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Haugen, D., Hufthammer, K.O., Gerlach, C. et al. (15 more authors) (2021) Good quality care for patients with cancer dying in hospitals, but information needs not met : bereaved relatives' survey within seven countries. The Oncologist, 26 (7). e1273-e1284. ISSN 1083-7159

https://doi.org/10.1002/onco.13837

The Oncologist®

Symptom Management and Supportive Care

Good Quality Care for Patients with Cancer Dying in Hospitals, but Information Needs Not Met: Bereaved Relatives' Survey within Seven Countries

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Disclosures of potential conflicts of interest may be found at the end of this article.

Key Words. Terminal care • Palliative care • Survey and questionnaire • Proxy • Bereaved relatives • Quality of health care

ABSTRACT

Background. Recognized disparities in quality of end-of-life care exist. Our aim was to assess the quality of care for patients dying from cancer, as perceived by bereaved relatives, within hospitals in seven European and South American countries.

Materials and Methods. Postbereavement survey by post, interview, or via tablet in Argentina, Brazil, Uruguay, U.K., Germany, Norway, and Poland. Next of kin to cancer patients were asked to complete the international version of the Care Of the Dying Evaluation (i-CODE) questionnaire 6–8 weeks postbereavement. Primary outcomes were (a) how frequently the deceased patient was treated with dignity and respect, and (b) how well the family member was supported in the patients' last days of life.

Results. From 1,683 potential participants, 914 i-CODE questionnaires were completed (response rate 54%). Approximately 94% reported the doctors treated their family member with dignity and respect "always" or "most of the time"; similar responses were given about nursing staff (94%). Additionally, 89% participants reported they were adequately supported; this was more likely if the patient died on a specialist palliative care unit (odds ratio, 6.3; 95% confidence interval, 2.3–17.8). Although 87% participants were told their relative was likely to die, only 63% were informed about what to expect during the dying phase.

Conclusion. This is the first study assessing quality of care for patients dying from cancer from the bereaved relatives' perspective across several countries on two continents. Our findings suggest many elements of good care were practiced but improvement in communication with relatives of imminently dying patients is needed. *Clinical trial information:* NCT03566732 ***The Oncologist*** ;9999:• •

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Received February 19, 2021; accepted for publication May 13, 2021. Received February 19, 2020; accepted for publication May 13, 2021. http://dx.doi.org/10.1002/onco.13837

Implications for Practice: Previous studies have shown that bereaved relatives' views represent a valid way to assess care for dying patients in the last days of their life. The Care Of the Dying Evaluation questionnaire is a suitable tool for quality improvement work to help determine areas where care is perceived well and areas where care is perceived as lacking. Health care professionals need to sustain high quality communication into the last phase of the cancer trajectory. In particular, discussions about what to expect when someone is dying and the provision of hydration in the last days of life represent key areas for improvement.

Introduction

Cancer is the second leading cause of death worldwide and responsible for nearly 10 million deaths in 2020 [1]. Consequently, care of the dying is an important and integral part of cancer care, and this phase deserves equal attention as other parts of the cancer trajectory.

On the American continent, 50% of cancer deaths take place in Latin America and the Caribbean [2]. With their combined population of 1.4 billion, Europe and South America account for almost 27% of the world's cancer deaths [2]. Reports have shown challenges and disparities in the quality of end-of-life care both between and within countries in these two regions [3–6]. The global inequalities for serious health-related suffering and the need to integrate palliative care into health care systems have been recognized [7]. Whereas most countries in Western Europe are categorized as having palliative care at advanced stage of integration into mainstream service provision, no countries in South America have reached this level. Some countries (e.g., Argentina and Uruguay) have palliative care at preliminary stage of integration, whereas Brazil, among others, is characterized by generalized palliative care provision, but without integration of palliative care services into mainstream health care provision [8].

