progress towards death may give rise to various emotions and acute psychosocial needs (e.g. confusion, existential anxiety, fear of loss of autonomy) as well as spiritual needs that should be considered. Health professionals need to be aware that a person's sense of dignity is a highly individual and multifaceted concept which is influenced by personal and cultural factors, as well as other factors. As the last phase of life may often be accompanied by a fear of loss of dignity, the person's sense of dignity or the wish to preserve it may take on particular significance during this time. Persons nearing death may still forge new, meaningful relationships. Nevertheless, the wish to maintain existing relationships or to mend previously broken or difficult ones may increase in significance during this time. Health care professionals and informal carers should take into consideration all of these aspects to ensure that the physical, psychosocial and spiritual needs of the person under their care are addressed appropriately."

Discussion

In the suggested definition, we address aspects of physical decline and symptoms, time, and the transition into the end-of-life phase and, therefore, provide support for recognizing the starting point of the end-of-life phase. Psychosocial needs, including the aspect of spirituality as dignity and relationships, were also addressed.

If there are any specific symptoms for end of life, these were discussed via the open-ended questions by the panel members. For instance, some authors of recent articles argue that the worsening of specific symptoms such as dyspnea, fatigue, or dry mouth may be predictors of survival time for patients with advanced cancer. Overall indications of a physical decline, such as increasing frailty, may also be predictors for nearing death (30, 31). Both in the literature and in the definition, a consensus is recognizable that an overall decline in physical and functional status accompanied by an increase of symptoms occurs at the end of life (32-34). For clinical practice, this might help raise awareness that such a perceived functional decline might indicate the transition into the end-of-life phase, which then might be a recognizable starting-point for adequate end-of-life care and for addressing the crucial aspect of setting an approximate time frame until death.

As described in the literature and confirmed by the panel experts, to define the remaining time until death is difficult or sometimes impossible, in particular in patients with e.g. dementia (9, 13, 31). Being able to predict the remaining time would be valuable for clinical practice to initiate and provide timely and dignified end-of-life care (35).Therefore, the panel members suggested to use prediction tools, which were then included in the definition to emphasize the importance of identifying the transition into the end-of-life phase. The advantages and disadvantages concerning their validity and diagnostic accuracy are discussed in the literature. Some sources suggest that by applying such tools the underlying disease, for instance, might be recognized (15, 36-38).

The high level of agreement reached in in the first round on the criterion of dignity clearly indicated that this needed to be part of the definition. For health care professionals, there might be no doubt that they are responsible for providing dignified care, particularly at the end of life, even if it has to mentioned that dignity is a multifaceted, individual aspect that can make it difficult to address this responsibility (17, 39-41)

As a main limitation of this Delphi Study it has to mentioned that the experts of the panel were only from Western European countries, North America and Australia and that no patients were involved in the expert panel.

Conclusion

Defining the end-of-life phase requires the consideration of multiple aspects. The process of recognizing the end-of-life phase in a timely manner can be supported by considering the patient’s physical decline and any psychosocial symptoms that occur. If it is possible and is in accordance with the patient’s wishes, a prognosis of the remaining time until death can be made. This prognosis is followed by the provision of appropriate care (i.e., end-of-life care) from a primarily holistic and patient-centered view, taking into account the patient’s dignity and the relationships they consider important.

Author’s contributions

G.S, F.G, and C.L. contributed to the recruitment of the panel members, the development of the questionnaires and the study design. Data analysis was performed by G.S. G.S. wrote the manuscript with critical feedback from F.G. and C.L. The manuscript, in particular its results, was discussed repeatedly by all authors.

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References

(1) Hui D, Mori M, Parsons HA, Kim SH, Li Z, Damani S, et al. The lack of standard definitions in the supportive and palliative oncology literature. J Pain Symptom Manage. 2012;43 (3):582-92.

(2) Ryan S, Wong J, Chow R, Zimmermann C. Evolving Definitions of Palliative Care: Upstream Migration or Confusion? Current treatment options in oncology. 2020;21 (3):20.

(3) Xiao J, Brenneis C, Ibrahim N, Bryan A, Fassbender K. Definitions of Palliative Care Terms: A Consensus-Oriented Decision-Making Process. J Palliat Med. 2021;24 (9):1342-50.

(4) Fliedner MC, Zambrano SC, Eychmueller S. Public perception of palliative care: a survey of the general population. Palliative Care and Social Practice. 2021;15:26323524211017546.

(5) Flierman I, Nugteren IC, van Seben R, Buurman BM, Willems DL. How do hospital-based nurses and physicians identify the palliative phase in their patients and what difficulties exist? A qualitative interview study. BMC Palliative Care. 2019;18 (1):54.

(6) Fliedner M, Zambrano S, Schols JM, Bakitas M, Lohrmann C, Halfens RJ, et al. An early palliative care intervention can be confronting but reassuring: A qualitative study on the experiences of patients with advanced cancer. Palliat Med. 2019;33 (7):783-92.

(7) Haun MW, Estel S, Rücker G, Friederich HC, Villalobos M, Thomas M, et al. Early palliative care for adults with advanced cancer. Cochrane Database Syst Rev. 2017;6 (6):Cd011129.

(8) Hui D, Nooruddin Z, Didwaniya N, Dev R, De La Cruz M, Kim SH, et al. Concepts and definitions for “actively dying,” “end of life,” “terminally ill,” “terminal care,” and “transition of care”: a systematic review. Journal of Pain & Symptom Management. 2014;47 (1):77-89.

(9) Stiel S, Krause O, Berndt CS, Ewertowski H, Müller-Mundt G, Schneider N. Caring for frail older patients in the last phase of life. Zeitschrift für Gerontologie und Geriatrie. 2020;53 (8):763-9.

(10) Dalkin SM, Lhussier M, Philipson P, Jones D, Cunningham W. Reducing inequalities in care for patients with non-malignant diseases: Insights from a realist evaluation of an integrated palliative care pathway. Palliative Medicine. 2016;30 (7):690-7.

(11) Kennedy C, Brooks-Young P, Brunton Gray C, Larkin P, Connolly M, Wilde-Larsson B, et al. Diagnosing dying: an integrative literature review. BMJ Support Palliat Care. 2014;4 (3):263-70.

(12) Radbruch L, De Lima L, Knaul F, Wenk R, Ali Z, Bhatnaghar S, et al. Redefining Palliative Care-A New Consensus-Based Definition. J Pain Symptom Manage. 2020.

(13) Browne B, Kupeli N, Moore KJ, Sampson EL, Davies N. Defining end of life in dementia: A systematic review. Palliat Med. 2021:2692163211025457.

(14) Cardona-Morrell M, Lewis E, Suman S, Haywood C, Williams M, Brousseau A-A, et al. Recognising older frail patients near the end of life: What next? European Journal of Internal Medicine. 2017;45:84-90.

(15) Chu C, White N, Stone P. Prognostication in palliative care. Clin Med (Lond). 2019;19 (4):306-10.

(16) Stow D, Spiers G, Matthews FE, Hanratty B. What is the evidence that people with frailty have needs for palliative care at the end of life? A systematic review and narrative synthesis. Palliative Medicine. 2019;33 (4):399-414.

(17) Jünger SDrm, Payne SBARNDPC, Brearley SP, Ploenes VMD, Radbruch LMD. Consensus Building in Palliative Care: A Europe-Wide Delphi Study on Common Understandings and Conceptual Differences. Journal of Pain and Symptom Management. 2012;44 (2):192-205.

(18) Mechelen Wv, Aertgeerts B, De Ceulaer K, Thoonsen BA, Vermandere M, Warmenhoven FC, et al. Defining the palliative care patient: A systematic review. VOLUME = 27;STARTPAGE = 197;ENDPAGE = 208;ISSN = 0269-2163;TITLE = Palliative Medicine. 2013.

(19) Weaver K, Mitcham C. Nursing concept analysis in North America: state of the art. Nursing philosophy : an international journal for healthcare professionals. 2008;9 (3):180-94.

(20) Rodgers BL, Jacelon CS, Knafl KA. Concept Analysis and the Advance of Nursing Knowledge: State of the Science. Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing. 2018;50 (4):451-9.

(21) Wong EL-Y, Kiang N, Chung RY-N, Lau J, Chau PY-K, Wong SY-S, et al. Quality of Palliative and End-Of-Life Care in Hong Kong: Perspectives of Healthcare Providers. International journal of environmental research and public health. 2020;17 (14):5130.

(22) McKenna HP. The Delphi technique: a worthwhile research approach for nursing? J Adv Nurs. 1994;19 (6):1221-5.

(23) Chia-Chien H, Sandford B. The Delphi Technique: Making Sense of Consensus. Pracitcal Asesseement, Research & Evaluation. 2007;12 (10).

(24) Jünger S, Payne SA, Brine J, Radbruch L, Brearley SG. Guidance on Conducting and REporting DElphi Studies (CREDES) in palliative care: Recommendations based on a methodological systematic review. Palliat Med. 2017;31 (8):684-706.

(25) Polit DF, Beck CT, Owen SV. Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. Research in nursing & health. 2007;30 (4):459-67.

(26) Schüttengruber G, Halfens R, Lohrmann C. „End of life“: A Concept Analysis. International Journal of Palliative Nursing. 2021;accepted.

(27) IBM C. SPSS statistics for Windows. Version 26.0. Armonk, NY2019.

(28) Software V. MAXQDA 2020. Berlin, Germany2019.

(29) Kuckartz U. Qualitative Inhaltsanalyse. Methoden, Praxis, Computerunterstützung. 4 ed: Beltz Juventa; 2018.

(30) Suh SY, Won SH, Hiratsuka Y, Choi SE, Cheng SY, Mori M, et al. Assessment of Changes in Symptoms Is Feasible and Prognostic in the Last Weeks of Life: An International Multicenter Cohort Study. J Palliat Med. 2021.

(31) Cardona-Morrell M, Lewis E, Suman S, Haywood C, Williams M, Brousseau AA, et al. Recognising older frail patients near the end of life: What next? Eur J Intern Med. 2017;45:84-90.

(32) Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at the end of life. JAMA. 2003;289 (18):2387-92.

(33) Stolz E, Gill TM, Mayerl H, Rásky É, Freidl W. Trajectories of Late-Life Disability Vary by the Condition Leading to Death. J Gerontol A Biol Sci Med Sci. 2021;76 (7):1260-4.

(34) Morgan DD, Tieman JJ, Allingham SF, Ekström MP, Connolly A, Currow DC. The trajectory of functional decline over the last 4 months of life in a palliative care population: A prospective, consecutive cohort study. Palliat Med. 2019;33 (6):693-703.

(35) Choo PY, Tan-Ho G, Dutta O, Patinadan PV, Ho AHY. Reciprocal Dynamics of Dignity in End-of-Life Care: A Multiperspective Systematic Review of Qualitative and Mixed Methods Research. Am J Hosp Palliat Care. 2020;37 (5):385-98.

(36) White N, Kupeli N, Vickerstaff V, Stone P. How accurate is the ‘Surprise Question’ at identifying patients at the end of life? A systematic review and meta-analysis. BMC Medicine [Internet]. 2017; 15 (1):[1-14 pp.].

(37) Downar J, Goldman R, Pinto R, Englesakis M, Adhikari NK. The “surprise question” for predicting death in seriously ill patients: a systematic review and meta-analysis. CMAJ : Canadian Medical Association journal = journal de l’Association medicale canadienne. 2017;189 (13):E484-e93.

(38) Simmons CPL, McMillan DC, McWilliams K, Sande TA, Fearon KC, Tuck S, et al. Prognostic Tools in Patients With Advanced Cancer: A Systematic Review. Journal of Pain and Symptom Management. 2017;53 (5):962-70.e10.

(39) Viftrup DT, Hvidt NC, Prinds C. Dignity in end-of-life care at hospice: An Action Research Study. Scand J Caring Sci. 2020.

(40) Bovero A, Tosi C, Botto R, Pidinchedda A, Gottardo F, Asta G, et al. A Qualitative Study to Explore Healthcare Providers’ Perspectives on End-of-Life Patients’ Dignity. How Can Dignity Be Defined, and Which Strategies Exist to Maintain Dignity? Journal of cancer education : the official journal of the American Association for Cancer Education. 2020.

(41) Staats K, Grov EK, Husebø BS, Tranvåg O. Dignity of older home-dwelling women nearing end-of-life: Informal caregivers’ perception. Nurs Ethics. 2020:969733020956372.

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ORIGINAL ARTICLE

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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 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.

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.

