Palliative Care Patients' Quality of Dying and Circumstances of Death—Comparison of Informal Caregivers' and Health-Care Professionals' Estimates

American Journal of Hospice
& Palliative Medicine®
2018, Vol. 35(7) 1023-1029
© The Author(s) 2018
Reprints and permission:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/1049909118756616
journals.sagepub.com/home/ajh

Stephanie Stiel, Dr. rer. medic.¹ , Maria Heckel, Dr. phil²,
Kim Nikola Wendt, BSc², Martin Weber, MD³,
and Christoph Ostgathe, MD²

Abstract

Background: Patient-reported outcomes are usually considered to be the gold standard assessment. However, for the assessment of quality of dying and death, ratings of informal caregivers (ICGs) or health-care professionals (HCPs) must be considered for ethical and methodological reasons. This article aims to present results of ICGs' and HCPs' estimates of the questionnaire, quality of dying and death (QoDD) on patients who died in PCUs and to compare the level of agreement of both ratings/raters. **Methods:** The parent validation study to this analysis assessed the ICG and HCP versions of the QoDD. Descriptive statistics are presented for each item in both versions. *T* tests for the estimation of differences between ICG and HCP were performed. Case-related absolute differences between estimates were analyzed regarding the extent of agreement and deviation. **Results:** Two hundred fifteen matched ICG and HCP ratings were analyzed. The ratings in all 6 QoDD dimensions were high; single items scored low. Mean absolute difference between both ratings was 0.33 (standard deviation [SD]: 3.08; median 0.05) on a 0 to 10 numerical rating scale and ranges between −8.24 (higher rating of ICGs compared to HCPs) and 9.33 (higher rating of HCPs compared to ICGs). **Conclusions:** The findings appear to show a high satisfaction with quality of dying and death as rated by ICGs and HCPs, but we suspect this might be indicative of a methodological challenge, that is, a ceiling effect in both assessments. Single low scoring items may provide important clues for improvement in end-of-life care. Although descriptive data show comparable mean values and standard deviations, the actual congruence of ratings is low. In summary, replacing one rating by another cannot be recommended.

Keywords

quality of dying and death, assessment tool, palliative care, significant others, informal caregiver

Introduction

With an increasing number of palliative care (PC) services and a continuously growing nationwide provision of comprehensive PC in Germany, there is a need for appropriate quality indicators to foster high level of quality in end-of-life care.^{1,2} In addition to structure and process, in the PC context, patient outcome is the most important yet the most challenging domain to determine. In the past years, numerous patient-reported outcome measures (PROMs) on, for example, quality of life^{3,4} or symptom burden,^{5,6} have been developed worldwide and were translated into many different languages. Patient-reported outcome measures are generally considered the gold standard of assessments.⁷⁻⁹ By nature, none of these instruments are feasible to be used by imminently dying patient. In particular, the issue of measuring the quality of dying and death (QoDD) is challenging. In this case, a surrogate assessment by proxies

may be used. Estimates on patient's QoDD provided by informal caregivers (ICG) and health-care professionals (HCPs) who accompanied them during their last days of life can be considered as indirect measures. Recent studies have compared

¹ Institute for General Practice, Hannover Medical School, Hanover, Germany

² Department of Palliative Medicine, Friedrich-Alexander-Universität Erlangen-Nürnberg (FAU), CCC Erlangen—EMN, Universitätsklinikum Erlangen, Germany

³ Interdisciplinary Palliative Care Unit, III. Department of Medicine, University Medical Centre of the Johannes Gutenberg University of Mainz, Mainz, Germany

Corresponding Author:

Stephanie Stiel, Institute for General Practice, Hannover Medical School, Hanover, Germany.