This situation led the Network of the European Union and the Community of Latin American and Caribbean States on Joint Innovation and Research Activities (ERANet-LAC) to select "Improving the quality of care and quality of life of dying cancer patients" as the health topic for their second Joint Call in 2016 [9]. The call specifically asked for multicenter studies with the aim of using data from patients or relatives to advance the international evidence-base in care for patients dying from cancer.

In response to the ERANet-LAC call, the current study aimed to conduct an international observational study of bereaved relatives to patients with cancer dying in hospitals across seven countries in Europe and South America. We sought to assess the current quality of care, provide cross-country comparisons, and identify areas where care needs to be improved. In particular, clear and timely communication with patients and family members is fundamentally important in this phase of illness [10, 11] with concerns about hydration being especially pertinent [12]. Therefore, within this manuscript, as well as the key outcomes (being treated with dignity and respect; adequacy of family support), we specifically report on aspects of communication in the last days of life.

Materials and Methods

Study Design and Participants

This study was an international postbereavement survey by postal questionnaire or interview after "expected" cancer deaths in hospitals within three South American and four European countries: Argentina, Brazil, Uruguay, Germany, Norway, Poland, and the U.K.

The patient cohort consisted of adult patients with cancer who died an expected death in one of the hospitals recruited as study sites. The patient must have been admitted to the hospital (any ward) for at least three calendar days, with the next of kin present at least some of the time during the patient's last two days. The attending physician was consulted if there was any doubt whether or not the death was expected; if not available, any death of a patient with cancer which did not involve cardiopulmonary resuscitation was accepted.

"Patient with cancer" was defined as any patient with a solid cancer or hematological malignancy, not necessarily dying from the malignancy.

The patients' next of kin were invited to complete the survey and constitute the study participants. "Next of kin" was defined as the person recorded as next of kin in the patient's hospital record.

Next of kin were eligible if they were ≥18 years of age and able to provide informed consent. They were ineligible if they were unable to complete the questionnaire due to language abilities or reduced cognitive functioning. Eligibility was evaluated by staff on the ward where the patient died, by research staff reviewing the medical file after the patient's death, and by research staff contacting next of kin to invite them to participate in the study (Table 1).

Data Collection Tools

Screening: The following information was recorded by the ward staff or taken from the medical record for all eligible cases: deceased patient's gender, age group, primary site of cancer (predefined groups), and type of ward they died on; length of hospital stay; whether the patient received support from a hospital specialist palliative care (SPC) team, and/or by an individualized care plan during the dying phase of their illness; next of kin's gender and age group. Ethical approval was obtained to store this information for all eligible cases, both participants and nonparticipants, but not to register information about ethnicity/nationality and religious affiliation for nonparticipant cases.

International version of the Care Of the Dying Evaluation (i-CODE): Data from next of kin were collected using the i-CODE questionnaire, the international version of the validated 42-item Care of the Dying Evaluation (CODE) questionnaire (supplemental online File 1) [13]. CODE is a shortened, more user-friendly version of the original instrument, Evaluating Care and Health Outcomes – for the Dying, which has been shown to be valid, reliable, and sensitive in detecting unmet needs and differing perceptions of care [14, 15]. Both questionnaires are unique as their conceptual basis originates from the key components recognized as best practice for "care for the dying" (last days of life) [16]. CODE assesses both quality of patient care and the level of family support, representing the fundamental "pillars" of palliative care [17]. It is composed of 32 main questions with 10 additional questions focused on demographic details. CODE includes assessment of pertinent issues such as the provision of fluids and what to expect when someone is dying, which are not covered within other available tools. The two key outcomes are: "How much of the time the patient was treated with dignity and respect" (question 30), and "How adequately the family were supported" (question 31).

Although there are a number of different post-bereavement tools, a previous review identified issues with instruments using "satisfaction" as an outcome measure [16]. A more recent systematic review identified CODE as an instrument, with some strong psychometric properties, which would benefit from further development and validation [18]. Hence, pretesting survey methods helped ensure the CODE questionnaire had good face and content validity and was suitable for use in the seven countries [19].