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

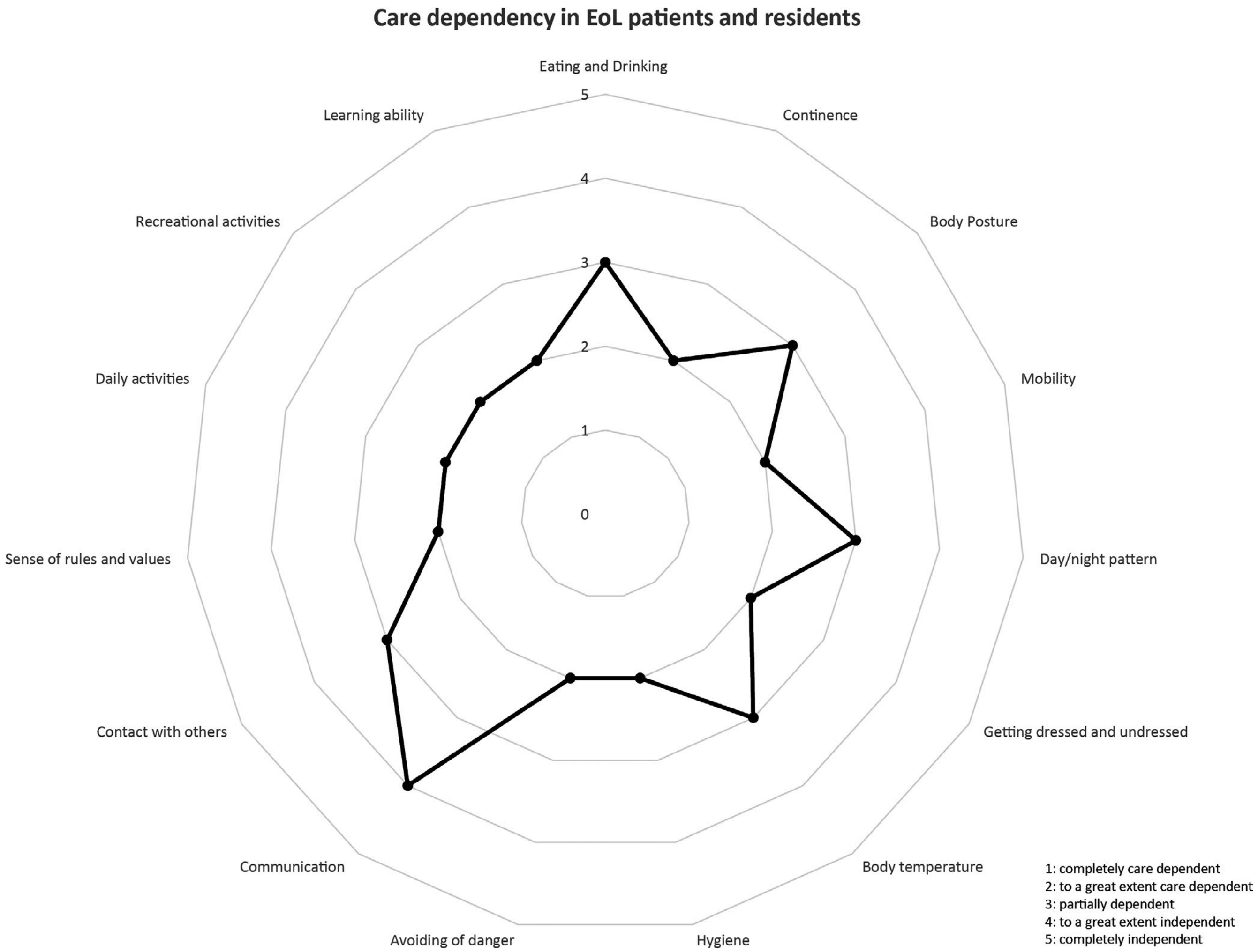

FIGURE 1 Care Dependency in EoL Patients and Residents on an Item Level

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

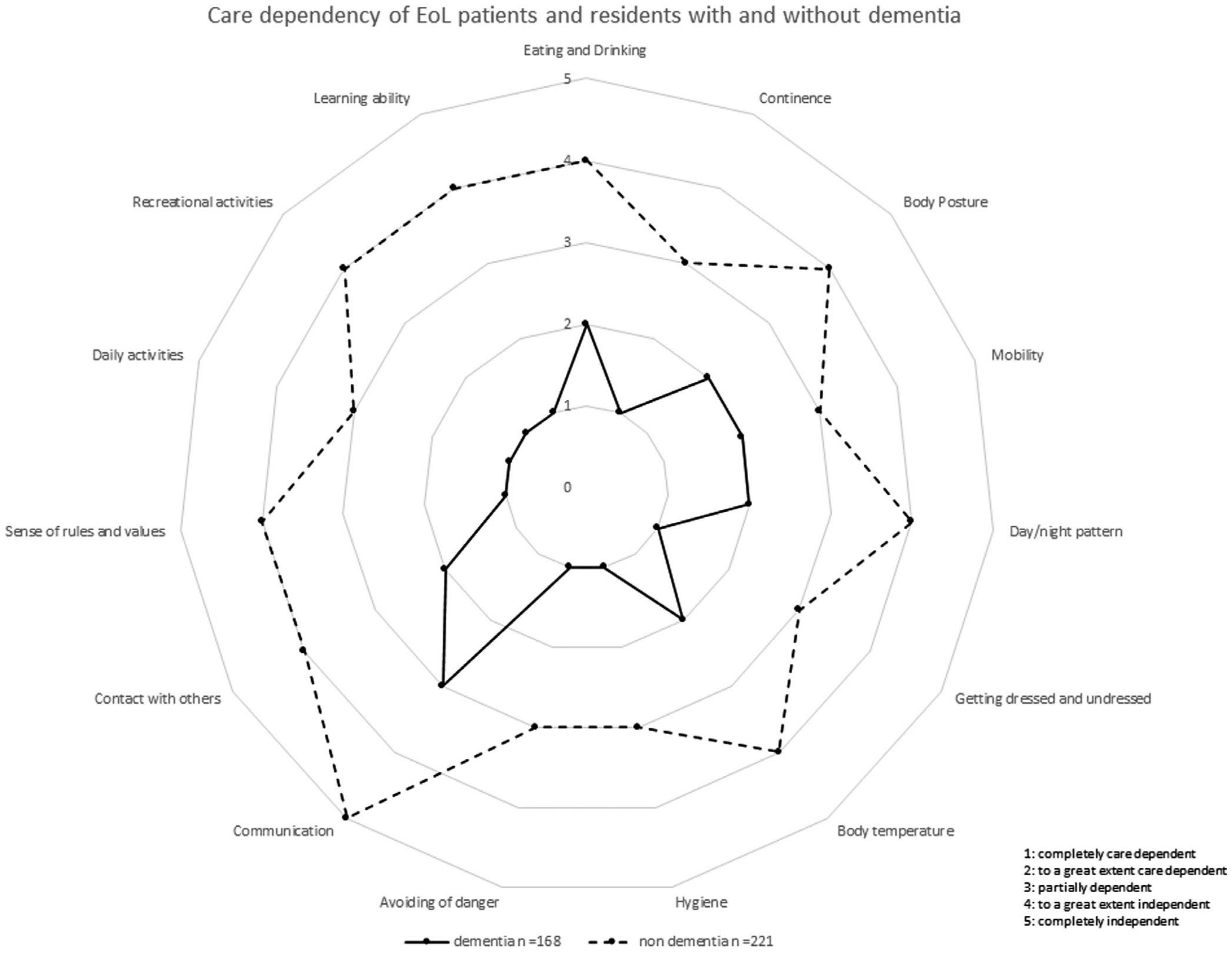

FIGURE 2 Care dependency of EoL patients and residents with and without dementia

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.

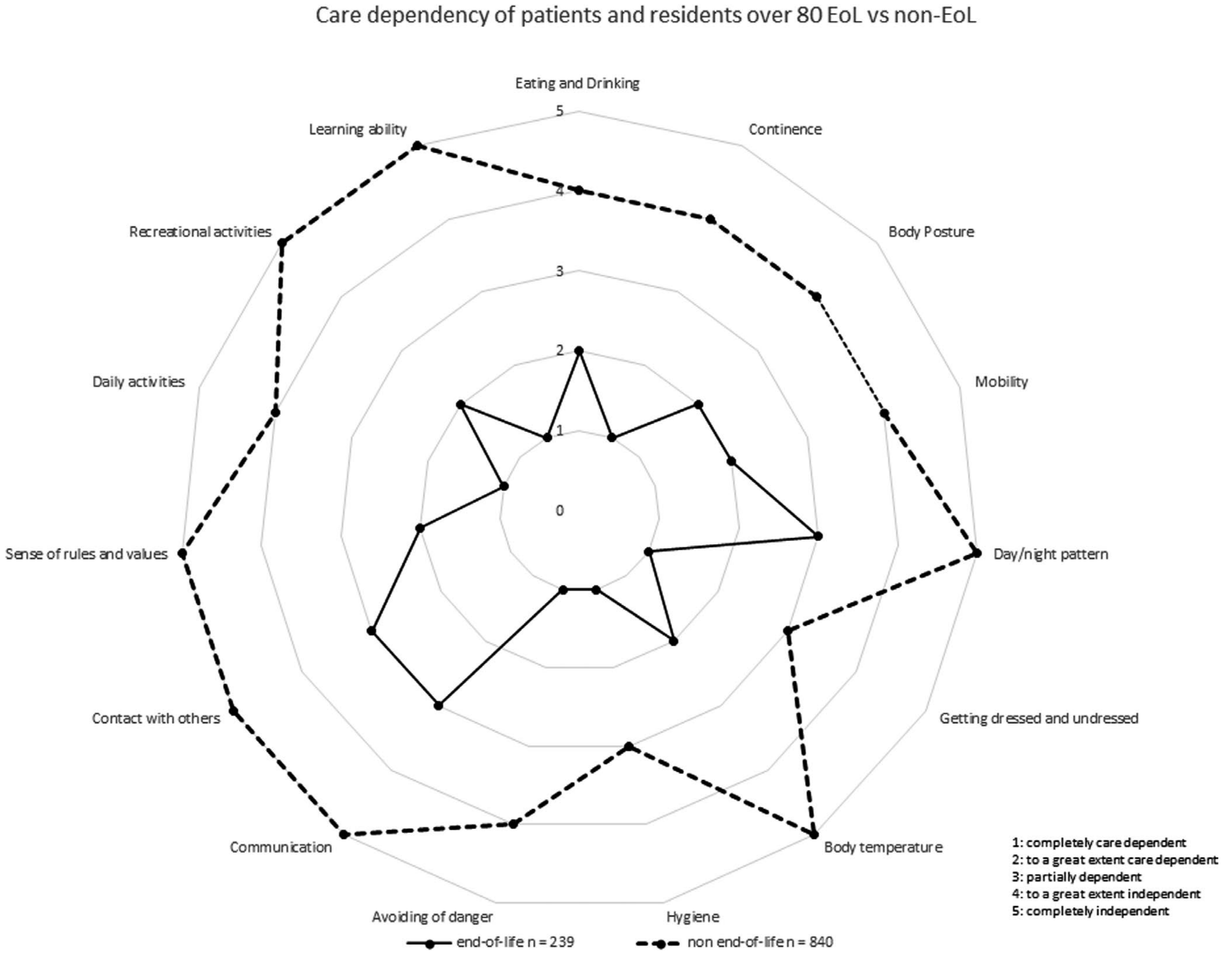

FIGURE 3 Care dependency of EoL and non-EoL patients and residents who were 80 years of age and older

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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REFERENCES

Amblàs-Novellas, J., Murray, S. A., Espaulella, J., Martori, J. C., Oller, R., Martinez-Muñoz, M., Molist, N., Blay, C., & Gómez-Batiste, X. (2016). Identifying patients with advanced chronic conditions for a progressive palliative care approach: A cross-sectional study of prognostic indicators related to end-of-life trajectories. *British Medical Journal Open*, *6*(9), e012340. https://doi.org/10.1136/bmjopen-2016-012340

Bamford, C., Lee, R., McLellan, E., Poole, M., Harrison-Dening, K., Hughes, J., Robinson, L., & Exley, C. (2018). What enables good end of life care for people with dementia? A multi-method qualitative study with key stakeholders. *BMC Geriatrics*, *18*(1), 302. https://doi.org/10.1186/s12877-018-0983-0

Bern-Klug, M. (2004). The ambiguous dying syndrome. *Health Soc Work*, *29*(1), 55–65. https://doi.org/10.1093/hsw/29.1.55.

Boggatz, T., Farid, T., Mohammedin, A., Dijkstra, A., Lohrmann, C., & Dassen, T. (2009). Psychometric properties of the extended Care Dependency Scale for older persons in Egypt. *Journal of Clinical Nursing*, *18*(23), 3280–3289. https://doi.org/10.1111/j.1365-2702.2009.02946.x

Boyd, M., Frey, R., Balmer, D., Robinson, J., McLeod, H., Foster, S., Slark, J., & Gott, M. (2019). End of life care for long-term care residents with dementia, chronic illness and cancer: prospective staff survey. *BMC Geriatrics*, *19*(1), 137. https://doi.org/10.1186/s12877-019-1159-2

Caljouw, M. A., Cools, H. J., & Gussekloo, J. (2014). Natural course of care dependency in residents of long-term care facilities: prospective follow-up study. *BMC Geriatrics*, *14*(1), 67. https://doi.org/10.1186/1471-2318-14-67

Dalkin, S. M., Lhussier, M., Philipson, P., Jones, D., & Cunningham, W. (2016). Reducing inequalities in care for patients with non-malignant diseases: Insights from a realist evaluation of an integrated palliative care pathway. *Palliative Medicine*, *30*(7), 690–697. https://doi.org/10.1177/0269216315626352

Delgado-Guay, M. O., Rodriguez-Nunez, A., De la Cruz, V., Frisbee-Hume, S., Williams, J., Wu, J., Liu, D., Fisch, M. J., & Bruera, E. (2016). Advanced cancer patients' reported wishes at the end of life: A randomized controlled trial. *Supportive Care in Cancer*, *24*(10), 4273–4281. https://doi.org/10.1007/s00520-016-3260-9

Dijkstra, A., Brown, L., Havens, B., Romeren, T. I., Zanotti, R., Dassen, T. W., & van den Heuvel, W. (2000). An international psychometric testing of the care dependency scale. *Journal of Advanced Nursing*, *31*, 944–952. https://doi.org/10.1046/j.1365-2648.2000.01354.x

Dijkstra, A., Buist, G., & Dassen, T. (1996). Nursing-care dependency. *Scandinavian Journal of Caring Sciences*, *10*(3), 137–143. https://doi.org/10.1111/j.1471-6712.1996.tb00326.x

Dijkstra, A., Buist, G., & Dassen, T. (1998). Operationalization of the concept of 'nursing care dependency' for use in long-term care facilities. *Australian and New Zealand Journal of Mental Health Nursing*, *7*, 142–151.

Dijkstra, A., Buist, G., Moorer, P., & Dassen, T. (1999). Construct validity of the Nursing Care Dependency Scale. *Journal of Clinical Nursing*, *8*(4), 380–388. https://doi.org/10.1046/j.1365-2702.1999.00245.x

Dijkstra, A., Smith, J., & White, M. (2006). *Measuring care dependency with the Care Dependency Scale (CDS): A manual*. https://www.umcg.nl/sitecollectiondocuments/research/institutes/share/assessment%20tools/cds%20manual%20english.pdf

Dijkstra, A., Tiesinga, L. J., Goossen, W. T., & Dassen, T. W. (2002). Further psychometric testing of the Dutch Care Dependency Scale on two different patient groups. *International Journal of Nursing Practice*, *8*(6), 305–314. https://doi.org/10.1046/j.1440-172X.2002.00384.x

Dijkstra, A., Yönt, G. H., Korhan, E. A., Muszalik, M., Kędziora-Kornatowska, K., & Suzuki, M. (2012). The Care Dependency Scale for measuring basic human needs: An international comparison. *Journal of Advanced Nursing*, *68*(10), 2341–2348. https://doi.org/10.1111/j.1365-2648.2011.05939.x

Doroszkiewicz, H., Sierakowska, M., & Muszalik, M. (2018). Utility of the Care Dependency Scale in predicting care needs and health risks of elderly patients admitted to a geriatric unit: A cross-sectional study of 200 consecutive patients. *Clinical Interventions in Aging*, *13*, 887–894. https://doi.org/10.2147/CIA.S159511

Dwyer, L. L., Nordenfelt, L., & Ternestedt, B. M. (2008). Three nursing home residents speak about meaning at the end of life. *Nursing Ethics*, *15*(1), 97–109. https://doi.org/10.1177/0969733007083938

Edjolo, A., Proust-Lima, C., Delva, F., Dartigues, J. F., & Pérès, K. (2016). Natural history of dependency in the elderly: A 24-year population-based study using a longitudinal item response theory model. *American Journal of Epidemiology*, *183*(4), 277–285. https://doi.org/10.1093/aje/kwv223

Eglseer, D., Hödl, M., & Lohrmann, C. (2018). Die Österreichische Pflegequalitätserhebung 2.0. *ProCare*, *23*(4), 44–45. https://doi.org/10.1007/s00735-018-0894-5

Eichhorn-Kissel, J., Dassen, T., Kottner, J., & Lohrmann, C. (2010). Psychometric testing of the modified Care Dependency Scale for Rehabilitation. *Clinical Rehabilitation*, *24*(4), 363–372. https://doi.org/10.1177/0269215509346091

Eichhorn-Kissel, J., Dassen, T., & Lohrmann, C. (2010). The clinical utility of the Care Dependency Scale in rehabilitation: Nurses' perception. *Journal of Research in Nursing*, *15*(6), 547–561. https://doi.org/10.1177/1744987110369461

Finucane, A. M., Stevenson, B., & Murray, S. A. (2017). Gradual physical decline characterises the illness trajectories of care home residents. *International Journal of Palliative Nursing*, *23*(9), 457–461. https://doi.org/10.12968/ijpn.2017.23.9.457

Flierman, I., Nugteren, I. C., van Seben, R., Buurman, B. M., & Willems, D. L. (2019). How do hospital-based nurses and physicians identify the palliative phase in their patients and what difficulties exist? A qualitative interview study. *BMC Palliative Care*, *18*(1), 54. https://doi.org/10.1186/s12904-019-0439-0

Hall, S., Petkova, H., Tsouros, A., Costantini, M., & Higginson, M. (2011). *Palliative care for older people: Better practices*. World Health Organization.

Henderson, V. (1966). *The nature of nursing a definition and its implications for practice, research, and education*. Collier-Macmillan, Limited.

Hill, E., Savundranayagam, M. Y., Zecevic, A., & Kloseck, M. (2018). Staff perspectives of barriers to access and delivery of palliative care for persons with dementia in long-term care. *American Journal of Alzheimer's Disease & Other Dementiasr*, *33*(5), 284–291. https://doi.org/10.1177/153331751876512

Horne, G., Seymour, J., & Payne, S. (2012). Maintaining integrity in the face of death: A grounded theory to explain the perspectives of people affected by lung cancer about the expression of wishes for end of life care. *International Journal of Nursing Studies*, *49*(6), 718–726. https://doi.org/10.1016/j.ijnurstu.2011.12.003

Hui, D., Nooruddin, Z., Didwaniya, N., Dev, R., De La Cruz, M., Kim, S. H., Kwon, J. H., Hutchins, R., Liem, C., & Bruera, E. (2014). Concepts and definitions for "actively dying," "end of life," "terminally ill," "terminal care," and "transition of care": A systematic review. *Journal of Pain & Symptom Management*, *47*(1), 77–89. https://doi.org/10.1016/j.jpainsymman.2013.02.021

IBM Corp. (2019). *SPSS statistics for Windows. Version 26.0*. IBM Corp.