Email: stiel.stephanie@mh-hannover.de

proxy assessments to PROMs and reported which (systematic) estimation errors and deviations may occur. The results are yet somewhat contradictory. Kutner et al found higher correlations in patient-HCP than in patient-ICG dyads concerning symptom distress and quality-of-life assessments and therefore conclude that HCP responses appear to be a fair substitute for patient response.¹⁰ In contrast, Dawber et al¹¹ and Lancker et al.¹² compared ICGs' and HCPs' symptom assessments with self-ratings of elderly patients dying in hospital and cancer patients. Both studies found higher agreement between patients and ICG than between patients and HCP.^{11,12} Jones et al analyzed quality-of-life ratings from terminally ill patients with cancer having ICGs' and HCPs' ratings, and both ratings were statistically and clinically significantly different from patient-reported experiences.¹³

The American questionnaire QoDD¹⁴ is 1 of 6 currently available instruments assessing this important issue of certainty¹⁵ in clinical care and research projects. The QoDD questionnaire was initially developed to improve care for the dying in intensive care settings. However, it has recently been validated for use in PC patients and is available in 2 versions, 1 for ICGs,¹⁶ and 1 for HCPs¹⁷ in German language and showed satisfactory psychometric properties.

Up to now, no data on the actual estimates of ICGs and HCPs provided in the German QoDD are published. To our knowledge, no comparison of both raters' estimates on patients' QoDD has been conducted. This is surprising, given the high clinical and methodological relevance of knowing whether ICG's and/or HCP's can provide satisfactory proxy measured for imminently dying relatives and patients, respectively.¹⁸

Study Aim

This manuscript aims to present the results of ICGs' and HCPs' estimates of the questionnaire QoDD on patients dying in 2 palliative care units (PCUs) and to compare estimates on identical items from the ICGs' and the HCPs' QoDD version.

Methods

Study Population and Design

Between August 2012 and December 2013, ICGs defined as family members, close friends, or significant others who were registered as attendants of deceased inpatients from 2 German PCUs (in Mainz and Erlangen, Germany) were invited to participate in a questionnaire validation study.¹⁶ A trained researcher phoned the ICG with information about the study and an invitation to participate. Details on the recruitment strategy were published elsewhere.¹⁹ Data were collected at the end of the fourth week after death at the earliest and no later than 4 months after. In case of consent, the interview took place face-to-face with the researcher in either the PC departments or their private homes, as preferred by the individual participant. Some participants wished to participate directly on the phone, so that the researchers deviated from the original

study plan in order to facilitate these wishes. During study participation, ICGs filled in the QoDD version developed specifically for ICGs.

In addition, members of 2 different professions from the PC teams, who were mainly responsible for the patient's care during the last 3 days, were asked to jointly fill in 1 QoDD questionnaire in the version for HCPs within 7 days after the patients' death.¹⁷ The rationale for this was we suspected that different professions would know and have observed different aspects during the patients' stay, which would be mutually important for the QoDD assessment. The authors were convinced that this method could raise more valid data than having the QoDD answered by 1 team member only. The HCP assessment was taken (i) to allow for the validation of both QoDD versions and (ii) to pave the way for a comparison of different ratings since we do not know how these 2 assessments are interconnected.

A partial comparison of both ICGs and HCPs questionnaires was conducted in a secondary data analysis, as 20 items are identical in both versions.

Study Measures

The QoDD questionnaire for ICGs covers 31 items. The items are assigned to 6 conceptual domains: symptoms and personal care, preparation for death, family concerns, treatment preferences, whole person concerns, and moment of death.^{14,20} Seven additional items assess the circumstances of death such as the presence of family members or friends during the last 7 days, and the patient's awareness of death. The last 2 items enquire about the quality of life in the last 7 days of life and the overall perception of the moment of death. Additionally, data on the relationship to the patient and the respondent's demographics were obtained.

Answering QoDD items requires 2 entries. In the first part, the ICG is invited to estimate the frequency of the item content on a verbal rating scale (0 = none of the time, 1 = a little bit of the time, 2 = some of the time, 3 = a good bit of the time, 4 = most of the time, 5 = always) or its existence (yes or no). In the second part, the participant rates the item content in terms of the quality of the patient's dying experience on a numerical rating scale (0 = terrible to 10 = almost perfect experience). Each second entry (0-10) on the quality of the patient's dying experience contributes to the QoDD total score.²¹

The total QoDD score is calculated by summing up the scores of all items and dividing the result by the number of items answered. This mean score is multiplied by 10 to construct a scale ranging from 0 to 100, with higher scores indicating a better estimation of QoDD.²²

Data Analyses

For the calculation of the total QoDD score, up to 20% of missing items were tolerated and replaced by the mean score of items completed by the same participant, as reported in the original version by Curtis et al.²¹ If there were more than 20%