Web survey of study sites: A short questionnaire assessing hospital characteristics and the level of palliative care provision was developed by the project team to collect background information about the study sites. The questionnaire was completed online by the local project coordinator at each participating hospital.

The survey software Corporater Surveyor (www.corporater.com) was used to collect all data. This software was developed in Norway specifically for collecting patient and relative generated outcomes. One screening database and one i-CODE database were set up for each country. The databases were set up in English because this was the common project language and it would ease merging of the data sets.

Procedures

Study participants were recruited by 22 hospitals in the seven countries (Table 1). The hospitals represented a range of different institutions and levels of palliative care provision, and all except two (one in Germany and one in Poland) had an SPC service that functioned as the local contact for the study. The study period commenced on August 15, 2017, with the last eligible patients included on September 15, 2018. Because of lengthy procedures for ethical approval, the U.K. joined the study from October 1, 2017. Information about how potential study participants were identified and approached, and the methods used for data collection, is given in Table 1.

Screening information was registered on paper forms by local ward staff or research staff upon identification of potential participants. The forms were collected by members of the local study team, who also entered the information into the screening databases. The i-CODE questionnaire was presented to all participants 6–8 weeks after the patient's death. This time frame was chosen because a previous study found no difference in terms of distress when approaching bereaved relatives 6 weeks and 3 months after the death [20]. Additionally, it was in keeping with the time frame used within our pretesting study [19].

The study was originally intended as a postal survey, but because of poorly functioning postal services, issues with literacy, or experiences with very low response rates, different data collection methods were selected in Poland (computer-assisted personal interviewing using tablet) and the South American countries (interview). Further details are given in Table 1 and Figure 1. The i-CODE responses were entered into the Corporater Surveyor database for each country by the national study coordinators or their local study teams. Free-text comments from within the i-CODE questionnaire were translated into English by the national study coordinators. Data were stored on a protected research server.

The study was approved by relevant ethical bodies in the participating countries (see Acknowledgments). Participants gave written informed consent. In Norway and the U.K., participants were informed that consent was implied when the next of kin completed and returned the questionnaire.

Outcomes

The two primary outcomes were the participants' (next of kin's) perceptions about (a) how much of the time the patient was treated with dignity and respect in the last days of life, by doctors and by nurses (question 30); and (2b) whether or not the participant was adequately supported during the same time period (question 31).

Additionally, we report on specific questions within the i-CODE questionnaire about the communication relating to preparedness prior to death and the provision of fluids.

Data Analysis and Statistical Methods

Data were exported from Corporater Surveyor to Excel files, quality assured for duplicates and wrong entries, and analyzed using R version 3.5.3 and 3.6.0 [21].

For the individual response options, we present the results as counts and percentages, both overall and stratified by country. All items, including binary and ordinal items, were scored on a 0–4 scale (with 2–5 response options, depending on the item), where "0" indicates a low and "4" a high quality of care [22]. For these items and their corresponding sum scores, we report mean values, SDs, and 95% confidence intervals (CIs). To calculate the CIs, we used the percentile bootstrap, with 9,999 bootstrap replications.

Question pairs with logical dependencies (questions 17 and 18, asking about the provision of fluids; and questions 24 and 25, asking about what to expect when their family member was dying) were recoded to be internally consistent (a "yes" on the first question implies "not applicable" on the second question; supplemental online File 1).

We also investigated if there was an association between the presence of SPC and the participants' perceptions about (a) whether the patient was treated with dignity and respect (by doctors and by nurses; question 30, part "a" and "b"), and (b) whether the participant was adequately supported during the patient's last days of life (question 31). We did this by fitting separate mixed-effects regression models for questions 30 (linear regression) and 31 (logistic regression). The main explanatory variables were (a) did the patient die on a specialist palliative care unit (PCU)? (b) Was a SPC team involved in the patient's care before death? and (c) was the care of the patient supported by an individualized care plan? We also included additional demographic variables: the patient's age, gender, and the country of the hospital. To adjust for any additional hospital-level differences, we included hospital as a random effect (random intercept). Reported p values have not been adjusted for multiple comparisons. The p values $\leq .05$ are considered statistically significant.