Institute of Nursing Science. (2020). *Pflegequalitätserhebung 2.0 (PQE 2.0)*. Retrieved from https://at.lpz-um.eu/de

Koppitz, A., Bosshard, G., Schuster, D. H., Hediger, H., & Imhof, L. (2015). Type and course of symptoms demonstrated in the terminal and dying phases by people with dementia in nursing homes. *Zeitschrift Fur Gerontologie Und Geriatrie*, *48*(2), 176–183. https://doi.org/10.1007/s00391-014-0668-z

Kottner, J., Halfens, R., & Dassen, T. (2010). Interrater reliability and agreement of the Care Dependency Scale in the home care setting in the Netherlands. *Scandinavian Journal of Caring Sciences*, *24*, 56–61. https://doi.org/10.1111/j.1471-6712.2009.00765.x

Lloyd, L., White, K., & Sutton, E. (2011). Researching the end-of-life in old age: Cultural, ethical and methodological issues. *Ageing & Society*, *31*(3), 386–407. https://doi.org/10.1017/S0144686X10000966

Lohrmann, C., Dijkstra, A., & Dassen, T. (2003a). The Care Dependency Scale: An assessment instrument for elderly patients in German hospitals. *Geriatric Nursing*, *24*(1), 40–43. https://doi.org/10.1067/mgn.2003.8

Lohrmann, C., Dijkstra, A., & Dassen, T. (2003b). Care dependency: Testing the German version of the Care Dependency Scale in nursing homes and on geriatric wards. *Scandinavian Journal of Caring Sciences*, *17*(1), 51–56. https://doi.org/10.1046/j.1471-6712.2003.00117.x

Mataqi, M., & Aslanpour, Z. (2019). Factors influencing palliative care in advanced dementia: A systematic review. *BMJ Supportive & Palliative Care*, *10*, 145–156. https://doi.org/10.1136/bmjspcare-2018-001692

McCleary, L., Thompson, G. N., Venturato, L., Wickson-Griffiths, A., Hunter, P., Sussman, T., & Kaasalainen, S. (2018). Meaningful connections in dementia end of life care in long term care homes. *BMC Psychiatry*, *18*(1), 307. https://doi.org/10.1186/s12888-018-1882-9

Murray, S. A., Kendall, M., Boyd, K., & Sheikh, A. (2005). Illness trajectories and palliative care. *BMJ*, *330*(7498), 1007–1011. https://doi.org/10.1136/bmj.330.7498.1007

Nie-Visser, N. C., Schols, J. M. G. A., Meesterberends, E., Lohrmann, C., Meijers, J. M. M., & Halfens, R. J. G. (2013). An International prevalence measurement of care problems: Study protocol. *Journal of Advanced Nursing*, *69*, e18–e29. https://doi.org/10.1111/jan.12190

Omar Daw Hussin, E., Wong, L. P., Chong, M. C., & Subramanian, P. (2018). Nurses' perceptions of barriers and facilitators and their associations with the quality of end-of-life care. *Journal of Clinical Nursing*, *27*(3–4), e688–e702. https://doi.org/10.1111/jocn.14130

Piredda, M., Bambi, S., Biagioli, V., Marchetti, A., Ianni, A., Lusignani, M., Rasero, L., Matarese, M., & De Marinis, M. G. (2020). Cross-validation of the Care Dependency Scale in intensive care unit (ICU-CDS). *Intensive & Critical Care Nursing*, *57*, 102787. https://doi.org/10.1016/j.iccn.2019.102787

Piredda, M., Bartiromo, C., Capuzzo, M. T., Matarese, M., & De Marinis, M. G. (2016). Nursing care dependence in the experiences of advanced cancer inpatients. *European Journal of Oncology Nursing*, *20*, 125–132. https://doi.org/10.1016/j.ejon.2015.07.002

Piredda, M., Biagioli, V., Gambale, G., Porcelli, E., Barbaranelli, C., Palese, A., & De Marinis, M. G. (2016). Psychometric testing of the modified Care Dependency Scale (Neuro-CDS). *NeuroRehabilitation*, *38*(2), 211–219. https://doi.org/10.3233/nre-161312

Santivasi, W. L., Partain, D. K., & Whitford, K. J. (2020). The role of geriatric palliative care in hospitalized older adults. *Hospital Practice*, *48*(sup1), 37–47. https://doi.org/10.1080/21548331.2019.1703707

Schmidt, H., Eisenmann, Y., Golla, H., Voltz, R., & Perrar, K. M. (2018). Needs of people with advanced dementia in their final phase of life: A multi-perspective qualitative study in nursing homes. *Palliative Medicine*, *32*(3), 657–667. https://doi.org/10.1177/0269216317746571

Schüssler, S., Dassen, T., & Lohrmann, C. (2015). Comparison of care dependency and related nursing care problems between Austrian nursing home residents with and without dementia. *European Geriatric Medicine*, *6*(1), 46–52. https://doi.org/10.1016/j.eurger.2014.04.015

Smets, T., Onwuteaka-Philipsen, B. B. D., Miranda, R., Pivodic, L., Tanghe, M., van Hout, H., Pasman, R. H. R. W., Oosterveld-Vlug, M., Piers, R., Van Den Noortgate, N., Wichmann, A. B., Engels, Y., Vernooij-Dassen, M., Hockley, J. O., Froggatt, K., Payne, S., Szczerbińska, K., Kylänen, M., Leppäaho, S., … Van den Block, L. (2018). Integrating palliative care in long-term care facilities across Europe (PACE): Protocol of a cluster randomized controlled trial of the 'PACE Steps to Success' intervention in seven countries. *BMC Palliative Care*, *17*(1), 47. https://doi.org/10.1186/s12904-018-0297-1

Stabenau, H. F., Morrison, L. J., Gahbauer, E. A., Leo-Summers, L., Allore, H. G., & Gill, T. M. (2015). Functional trajectories in the year before hospice. *Annals of Family Medicine*, *13*(1), 33–40. https://doi.org/10.1370/afm.1720

Statistics Austria. (2020). *Gestorbene Gestorbene nach ausgewählten Merkmalen, Lebenserwartung und Säuglingssterblichkeit seit 2009*. Retrieved from http://www.statistik.at/web_de/statistiken/menschen_und_gesellschaft/bevoelkerung/gestorbene/index.html

Stow, D., Spiers, G., Matthews, F. E., & Hanratty, B. (2019). What is the evidence that people with frailty have needs for palliative care at the end of life? A systematic review and narrative synthesis. *Palliative Medicine*, *33*(4), 399–414. https://doi.org/10.1177/0269216319828650

Threapleton, D. E., Chung, R. Y., Wong, S. Y. S., Wong, E. L. Y., Kiang, N., Chau, P. Y. K., Woo, J., Chung, V. C. H., & Yeoh, E. K. (2017). Care toward the end of life in older populations and its implementation facilitators and barriers: A scoping review. *Journal of the American Medical Directors Association*, *18*(12), 1000–1009.e1004. https://doi.org/10.1016/j.jamda.2017.04.010

Tork, H., Lohrmann, C., & Dassen, T. (2008). Psychometric testing of the modified Care Dependency Scale among hospitalized school-aged children in Germany. *Nursing & Health Sciences*, *10*(1), 17–22. https://doi.org/10.1111/j.1442-2018.2007.00337.x

Van Der Steen, J. T., Gijsberts, M.-J.-H.-E., Muller, M. T., Deliens, L., & Volicer, L. (2009). Evaluations of end of life with dementia by families in Dutch and U.S. nursing homes. *International Psychogeriatrics*, *21*(2), 321–329. https://doi.org/10.1017/S1041610208008399

van der Steen, J. T., Lemos Dekker, N., Gijsberts, M. H. E., Vermeulen, L. H., Mahler, M. M., & The, B. A. (2017). Palliative care for people with dementia in the terminal phase: a mixed-methods qualitative study to inform service development. *BMC Palliative Care*, *16*(1), 28. https://doi.org/10.1186/s12904-017-0201-4

WHO. (2020). *Palliative Care* Fact sheets. Retrieved from https://www.who.int/news-room/fact-sheets/detail/palliative-care

Worldwide Hospice Palliative Care Alliance. (2014). *Global Atlas of Palliative Care at the End of life*. WHO. Retrieved from https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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ORIGINAL ARTICLE

Attitudes towards older adults (80 years and older): A measurement with the ageing semantic differential - A cross-sectional study of Austrian students

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Abstract

Introduction: The aims of the study were to investigate the four-factor structure of the German version of the Aging Semantic Differential (ASD) and to gain initial insights into the attitudes of nursing, medical and humanities students towards older people in Austria.

Method: A cross-sectional study design with a convenience sample was chosen.

Results: The ASD was completed by 255 Austrian nursing, medicine, and humanities students, who described their attitudes towards persons who are 80 years of age and older. The applicability of the four-factor structure (instrumentality, autonomy, acceptability and integrity) of the German version was confirmed by performing a confirmatory factor analysis. The mean age of students in our sample was 23.6 years; 79% of these were female. The sample displayed negative attitudes regarding the factors of autonomy and instrumentality, but more positive attitudes regarding the factors integrity and acceptability. The attitudes of the students in the three study programmes differed, with the medical students displaying the most negative attitudes. Students who displayed positive attitudes had statistically significantly higher levels of knowledge about ageism and better possibilities to hold personal conversations with older people (80+) in the family or circle of friends.

Conclusion: We conclude that having more knowledge about ageism and close personal contacts to older persons can support positive attitudes towards older individuals.

KEYWORDS
age, ageing, ageism, aging semantic differential, ASD, gerontology, nursing students

1 | INTRODUCTION

An 'ageing society' or 'ageing population' reflects the fact that the proportion of older persons in the total population is steadily increasing (United Nations, 2013). In the 27 member states of the European Union (EU 27) in 2020, 20.8% of the total population was 65 years and older. In *The 2018 Ageing Report* issued by the European Commission, this group is referred to as the elderly population. In this report, people 80 years and older are referred to as the very elderly population and represented 6.1% of the total population in 2020 (European Commission, 2018). The size of this very elderly population group is expected to double (13%) by 2070 in the EU 27 (European Commission, 2020). The global very elderly population is expected to triple between 2019 and 2050 (United Nations et al., 2019).

Kydd et al. (2020) showed that the age groups of people 75, 80, or 85 years of age and older are mostly referred to as the 4th age or oldest old. Enßle and Helbrecht (2020) described two predominant stereotypes that exist in society regarding these age groups and, namely, that refer to people in these groups as the 'active ageing' or 'frail and dependent elders'.

Stereotypes are defined as a 'set of cognitive generalisations (e.g. beliefs and expectations) about the qualities and characteristics of the members of a group or a social category' (American Psychological Association, 2020). If these stereotypes are based on negative attitudes about ageing and age, these attitudes are described as ageism (WHO, 2020). The term was coined by Robert Butler in his article entitled *Age-Ism: Another form of Bigotry* (Butler, 1969). The negative impact of ageism – especially in health care – was recently shown in a systematic review by Chang et al. (2020). The authors stated that the poor quality of life of older people or reduced longevity is influenced by ageism and showed that older people are more often excluded from health care research. This is even the case when diseases with a high prevalence in older age groups are investigated, such as Parkinson disease (Chang et al., 2020). This implies that health care professionals should be especially sensitive to detecting negative attitudes towards older people and ageing as a result. Ageist attitudes or negative perceptions may be held by professionals in all sectors of health care, but nurses represent a highly influential group as the largest group to provide direct care to patients and residents (Ben-Harush et al., 2017; WHO, 2017). Veronek et al. (2020) measured the attitudes of 825 nursing students in Slovenia and Croatia towards advanced age and ageing. Positive attitudes were expressed more frequently by students who were studying full-time and had received previous education in gerontic nursing. Negative attitudes were more frequently detected among students who were married at the time of the study and had had previous work experience with the elderly. An investigation of 1100 Finnish nursing students showed that most held positive attitudes towards older adults. The attitudes were measured with the Kogan´s Attitude towards Old People (KAOP) tool, whereby the participants are asked to agree or disagree with 17 statements. High levels of agreement were reported for statements about the experiences of older people, the diversity of older people, and that they are capable of independent actions. Participants with more than five years of work experience in the field of nursing displayed more positive attitudes than those who had no or less working experience. The participants in the older age group (30–56) displayed more positive attitudes than those in the younger age groups (Salin et al., 2020). A longitudinal mixed method study conducted with 310 undergraduate nurses in the UK showed that the nurses' attitudes improved during the

What does this research add to existing knowledge in gerontology?

- The applicability of the four-factor structure of the Aging Semantic Differential (ASD) can be confirmed for describing attitudes and stereotypes towards people aged 80 years and older.
- Attitudes of students (nursing, medicine, humanities) towards people aged 80 years and older are slightly negative, by attributing them as dependent on others, insecure and unhealthy.
- Knowledge about the meaning of ageism and having the possibility of personal conversation with people over 80 years of age in the family/circle of friends are predictors of more positive attitudes.

What are the implications of this new knowledge for nursing care with older people?

- Educational interventions regarding the diversity of older people's degrees of dependency are of critical importance for nursing practice.
- Educators in practice settings should be aware that students can have stereotypical attitudes
- about older people and should conduct special educational interventions.
- While providing supervision for health care professionals, supervisors should provide opportunities for reflection regarding their attitudes towards old people and guide the ensuing discussions to raise awareness and increase self-reflection.
- How could the findings be used to influence policy or practice or research or education?
- Further research including a larger sample measuring the attitudes towards people aged 80 years and older will generate more representative data that can be used to raise awareness in health care practice institutions to stimulate the adaption of policies concerning ageism.
- Content referring to the care of older people and especially content which can influence the attitudes of professionals in health care positively should be included in all education programmes for health care professionals.

longitudinal study, which required them to answer questionnaires, make drawings and take part in photo-elicitation interviews. The authors concluded that theoretical and practical educational experience influenced the nurses' attitudes and perceptions positively (Ridgway et al., 2018). Jeste et al. (2018) showed that taking part in a geriatric research programme positively influenced the attitudes of medical students towards ageing.

The positive impact of educational interventions was also shown in a meta-analysis by Burnes et al. (2019). These study findings indicate extensive, detailed knowledge about the attitudes of health care professionals is needed to tailor educational interventions that can improve their attitudes towards older adults.

Various instruments can be used to measure attitudes towards and stereotypes about older people and ageing or ageism. In their review, Klusmann et al. (2020) identified 89 instruments that could be used as self-report measures to assess views on ageing. Frequently used instruments include the Attitudes Toward Older People Scale (Tuckman), Ageing Semantic Differential (ASD), Subjective Age (SA) measure, Fabroni Scale of Ageism (FSA), Anxiety About Aging Scale (AAS), Kogans´ Old People Scale and Palmore´s Facts on Aging Quiz (FAQs). In an integrated review, Hovey et al. (2017) described nine instruments which were used especially to measure the nursing students´ attitudes towards older persons, including the Kogan´s Attitudes Toward Old People Scale (KATOPS), Perspectives of Caring for Older People Scale (PCOP), Palmore´s Facts on Ageing Quiz (FAQs) and the Aging Semantic Differential (ASD).

Wilson et al. (2018) conducted a critical review of instruments used to measure attitudes towards older people, describing the ASD as one of the most widely used instruments. These conclusions had been previously reached by Iwasaki and Jones (2008). The ASD was originally developed by Rosencranz and McNevin in 1969 in the United States to measure the attitudes of young adults towards older people. The original instrument comprises 32 binary adjective terms which are assessed on a 7-point Likert scale (from 1 = most positive adjective to 7 = most negative adjectives). The binary adjectives in the ASD are applied with the so-called semantic differential technique, which is technique recommended to measure attitudes and especially to measure social stereotypes. Adjective pairs – to be precise, an adjective and its antonym – are used to describe a concept (Rosenberg and Navarro 2018). The German version of the ASD is based on a four-factor model of the English version, which was confirmed by Intrieri et al. (1995). The factors are instrumentality, autonomy, acceptability and integrity. Instrumentality is a measure of adaptability, vitality, or the active pursuit of a goal. Acceptability reflects the extent to which one is socially at ease and pleasing to others. Autonomy is a measure of self-sufficiency and active participation in social life. Integrity reflects a sense of personal satisfaction or inner peace (Intrieri et al., 1995). This four-factor structure was also confirmed once for the German version by Gluth et al. (2010). The four-factor version of the ASD shows acceptable internal reliability, and the construct validity has been confirmed several times by performing confirmatory factor analyses (Gluth et al., 2010; Holmberg et al., 2020; Intrieri et al., 1995). As an overall concept, the ASD can be applied to measure 'stereotypic attitudes towards older persons' (Ayalon et al., 2019; Gonzales et al., 2010).