Table 1. Descriptive Statistics to Single Items Estimates of Informal Caregiver (ICG) and Health-Care Professional (HCP).^a

Dimension	Item	ICG (Mean [SD])	HCP (Mean [SD])	Weighted κ	Paired n
Symptoms and personal control	Having pain under control	7.55 (2.54)	8.38 (1.40)	0.0482	204
	Having control over what is going on around you	6.95 (3.11)	7.91 (2.27)	0.1017	193
	Being able to feed oneself	4.91 (3.44)	6.70 (2.63)	0.0778	197
	Being able to breathe comfortably	6.26 (3.28)	7.45 (2.65)	0.1194	204
	Having control of bladder, bowels	5.26 (3.93)	NA	NA	186
	Having energy to do things one wants to do	3.24 (3.36)	NA	NA	197
Preparation for death	Feeling unafraid of dying	7.08 (3.32)	7.45 (2.95)	0.2291	114
	Feeling at peace with dying	7.33 (3.07)	7.00 (3.27)	0.1587	112
	Saying goodbye to loved ones ^b	8.23 (2.54)	8.32 (2.48)	-0.0293	78
	Clearing up bad feelings ^b	7.45 (3.47)	7.75 (3.29)	0.1429	20
	Having visits from a religious leader	8.67 (2.23)	8.96 (1.67)	0.0692	135
	Having a spiritual service or ceremony before death	8.88 (2.12)	8.93 (2.03)	0.0291	112
	Attending important events ^c	6.63 (3.75)	NA	NA	52
	Having funeral arrangements in order	8.80 (2.27)	NA	NA	193
	Avoiding strain on loved ones	5.78 (3.38)	NA	NA	172
	Having health-care costs covered	9.44 (1.83)	NA	NA	195
Family	Spending time with family, friends	8.80 (1.93)	8.37 (2.54)	0.1110	200
	Spending time alone	7.81 (2.70)	8.37 (2.21)	0.1229	187
	Spending time with spouse/partner	9.01 (2.10)	NA	NA	144
	Spending time with children	8.52 (2.48)	NA	NA	172
	Spending time with pets ^c	5.72 (3.87)	NA	NA	58
Moment of death	Having desired people present at the time of one's death	9.19 (1.88)	9.11 (1.99)	0.2313	150
	Dying in the state of one's choice	9.09 (1.96)	9.27 (1.33)	0.2313	124
	Dying in the place of one's choice	8.98 (2.07)	NA	NA	205
Whole person concerns	Being touched and hugged	9.31 (1.29)	8.83 (1.87)	0.0111	178
	Being able to laugh and smile	6.13 (3.32)	6.66 (2.48)	0.0840	180
	Keeping one's dignity and self-respect	7.95 (2.83)	7.84 (2.58)	0.1104	166
	Finding meaning and purpose	7.60 (2.83)	NA	n.a.	160
Treatment preferences	Have discussed end-of-life wishes with your doctor	8.88 (2.03)	8.75 (2.18)	0.0044	140
	Avoid using dialysis ^{b,c}	9.34 (2.02)	9.86 (0.96)	0.0177	71
	Avoid using a ventilator ^{b,c}	9.44 (1.63)	9.97 (0.17)	-0.0200	72
Quality of dying	Quality of patient's moment of death	8.69 (2.08)	8.12 (1.67)	0.0474	191
Quality of life	Quality of life in the last 7 days of life	5.44 (3.73)	NA	n.a.	205
QoDD total score	Total Score ^d	76.7 (12.82)	83.4 (9.75)	0.241 ^e	150

Abbreviations: HCP, health-care professional; ICG, informal caregiver; NA, not applicable/item not included in questionnaire version; SD, standard deviation.

^aValues based on estimates of the contribution of the respective aspect to the quality of the patient's dying and death experience on a numerical rating scale (NRS: 0 = terrible to 10 = almost perfect experience).

^bItems not included in total score of HCP version.

^cItems not included in total score of ICG version.

^dSpearman- ρ correlation.

