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Original Article

Measuring the Quality of Dying and Quality of Care When Dying in Long-Term Care Settings: A Qualitative Content Analysis of Available Instruments

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Abstract

Context. Long-term care (LTC) settings have become a significant site for end-of-life care; consequently, instruments that assess the quality of dying and care may be useful in these settings.

Objectives. To evaluate the content of available measurement instruments to assess the quality of dying and care when dying.

Methods. Qualitative content analysis to categorize items as structure of care, process of care, satisfaction with health care (the first three representing quality of care and its evaluation), quality of dying, or patient factors.

Results. Instruments that measure mostly quality of care and its evaluation are the Family Perception of Physician-Family Caregiver Communication, End-of-Life in Dementia (EOLD) Satisfaction With Care, Family Perception of Care Scale, Toolkit of Instruments to Measure End-of-Life Care after-death bereaved family member interview (nursing home version), and the Family Assessment of Treatment at the End-of-Life Short version. Instruments measuring quality of dying are the EOLD-Comfort Assessment in Dying, EOLD-Symptom Management, Mini-Suffering State Examination, and Palliative Care Outcome Scale. The Quality of Dying in Long-Term Care measures care and dying. The Minimum Data Set-Palliative Care measures mostly dying and patient factors. The instruments differ in dementia specificity, time of administration, and respondent.

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Conclusion. Instruments that assess quality when dying differ in several ways and most do not measure a single construct, which is relevant to guiding and evaluating care. Comparing psychometric properties and usefulness of instruments that measure similar constructs is the next step in determining which are best suited for use in LTC. J Pain Symptom Manage 2011;42:852–863.

Key Words
Quality of dying, quality of care, dementia, nursing homes, residential care, assisted living, end of life, palliative care, measurement instruments

Introduction

As the number of elderly people has increased, so has the number of people living and dying in long-term care (LTC) settings. In the U.S. and The Netherlands, for example, nearly one-quarter of all deaths occurs in nursing homes alone, and another significant proportion occurs in residential care homes/assisted living.[1–3] Further, in the U.S., The Netherlands, Belgium, England, Scotland, and Wales, between 50% and 92% of dementia sufferers die in nursing homes.[3,4] Residents of LTC settings have special care needs at the end of life because of their often multiple and complex problems.[5] Unfortunately, there also are widespread reports of shortcomings in end-of-life care in LTC, including resident suffering and unmet family needs in countries that include the U.S., England, Canada, Israel, and Italy.[4,6–14] There is good cause, then, to evaluate the quality of end-of-life care in LTC toward the end of better understanding and improvement.

When evaluating the quality of the end of life, it is important to distinguish between the constructs "quality of care" and "quality of dying." Quality of care reflects elements of the setting in which dying takes place whereas the quality of dying includes symptom burden and other resident experiences that can be influenced by care and various patient-related factors. For example, an individual may experience pain (symptom burden) that was treated with medications and massage (care) but which was not completely relieved. He may have been more bothered by the pain because of his cognitive status (patient factor), and the extent to which pain was detected may reflect the time at which it was assessed. Further, as a broad term, quality of dying may be considered synonymous with quality of life while dying and outcomes while dying because the former reflects that one is still living while dying and the latter notes that quality reflects outcomes (of care and patient factors).

The distinction between measures of quality of care and dying is further important because quality of care-related measures can guide quality improvement and other intervention efforts whereas quality of dying-related measures can be used to evaluate the effectiveness of those efforts. Thus, it is important to disentangle one from the other. Therefore, this article evaluates and distinguishes the constructs and content of available measurement instruments to assess the quality of care and dying for residents dying in LTC.

Methods

Search for Measurement Instruments

We began our search for instruments with a field search, in which we first identified all available instruments that were in use at our institutions and in use or known by our international network of researchers in end-of-life care and care for elderly people. Then, we used PubMed to search the international literature for additional instruments, being sure to use the key words from the citations in which those instruments were published as well as others. We reviewed articles published between January 1988 and March 2010, using the following search terms: measure, scale, scaling, subscale, rating, rate(s), self rating, index, indices, score, scoring, instrument(s), interview, questionnaire, respondent, survey, inventory, inventories, assessment, assessing, test(s), testing, self report, clinimetric, psychometric, nursing home(s), residential home(s), hospital(s), institutional, place of care, long-term care, residential care, assisted living, palliative, terminal care, hospice care, hospice, end of life, terminal, dying, dementia, and cognitive problems. The PubMed search resulted in a total of 171 articles, of which were no duplicates. The abstracts and references were screened to identify relevant instruments.