No data, however, have been published on the attitudes of health care professionals towards older persons in Austria. Therefore, the first aim of the study was to obtain more comprehensive and detailed knowledge about the attitudes of these professionals towards older persons and specifically towards a cohort that is mainly located in a health care setting. Individuals in the age group of 80 years and more were addressed based on the theoretical assumption that the stereotype of these individuals as frail and dependent mainly is applied to people who are 80 years of age and older. This assumption was supported by the existence of two predominant, yet contrary stereotypes of these individuals as either active ageing or frail and dependent elders (Enßle & Helbrecht, 2020). We assumed that the stereotype of active ageing is more frequently applied to adults between 65 and 80 years old, although this term is somewhat unclear, while the adjectives frailty and dependency are more frequently applied to adults aged 80 years and older (i.e. those individuals in the 4th age or the oldest old) (Kydd et al., 2020).

It is also necessary to gain more knowledge about the attitudes held by health care students and professionals towards older people, because studies have shown that these attitudes influence whether and how these professionals choose to work in settings where care is primarily provided to older people (i.e. as long-term care) (Zisberg et al., 2021). After conducting a comprehensive literature review to identify a suitable instrument, we chose the Aging Semantic Differential as the measurement instrument. The psychometrically tested German version of the ASD was used, as the semantic differential is suitable for measuring stereotypes and can be used to measure complex attitudes in a short time (Gluth et al., 2010; Rosenberg & Navarro, 2018; Wilson et al., 2018). Seaman et al. (2017). for example, used the ASD to measure the attitudes of students from different study programmes, such as nursing, social work, physiotherapy and occupational therapy. The second aim of our study was to confirm the previous results of Gluth et al. (2010), namely, the applicability of the four-factor structure of the ASD to the Austrian sample, and especially to a young cohort of health care students.

2 | RESEARCH DESIGN

We chose a cross-sectional study design with a convenience sample of students from three different study programmes.

2.1 | Data collection

Data were collected in May and June 2019 with a paper-based, self-reported questionnaire distributed to students in the nursing science and medicine programme offered at the Medical

University of Graz and to students in the humanities programme at the University of Graz. The students were recruited in seminar rooms by lecturers who were involved in this project and were asked to participate voluntarily in the research project by filling out the questionnaire at the end of the courses. The sample comprises students in the nursing science programme who were in their 3rd and 4th years of a four-year bachelor's degree programme and medical students who attended a study module entitled *Society and Health*, which is recommended to students in their third year of the 6-year programme. Since we decided to conduct this study with a convenience sample, we also invited students from the humanities, social sciences and law programmes who attended an elective course entitled *Specialized Topics in Cultural Studies*: *Forget – Forgot – Forgotten*: *Dementia in Film and Literature*. Based on the results of a pilot test, the questionnaire took a maximum of 10 minutes to complete. A targeted sample of 350 (CI 95% SD +/- 5%) participants in this particular group of students was calculated by conducting a power analysis to measure the attitudes towards people aged 80 years and older.

2.2 | Ethical considerations

The Ethical Committee of the Medical University of Graz approved this study. Participation was on a voluntary basis, and students were informed that non-participation had no influence on their grade. Participation was implied by their consent.

2.3 | Measuring instrument

In addition to the German version of the Aging Semantic Differential (ASD) comprising 32 items, the survey contained demographic questions about the academic field (nursing, medicine, humanities, social sciences, or law), sex and age. Further questions were asked to assess the participants' knowledge of ageism, experience with assisting or caring for people over 80 in practical placements, private contacts with people over 80 in their families or circle of friends, and personal conversations about personal relationships with people over 80 in their families or circle of friends.

To measure the potential effects of personal influencing factors on attitudes, some characteristics of the students were measured with the Big Five Inventory 10 (BFI-10). The complete Big Five Inventory is used to assess personal characteristics such as neuroticism, extraversion, openness, agreeableness and conscientiousness (Gluth et al., 2010; Musek, 2007). The BFI-10 is a short form of the inventory with 10 questions, comprising two questions to describe each characteristic. Each question can be rated with a 5-point Likert scale. For instance, the characteristic of openness is assessed by asking the questions 'I see myself as someone who has few artistic interests' and 'I see myself as someone who has an active imagination.' The psychometric test included in the German version showed satisfying reliability and stability results (Rammstedt et al., 2010, 2013; Rammstedt & John, 2007).

2.4 | Analytic strategy

Data analyses were conducted with the IBM SPSS Statistics 26 (IBM 2019) and R-package lavaan (v0.6–4) software (Rosseel, 2012).

A confirmatory factor analysis (CFA) was carried out to verify the previously tested four-factor structure of the German version with the Austrian sample of a young cohort. The CFA was also chosen because the number of factors and the pattern of the indicator-factor loadings could be specified in advance based on the previously performed CFA by Gluth et al. (2010) (Brown & Moore, 2013). In order to measure both the four constituting factors (instrumentality, autonomy, acceptability, integrity) and the overall construct 'attitudes towards older persons,' we assessed the fit of a second-order model (see Figure 1) based on the items outlined by Gluth et al. (2010). Missing values per item (< 3%) and in total (9.4%) were addressed by making a full information maximum likelihood (FIML) estimation.

To perform some descriptive analyses, the sample was stratified by study programme to detect possible differences among the groups. Regarding statistical tests, the chi-square test was performed; to analyse ordinal data, we used the Kruskal–Wallis *H* test and for the interval-scaled data, the one-factorial ANOVA was used. For descriptive analyses of the subscales, the mean value was used. *P*-values <.05 were considered as statistically significant.

A linear regression analysis was performed to analyse possible influencing factors of the attitudes.

3 | RESULTS

3.1 | Sample description

The study sample included 255 students as participants. Of these, 154 (60%) participants studied nursing science, 75 studied medicine and 26 studied a humanity discipline. Even though not all questionnaires were completed fully, all useable data were included in the data analysis. The mean age of the entire student sample was 23.6 years (SD: 3.4 years), and 96% of the participants were younger than 30 years. In this sample, 79% of the participants were female. Regarding their experience, 208 (82%) had experience in caring for and/or assisting people over the age of 80. Eighty-four per cent of the students reported that they had a person over the age of 80 in their family or circle of friends, and 60% were aware of the meaning of ageism. Over 80% had the possibility to talk about personal topics with a person over the age of 80 (referred to as a 'personal conversation' in Table 1). The sample characteristics stratified by

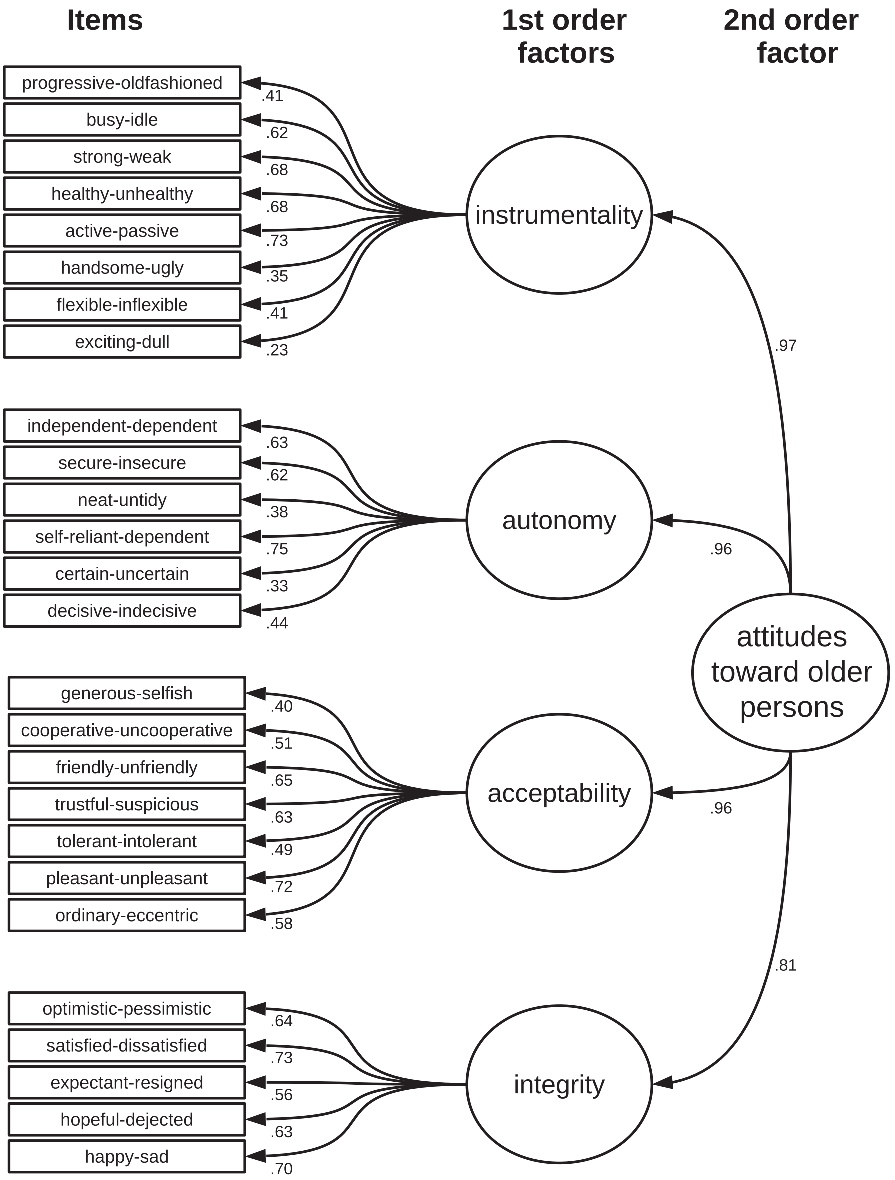

FIGURE 1 ASD Confirmatory factor analysis

study programme are shown in Table 1. Regarding the BFI-10 values, significant differences were detected for two items (Table 1).

3.2 | ASD

The model fit was acceptable (Chi^2 = 647715, df = 295, p-value = 0.000; CFI = 0.822; TLI = 0.803; RMSEA = 0.07, SMR = 0.07). Reliability as measured by applying the coefficient omega to the four first-level factors (instrumentality = 0.743, autonomy = 0.666, acceptability = 0.778, integrity = 0.789) and the second-order factor (overall structure = 0.921) was also acceptable. Based on these results, we constructed a sum index for the second-order factor (attitudes towards older persons) and for each constituting factor (instrumentality, integrity, acceptability, autonomy) (Figure 1). Six item pairs could not be allocated to the four-factor structure (rich–poor, aggressive-defensive, productive-unproductive, organised-disorganised, liberal-conservative, consistent-inconsistent) and were not used for further analysis.

3.3 | Descriptive analysis

The mean sum score for the ASD for the whole sample was 125.3 (SD = 40.0). The mean sum scores for female participants (125.3, SD: 40.4) and male participants (125.4, SD: 38.5) were similar. Stratified by study programme, the mean sum scores differed significantly ($p >$ 0.05) between the programmes of nursing 122.68 (SD: 39.0), medicine 132.44 (SD: 40.1) and the humanities, social sciences, or law. 120.1 (SD: 41.6). (Table 2).

In a first step, the differences among the sum scores of the four factors between the study groups regarding the attitudes were analysed. Significant differences were identified between the study programmes regarding the instrumentality and autonomy of the subscales.

TABLE 1 Sociodemographic Characteristics and BFI 10

	Nursing science	Medicine	Humanities
n	154	75	26
Sex (female)*	90%	55%	92%
Age (mean, (SD))	24.16 (3.88)	22.65 (1.72)	23.12 (3.65)
Experience (care/assistance) % *	100	62.7	28
Old person in the family %	86	81	71
Meaning of ageism %*	96.8	12	65.4
Personal conversation %	89.6	85.2	80
BFI–10			
Reserved (mean (SD))	2.52 (1.19)	2.65 (1.15)	3.15 (1.27)
Generally trusting (mean (SD))	3.69 (1.02)	3.48 (1.01)	3.5 (1.17)
Tends to be lazy (mean (SD))	2.41 (1.18)	2.45 (1.13)	2.88 (1.21)
Is relaxed, handles stress well (mean (SD))	3.48 (2.65)	3.01 (1.12)	3.03 (1.34)
Has few artistic interests (mean (SD))*	2.94 (1.36)	2.57 (1.31)	2 (1.29)
Is outgoing, sociable (mean (SD))*	4.0 (0.98)	3.6 (0.98)	3.46 (1.06)
Tends to find fault with others (mean (SD))	2.81 (1.08)	3.0 (1.0)	2.73 (1.18)
Does a thorough job (mean (SD))	4.22 (0.85)	4.25 (0.73)	3.96 (1.03)
Gets nervous easily (mean (SD))	3.06 (1.12)	3.21 (1.24)	3.03 (1.28)
Has an active imagination (mean (SD))	3.84 (0.97)	3.69 (1.13)	4.15 (0.92)

*$p < .05$.

TABLE 2 Mean Scores of Subscales

	Total	Nursing	Medicine	Humanities
Instrumentality (SD)*	4.34 (0.72)	4.23 (0.72)	4.65 (0.56)	4.08 (0.85)
Autonomy (SD)*	3.84 (0.80)	3.77 (0.79)	4.0991 (0.77)	3.52 0.78)
Acceptability (SD)	3.28 (0.81)	3.2056 (0.76)	3.4530 (0.84)	3.27 (0.90)
Integrity (SD)	4.02 (0.91)	3.9562 (0.84)	4.1987 (0.85)	3.9 1.18)

*$p < 0.001$.

The subscale instrumentality showed the highest values (i.e. the most negative attitudes) followed by the subscale integrity.

The highest values were observed among medical students as compared to those of the other student groups (Figure 2).

3.4 | Bivariate correlation

A bivariate correlation was performed between each subscale of the ASD and every item of the BFI 10 to identify possible correlations between personal factors and the attitudes. Only four items (reserved, generally trusting, has an active imagination and tends to find fault with others) showed significant correlations in each case with one or more factors, but the correlation coefficient was very low (< 0.2), so no further data analyses were performed.

Another bivariate correlation was performed for factors identified in the literature review as possibly influencing attitudes towards older persons. A correlation analysis was performed for each subscale, and the items sex, age, study programme, the knowledge about the meaning of ageism, experience in caring for/assisting people over the age of 80, having the possibility to hold personal conversations with people over 80 in the family or circle of friends, and if an older person lives in the family were correlated with each of these subscales. Statistically significant correlations are displayed in Table 3.