^eSignificance < 0.01.

of missing items in a single questionnaire, the total score was not calculated. Independent from the derivation of a total score, all answers received to single QoDD items were considered for the comparison of ratings. IBM SPSS Statistics 21 (SPSS Inc, Chicago, Illinois) for Windows was used for statistical evaluation. First, we calculated descriptive statistics including mean values and standard deviation (SD) for each single item of the ICGs' and the HCPs' version (see Table 1).

Secondly, in order to compare the degree of agreement of paired estimates on identic items (from ICGs' and the HCPs' QoDD versions assessing the same patient), weighted κ coefficients were performed (see Table 1). Weighted κ coefficients assume that the probability of raters' agreement by chance alone is 50%. κ values lower than zero indicate an empirical

agreement lower than the expected 50%, and positive κ values indicate higher agreement. The interrater comparison of the QoDD total scores ranging from 0 to 100 with higher scores indicating better QoDD is presented as a Spearman ρ correlation.

Ethics Approval and Consent to Participate

The project did not include any changes to patient care or treatment. Only anonymized data were saved and processed electronically. Ethical issues such the weighing up of potential participant burden caused by the assessment versus potential for positive effects due to the attention received by the study participation were discussed within the working group. The

study was conducted with the approval of the local ethics committees at both institutions (Erlangen Ethik-Kommission der Medizinischen Fakultät: 4427 04/13/2011; Mainz Landessärztekammer Rheinland/Pfalz: 837.379.1 1 (7921) 10/24/2011). All participating ICGs gave written informed consent, and they were aware that during and after the interview they could withdraw their consent at any point in time.

Results

Study Population and Study Conduction

Informal caregivers. During the study period, 369 patients died in the 2 participating PCU, and a total of 297 ICGs met the inclusion criteria. Among these, 71 refused to participate ($n = 48$) or dropped out due to other reasons, so that finally 226 ICGs (76.1% of eligible cases) participated. In 11 cases, the researcher rated data quality as insufficient, leading to exclusion from further analysis. The final data set thus contains $n = 215$ cases.

The mean interval between the patient's death and the ICGs' study participation was 57.3 days (range: 26-176 days). Study participation took place mainly in face-to-face meetings (69.0%) and via phone call (27%) and lasted mean 39.7 ± 18.8 minutes (range: 14-165 minutes; data available for $n = 186$; $n = 29$ missing values).

The mean age of participating ICGs was 55.5 years (range: 22.3-85.0 years), and there was a slight overbalance of 61.1% females, and of Christian confession (70.4%). Most were spouses (45.1%) or children (40.7%) of the deceased and 75.2% of the participants had known the patient for longer than 30 years. The majority had daily contact with the patient during the last year (60.2%) and 42% lived in the same place.

Health-Care Professionals. It were mainly physicians ($n = 203$) and nurses ($n = 190$) who answered the QoDD questionnaire for HCPs. In other cases, a psychologist ($n = 1$), spiritual counselor ($n = 3$), or social worker ($n = 1$) was included as second rater. In 190 cases, the QoDD questionnaire for HCPs was answered by 2, in 23 cases by 1 single rater, and in 1 case by 3 HCPs ($n = 1$ missing value on the number of respondents). More details on the demographic data of the HCP and further information on the patients being assessed have been previously reported by Heckel et al.¹⁷ The actual patients whose QoDD was assessed after their deaths had a mean age of 67.4 years (range: 23.6-95.2 years), and 51.2% of them were female. Their median length of stay at the PCU was 11.3 days. The majority (82.8%) of them were diagnosed with cancer.

QoDD Dimensions and Single Items

The HCP and ICG versions of the QoDD share 20 items that were deemed applicable to both types of respondents. Moreover, there are 11 items that are only included in the ICG version of the questionnaire. The answers to all 20 matched and 11 ICG single items are reported in Table 1.

Following the structure of the QoDD dimensions, within the dimension "Symptoms and Personal Care," both ICGs and HCPs rated the item "Having pain under control" with highest quality of the patient's dying experience (mean 7.55 vs 8.38; $P < .01^*$). Informal caregivers perceived "having energy to do things one wants to do" (mean 3.42) and HCPs "Being able to feed oneself" (mean 6.70) of lowest quality (see Table 1).