Definitions: The following definitions were used for the main exploratory variables. SPC team: interdisciplinary palliative care team with consultation available in both outpatient and inpatient settings, consisting of palliative care physicians and palliative care nurses, at a minimum, and social worker, chaplain, and/or rehabilitation specialist (physical therapy, occupational therapy, or rehabilitation medicine). Palliative care consultations provide comprehensive baseline and ongoing assessments that include evaluation of quality of life and physical, psychological, spiritual, and social domains and prognostic disclosure [23].Specialist PCU: hospital inpatient unit with a SPC staff team responsible for patient care. PCUs admit palliative care patients with the most complex and difficult needs, and although the main focus is short-term symptom management, some patients need specialized inpatient care until death [24]. Individualized care plan: a plan of care specifically for the dying phase, personalized to the individual and covering their specific end-of-life care needs such as food and drink, symptom control, psychological, social and spiritual support [25]. One example of a framework for an individualized care plan is the PAMPA plan used in Argentina [26].

Missing data: There were little missing data on the primary outcome variables (<5%) and on the variables included in the regression models (<10%), so we used complete case analysis for all analyses.

Sample size considerations: The study aimed for at least 100 completed i-CODE questionnaires per country, to ensure that estimates of any country-specific percentage value could be provided with a precision within ± 10 percentage points (95% CIs).

RESULTS

Study sites

All 22 participating hospitals answered the web survey, representing both public and private hospitals. The number of beds used for study recruitment ranged from 115 (Poland) to 2,244 (Germany; Table 1). None of the South American hospitals had an inpatient PCU, whereas 86% of the participants in Poland were recruited from PCUs.

Participants and Patients

From 1,683 potential participants who met study eligibility criteria and were screened for participation, 914 i-CODE questionnaires were completed and returned (response rate 54%). Variability in response rates was seen between countries for the postal administration (range, 34%-–8%) and the interview-administered questionnaire (range, 58%–95%; Fig. 1). Participants tended to be female (67%) and the spouse or partner to the deceased patient (45%; Table 2), although there was variability between countries (supplemental online file 2). Almost half (49%) of the patients died on Medical and Surgical wards (Table 2).

Participants and nonparticipants were similar in terms of age and gender (for both participant and deceased patient), cancer diagnosis, type of ward, involvement of a SPC team, and support by an individualized care plan (data available on request).

i-CODE Questionnaire Results

Key Outcomes

Generally, the participants' perception of the patient's care was very good. Approximately 94% (820/876) perceived that the doctors treated their family member with dignity and respect "always" or "most of the time" and similar responses were given for perceptions about nursing staff (94%, 849/902; Table 3). With 0 (never) and 4 (always) as the minimum and maximum obtainable scores, the intercountry variation was 3.3–4.0 (Table 3). Additionally, 89% (788/884) of participants reported they were adequately supported in the patient's last days of life, with more than 80% responding positively for each individual country (Fig. 2).

Regression analyses demonstrated that the participants' perceptions about how much of the time the patient was treated with dignity and respect in the last days of life (question 30) was higher if the patient died on a PCU as compared with other wards (Table 4). For doctors, the score difference was 0.28 (95% CI, 0.10–0.46; $p = .003$), and for nurses, it was 0.17 (95% CI, 0.01–0.33; $P = .04$).

Whether the patient died on a PCU was also strongly associated with participants' perceptions about whether they were adequately supported during the patient's last days of life (question 31), with an odds ratio of 6.3 (95% CI, 2.3–17.8). The unadjusted proportion of participants responding "yes" to this question was 98% for patients who died on a PCU and 86% for other patients.