An instrument identified through the field search and/or PubMed search was included as relevant if all the following inclusion criteria were met:

- used to assess the quality of dying and/or quality of care when dying (according to our definition);
- used in formal LTC settings (nursing homes/residential care/assisted living/LTC/hospital);
- developed for, or validated in, a population with dementia, or widely used in populations that include many people with dementia or cognitive problems. This criterion was included because of the large number of cognitively impaired people dying in LTC settings; and
- possibility to calculate (sub)scale scores or ongoing efforts to develop scales by the developers.

The following information was extracted for each instrument, if available: respondent (patient, professional caregivers, and/or family members), time of administration, recall period, setting of development and use, decedent population, number of items, domains, and type of response options.

Eleven instruments that satisfied the criteria for relevant measurement instruments were identified by the field search and PubMed search and are included in Table 1. These include the End-of-Life in Dementia Comfort Assessment in Dying (EOLD-CAD),[15] End-of-Life in Dementia Symptom Management (EOLD-SM),[15] End-of-Life in Dementia Satisfaction With Care (EOLD-SWC),[15] Family Assessment of Treatment at the End-of-Life Short version (FATE-S),[16] Family Perception of Care Scale (FPCS),[17] Family Perception of Physician-Family Caregiver Communication (FPPFC),[18] Minimum Data Set-Palliative Care (MDS-PC),[19,20] Mini-Suffering State Examination (MSSE),[21] Palliative Care Outcome Scale (POS),[22] Quality of Dying in Long-Term Care (QOD-LTC),[23] and the nursing home version of the Toolkit of Instruments to Measure End-of-Life Care (TIME) after-death bereaved family member interview.[24,25] Of note, the FPPFC focuses on a single aspect of quality (communication) and was included because of the importance of good family communication and our special interest in this instrument.

Most of the 11 instruments explicitly aimed at evaluation of palliative or end-of-life care. Only four (EOLD-CAD, EOLD-SM, EOLD-SWC, and MSSE) were, according to the developers, specifically developed for use with individuals with dementia at the end of life. One (the QOD-LTC) was explicitly developed and tested for applicability in residents with dementia although it also targeted the larger population of LTC residents. Development and testing of the other six instruments was in the nonspecific, mixed samples of people both with and without dementia. Table 1 summarizes various characteristics of the different instrument properties. The measurement instruments differed in type of respondent (patient, family member, or professional caregiver), time of administration, recall period, setting in which the instrument was developed or applied, number of items and domains, and type of response options.

Content Analysis

The constructs (quality of care and quality of dying) assessed by the measurement instruments were differentiated by qualitative content analysis. The analysis organized constructs according to the classification system detailed by Stewart et al.,[26] which distinguishes these two constructs. This model was chosen over others[27–32] because it captures—and also separates—quality of care from quality of dying. Additional advantages of the Stewart et al. model are that it distinguishes and defines (sub)categories and is consistent with the Donabedian structure, process, and outcome model of health care that is widely used across settings.[33]

The Stewart et al. model comprises three overarching categories: 1) patient factors affecting health care and its outcomes (reflecting characteristics of the personal and social environment), 2) structure and process of care, and 3) outcomes of care (Fig. 1). The categories "structure" and "process" of care represent the construct "quality of care."