Considering the dimension "preparation for death," both groups agreed on "having visits from a religious leader" (mean 8.67 vs 8.96; $P < .21$) and "having a spiritual service or ceremony before death" (mean 8.88 vs 8.93; $P < .87$) having the highest quality. Informal caregivers scored the item "untroubled about strain on loved one" and HCPs the item "feeling at peace with dying" (mean 7.00) of relatively lowest quality (mean 5.78; see Table 1).

Taking a closer look at the dimension "Family," ICGs rated "Spending time with spouse/partner" (mean 9.01) best and "spending time with pets" (mean 5.72) in proportion worst (see Table 1).

"Being touched and hugged" (mean 9.31 vs 8.83; $P < .01^*$) scored highest and "being able to laugh and smile" (mean 6.13 vs 6.66; $P < .06$) scored lowest in the dimension "whole person concerns" in both target groups.

"Avoid using dialysis" (mean 9.34 vs 9.86; $P < .06$) and "avoid using a ventilator" (mean 9.44 vs 9.97; $P < .01^*$) were each rated with highest quality in the dimension "treatment preferences".

All 3 items from the dimension "moment of death" were rated to a mean score of 8.98 to 9.19 by the ICGs. Two of these items were rated to mean score of 9.11 and 9.27 by HCPs (see Table 1).

QoDD Total Scores

The overall "quality of dying" was rated higher scores by ICG than HCP (mean 8.69 vs 8.12), whereas the "QoDD total score" was higher in HCP as compared to ICG (mean 83.4 vs 76.7). ICGs rated the "quality of life" of their deceased loved ones to a mean score of 5.44 in an empirical range between 0 and 10. This item was not included in the HCP version (see Table 1).

Differences in Estimates

For 20 matched QoDD single items included in both questionnaire versions, weighted κ coefficients varied between -0.0200 and 0.2313 (see Table 1).

The lowest percentages of raters' agreements were found in the dimension "preparation for death" ranging from 2.4% to 20.7% and in "symptoms and personal control" ranging from 9.5% to 13.2% agreement (see Table 2). The most frequent overestimation from ICGs over HCPs took place in "Quality of patient's moment of death" (54.4%), "Keeping one's dignity and self-respect" (45.2%), and "Being able to laugh and smile" (41.0%). Conversely, overestimations from HCPs over ICGs were found most often in "avoid using a ventilator" (77.5%), "avoid using dialysis" (77.2%), "clearing up bad

Table 2. Percentage of Agreement, Overestimation of ICGs over HCPs, and Overestimations of HCPs over ICGs on All Identic QoDD Items.^a

Dimension	Item	ICG-HCP Agreement (%)	ICGs' Overestimation (%)	HCPs' Overestimation (%)	Paired n
Symptoms and personal control	Having pain under control	12.9	35.9	51.2	204
	Having control over what is going on around you	12.9	34.4	52.7	193
Preparation for death	Being able to feed oneself	9.5	24.6	65.9	197
	Being able to breathe comfortably	13.2	32.2	54.6	204
	Feeling unafraid of dying	8.5	38.4	53.1	114
	Feeling at peace with dying	8.8	35.3	55.9	112
	Saying goodbye to loved ones	7.8	34.6	57.6	78
	Clearing up bad feelings	2.4	30.6	67.0	20
	Having visits from a religious leader	20.7	26.3	53.0	135
	Having a spiritual service or ceremony before death	19.0	27.2	53.8	112
Family	Spending time with family, friends	27.8	27.9	44.3	200
	Spending time alone	21.0	29.3	49.7	187
Moment of death	Having desired people present at the time of one's death	34.2	15.7	50.1	150
	Dying in the state of one's choice	20.7	25.0	54.3	124
Whole person concerns	Being touched and hugged	27.8	35.9	36.3	178
	Being able to laugh and smile	5.8	41.0	53.2	180
	Keeping one's dignity and self-respect	12.5	45.2	42.3	166
Treatment preferences	Have discussed end-of-life wishes with your doctor	21.0	29.8	49.2	140
	Avoid using dialysis	20.0	2.8	77.2	71
	Avoid using a ventilator	19.7	2.8	77.5	72
Quality of dying	Quality of patient's moment of death	14.6	54.4	31.0	191

Abbreviations: HCP, health-care professional; ICG, informal caregiver.