3.5 | Multivariable Analysis

A model for the linear multiple regression analysis had already been established for the multivariable analysis. Those factors which showed significant correlations in the bivariate analysis results were included in the model. This resulted in a linear multiple regression for the subscale instrumentality, with the independent factors 'older person lives in the family', 'personal conversation' and 'knowledge about ageism'. For the other three factors, a simple linear regression model was used with the independent factors of 'knowledge of ageism' and 'personal conversation'. The factors 'possibility to talk about personal topics with a person

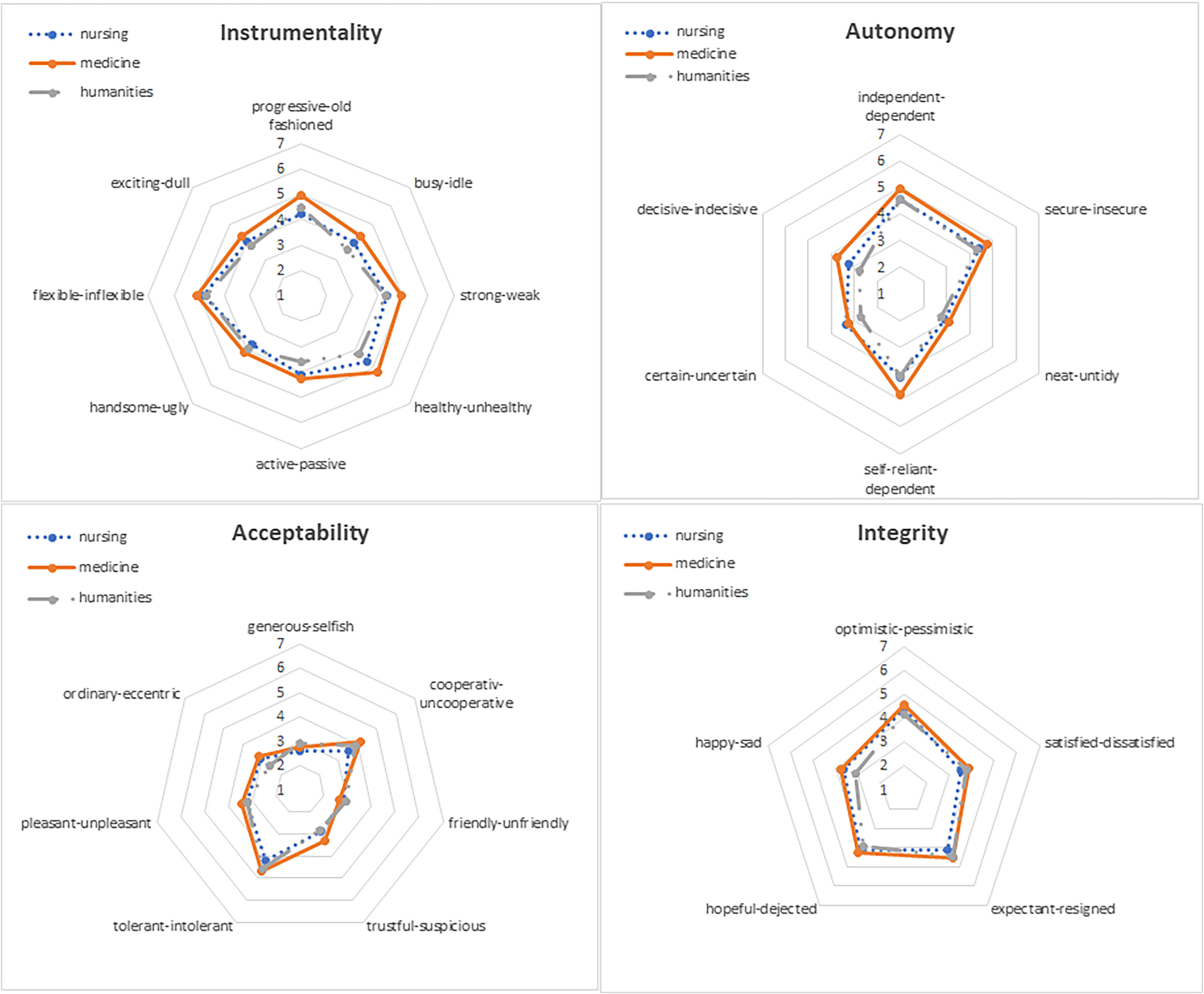

FIGURE 2 Analysis on item level per study programme

TABLE 3 Bivariate Correlation

Variable	*N*	Older person lives in the family	Possibility to talk with an older person about personal affairs	Knowledge about ageism
Instrumentality	255	.131*	.206*	.221*
Autonomy	255	.093	.101	.200*
Acceptability	255	.078	.192*	.102
Integrity	255	.063	.159*	.061

**p* <.05.

aged 80 and older' and the 'knowledge about ageism' emerged as significant influencing factors (Table 4). Those participants who had the possibility to talk about personal topics with people over the age of 80 and knew what the term ageism meant held more often positive attitudes than those who did not know the meaning of ageism and who did not have the possibility to talk about personal topics with older people.

4 | DISCUSSION

The results presented in this study contribute to those of other international psychometric ASD studies in that they provide valuable information about the applicability of the four-factor structure in Austria. Our findings enabled us to further confirm the applicability of the four-factor structure of the German version of the ASD.

TABLE 4 Linear regression analysis

			95% CI		
	B	SE	LL	UL	*p*
Instrumentality					
Older person lives in the family	.59	.336	.073	1.254	.081
Personal conversation	.121	.038	.046	.196	.002
Knowledge ageism	.395	.103	.191	.599	.000
Autonomy					
Knowledge ageism	.323	.107	.112	.534	.003
Acceptability					
Personal conversation	.121	.045	.032	.210	.008
Integrity					
Personal conversation	−113	.052	.012	.215	.029

*p <.05.

Our study reveals a slight general tendency for a young cohort of Austrian students to hold negative attitudes towards people over 80 years of age. A stratification of the data by study programme (nursing, medicine, humanities) revealed small differences regarding the attitudes held by members of the investigated groups. Medical students displayed more negative attitudes as compared to nursing and humanities students. Our findings from the regression analysis of factors influencing attitudes lead us to conclude that having a possibility to talk about personal affairs with an older person and having greater knowledge about the definition of ageism influence people's attitudes towards older people.

To the best of our knowledge, this was the first study in which the attitudes of students towards people aged 80 and older were specifically investigated in Austria. By confirming the four-factor structure (instrumentality, autonomy, acceptability, integrity), our results support those of other authors (Gluth et al., 2010; Holmberg et al., 2020; Intrieri et al., 1995). Intrieri et al. (1995) confirmed the four-factor structure of ASD in the USA, and Gluth et al. (2010) confirmed the German version of the ASD. Holmberg et al. (2020) confirmed the four-factor structure for the adapted Swedish version of the ASD. Confirmation of the four-factor structure for the adapted Mandarin version of the ASD could not be achieved. The Mandarin ASD was tested with 380 college students in Shanghai, China, who had with a mean age of 21.6 years. With these data, a three-factor structure (personality and mental health, societal participation and physical) could be confirmed. The authors of the Mandarin ASD concluded that the four-factor structure was not appropriate for use with the students from different (i.e. Chinese and Western) cultural backgrounds (Gonzales et al., 2017).

Our analysis of the ASD showed that they students – most of whom were young, female nursing students – had an overall slight tendency to hold negative attitudes towards persons who are 80 years and older. The Swedish study (Holmberg et al., 2020), reported slightly more positive attitudes as compared to our study and had the same target group regarding attitudes, but only investigated nursing students. Interestingly, the items concerning dependency (independent/dependent, self-reliant/dependent) showed high mean values in both studies. This result supports the assumption that especially individuals over 80 are viewed as dependent (Heckemann et al., 2021). We chose this special age group by following the recommendation of Kydd et al. (2020), who used the defined age group especially for research purposes.

Half of the items regarding instrumentality and autonomy showed values over 4.5. These two subscales comprise the item pairs independent/dependent, self-reliant/dependent, active-passive and healthy/unhealthy. This finding may serve as evidence that supports the prevalence of the predominant stereotype as described by Enßle and Helbrecht (2020), whereby older persons are perceived as 'frail and dependent'.

Using regression analyses, we were able to show significant correlations among more positive attitudes and the factors 'knowledge about ageism' and 'the possibility to talk about personal affairs to older persons'. The importance of the factor 'talking about personal affairs to older persons', which can be interpreted as indicating that a close relationship with an older person exists, has been confirmed in other studies as well. In a study with undergraduate nursing students (mean age 24.5 year, 63% females) in Sri Lanka, about 50% of the students held slightly positive and 45% held slightly negative attitudes. The attitudes held did not depend on gender, ethnic group, religious group, or academic year, but they showed statistically significant differences when participants lived together with older people. Specifically, participants who lived together with older people generally held more positive attitudes (Rathnayake et al., 2016). The important of having close contact to an older person was already discussed during the ASD development, and the authors showed that persons who had close contact to their grandparents viewed ageing and older people more favourably (Rosencranz & McNevin, 1969). Beside the importance of close contact to an older person, we showed that having knowledge about ageism statistically significantly and positively influenced the attitudes held towards people aged 80 and older. This knowledge may be a result of a specific course that the students took at the time of our study. The influence of knowledge and education on attitudes has already been confirmed by several authors (Donizzetti, 2019; Liu et al., 2013; Rush et al., 2017). Other possible influencing factors were not revealed by our data analysis, maybe due to the relatively small sample size of our convenience sample, which limits our ability to draw broader conclusions or extrapolate our results. A relatively small convenience sample was chosen, because the focus in this investigation was placed on obtaining initial insights into the situation in Austria and testing the ASD. In addition, the sample was not equally distributed with regard to the participants' study programmes, possibly weakening the results with respect to our ability to compare among the groups. One strength of the ASD is that it has often used to measure attitudes of health care professionals. This study enabled us to confirm applicability of the four-factor structure in Austria, which contributes to the validity of the instrument.

5 | CONCLUSION

The ASD is an appropriate instrument to measure attitudes towards older persons in Austria.

The nursing, medical and humanities students who served as study participants held slightly negative attitudes towards people over 80. The main influencing factors were identified as having close contact to older people and having knowledge about ageism. Old people, respectively people over 80 years of age, were mainly viewed by the participants as dependent on others.

Further investigations into images of ageing, and especially among health care professionals, should be performed. The factors that influence images of ageing should be investigated in depth, and a special focus should be placed on factors like the cultural background, which may influence these attitudes.

CONFLICT OF INTERESTS

none.

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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REFERENCES

American Psychological Association. (2020). Stereotype. American Psychological Association. Retrieved from: https://dictionary.apa.org/stereotype

Ayalon, L., Dolberg, P., Mikulioniene, S., Perek-Bialas, J., Rapoliene, G., Stypinska, J., Willinska, M., & de la Fuente-Nunez, V. (2019). A systematic review of existing ageism scales. *Ageing Research Reviews*, *54*, 100919. https://doi.org/10.1016/j.arr.2019.100919

Ben-Harush, A., Shiovitz-Ezra, S., Doron, I., Alon, S., Leibovitz, A., Golander, H., Haron, Y., & Ayalon, L. (2017). Ageism among physicians, nurses, and social workers: findings from a qualitative study. *European Journal of Ageing*, *14*(1), 39–48. https://doi.org/10.1007/s10433-016-0389-9.

Brown, T., & Moore, M. (2013). Confirmatory Factor Analysis In. *Boston University*, https://www.researchgate.net/publication/251573889

Burnes, D., Sheppard, C., Henderson, C. R. Jr, Wassel, M., Cope, R., Barber, C., & Pillemer, K. (2019). Interventions to Reduce Ageism Against Older Adults: A Systematic Review and Meta-Analysis. *American Journal of Public Health*, *109*(8), e1–e9. https://doi.org/10.2105/ajph.2019.305123

Butler, R. N. (1969). Age-Ism: Another Form of Bigotry. *The Gerontologist*, *9*(4_Part_1), 243–246. https://doi.org/10.1093/geront/9.4_Part_1.243.

Chang, E. S., Kannoth, S., Levy, S., Wang, S. Y., Lee, J. E., & Levy, B. R. (2020). Global reach of ageism on older persons' health: A systematic review. *PLoS One*, *15*(1), e0220857. https://doi.org/10.1371/journal.pone.0220857

Commission, E. (2018). *The 2018 Ageing Report: Economic & Budgetary Projections for the 28 EU Member States (2016–2070)*. Publications Office on the European Union Retrieved from https://ec.europa.eu/info/sites/info/files/economy-finance/ip079_en.pdf

European Commission (2020). European Commission Report on the Impact of Demographic Change. https://ec.europa.eu/info/sites/default/files/demography_report_2020.pdf

Donizzetti, A. R. (2019). Ageism in an Aging Society: The Role of Knowledge, Anxiety about Aging, and Stereotypes in Young People and Adults. *International Journal of Environmental Research and Public Health*, *16*(8), 1329. https://doi.org/10.3390/ijerph16081329

Enßle, F., & Helbrecht, I. (2020). Understanding diversity in later life through images of old age. *Ageing and Society*, *41*(10), 2396–2415. https://doi.org/10.1017/S0144686X20000379.

Gluth, S., Ebner, N. C., & Schmiedek, F. (2010). Attitudes toward Younger and Older Adults: The German Aging Semantic Differential. *International Journal of Behavioral Development*, *34*(2), 147–158. https://doi.org/10.1177/0165025409350947

Gonzales, E., Marchiondo, L. A., Tan, J., Wang, Y., & Chen, H. (2017). The Aging Semantic Differential in Mandarin Chinese: Measuring Attitudes toward Older Adults in China. *Journal of Gerontological Social Work*, *60*(3), 245–254. https://doi.org/10.1080/01634372.2017.1295122

Gonzales, E., Tan, J., & Morrow-Howell, N. (2010). Assessment of the Refined Aging Semantic Differential: Recommendations for Enhancing Validity. *Journal of Gerontological Social Work*, *53*(4), 304–318. https://doi.org/10.1080/01634371003715791

Heckemann, B., Schüttengruber, G., Grosschädel, F., Holmberg, C., Wolf, A., Heckemann Birgit, Schüttengruber Gerhilde, Wolf Axel, Großschädl Franziska & Holmberg Christopher (2021). Attitudes towards oldest-old adults (age ≥80 years): A survey and international comparison between Swedish and Austrian nursing students. Scandinavian Journal of Caring Sciences, http://dx.doi.org/10.1111/scs.13005

Holmberg, C., Wolf, A., Eide, C., Großschädl, F., Schüttengruber, G., Patel, H., & Heckemann, B. (2020). Classic Tool, New Opportunities: A Psychometric Analysis of a Swedish Online Version of the Aging Semantic Differential Scale. *Research on Aging*, *43*(9-10), 378–387. https://doi.org/10.1177/0164027520963618

Hovey, S., Dyck, M. J., Reese, C., & Kim, M. (2017). Nursing students' attitudes toward persons who are aged: An integrative review. *Nurse Education Today*, *49*, 145–152. https://doi.org/10.1016/j.nedt.2016.11.018

Intrieri, R. C., von Eye, A., & Kelly, J. A. (1995). The aging semantic differential: a confirmatory factor analysis. *The Gerontologist*, *35*(5), 616–621. https://doi.org/10.1093/geront/35.5.616

Iwasaki, M., & Jones, J. (2008). Attitudes Toward Older Adults: A Reexamination of Two Major Scales. *Gerontology & Geriatrics Education*, *29*(2), 139–157. https://doi.org/10.1080/02701960802223209

Jeste, D. V., Avanzino, J., Depp, C. A., Gawronska, M., Tu, X., Sewell, D. D., & Huege, S. F. (2018). Effect of short-term research training programs on medical students' attitudes toward aging. *Gerontology & Geriatrics Education*, *39*(2), 214–222. https://doi.org/10.1080/02701960.2017.1340884

Klusmann, V., Notthoff, N., Beyer, A.-K., Blawert, A., & Gabrian, M. (2020). The assessment of views on ageing: a review of self-report measures and innovative extensions. *European Journal of Ageing*, *17*(4), 403–433. https://doi.org/10.1007/s10433-020-00556-9

Kydd, A., Fleming, A., Paoletti, I., & Hvalič Touzery, S. (2020). Exploring Terms Used for the Oldest Old in the Gerontological Literature. *The Journal of Aging and Social Change*, *10*(2), 53–73. https://doi.org/10.18848/2576-5310/CGP/v10i02/53-73

Liu, Y. E., Norman, I. J., & While, A. E. (2013). Nurses' attitudes towards older people: a systematic review. *International Journal of Nursing Studies*, *50*(9), 1271–1282. https://doi.org/10.1016/j.ijnurstu.2012.11.021

Musek, J. (2007). A general factor of personality: Evidence for the Big One in the five-factor model. *Journal of Research in Personality*, *41*(6), 1213–1233. https://doi.org/10.1016/j.jrp.2007.02.003

Rammstedt, B., Goldberg, L. R., & Borg, I. (2010). The measurement equivalence of Big Five factor markers for persons with different levels of education. *Journal of Research in Personality*, *44*(4), 53–61. https://doi.org/10.1016/j.jrp.2009.10.005

Rammstedt, B., & John, O. P. (2007). Measuring personality in one minute or less: A 10-item short version of the Big Five Inventory in English and German. *Journal of Research in Personality*, *41*(1), 203–212. https://doi.org/10.1016/j.jrp.2006.02.001