Table 1

Available Measurement Instruments to Assess End of Life That Met Review Criteria

Measurement Instrument	Measurement Aim	Respondent	Time of Administration	Recall Period	Setting Developed	Settings Validated/ Used	Dementia Specific	Items/Domains/ Response Options
EOLD[15]					United States: nursing homes, hospitals, and homes	Nursing homes, hospitals, and homes[41]		
EOLD-CAD	Perceptions of symptom intensity and conditions common during dying process	Family in development and nurses in validation[42]	Postdeath	Original dying process, also used last week			Yes	14 items in four domains; three-point intensity
EOLD-SM	Perceptions of frequencies of decedent's physical and emotional symptoms	Family in development and nurses in validation[42]	Original postdeath, also used predeath	Original last 90 days of life, also used last month and last week[14]			Yes	Nine items; no domains distinguished; six-point frequency
EOLD-SWC	Satisfaction with care	Family members	Original postdeath, also used predeath	Original last 90 days of life, also used last month and last week[15]			Yes	10 items; no domains distinguished; four-point Likert scale
FATE-S[16]	Perceptions of care for decedents receiving in- or outpatient care	Family members	Postdeath	Last month of life	United States: VA health care setting for veterans dying with cancer	Nursing homes, homes, inpatient wards, intensive care units, and inpatient hospice unit[43–45]	No	12 items; no domains distinguished; four-point Likert scale for 11 items
FPCS[17]	Perceptions of the care provided to long-term decedents	Family members	Postdeath	Last month of life	Canada: LTC facilities	LTC facilities	No	27 items in four domains: resident care, family support, communication, and rooming; seven-point Likert scale
FPPFC[18]	Perception of physician communication during dying	Family members	Postdeath	Last three months of life	United States: LTC settings	Nursing homes and residential care/ assisted living settings	No	Seven items; no domains distinguished; four-point Likert scale

(*Continued*)

Table 1
Continued

Measurement Instrument	Measurement Aim	Respondent	Time of Administration	Recall Period	Setting Developed	Settings Validated/Used	Dementia Specific	Items/Domains/Response Options
MDS-PC[19,20]	Clinician assessment of palliative care needs	Professional caregivers but family members are used as a source of information on the patient	Predeath	Last three days	United States: several settings, development sample included nursing home residents and small number of residential care/assisted living residents	Nursing homes, residential homes, home care, hospital, and hospice[46]	No	182 items in 17 domains,[a] varying response options
MSSE[21]	Clinician's perspective of suffering in dying in end-stage dementia patients	Professional caregivers, but includes one overall rating of families, physicians, and nurses	Predeath	Not described	Israel: Alzheimer research and treatment center	Geriatrics departments, general hospital, hospice, and nursing homes[47–50]	Yes	10 items; no domains distinguished; dichotomous, presence/absence
POS[22]	Patient- and staff-reported outcomes of palliative care	Patients, family members, and professional caregivers	Predeath	Past three days	Great Britain: cancer patients	Nursing homes and diverse palliative care settings[51–56]	No	10 items; no domains distinguished; four point with mix of response sets
QOD-LTC[23]	Family and staff perceptions of the psychosocial quality of dying	Family members and professional caregivers	Postdeath	Last month of life	United States: LTC settings	Nursing homes and residential care/assisted living settings[57]	Both cognitively impaired and intact patients	11 items in three domains: personhood, closure, and preparatory tasks; five-point Likert scale
TIME[24,25]	Quality of care during the dying process from the family perspective	Family members	Postdeath	Last week of life	United States: development sample included 21% nursing homes	Nursing home residents with dementia, and in hospital and hospice[58]	No	36 items in eight domains,[b] varying response options

[a] Identification information, intake and initial history, health conditions, oral and nutritional status, skin condition, cognition, communication, mood, psychosocial well-being, functional status, continence, medications, treatments and procedures, responsibility/directives, social support, discharge, and assessment information.

[b] Physical comfort and emotional support, inform and promote shared decision making, encourage advance care planning, focus on individual, attend to the emotional and spiritual needs of the family, provide coordination of care, support the self-efficacy of the family, and overall rating scale for patient-focused, family-centered care.