^aBased on estimates of the contribution of the respective aspect to the quality of the patient's dying and death experience on a numerical rating scale (NRS: 0 = terrible to 10 = almost perfect experience).

feelings" (67.0%), and "being able to feed oneself" (65.9%; see Table 2).

Discussion

This questionnaire validation study^{16,17,19} is the first that allows the comparison of QoDD ratings of 2 types of proxies responding for their loved ones or their patients, respectively, in 2 PCUs in Germany. These content-related results are supplemented by an empirical interrater comparison of identical items from both QoDD versions. This comparison takes a closer look at the case-related agreement and differences in ratings between both target groups.

All in all, the quality ratings of both ICGs and HCPs on all items from 6 dimensions were high as shown by mean values and SD, which is in agreement with the current QoDD literature.^{23,24} This points to a high satisfaction with end-of-life care in both respondent groups. This observation may reflect true satisfaction but also a result of a wider methodological issue. It is possible that a ceiling effect occurred due to social desirability and item overestimation by both ICGs and HCPs:

The first observation could be explained by ICGs who were particularly satisfied with the PCUs' performance and were also more willing to participate in the study and give positive feedback on patients' QoDD. This has been observed in other

ICG questionnaire studies in PC worldwide.^{25,26} Additionally there might be a systematic ICG overrating bias caused by the face-to-face interview administration that might be avoided by self-completion²⁷ in future research. Considering the inclusion of ICG in this validation study, the authors cannot exclude a certain selection bias, because the 1 ICG taking over responsibility and accompanying the dying phase of a certain patient at the PCU was invited for study participation to rate this certain patient. Considering QoDD as a proxy outcome measure, only single items were scored lower quality which might give valuable ideas and important clues on what can be improved in terms of QoDD in end-of-life care.

Another option is that HCPs might have displayed an over tendency to positive estimations, as they found themselves evaluating their own work. The relative proportion of HCPs' overestimation compared to ICGs' ratings has led us to the conclusion that their overestimation might even be stronger than that of ICGs. The literature on pediatric end-of-life care shows that QoDD ratings from staff members might deviate from best marks. For example, Bennett et al found that "8.8% of death experiences were rated 'worse possible' or 'poor' by staff."²⁸

In summary, the mutual overestimations and rare estimate agreement between ICGs and HCPs explain the rather low κ coefficients of QoDD single items and the low correlation of

the QoDD total score. Similar rater differences between family members and nurses were also found in an American–Dutch study. Here, the authors hypothesize that these differences may be partly due to organizational or cultural differences between the 2 countries or expectations of respondents.²⁹ Considerable variations of QoDD estimates in the context of ICUs were also observed between different staff members such as nurses, attending physicians, resident physicians, and family members.¹⁸

In this study, the actual timing of filling in the questionnaires was quite different between the 2 groups. Being aware that we are dealing with a time-dependent issue, the evaluation of QoDD, the rationale for different time intervals for questionnaire participation of ICGs and HCPs stems from the funding application. The working group aimed to balance (i) memory effects especially in HCPs who might not remember a certain patient case after a latent period longer than 1 or 2 weeks versus (ii) psychosocial burden on ICGs who might experience considerable levels of stress, sadness, and grief in the first 4 weeks after death but should also not be interviewed too late in order to have a relatively accurate recall of the dying phase and death of their loved one. Other workgroups dealing with the same issue followed the same procedure as us and allowed ICG to participate between the 4th and 12th week after their relatives' death.^{18,30}

Study Limitations

The QoDD questionnaires for both target groups are not fully comparable due to a certain amount of different items in both versions. In the data analysis, 20% of missing items were tolerated as reported for the initial validation by Curtis et al.²¹ However, this level is rather high and may reduce validity of the results. Data are collected from 2 inpatient PCUs, so that the results from these 2 sites might not be transferable to other end-of-life care settings or service providers.

The time frames for filling in the QoDD questionnaires varied considerably between the 2 target groups, which challenges the methodology and interpretation of the results. Nevertheless, our methods allowed for a high participation rate while causing low burden for ICGs and HCPs.

Conclusion

Informal caregivers and HCPs perceived high QoDD in their loved ones and patients being cared for at 2 German PCUs. Future research should investigate whether both ratings are lower when self-assessed by ICGs and HCPs without personal support of the research team to control for potential sources of bias such as social desirability.