Rammstedt, B., Kemper, C. J., Klein, M. C., Beierlein, C., & Kovaleva, A. (2013). Eine kurze Skala zur Messung der fünf Dimensionen der Persönlichkeit: 10 Item Big Five Inventory (BFI-10). *Social Science Open Access Repository*, 233–249. https://doi.org/10.12758/mda.2013.013

Rathnayake, S., Athukorala, Y., & Siop, S. (2016). Attitudes toward and willingness to work with older people among undergraduate nursing students in a public university in Sri Lanka: A cross sectional study. *Nurse Education Today*, *36*, 439–444. https://doi.org/10.1016/j.nedt.2015.10.007

Ridgway, V., Mason-Whitehead, E., & McIntosh-Scott, A. (2018). Visual perceptions of ageing; A longitudinal mixed methods study of UK undergraduate student nurses' attitudes and perceptions towards older people. *Nurse Education in Practice*, *33*, 63–69. https://doi.org/10.1016/j.nepr.2018.08.005

Rosenberg, B. D., & Navarro, M. (2018). "Semantic Differential Scaling". *The SAGE Encyclopedia of Educational Research, Measurement, and Evaluation*. https://doi.org/10.4135/9781506326139.n624

Rosencranz, H. A., & McNevin, T. E. (1969). A factor analysis of attitudes toward the aged. *The Gerontologist*, *9*(1), 55–59. https://doi.org/10.1093/geront/9.1.55

Rosseel, Y. (2012). lavaan: An R Package for Structural Equation Modeling. *48*(2), 36. https://doi.org/10.18637/jss.v048.i02

Rush, K. L., Hickey, S., Epp, S., & Janke, R. (2017). Nurses' attitudes towards older people care: An integrative review. *Journal of Clinical Nursing*, *26*(23–24), 4105–4116. https://doi.org/10.1111/jocn.13939

Salin, S., Hautsalo, K., Vänni, K., Seitsamo, S., & Yli-Koivisto, L. (2020). Finnish nurse students' attitudes towards older adults and the teaching of gerontological nursing - A survey study. *Nurse Education Today*, *88*, 104379. https://doi.org/10.1016/j.nedt.2020.104379

Seaman, K., Saunders, R., Williams, E., Harrup-Gregory, J., Loffler, H., & Lake, F. (2017). An examination of students' perceptions of their interprofessional placements in residential aged care. *Journal of Interprofessional Care*, *31*(2), 147–153. https://doi.org/10.1080/13561820.2016.1262338

United Nations (2013). *World Population Ageing 2013*. United Nations. https://www.un.org/en/development/desa/population/publications/pdf/ageing/WorldPopulationAgeing2013.pdf

United Nations, Department of Economic and Social Affairs, and Division. P. (2019). World Population Prospects 2019: Highlights. https://population.un.org/wpp/Publications/Files/WPP2019_Highlights.pdf

Veronek, J., Bajs Janović, M., Janović, Š., Barić, H., Zurc, J., & Gvozdanović, Z. (2020). Attitudes Towards Older People in Croatian and Slovenian Nursing Students. *Psychiatr Danub*, *32*(Suppl 4), 484–490.

WHO (2017). *Report of the Policy Dialogue Meeting on the Nursing Workforce*. https://www.who.int/hrh/news/2017/NursingApril2017-2.pdf

WHO (2020). *Ageism*. Retrieved 29.05.2020 from https://www.who.int/ageing/ageism/en/

Wilson, M., Kurrle, S., & Wilson, I. (2018). Medical student attitudes towards older people: a critical review of quantitative measures. *BMC Research Notes*, *11*(1), 71. https://doi.org/10.1186/s13104-018-3186-z

Zisberg, A., Shulyaev, K., & Van Son, C. (2021). Assessing attitudes and intention to work with older adults by American and Israeli nursing students: Adapting and testing a measure. *Nurse Education Today*, *98*, 104735. https://doi.org/10.1016/j.nedt.2020.104735

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Care dependency in individuals aged 80 years and older: analysis of 2009–2021 data for residents and patients in long-term care facilities and hospitals in Austria

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Submitted

Abstract

Introduction: The initially perceived stereotype of people aged 80 years and older is that individuals of this age group are frail and care dependent. Care dependency has not been measured sufficiently up until now in this particular group of individuals.

Aim: The study aims were to describe the care dependency of individuals aged 80 years and older and to find possible predictors for high care dependency.

Method: A secondary analysis was performed of data from cross-sectional studies annually conducted between 2009 and 2021.

Data analysis: In addition to the descriptive analysis, a logistic regression analysis was performed.

Results: The highest care dependency was observed in the age group of 91 years and older. The main predicting factors for care dependency in individuals aged 80 years and older are the diseases dementia and hemiparesis/stroke.

Discussion/Conclusion: Individuals who are not affected by dementia or hemiparesis/stroke might remain quite independent until they reach a high age. Therefore, age might only rarely be a single predictor for care dependency.

Keywords: Care dependency, oldest old, very old, secondary data analysis, hospital, long term care facilities; 80 years and older

Introduction

The demographic development all over the world has shown that life expectancy is increasing, which implies that the group of people aged 65 years and older is growing (1). In more developed regions such as Northern America and Europe, the group of people aged 80 years and older is growing particularly quickly; in Europe, the size of this group is expected to double by 2070 (1, 2). This development is positive, because it means that many people all over the world will enjoy a long life, but this development might also present challenges for health care systems, since the risk of chronic disease, such as cardiovascular diseases or severe diseases like dementia, increases as people grow older (3). Chronic diseases can lead to disabilities, especially in old age (4). Different terms exist for this phenomenon, such as a decrease in or loss of abilities/self-care abilities, physical decline, loss of functioning or functional decline (3, 5). To quantify the functional impairment, three instruments are often used: the Lawton – Brody Instrumental Activities of Daily Living Scale (IADL), the Katz Index of Independence on Activities of Daily Living (ADL) and the Barthel Index (6). All three instruments place a focus on physical abilities. The Care Dependency Scale (CDS) in comparison can be used to measure the loss of self-care abilities in a more comprehensive way. The CDS definition based on the care model of Virginia Henderson is defined as *“Nursing care dependency is 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”* (7). The model of V. Henderson describes 14 activities, including breathing normally, keeping the body clean, avoiding dangers in the environment, as well as communicating, playing, or participating in various forms of recreation (8). Based on these 14 activities, Dijkstra and colleagues operationalized the 15 items of the CDS in 1996 (7-10). The 15 items are eating and drinking, continence, body posture, mobility, day/night pattern, getting dressed and undressed, body temperature, hygiene, avoidance of danger, communication, contact with others, sense of rules and values, daily activities, recreational activities and learning activities. The CDS has been translated into more than 16 languages and has shown good reliability, validity, responsiveness and clinical utility (10-17).

The general assumption that care dependency increases with age must be considered carefully, since no scientific consensus regarding what old age really means has been made. Even if individuals aged 65 years and older are considered to have reached “old age”, these do not represent a homogenous group regarding their health status and care dependency (18-20). Additionally, the high life expectancy and the compression of morbidity allow the researcher to assume, if age is a factor, that a much greater age than 65 for the onset of care dependency must be considered (20, 21). Especially regarding care dependency, Lohrmann and colleagues stated in 2003 that patients who were 80 years and older were at higher risk of being care dependent (22). Other studies have cited some reasons for increasing care dependency, such as advanced age, dementia, or being in an end-of-life phase (23-25). A careful investigation of care dependency in a specific older age cohort has still not been performed. Concerning the investigation of a phenomenon related to an increased age, defining a specific age group as the cohort is recommended (26). By using a specific age cohort and referring to it with a specific chronological age, the use of ageist terms such as oldest old can be avoided; the use of such clearly defined terms is always preferable in research (26). Based on our assumption that care dependency might be higher in cohorts composed of individuals aged 80 years and older, this specific age group was defined in this study. Gaining more comprehensive and deeper knowledge about the phenomenon of care dependency in individuals aged 80 years and older might improve the understanding of the care needs of this age group. Therefore, this study was carried out to develop a comprehensive description of care dependency in individuals aged 80 years and older and to gain deeper knowledge about potential influencing factors (e.g. diseases, end-of-life phase, age and sex).

Method

A secondary data analysis was performed with data collected from 2009 to 2021 from the annually conducted Austrian Nursing Quality Measurement. In 2020, no measurement was performed due to the COVID-19 pandemic situation. All Austrian hospitals and long-term care facilities that have more than 50 beds can participate voluntarily in the Austrian Nursing Quality Measurement.

For this analysis, only the data of patients/residents who were aged 80 years and older on the Austrian Nursing Quality Measurement collection date were used.

The allocation to end of life was first requested in 2017; therefore, the data for end of life are only available for the years 2017 to 2021.

Ethical considerations

The study was first approved by the local ethics committee in 2009 and assigned the EK number 20-192 ex 08/09. For every subsequent measurement (2009–2021), a separate approval was obtained from the local ethics committee.

Data collection and variables

Institutions that chose to take part in the Austrian Nursing Quality Measurement gave one or more members of their staff (i.e. coordinators) the responsibility for collecting the data. The research team offered these coordinators the possibility to complete a special training for the measurement. Additional written material, including a guideline on how to fill out the questionnaires, was also provided by the research team. The coordinators were responsible for training the nurses who ultimately performed the data collection. The measurement comprises a standardized questionnaire to assess several nursing-sensitive indicators, such as falls or pain, nursing interventions, nursing quality indicators and care dependency. The questionnaire, which is based on Donabedian´s quality model of structure, process and outcome, was initially developed by a team of researchers at Maastricht University (27). It has three parts with items for evaluating individuals at the institutional, ward and patient/resident levels. The questionnaire is subject to continual improvement and further development by an international research team (Austria, Switzerland, Netherlands and UK) (28). The measurement on the patient/resident level was performed over a period of one or two days up until 2019, but it has been performed over a period of three days since 2021, by two trained nurses from different wards.

The questionnaire also includes a question regarding whether the patient/resident is on a pathway established to manage patients at the end of life. In the questionnaire, the end of life is defined as a timeframe that extends over days, weeks, months, or the year before death. End-of-life care is defined as a process in which patients/residents are assessed to identify their needs and in which care planning is done in good time. Palliative care is defined as a part of end-of-life care, and terminal care should be provided in the last days in life. A pathway is defined in the questionnaire guidelines, whereby the interdisciplinary team comes to a consensus that the patient/resident is in the end of life phase, conversations concerning the end of life are held with the patient/resident and close family members, and their wishes regarding treatment and care are documented in a written document.

The phenomenon of care dependency is measured with the Care Dependency Scale (CDS), which is included in the questionnaire.

Care Dependency Scale (CDS)

Each of the 15 items of the German version of the CDS is assessed on a 5-point Likert scale (i.e. completely dependent = 1, to a great extent dependent = 2, partially dependent = 3, to a great extent independent = 4, completely independent = 5). The values for each item are added up; therefore, these values can range from 15 to 75, with higher values representing higher levels of independence.

Data analysis

The IBM SPSS Statistic software versions 26 and 27 were used to perform the statistical analysis (29, 30).

Crosstabs with X^2 tests were used to perform the descriptive analysis. For this analysis, a comparison of the categorical data as age groups, sex and medical diagnoses was made.

Care dependency was defined as a dependent variable for the binominal logistic regression. Basically, care dependency is a categorical variable with five characteristics, ranging from completely independent to completely dependent. Since we decided to analyse care dependency on an item level to obtain more precise results, we applied the logistic regression analysis method and converted care dependency into a dichotomous variable. For each item, characteristics 1 and 2 were defined as independent/almost independent, and characteristics 3, 4 and 5 were defined as dependent/completely dependent. Age (continuously scaled), sex and the most frequent medical diagnoses (categorically scaled) were defined as independent variables for all 15 items. Since the analysis was performed for all 15 items, 15 regression models were performed.

Tests for linearity using the continuous variable age with respect to the logit of the dependent variable were assessed by following the Box -Tidwell procedure for all 15 regression models. A Bonferroni correction was applied for the model of the item getting dressed and undressed. Using all 11 terms in the model resulting in statistical significance being accepted when $p < .045$. A survey for outliers was also performed and, due the low numbers of outliers, all data were used for the analyses. A survey for multicollinearity was also performed, and no values higher than 0.7 between the factors were observed. A p-value < 0.05 was defined as significant.

Results

Patients' characteristics

Data for 14,509 participants aged 80 years and older were included in the analysis. In this sample, 72.5 % were female: Three age groups were identified: 46.2 % of the participants were aged 80 to 85 years, 34.9 % of the participants were aged 86 to 90 years, and 18.9 % were older than 91 years. More than half of the participants were in hospital on the data collection date, and 37.6 % of the participants lived in a long-term care facility. More than half of the individuals aged 80 years and older were diagnosed with cardiovascular diseases (66.6 %) followed by diseases of the musculoskeletal system (39.6 %). Dementia affected 30 % of the individuals aged 80 years and older. More than 20 % of the patients/residents had two or three diagnoses. In this sample, 497 participants were allocated to a pathway for end-of-life management (Table 1).

Table 1: Demographic data for patients and residents

***N* (≥ 80 years)**	**14,509**
sex	72.5 % female
Age groups	% (*n*)
80–85	46.2 (6703)
86–90	34.9 (5067)
≥ 91	18.9 (2739)
Institutions	% (*n*)
Hospital	56.9 (8253)
Geriatric hospital	2.3 (335)
Long-term care facility	37.6 (5455)
Rehabilitation facility	0.4 (64)
Facility for the physical disabled	1.6 (132)
Other	1.3 (170)
Medical diagnoses	**%**
Cardiovascular diseases (CVD)	66.6
Diseases of the musculoskeletal system	39.6
Dementia	30.6
Diseases of kidney/urinary tract	26.9
Diseases of the digestive tract	24.5
Endocrine-nutritional or metabolic disease	20.4
Respiratory diseases	19.6

Diabetes mellitus	18.4
Psychological diseases	15.1
Nervous system disorder/excluding CVA	14.0
CVA/hemiparesis	11.5
Cancer	10.2
***N* (≥ 80 years, 2017–2021)**	**2947**
On a pathway for management of patients at end of life	*n* = 497 (15 %)

Overall care dependency stratified by age groups

The level of care dependency stratified by age groups showed that the level of care dependency was higher in older age groups. The three age groups (80–85, 86–90; 91 and older) differed significantly in all CDS items concerning the level of care dependency. For the items of continence, getting dressed and undressed, hygiene and daily activities, we observed that approximately 50 % of the individuals are completely dependent or to a great extent dependent in the 91+ age group. For the items of day/night pattern, communication, contact with others, and sense of rules and values, a maximum of 30 % are completely or to a great extent care dependent in the 91+ age group. More detailed results concerning care dependency in the different age groups can be found in Supplement 1.

Care dependency on the item level in EOL situations and specific diseases

To obtain a detailed understanding of how care dependent individuals aged 80 years and older were at the time of data collection, the results are displayed on the item level, i.e. the care dependency was analysed for each of the 15 CDS items.

Care dependency at the end of life

Individuals allocated to a management pathway at the end of life displayed median care dependency values of two to three for all 15 CDS items, indicating that these individuals had high levels of care dependency (Figure 1). Care dependency in the areas of continence, mobility, getting dressed and undressed, hygiene, avoidance of danger, sense of rules and values, daily activities, recreational activities and learning activities was particularly high. Of the individuals allocated to a management pathway at the end of life, 47.5 % were diagnosed with dementia.