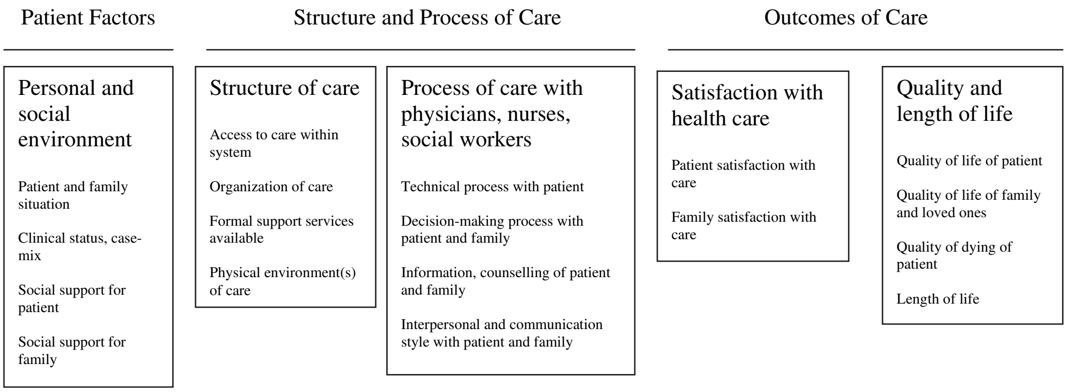

Fig. 1. Stewart et al. conceptual model of characteristics related to the quality of care and dying.[26]

"Satisfaction with health care" is a separate outcome when instruments are used in practice, but conceptually, it is an evaluation of "process of care." "Quality of dying" is represented in "quality and length of life." Because we used the model to assess dying, we more simply conceptualize this heading to refer to quality of dying rather than quality of life.

Three Dutch researchers (J. T. v. d. S., H. C. W. d. V., and M. C. v. S. -P.) and three U.S. researchers (S. Z., L. W. C., and J. M.) independently coded each individual item of all measurement instruments and categorized these into the model's categories. Within each country, the researchers resolved differences in item classification by reviewing and discussing each differently coded item, iteratively, until within-country agreement was reached. Subsequently, a similar procedure was performed combining the U.S. and Dutch categorizations into a single agreed-on version. The process was iterative as some decision rules were developed during the process of coding and during discussions about differently coded items. The following decision rules were applied:

- the verb (i.e., the action) takes priority over the other words of the item;
- if professional caregivers potentially influence the item, it is categorized as process of care (e.g., received nursing assistance);
- the structure and process of care, satisfaction with health care, and quality of dying take priority over patient factors (e.g., pre-existing medical problems);
- an item is coded as a satisfaction item if all-coders agree that the item or its responses implied a "best" or "correct" answer or standard of care;
- the purpose of the instrument, as stated by the instrument's developers, should be considered;
- the question is more important than the answering options;
- words written with capital or italicized letters are more important than words without;
- if a medical problem is likely not a new problem in this phase of life (e.g., diabetes), it should be coded as a patient factor; and
- if family could influence a process item, it should be coded in the subcategory decision-making process.

Results

Coding Agreement

The individual Dutch and U.S. researchers initially agreed on 67% and 72% of the items, respectively, and initial agreement between the Dutch and the U.S. categorization was 65%. Full consensus was reached after discussing the differences in coding. Coding agreement was best for measurement instruments with symptom items. For example, all EOLD-CAD items were coded as quality of dying by all researchers (e.g., "pain" and "anxiety").

Constructs Measured by the Instruments

The 340 items of the 11 instruments were categorized into the conceptual model shown in Fig. 1. Most items were coded as quality of dying (38%) or process and structure of care (33%). Other items were categorized as satisfaction with health care (9%) or patient factors (17%) or not relevant for classification (3%, e.g., patient name, facility number, and dates). Therefore, in total, 42% of items represents the process and structure of care and its evaluation.

Fig. 2 presents information on the constructs captured by the measurement instruments as categorized in the conceptual model. Our results show that the FPPFC and EOLD-SWC measure quality of care exclusively. Specifically, the FPPFC is 100% comprised, and the EOLD-SWC is 90% comprised of process of care items. The EOLD-SWC also contains one satisfaction item, which is an evaluation of the process of care: "I feel that my care recipient needed better medical care during the last month of [HIS/HER] life." The EOLD-CAD and EOLD-SM both measure the quality of dying (100%). The items of the FPCS, TIME, and FATE-S mostly measure quality of care, whereas the POS and MSSE mostly measure quality of dying. The FPCS process of care items represented different aspects of the care process. For example, the FPCS item "The staff put decisions I made into action quickly, with regard to my family member's care" is about the decision-making process, and "The staff were friendly to me" is about interpersonal and communication style. The FPCS also contains five items about the structure of care, for example, "Chaplaincy services were at hand for my family member."