In contrast, neither the support from a SPC team nor via an individualized care plan was statistically significantly associated with the primary outcomes (Table 4).

Communication

Analysis of the questions relating to communication showed that 87% of the participants had been told their relative was likely to die soon (intercountry range, 79%–96%). Fewer participants reported discussions, however, about what to expect when their family member was dying (question 24, 63%) and about the provision of fluids (question 17, 55%; Fig. 2). Answers to the subsequent questions 25 and 18 showed that, respectively, 61% and 34% of the participants who did not have these discussions, would have wanted them.

DISCUSSION

This study represents the first time a comparison of hospital care has been undertaken from the bereaved relatives' perspective, about the quality of care for dying patients in Europe and South America. Overall, this international postbereavement survey showed quality of care for dying patients was generally perceived as good. Participants indicated that their family members had been treated with dignity and respect and perceived themselves to be adequately supported. The participants to those patients who died in a PCU gave, on average, higher perceived quality of care scores. Participants perceived that care was lacking in terms of unmet information and communication needs: in particular, regarding the provision of information about what to expect when their family member was dying and the provision of hydration in the last days of life.

The finding that care and support were rated more highly when the death occurred in a PCU is in keeping with previous studies [27–29]. Another study showed the provision of information was perceived to be better when death occurred within a hospital PCU compared with a general hospital ward supported by a hospital SPC team [30]. The majority of cancer deaths, however, do not occur in specialized units, and within South America, none of the recruiting hospitals had a PCU. Ways to upskill the generic hospital health care workers are needed to improve the cultural approach toward the dying and provide a more equitable level of care. Initiatives involving a focus on the last days of life have been tested for feasibility and the need for ongoing training and supervision reinforced [26].

Ongoing communication between the health care team, the patient (where able), and the family members is a vital part of care during the dying phase [31–34]. Although there is a current emphasis on advance care planning and involvement in decision-making, this should not lead to less focus on information about what to expect (symptoms, signs) when someone is dying [35, 36]. Our results showed that even though information about impending death was given in most cases, subsequent discussions about the actual dying process were insufficient from the bereaved relatives' perspective. This potentially could have impact on the subsequent psychological well-being of the bereaved [37–39].

In particular, the issue of hydration was recognized as an unmet need and is consistent with previous postbereavement studies [40, 41]. Hydration in the last days of life is an emotive and challenging area, with very limited evidence about benefits and burdens [42, 43]. The lack of discussions about this issue may reflect health care professionals' uncertainties about how to broach the topic [44]. With training in end-of-life care often being inconsistent and variable [45], this represents an ongoing educational need.

The strengths of this study include the international participation and the focus specifically on the dying phase. Additionally, although there are several postbereavement questionnaires assessing quality of care, the "CODE" questionnaire is regarded as having the strongest psychometric properties [18]. The "i-CODE" questionnaire was developed and validated with target users at every step, including the latest pretesting for the present survey [19]. Although evaluating care from the patients' perspective is the "gold" standard, using views from those close to them such as their family members has recognized validity [46]. Next of kin are able to provide perceptions about the quality of care provided to their family member as well as their own recollections about their experience. Finally, participants were recruited consecutively and many countries had a good response rate.

The study has limitations. First, the postbereavement survey was only performed in a limited number of hospitals in each country. Although the South American hospitals were generally representative for their country or region, being both public and private hospitals, we cannot generalize the results to be representative of each country, especially because all the hospitals had a SPC service. Additionally, although Poland included general hospital wards, the majority of participants were recruited from PCUs as dying patients within the hospital tended to be transferred there. This may have led to bias in terms of care being perceived more favorably than it would have been for other hospitals within the country. Second, different approaches to recruitment and completion of the questionnaire were used, and there was variability in the individual country response rates. Proxy characteristics play a role in influencing response rates [47], and variability was seen between different countries. Both these factors could potentially lead to response bias. The different recruitment approaches and the criteria for "expected death" were pragmatic decisions. We perceived that with clinician involvement, this would help identify appropriate deceased individuals. Postal administration would not have been feasible within the South American countries.