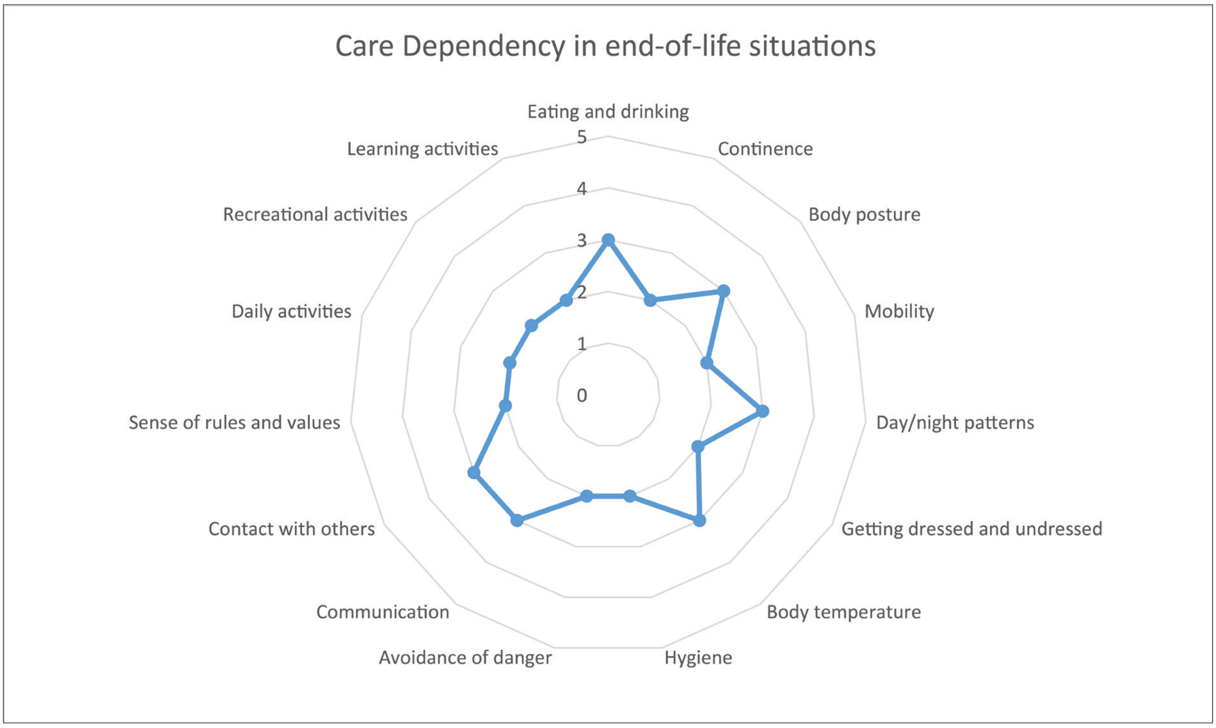

Figure 1: Care dependency in end-of-life situations

Care dependency by frequent diseases

The results of the descriptive analysis show that care dependency was high in individuals diagnosed with dementia. Therefore, results for individuals affected by dementia were compared with those for individuals who were not. The two groups differ significantly from each other with respect to the care dependency (X^2 tests) (Figure 2).

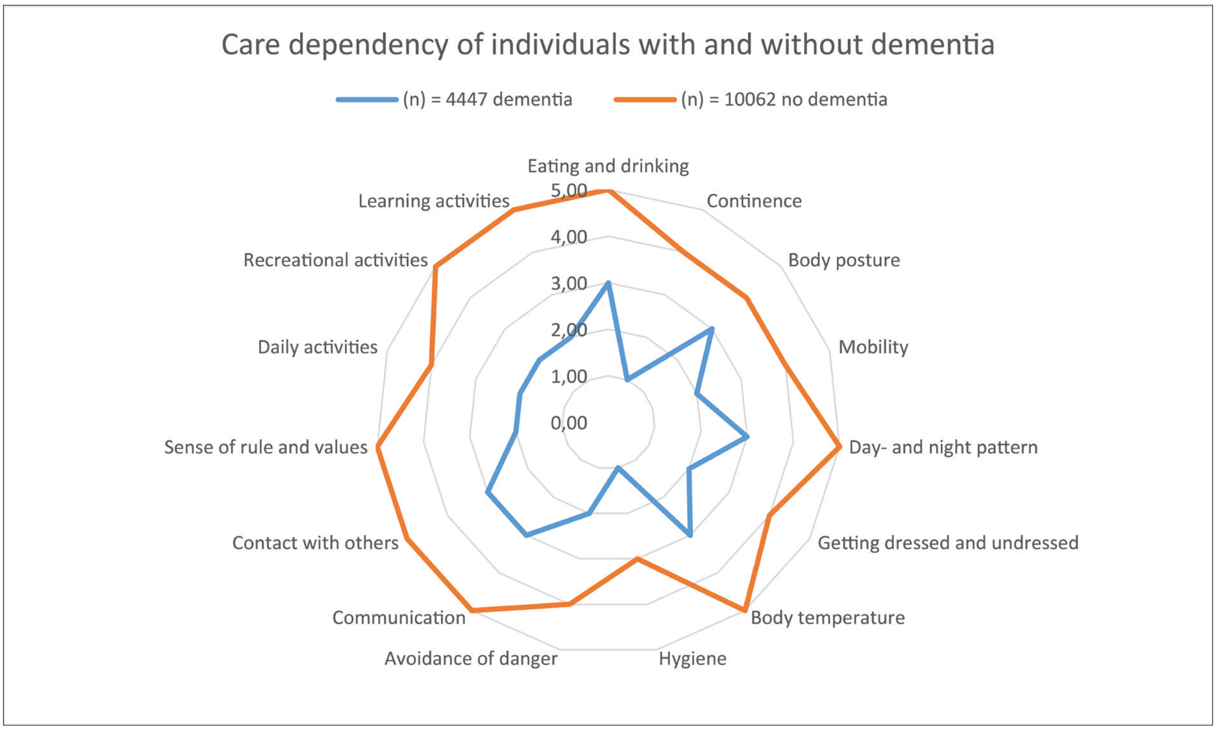

Figure 2: Care dependency of individuals with and without dementia

In Figure 3, the care dependency is displayed of individuals who were diagnosed with cardiovascular diseases, respiratory diseases, motoric diseases and diseases of kidney or urinary tract but who had not been diagnosed with dementia. Individuals with these diseases had mean score values ranging from 3 to 4.5 (Figure 3).

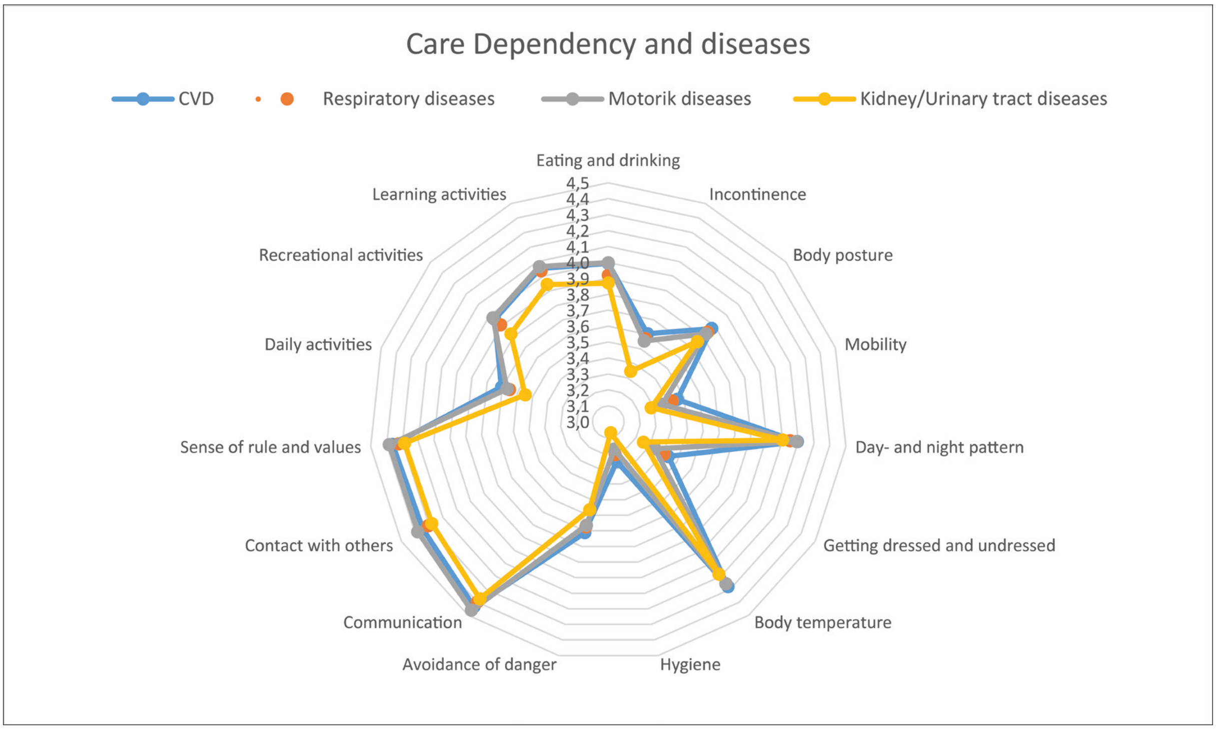

Figure 3: Care dependency and diseases

Binominal logistic regression analysis of age, gender and medical diagnoses

A bivariate logistic regression analysis was conducted to determine predictors for care dependency in old age. We defined care dependency as a dependent variable, which was dichotomized as care dependent or independent for each CDS item. We defined age, sex and 12 of the most frequent diseases as dependent variables (Table 2). We performed the regression analysis for each of the 15 CDS items. Due the high number of results obtained for the 15 models, the two sociodemographic factors and all diseases that had a significant value with an Exp (B) value greater than 1.5 are displayed in Table 4 for each model. Age and gender/sex exhibited significant values for all items, but had a low Exp (B). Significant values associated with a high care dependency risk for all 15 items were observed for dementia. The diagnosis with CVA/hemiparesis (stroke) incurred a risk ratio of 1.5 for almost all 15 CDS items, except body temperature. Respiratory diseases showed significant values in the regression analysis for the items of eating and drinking, continence, mobility, body position, day/night pattern, (un-) dressed, hygiene, contact with others, daily activity and recreation activity, but seemed to incur a low risk of care dependency, since the Exp (B) values were around 1 (Supplement 1). For the items of continence, day/night pattern, getting (un) dressed, body temperature, hygiene, avoidance of danger, communication, contact with others, rules and values, daily activities, recreational activities and learning activities, the diagnosis of dementia was also associated with a risk ratio of more than 5 for most of these items (Table 2).

Table 2: Binominal regression analysis for care dependency (15 model/CDS items)

CDS item							**95 % confidence interval for EXP (B)**	
Covariate and factors	**Regression coefficient B**	**Standard error**	**Wald**	***df***	***sig***	**Exp (B)**	**Lower value**	**Higher value**
Eating and drinking								
Age	.059	.004	206.03	1	.000	1.061	1.053	1.070
Gender/Sex	.130	.043	9.12	1	.003	1.139	1.047	1.239
Dementia	1.548	.041	1412.35	1	.000	4.700	4.336	5.095
CVA/hemiparesis (stroke)	.931	.058	255.87	1	.000	2.537	2.263	2.843

Continence								
Age	.068	.004	257.68	1	.000	1.070	1.061	1.079
Gender/Sex	.321	.042	57.77	1	.000	1.378	1.269	1.497
Dementia	1.686	.046	1369.31	1	.000	5.398	4.937	5.903
CVA/hemiparesis (stroke)	.826	.061	181.00	1	.000	2.285	2.026	2.577
Disorder/Disease of kidney/urinary tract	.429	.043	97.87	1	.000	1.536	1.411	1.673
Body posture								
Age	.049	.004	149.96	1	.000	1.050	1.042	1.058
Gender/Sex	.219	.042	27.85	1	.000	1.245	1.148	1.351
Dementia	1.081	.039	748.86	1	.000	2.947	2.728	3.184
CVA/hemiparesis (stroke)	.869	.056	238.44	1	.000	2.385	2.135	2.663
Mobility								
Age	.054	.004	183.71	1	.000	1.055	1.047	1.064
Gender/Sex	.195	.040	23.74	1	.000	1.215	1.123	1.314
Dementia	.934	.041	528.02	1	.000	2.544	2.350	2.755
CVA/hemiparesis (stroke)	.806	.059	187.61	1	.000	2.240	1.995	2.513
Day/night pattern								
Age	.050	.004	140.58	1	.000	1.052	1.043	1.061
Gender/Sex	.130	.046	8.10	1	.004	1.138	1.041	1.245
Dementia	1.679	.041	1678.37	1	.000	5.360	4.947	5.809
CVA/hemiparesis (stroke)	.729	.058	158.12	1	.000	2.073	1.850	2.322
Getting (un)dressed								
Age	.075	.004	299.243	1	.000	1.077	1.068	1.087
Gender/Sex	.263	.042	39.49	1	.000	1.301	1.199	1.413
Dementia	1.620	.048	1128.51	1	.000	5.055	4.599	5.557
CVA/hemiparesis (stroke)	.843	.064	172.28	1	.000	2.323	2.048	2.634
Body temperature								
Age	.059	.004	181.2	1	.000	1.061	1.052	1.070
Gender/Sex	.270	.048	32.15	1	.000	1.309	1.193	1.437
Dementia	1.802	.042	1879.24	1	.000	6.063	5.589	6.578
CVA/hemiparesis (stroke)	.804	.059	185.64	1	.000	2.235	1.991	2.510

Hygiene								
Age	.084	.005	333.34	1	.000	1.087	1.077	1.097
Gender/Sex	.302	.043	49.87	1	.000	1.353	1.244	1.472
Dementia	1.789	.056	1028.73	1	.000	5.983	5.363	6.674
CVA/hemiparesis (stroke)	.787	.069	131.87	1	.000	2.197	1.921	2.513
Avoidance of danger								
Age	.073	.004	283.76	1	.000	1.075	1.066	1.084
Gender/Sex	.217	.043	25.23	1	.000	1.242	1.141	1.352
Dementia	2.034	.048	1812.21	1	.000	7.642	6.959	8.392
CVA/hemiparesis (stroke)	.825	.062	178.12	1	.000	2.281	2.021	2.575
Communication								
Age	.053	.005	137.54	1	.000	1.055	1.045	1.064
Gender/Sex	.025	.050	.259	1	.611	1.026	.930	1.130
Dementia	1.824	.043	1807.74	1	.000	6.197	5.697	6.740
CVA/hemiparesis (stroke)	.869	.060	210.25	1	.000	2.386	2.121	2.683
Contact with others								
Age	.055	.004	155.34	1	.000	1.057	1.048	1.066
Gender/Sex	.089	.048	3.46	1	.063	1.094	.995	1.202
Dementia	1.832	.042	1895.89	1	.000	6.248	5.754	6.785
CVA/hemiparesis (stroke)	.926	.059	243.94	1	.000	2.525	2.248	2.836
Rules and values								
Age	.049	.005	117.72	1	.000	1.051	1.041	1.060
Gender/Sex	.068	.049	1.914	1	.166	1.070	.972	1.178
Dementia	2.221	.043	2625.43	1	.000	9.216	8.465	10.033
CVA/hemiparesis (stroke)	.874	.061	202.69	1	.000	2.396	2.125	2.703
Psychological disorder	.497	.056	78.98	1	.000	1.644	1.473	1.834
Daily activities								
Age	.056	.004	179.13	1	.000	1.058	1.049	1.066
Gender/Sex	.217	.042	26.40	1	.000	1.243	1.144	1.350
Dementia	1.809	.045	1595.88	1	.000	6.104	5.586	6.670
CVA/hemiparesis	.783	.060	167.96	1	.000	2.187	1.943	2.462

Recreational activities								
Age	.063	.004	211.96	1	.000	1.065	1.056	1.074
Gender/Sex	.201	.045	20.45	1	.000	1.223	1.121	1.335
Dementia	2.081	.045	2165.40	1	.000	8.011	7.339	8.745
CVA/hemiparesis (stroke)	.847	.060	196.59	1	.000	2.333	2.072	2.626
Learning activities								
Age	.071	.004	250.49	1	.000	1.073	1.064	1.083
Gender/Sex	.134	.046	8.36	1	.004	1.144	1.044	1.253
Dementia	2.414	.047	2657.24	1	.000	11.178	10.198	12.253
CVA/hemiparesis (stroke)	.938	.062	228.40	1	.000	2.556	2.263	2.886

*significant *p*-value: < 0.05

Discussion

The results of our analyses clearly demonstrate that the care dependency of age groups identified in the sample population of 80 years and older, reaching a maximum at 91 years and older, can be distinguished. These results show that not all patients over 80 years of age are care dependent to the same extent, indicating that this group is heterogeneous with regard to care dependency.