The QOD-LTC clearly covers both quality of care (64% of items) and quality of dying (36% of items). However, the subscales are more uniform. The subscales of preparatory tasks (consisting of three items: "[Resident] had treatment preferences in writing," "[Resident] had named a decision maker in the event that [he/she] was no longer able to make decisions," and "[Resident] had funeral arrangements planned") and personhood (five items; e.g., "[Resident] was kept clean") wholly measure the quality of care whereas the subscale of closure (consisting of three items: "[Resident] was able to retain [his/her] sense of humor," "[Resident] indicated [he/she] was prepared to die," and "[Resident] appeared to be at peace") wholly measures the quality of dying. The MDS-PC measures the quality of dying (almost half of the items; e.g., "dyspnea (shortness of breath)," and "made negative statements") and also a variety of patient factors (almost one-third; e.g., "marital status," "time since last hospital stay," and "social supports").

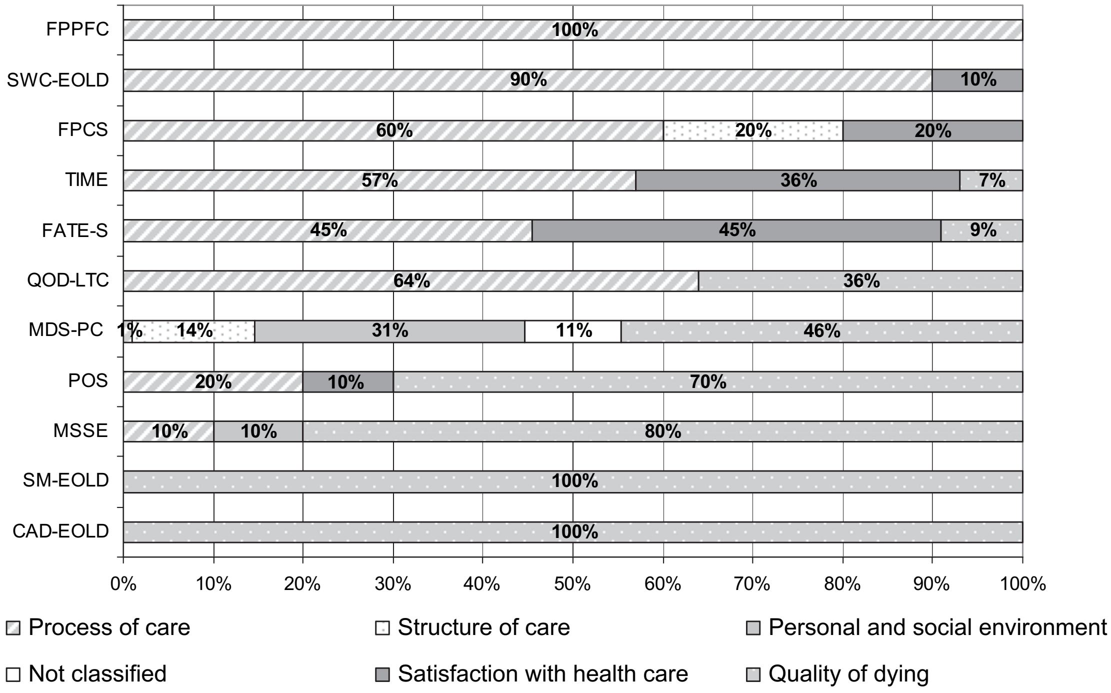

Fig. 2. Quality of care and dying constructs captured by the 11 measurement instruments.