The main implication of our study is the need for health care professionals to sustain high quality communication into the last phase of the cancer trajectory. This is in keeping with recommendations from some of the participating countries [48]. Family members may have no experience with death and dying and look for guidance in an unknown territory. Further research should address optimal ways of meeting their needs and assess how the present results may be transferred into clinically useful approaches. We believe the i-CODE questionnaire can be a useful tool for quality improvement, and in the next phase of the research, quality improvement projects based on the bereaved relatives' identified concerns are being carried out in several of the participating hospitals.

CONCLUSION

To our knowledge, this is the first study assessing the care of patients dying from cancer across several countries on two continents. Our findings suggest that many elements of good care for dying patients were practiced. At the same time, areas for improvement were identified, with communication by health care professionals with relatives of dying patients being the most pertinent across the study sites.

ACKNOWLEDGMENTS

We thank the study participants for sharing their time and views, and hospital staff for help in organizing the data collection. We also thank our colleagues within the International Collaborative for Best Care for the Dying Person for valuable discussions and support.

The ERANet-LAC CODE project: “International Care Of the Dying Evaluation (CODE): quality of care for cancer patients as perceived by bereaved relatives” (reference ELAC2015/T07–0545, January 2017–January 2020) was funded through the second Joint Call for Transnational Research and/or Innovation Projects within the ERANet-LAC framework, cofunded by the European Commission’s seventh Framework Programme, with the overall aims to improve the quality of care and quality of life of patients dying from cancer.

The following national funding agencies are acknowledged: Ministry for Science, Technology and Productive Innovation, Argentina; Research Support Foundation of the State of Sao Paulo, Brazil; Federal Ministry of Education and Research, Germany; The Research Council of Norway (grant number 271051); National Centre for Research and Development, Poland; and Marie Curie and the Northwest Coast Clinical Research Network Funding, U.K.

Study approval was given by the Regional Committee for Medical and Health Research Ethics West (2017/640/REK vest), Norway; Ethics Committee of the Medical Council of the province of Rhineland-Palatine, Germany (approval nos. 837.331.13(901 6F) and 837.292.17 (111261); Guía de Buenas Prácticas de Investigación Clínica en Seres Humanos, Ministerio de Salud de la Nación Argentina (Resolución 1480/2011); Bioethics Committee, Poland - KB507/2017 (13.06.17); Health Research Authority and East of England – Cambridge East Research Ethics Committee, U.K. (IRAS project ID 225922; REC 17/EE/0302); National Research Ethics Commission, Brazil (ref. 2.308.216); and Committee on Bioethics from the “Mutualista Asociacion Hospital Evangelico,” Uruguay (ref. 29/5/2017/01).

Data management and sharing: Data are archived at the Norwegian Centre for Research Data and can be made available upon reasonable request. Any enquires should be directed through the Chief Investigator Professor Dagny Faksvåg Haugen, Regional Centre of Excellence for Palliative Care, Western Norway, Haukeland University Hospital, Bergen, Norway (e-mail: dagny.haugen@uib.no)

If anyone would wish to use the CODE questionnaire, enquiries should be directed to Dr. Catriona Mayland (c.r.mayland@sheffield.ac.uk or catriona.mayland@liverpool.ac.uk) so a Material Transfer Arrangement can be facilitated. CODETM should not be altered without request.

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Dr. Catriona Mayland is funded by Yorkshire Cancer Research.

The funders of the study played no role in the study design, data collection, data analysis, data interpretation, or writing of the report.