Although descriptive data comparing both raters show comparable mean values and standard deviations in almost all items, the actual congruence of ratings was rather low. Therefore, replacing 1 rating by another cannot be recommended based on our findings. Further studies are needed to explain these differences

and determine the utility of the QoDD instrument for assessing and improving the quality of end-of-life care in PCUs.

Future research is needed to harmonize the 2 versions into 1 single QoDD questionnaire which could ease the comparability in clinical evaluations and research projects. A scientifically justified reduction in the item numbers by deleting those displaying many missing values or identical answers within 1 dimension is recommended.

Authors' Note

S.S. wrote the application for funding, developed the study design, carried out the study statistics, and wrote the manuscript. M.H. contributed to the data collection, data analysis, and writing of the manuscript. K.N.W. contributed to the study statistics and supported the development of tables and figures for the manuscript. M.W. wrote the application for funding and contributed to the proofreading of the manuscript. C.O. wrote the application for funding, supported the development of the study design, and contributed to the proofreading of the manuscript. All authors have read and approved the final manuscript.

Acknowledgments

We would like to thank all informal caregiver and health-care professionals from the two palliative care units for their participation, and we highly appreciate their courage in supporting this study.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The authors received financial support for the parent validation study of QoDD by Deutsche Krebshilfe e.V., but no funding for authorship, and/or publication of this specific article.

ORCID iD

Stephanie Stiel <http://orcid.org/0000-0002-5963-2526>

References

1. Ostgathe C, Voltz R. Quality indicators in end-of-life care. *Curr Opin Support Palliat Care*. 2010;4(3):170-173.
2. Pastrana T, Radbruch L, Nauck F, et al. Outcome indicators in palliative care—how to assess quality and success. Focus group and nominal group technique in Germany. *Support Care Cancer*. 2010;18(7):859-868.
3. Becker G, Merk CS, Meffert C, Momm F. Measuring individual quality of life in patients receiving radiation therapy: the SEIQoL-Questionnaire. *Qual Life Res*. 2014;23(7):2025-2030.
4. Groenvold M, Petersen MA, Aaronson NK, et al. EORTC QLQ-C15-PAL: the new standard in the assessment of health-related quality of life in advanced cancer? *Palliat Med*. 2006;20(2):59-61.
5. Gilbody S, Richards D, Brealey S, Hewitt C. Screening for depression in medical settings with the Patient Health