Some instruments seem to measure aspects other than what the developer intended or what the name of the instrument suggests. The measurement aim (Table 1) of the MSSE and QOD-LTC suggests that the instruments measure quality of dying. In line with that, both instruments include items about quality of dying but also include items of other categories. The MSSE includes one item about the process of care and a patient factor. The QOD-LTC includes 64% quality-of-care items as opposed to quality-of-dying items. The aim of the POS as an "outcome scale" suggests that the instrument includes items about satisfaction with health care and quality of dying (both outcomes), but it also includes two items about process of care (e.g., "Over the past three days, how much time do you feel has been wasted on appointments relating to the health care of this patient, e.g., waiting around for transport or repeating tests"). The TIME also measures aspects that are not in line with the measurement aim (i.e., family perceptions on quality of care during the dying process) because 7% of the items reflects the quality of dying. Similarly, although the name of the EOLD-SWC (satisfaction with care) suggests that items are about satisfaction, our classification concluded that most items evaluate process of care without explicitly referring to family's satisfaction about care. Finally, the MDS-PC is the only instrument that measures a variety of patient factors that could influence care and outcomes. The MDS-PC was developed to identify palliative care needs by considering the impact of symptoms on an individual's quality of life and that of the patient's informal caregivers and for that purpose also includes patient factors.

Discussion

Our qualitative content analysis of the items of 11 instruments that measure quality at the end of life in LTC settings characterized four measures as measuring a single construct of quality of care or its evaluation (FPPFC and EOLD-SWC) and quality of dying (EOLD-CAD and EOLD-SM), whereas all the other instruments captured a mix of constructs. We regard a mixture of process and structure of care items (and their evaluation) as less problematic than other combinations in which outcomes are included in the measure along with processes and structures of care. In regard to the first point, whereas theoretically the evaluation of (i.e., satisfaction with) processes and structures is an outcome, in the coding we found that the difference between "satisfaction" and a more neutral report of process or structure was often implicit, one or two words seeming to differentiate the two. For example, the EOLD-SWC item: "I would probably have made different decisions if I had had more information" was coded as process of care whereas the FATE-S item "During patient's last month of life, how often did patient receive medication or treatment that you and he/she did NOT want?" was coded as satisfaction with health care. By contrast, when an instrument includes items about the process or structure of care along with outcomes that reflect the quality of dying, two clearly different constructs are measured, which complicates the ability to separately understand the quality of care and the quality of dying. For example, the POS is one of the instruments that includes items about process of care and quality of dying, but one overall score may be calculated for the instrument. A recently performed factor analysis[34] confirmed our finding that the POS consists of multiple constructs, so it is preferable to calculate separate subscale scores for the different constructs.

The model developed by Stewart et al. does not define satisfaction with the structure of care. In line with this, we did not find any items related to satisfaction with the structure of care in the instruments. Only 31 of the 340 items addressed the structure of care, suggesting that the developers of the measures did not consider the structure of care to be as relevant or as modifiable as the process of care when considering the quality of that care or alternatively, that items such as facility size would be measured separately from the instrument. However, there is no assurance that researchers will know to include such items, and doing so is important because end-of-life care is increasingly provided in a diverse number of settings. Private homes, hospitals, residential hospice settings, residential care/assisted living settings, and nursing homes vary dramatically, and whereas some components of the structure will be expressed in the processes of care (e.g., the availability of nurses [structure] will be reflected in the care provided by nurses [process]), such is not true for all structures of care. For example, residential care/assisted living settings are considered to be more homelike than nursing homes, and to the extent that measures do not capture such differences, potentially important components of quality may be overlooked. Further, cross-national studies in particular may benefit from instruments addressing the structure of care. However, processes of care are typically more easily amenable to change than are structures of care, and so the predominance of these items is justified.

Relatively, many quality-of-dying items (38%) were included in these measures that were developed largely for family respondents, indicating that the family is indeed acknowledged as an important judge of outcomes.[35] Of note, only three (items of the TIME) of the 32 satisfaction with health care items asked family views of patient satisfaction, which may reflect the difficulty families—especially those of individuals with dementia—face when attempting to understand and gauge a patient's end-of-life experience. Further, the Stewart model category quality of dying included the length of life, which may not be an appropriate outcome of the quality of dying for many individuals, including those with advanced dementia; consistent with this stance, it was not reflected in any of the measurement instruments we evaluated.