They indicate that age is a predicting factor for care dependency but only in individuals 91 years and older. The regression analysis results show significant values for this factor, but a low odds ratio for being care dependent. Age as predicting factor for the risk of higher care dependency in individuals aged 80 years and older was shown in 2003 by Lohrmann et al.

The relation between higher care dependency and higher age has been shown by several authors (23, 31, 32). Studies have also shown that higher age is an influencing factor for functional decline (33, 34). Age as a predictor for high care dependency or increasing functional decline has to be considered carefully, because age might instead represent a proxy variable for illnesses (6, 35). The results of our data analyses show that the age cohort of individuals between 80 and 85 years of age is rather independent for all care dependency items. That older cohorts have a considerable share of independent individuals was also shown by Jagger et al. in 2011. These authors investigated 841 people in North East England aged 85 years and older and found that 41 % of this cohort was independent. A systematic review performed to characterize the cognitive, functional, nutritional and physical status of individuals aged 90 years and older stated that this group is heterogeneous, containing a certain proportion of individuals with a good functional status (37).

Factors other than age, such as being in an end-of-life phase and/or having specific medical diagnoses, seem to be closely more related to high levels of care dependency. An especially high care dependency was observed in individuals who were identified as being in the end-of-life phase. A functional decrease at the end of life has often been cited in the international literature (38-40). A previously conducted study indicated that the end of life is a predictor for care dependency, and especially in individuals with advanced age (80 years and older) and in individuals at the end of life who have been diagnosed with dementia (25). Individuals with dementia have been shown to suffer from a higher symptom burden at the end of life, and these individuals would benefit from an earlier onset of palliative or end-of-life care (41).

Concerning the medical diagnoses, the descriptive analysis results on item level reveal that individuals who are not affected by dementia are on average partly dependent or to a great extent independent (mean values of 3 to 4.1) for almost all care dependency items. Accordingly, the regression analysis results show that dementia and CVA/hemiparesis/stroke are associated with significantly higher odds ratios for being care dependent than age, sex, or other diseases.

In support of our findings, Schüssler et al. demonstrated that individuals with dementia are more care dependent than individuals without dementia in studies performed in 2015 and 2016 (24, 42, 43). In a Swedish study with 2385 patients with a mean age of 73 years, cardiovascular diseases were less strongly associated with functional decline than neuropsychiatric diseases, including dementia (4). Our results confirm that especially dementia is a significant predictor that is associated with a high odds ratio for being care dependent.

The second disease group which displayed significant values with a high odds ratio (> 1.5 for all items) was the CVA/hemiparesis/stroke group. Few studies have investigated care dependency in individuals with stroke. One study performed in 2017 in Indonesia investigated 109 stroke patients to assess care dependency, revealing mean values for all CDS items between 2.65 and 3.46 upon admission to hospital (44). However, this small sample had a lower mean age (60.33) than the sample in our data analysis; therefore, it is not perfectly suitable for comparison. Nevertheless, these results indicate that even a young sample with a severe illness such as stroke shows high care dependency. A study that was conducted in the USA in 2012 with 210 individuals to examine their care dependency before and in the years after a stroke revealed a linear functional decline after the stroke (45).

Significant values were identified in the regression analysis results for other diseases such as respiratory diseases, but the odds ratios were around 1 for being care dependent, indicating that respiratory diseases cannot be used as a strong predictor for being care dependent. In our sample, 66 % of the individuals had a diagnosis of cardiovascular diseases, and no models displayed a significant odds ratio for being care dependent. The correlation between care dependency and heart failure was investigated in a cross-sectional study in a hospital in Spain. Of the 187 patients with a mean age of 81.06 years, only 15 % were highly care dependent. The mean values for the 15 items ranged from 3.72 to 4.14 (46). Low care dependency was also shown in a study of data collected from 2007 to 2011, where the care dependency of 248 patients with heart failure or COPD and a mean age of 75.6 years was analysed. The median score of the whole sample showed that either patients with heart failure or patients with COPD were dependent only to a limited extent (47).

Beside the illnesses as predictors of being care dependent, the factor of gender/sex should be considered as well. The regression analysis results revealed significant values for the female sex but also odds ratios of around 1 in all 15 regression models. In some studies, the female sex has been identified as a predictor for higher care dependency or higher functional decline. In a recent study conducted to identify sociodemographic factors that could influence care dependency, the authors demonstrated that gender had a significant impact on the level of care dependency. Females more frequently displayed a medium or high level of care dependency (32). In another study carried out to investigate the influence of social determinants on care dependency onset and progression, the authors also found an association between sex and care dependency, but men demonstrated higher levels of care dependency (48).

Conclusion

For individuals aged 80 years and older, the odds ratio of being care dependent is significantly increased by the diagnoses of dementia and CVA/hemiparesis/stroke. This also means that individuals aged 80 years and older have the ability to be partly or to a great extent independent, even if they are affected by other diseases, such as cardiovascular diseases. Age as a predictor for care dependency has to be considered carefully and other possible predictors have to be taken into account. Since the descriptive analysis results show that the age cohort composed of individuals 91 years and older have higher values of care dependency, the risk of being care dependent might be higher in such high age groups (91 years and older).

Recommendation for research and clinical practice

In clinical practice, the underlying disease has to be considered when care dependency is assessed. Patients and residents who are not affected by dementia or stroke may be highly independent even when they are 80 years and older. Individuals aged 80 years and older are a heterogeneous group, and the single factor of age cannot be used as a predicting variable for care dependency or functional decline.

Further research is necessary to focus on other possible influencing factors, such as multimorbidity, institutionalization, or specific diseases such as stroke.

Strengths and Limitations

One main strength of this study is the large sample size. The analysed data were obtained from different institutions and collected over the period of the last 12 years. The CDS is a frequently tested, valid and reliable instrument. The standardized questionnaire was filled out by two nurses which reduced the risk of observer bias.

Limitations of the study include the use of the secondary data analysis method, the cumulative analysis of the longitudinal data, and the failure to perform a trend analysis. Other possible predicting factors, including sociodemographic variables such as income or education, were not investigated and may have had an influence on the evaluation of care dependency.

References

(1) United Nations. World Populations Prospects 2019: Volume II Demographic Profiles. Departement of Economic and Social Affairs; 2019. Contract No: 978-92-1-148328-4.

(2) European Commission. European Commission Report on the Impact of Demographic Change. 2020.

(3) Livingston G, Sommerlad A, Orgeta V, Costafreda SG, Huntley J, Ames D, et al. Dementia prevention, intervention, and care. The Lancet. 2017;390 (10113):2673-734.

(4) Vetrano DL, Rizzuto D, Calderón-Larrañaga A, Onder G, Welmer AK, Bernabei R, et al. Trajectories of functional decline in older adults with neuropsychiatric and cardiovascular multimorbidity: A Swedish cohort study. PLoS Med. 2018;15 (3):e1002503.

(5) Chan E-Y, Samsudin SA, Lim YJ. Older patients' perception of engagement in functional self-care during hospitalization: A qualitative study. Geriatric Nursing. 2020;41 (3):297-304.

(6) Hajek A, Brettschneider C, Eisele M, Mallon T, Oey A, Wiese B, et al. Social Support and Functional Decline in the Oldest Old. Gerontology. 2021:1-9.

(7) Dijkstra A, Buist G, Dassen T. Operationalization of the concept of ´nursing care dependency`for use in long-term care facilities. Australian and New Zealand Journal of Mental Health Nursing. 1998;7:142-51.

(8) Henderson V. The Nature of Nursing A Definition and Its Implications for Practice, Research, and Education: The Macmillan Company, New York Collier-Macmillan, Limited, London; 1966.

(9) Dijkstra A, Buist G, Dassen T. Nursing-Care Dependency. Scandinavian Journal of Caring Sciences. 1996;10 (3):137-43.

(10) Dijkstra A, Buist G, Moorer P, Dassen T. Construct validity of the Nursing Care Dependency Scale. J Clin Nurs. 1999;8 (4):380-8.

(11) Dijkstra A, Coleman M, Tomas C, Valimaki M, Dassen T. Cross-cultural psychometric testing of the Care Dependency Scale with data. J Adv Nurs. 2003;43 (2):181-7.

(12) Lohrmann C, Dijkstra A, Dassen T. Care dependency: testing the German version of the Care Dependency Scale in nursing homes and on geriatric wards. Scand J Caring Sci. 2003;17 (1):51-6.

(13) Eichhorn-Kissel J, Dassen T, Kottner J, Lohrmann C. Psychometric testing of the modified Care Dependency Scale for Rehabilitation. Clinical Rehabilitation. 2010;24 (4):363-72.

(14) Dijkstra A, Muszalik M, Kedziora-Kornatowska K, Kornatowski T. Care Dependency Scale--psychometric testing of the Polish version. Scand J Caring Sci. 2010;24 Suppl 1:62-6.

(15) Dijkstra A, Yönt GH, Korhan EA, Muszalik M, Kędziora-Kornatowska K, Suzuki M. The Care Dependency Scale for measuring basic human needs: an international comparison. Journal of Advanced Nursing. 2012;68 (10):2341-8.

(16) Eichhorn-Kissel J, Dassen T, Lohrmann C. Responsiveness of the Care Dependency Scale for Rehabilitation (CDS-R). Scandinavian Journal of Caring Sciences. 2012;26 (1):194-202.

(17) Eichhorn-Kissel J, Dassen T, Lohrmann C. The clinical utility of the Care Dependency Scale in rehabilitation: nurses' perception. Journal of Research in Nursing. 2010;15 (6):547-61.

(18) Ouchi Y, Rakugi H, Arai H, Akishita M, Ito H, Toba K, et al. Redefining the elderly as aged 75 years and older: Proposal from the Joint Committee of Japan Gerontological Society and the Japan Geriatrics Society. Geriatrics & Gerontology International. 2017;17 (7):1045-7.

(19) Daignault M, Wassef A, Nguyen QD. How old is old? Identifying a chronological age and factors related with the perception of old age. J Am Geriatr Soc. 2021;69 (11):3330-3.

(20) Seaman R, Höhn A, Lindahl-Jacobsen R, Martikainen P, van Raalte A, Christensen K. Rethinking morbidity compression. Eur J Epidemiol. 2020;35 (5):381-8.

(21) Fries JF. The compression of morbidity. Ann Acad Med Singap. 1983;12 (3):358-67.

(22) Lohrmann C, Dijkstra A, Dassen T. The Care Dependency Scale: an assessment instrument for elderly patients in German hospitals. Geriatric nursing (New York, NY). 2003;24 (1):40-3.

(23) Doroszkiewicz H, Sierakowska M. Factors associated with risk of care dependency in disabled geriatric patients. Scandinavian Journal of Caring Sciences. 2021;35 (1):134-42.

(24) Schussler S, Dassen T, Lohrmann C. Care dependency and nursing care problems in nursing home residents with and without dementia: a cross-sectional study. Aging clinical and experimental research. 2016;28 (5):973-82.

(25) Schüttengruber G, Halfens RJG, Lohrmann C. 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. J Clin Nurs. 2021.

(26) Kydd A, Fleming A, Paoletti I, Hvalič Touzery S. Exploring Terms Used for the Oldest Old in the Gerontological Literature (Published in The Journal of Aging and Social Change). 2020;10:53-73.

(27) Nie-Visser NC, Schols JMGA, Meesterberends E, Lohrmann C, Meijers JMM, Halfens RJG. An International prevalence measurement of care problems: study protocol. J Adv Nurs. 2013;69.

(28) Eglseer D, Osmancevic S, Hoedl M, Lohrmann C, Bauer S. Improving the quality of nursing care in Austria: 10 years of success. J Nurs Manag. 2021;29 (2):186-93.

(29) IBM C. SPSS statistics for Windows. Version 26.0. Armonk, NY2019.

(30) IBM C. IBM SPSS Statistics for Windows, Version 27.0. . Armonk, NY: IBM Corp; 2020.

(31) Doroszkiewicz H, Sierakowska M, Muszalik M. Utility of the Care Dependency Scale in predicting care needs and health risks of elderly patients admitted to a geriatric unit: a cross-sectional study of 200 consecutive patients. Clin Interv Aging. 2018;13:887-94.

(32) Puto G, Sowińska I, Ścisło L, Walewska E, Kamińska A, Muszalik M. Sociodemographic Factors Affecting Older People's Care Dependency in Their Daily Living Environment According to Care Dependency Scale (CDS). Healthcare (Basel, Switzerland). 2021;9 (2).

(33) Palese A, Gonella S, Moreale R, Guarnier A, Barelli P, Zambiasi P, et al. Hospital-acquired functional decline in older patients cared for in acute medical wards and predictors: Findings from a multicentre longitudinal study. Geriatric Nursing. 2016;37 (3):192-9.

(34) Zhang PD, Lv YB, Li ZH, Yin ZX, Li FR, Wang JN, et al. Age, Period, and Cohort Effects on Activities of Daily Living, Physical Performance, and Cognitive Functioning Impairment Among the Oldest-Old in China. J Gerontol A Biol Sci Med Sci. 2020;75 (6):1214-21.

(35) Fong JH. Disability incidence and functional decline among older adults with major chronic diseases. BMC Geriatr. 2019;19 (1):323.

(36) Jagger C, Collerton JC, Davies K, Kingston A, Robinson LA, Eccles MP, et al. Capability and dependency in the Newcastle 85+ cohort study. Projections of future care needs. BMC Geriatrics. 2011;11 (1):21.

(37) Escourrou E, Durrieu F, Chicoulaa B, Dupouy J, Oustric S, Andrieu S, et al. Cognitive, functional, physical, and nutritional status of the oldest old encountered in primary care: a systematic review. BMC Fam Pract. 2020;21 (1):58.

(38) Stolz E, Gill TM, Mayerl H, Rásky É, Freidl W. Trajectories of Late-Life Disability Vary by the Condition Leading to Death. J Gerontol A Biol Sci Med Sci. 2021;76 (7):1260-4.

(39) Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at the end of life. JAMA. 2003;289 (18):2387-92.

(40) Lloyd A, Kendall M, Starr JM, Murray SA. Physical, social, psychological and existential trajectories of loss and adaptation towards the end of life for older people living with frailty: a serial interview study. BMC Geriatr. 2016;16 (1):176.

(41) Amjad H, Snyder SH, Wolff JL, Oh E, Samus QM. Before Hospice: Symptom Burden, Dementia, and Social Participation in the Last Year of Life. J Palliat Med. 2019;22 (9):1106-14.

(42) Schüssler S, Dassen T, Lohrmann C. Comparison of care dependency and related nursing care problems between Austrian nursing home residents with and without dementia. European Geriatric Medicine. 2015;6 (1):46-52.

(43) Schussler S, Lohrmann C. Change in Care Dependency and Nursing Care Problems in Nursing Home Residents with and without Dementia: A 2-Year Panel Study. PloS one. 2015;10 (10):e0141653.

(44) Nursiswati N, Halfens RJG, Lohrmann C. Change in Care Dependency of Stroke Patients: A Longitudinal and Multicenter Study. Asian nursing research. 2017;11 (2):113-8.

(45) Dhamoon MS, Moon YP, Paik MC, Sacco RL, Elkind MS. Trajectory of functional decline before and after ischemic stroke: the Northern Manhattan Study. Stroke. 2012;43 (8):2180-4.

(46) Juárez-Vela R, Durante Á, Pellicer-García B, Cardoso-Muñoz A, Criado-Gutiérrez JM, Antón-Solanas I, et al. Care Dependency in Patients with Heart Failure: A Cross-Sectional Study in Spain. International journal of environmental research and public health. 2020;17 (19).

(47) Köberich S, Lohrmann C, Dassen T. Care dependency in patients with chronic obstructive pulmonary disease and heart failure - a secondary data analysis of German prevalence studies. Scand J Caring Sci. 2014;28 (4):665-74.

(48) Schneider A, Blüher S, Grittner U, Anton V, Schaeffner E, Ebert N, et al. Is there an association between social determinants and care dependency risk? A multi□state model analysis of a longitudinal study. Research in Nursing & Health. 2020;43 (3):230-40.