- Questionnaire (PHQ): a diagnostic meta-analysis. *J Gen Intern Med.* 2007;22(11):1596-1602.
6. Stiel S, Matthes ME, Bertram L, Ostgathe C, Elsner F, Radbruch L. Validation of the new version of the minimal documentation system (MIDOS) for patients in palliative care: the German version of the Edmonton symptom assessment scale (ESAS). *Schmerz.* 2010;24(6):596-604.
 7. Bausewein C, Le Grice C, Simon S, Higginson I; PRISMA. The use of two common palliative outcome measures in clinical care and research: a systematic review of POS and STAS. *Palliat Med.* 2011;25(4):304-313.
 8. Bausewein C, Simon ST, Benalia H, et al. Implementing patient reported outcome measures (PROMs) in palliative care—users' cry for help. *Health Qual Life Outcomes.* 2011;9:27.
 9. Simon ST, Higginson IJ, Harding R, et al. Enhancing patient-reported outcome measurement in research and practice of palliative and end-of-life care. *Support Care Cancer.* 2012;20(7):1573-1578.
 10. Kutner JS, Bryant LL, Beaty BL, Fairclough DL. Symptom distress and quality-of-life assessment at the end of life: the role of proxy response. *J Pain Symptom Manage.* 2006;32(4):300-310.
 11. Dawber R, Armour K, Ferry P, Mukherjee B, Carter C, Meystre C. Comparison of informal caregiver and named nurse assessment of symptoms in elderly patients dying in hospital using the palliative outcome scale. *BMJ Support Palliat Care.* 2016. Published online. doi:10.1136/bmjspcare-2015-000850.
 12. Lancker A, Cypers S, Vanwynsberghe E, Verhaeghe S, Hecke A, Beeckman D. Symptom assessment in hospitalized older palliative patients with cancer: agreement among patients, nurses, and proxies. *Oncol Nurs Forum.* 2015;42(2):E73-E90.
 13. Jones JM, McPherson CJ, Zimmermann C, Rodin G, Le LW, Cohen SR. Assessing agreement between terminally ill cancer patients' reports of their quality of life and family caregiver and palliative care physician proxy ratings. *J Pain Symptom Manage.* 2011;42(3):354-365.
 14. Patrick DL, Engelberg RA, Curtis JR. Evaluating the quality of dying and death. *J Pain Symptom Manage.* 2001;22(3):717-726.
 15. Hales S, Zimmermann C, Rodin G. Review: the quality of dying and death: a systematic review of measures. *Palliat Med.* 2010;24(2):127-44.
 16. Heckel M, Bussmann S, Stiel S, Weber M, Ostgathe C. Validation of the German Version of the Quality of Dying and Death Questionnaire for Informal Caregivers (QODD-D-Ang). *J Pain Symptom Manage.* 2015;50(3):402-413.
 17. Heckel M, Bussmann S, Stiel S, Ostgathe C, Weber M. Validation of the German version of the quality of dying and death questionnaire for health professionals. *Am J Hosp Palliat Med.* 2016;33(8):760-769.
 18. Levy CR, Ely EW, Payne K, Engelberg RA, Patrick DL, Curtis JR. Quality of dying and death in two medical ICUs: perceptions of family and clinicians. *Chest.* 2005;127(5):1775-1783.
 19. Stiel S, Heckel M, Bussmann S, Weber M, Ostgathe C. End-of-life care research with bereaved informal caregivers—analysis of recruitment strategy and participation rate from a multi-centre validation study. *BMC Palliat Care.* 2015;14:21.
 20. Mularski RA, Heine CE, Osborne ML, Ganzini L, Curtis JR. Quality of dying in the ICU: ratings by family members. *Chest.* 2005;128(1):280-287.
 21. Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. *J Pain Symptom Manage.* 2002;24(1):17-31.
 22. Patrick DL, Curtis JR, Engelberg RA, Nielsen E, McCown E. Measuring and improving the quality of dying and death. *Ann Intern Med.* 2003;139(5 Pt 2):410-415.
 23. Hales S, Chiu A, Husain A, et al. The quality of dying and death in cancer and its relationship to palliative care and place of death. *J Pain Symptom Manage.* 2014;48(5):839-851.
 24. Gerritsen RT, Hofhuis JGM, Koopmans M, et al. Perception by family members and ICU staff of the quality of dying and death in the ICU: a prospective multicenter study in The Netherlands. *Chest.* 2013;143(2):357-363.
 25. Paiva BS, de Carvalho AL, Kolcaba K, Paiva CE. Validation of the holistic comfort questionnaire-caregiver in Portuguese-brazil in a cohort of informal caregivers of palliative care cancer patients. *Support Care Cancer.* 2015;23(2):343-351.
 26. Minaya P, Baumstarck K, Berbis J, et al. The CareGiver Oncology Quality of Life questionnaire (CarGOQoL): development and validation of an instrument to measure the quality of life of the caregivers of patients with cancer. *Eur J Cancer.* 2012;48(6):904-911.
 27. Lyons RA, Wareham K, Lucas M, Price D, Williams J, Hutchings HA. SF-36 scores vary by method of administration: implications for study design. *J Public Health Med.* 1999;21(1):41-45.
 28. Bennett R, Proudfoot J, What Does the Staff Think? Factors associated with clinical staff perceptions of what constitutes high-quality dying and death at a tertiary pediatric hospital. *J Hosp Palliat Nurs.* 2016;18(5):470-476.
 29. Gerritsen RT, Koopmans M, Hofhuis JG, et al. Comparing quality of dying and death perceived by family members and nurses for patients dying in US and Dutch ICUs. *Chest.* 2017;151(2):298-307.
 30. Pérez-Cruz PE, Padilla Pérez O, Bonati P, et al. Validation of the Spanish Version of the Quality of Dying and Death Questionnaire (QODD-ESP) in a Home-Based Cancer Palliative Care Program and Development of the QODD-ESP-12. *J Pain Symptom Manage.* 2017;53(6):1042-1049 e3.