Difference in coding between the Dutch and the U.S. researchers seemed sometimes to be caused by the differences in the health care systems between the countries. This pertained, for example, to two TIME items: "Did [RESIDENT] have a signed Durable Power of Attorney for Health Care naming someone to make decisions about medical treatment if [HE/SHE] could not speak for [HIM/HERSELF]?" and "Did [RESIDENT] have a signed Living Will giving directions for the kind of medical treatment [HE/SHE] would want if [HE/SHE] could not speak for [HIM/HERSELF]?" There was also a difference in coding because of apparent country differences for a POS item: "Over the past three days, have any practical matters resulting from the illness, either financial or personal, been addressed?" The Dutch researchers coded these three items as a patient factor that could influence care and outcomes because professional caregivers usually do not intervene into financial or personal matters in The Netherlands. On the other hand, the U.S. researchers noted that in their country, it is the responsibility of professional caregivers to inquire about these matters. The item was finally coded as process of care because of the decision rule stating priority when professional caregivers—in at least one country—could influence it. Still, to a limited extent, it should be recognized that constructs differ across countries, reflecting different components of their health care systems. Content analyses of instruments used across countries are, therefore, best done by an international team.

Limitations and Strengths

The limitation of every search strategy is that studies may be missed, so we took care to identify the instruments we already knew of within our search strategy and to include their key words in our search efforts. Even with sensible search terms, studies that are poorly indexed may be missed. Fortunately, we were able to compare the instruments we identified with a recent systematic review of palliative care outcome measures used to assess the quality of palliative care provided in residential aged-care facilities[36,37] and found that Parker et al. identified nine of the same instruments evaluated by our analysis. The MSSE was not identified in that review, perhaps because it is specific to people with dementia and the review did not focus on dementia. The FPPFC also was not identified in that review. Three additional measurement instruments that were identified in the Parker et al. review were not included in ours because these instruments have been tested only with respondents who were cognitively able to participate, and they did not fit our criteria for inclusion (i.e., the Quality of Dying and Death, the Quality-of-Life Concerns in the End of Life Questionnaire, and the modified Quality-of-Life Concerns in the End of Life Questionnaire[38–40]).

We limited our search to LTC settings because most people dying with dementia die in an LTC setting[3,4] and there are distinct structures and processes of care within these settings; by doing so, we excluded other settings, such as community settings. Consequently, we did not review instruments exclusively developed for or used in these other settings. Still, our intent was to be responsive to the need for specific instruments for dementia patients residing in the LTC setting.

The somewhat subjective coding of the individual items of all measurement instruments for the content analysis also could be seen as a limitation of the study. For example, we found that the difference between satisfaction with care and more neutral report of care was often implicit. However, our content analysis was rigorous by involving six researchers in two countries, including independent coding, followed by review, discussion, and consensus agreement. Further, little of the disagreement related to whether the item in question was an outcome vs. structure, process, or evaluation of structure or process. Thus, the strength of our design and results is that, for researchers and clinicians who intend to use one of the included instruments in the future, the construct validity of the chosen instrument is clear in regard to care vs. outcomes, measurements may be properly interpreted, and care and outcomes understood separately.

Conclusion

To guide quality improvement efforts, we recommend that measurement instruments be selected for use that capture a single construct (quality of care or quality of dying), grounded on a theoretical model as was done in this study. Given that only four of the tested measures were specific to either quality of care or quality of dying, reports that have used other measures have reflected, in combination, components of quality of care, quality of dying, and in some cases, the characteristics of the individual. Each of these constructs has different implications, meaning that findings and conclusions must be presented accordingly. When possible and indicated, researchers and clinicians may choose to report subscales of instruments (e.g., two of the three QOD-LTC subscales measure quality of care, and one subscale measures quality of dying) but at minimum should carefully consider the implications of their results when more than one domain is being captured by the instruments. We also found that some instruments seem to measure aspects other than what the developer intended or what the name of the instrument suggests. Therefore, when deciding which instrument to use for research or practice, it is important to consider the actual constructs that are measured; in this regard, our results may facilitate such choices. For example, a clinician might choose the MSSE as a presumed measure of the quality of dying, but based on our analysis, it is clear that the MSSE also includes an item of satisfaction with care and a patient factor.

Of course, the content of a measure is only the first consideration when choosing a measurement instrument, and usefulness and measurement properties also are important when determining the optimal instrument. Further work on usefulness and the psychometric properties of the available measurement instruments will help to guide which are best to use to assess and improve the quality of care and quality of dying in LTC settings.

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The authors declare no conflicts of interest.

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