Presented at the 5th Annual Research Conference of the International Collaborative for Best Care for the Dying Person, Buenos Aires, Argentina, November 8–9, 2018; and the 16th World Congress of the European Association for Palliative Care, Berlin, Germany, May 23–25, 2019.

Open access funding enabled and organized by Projekt DEAL.

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DISCLOSURES

The authors indicated no financial relationships.

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See http://www.TheOncologist.com for supplemental material available online.

Table 1. CODE International Survey: Information about the study sites, identification and approach of participants, and data collection methods

	Study sites (type of hospital and wards; number of beds for study recruitment)	Method of identifying potential participants	Method of approach and recruitment	Data collection methods
Argentina	3 university hospitals (2 public, 1 private) Medical, surgical, and oncology wards, ICU ($n = 395$)	Review by local study team, using lists of deceased patients during the last month (provided by key administrative personnel or the Department of Quality and Patient Safety at the hospitals)	Mostly via telephone invitation from a study team member, at least 6 wk after bereavement; or verbal information was given to next of kin at the hospital by members of the specialist palliative care team.	Telephone (50%) or face-to-face interviews (37%) (at the hospital or in the patient's home) by local study team members (social workers or physicians with relevant research experience), or questionnaire answered by e-mail (13%)
Brazil	2 public university hospitals Medical, surgical, and emergency HDU wards, ICU ($n = 330$)	By the specialist palliative care team on the wards, or by the hospital's Obituary Committee when reviewing charts of deceased patients (who passed on information to the local study team)	By telephone from a study team member 6–8 wk postbereavement, supplemented by written information via e-mail, surface mail, or WhatsApp mobile phone app.	Face-to-face interviews at the hospital (43%) or interviews by telephone or e-mail (57%) by local study team members (specialist palliative care physiotherapists with relevant research experience)
Germany	2 university hospitals (1 public, 1 private) Medical, surgical, and oncology wards, ICU, PCU ($n = 2,244$)	By the Department of Medical Controlling or the Department of Quality Assurance in cooperation with the local study team, when reviewing the medical documentation 4–6 wk after the death of a patient	Via surface mail by the Department of Quality Assurance 6–8 wk postbereavement. Questionnaire pack sent out 2 wk later by surface mail to all who did not actively opt out.	Postal survey; 1 postal reminder to nonrespondents after 4 wk (94% of the respondents answered to the first postage, 6% to the reminder)
Norway	3 university hospitals and 4 acute care hospitals (all public hospitals) Medical, surgical, and oncology wards, PCU ($n = 423$)	By the ward staff, who immediately upon the death of a patient screened the case notes according to the inclusion criteria	Verbal information and through a leaflet prior to the next of kin leaving the hospital after the patient's death. If missed, leaflet was sent by surface mail. Questionnaire pack sent out 6–8 wk later by surface mail to all who did not actively opt out.	Postal survey; 1 postal reminder to nonrespondents after 4 wk (60% of the respondents answered to the first postage, 40% to the reminder)
Poland	4 public hospitals including 1 specialist hospital (pulmonology) Medical, and surgical wards, PCU ($n = 115$)	By ward staff (physicians and nurses) within 3 d after the death of a patient. Contact information sent to the local study coordinator	Via telephone invitation from a psychologist in the local study team 4 wk postbereavement. If the patient did not refuse, an appointment for a home visit 2–4 wk later was made.	Computer-assisted personal interviewing using tablets. Psychologist visited next of kin in their homes (or a different place at their choice). The questionnaire was completed by the participants themselves, but some older participants needed assistance from the interviewer to enter their answers
U.K.	2 public university hospitals Medical, surgical, and emergency HDU wards, ICU, PCU ($n = 1,425$)	By staff at the hospital's Bereavement office within 72 hours of the death, highlighting patients who had cancer recorded on their death certificate. Local study team then screened the case notes of the patients highlighted to determine eligibility	Verbal information and through a leaflet when the next of kin came to collect the death certificate from the Bereavement office, between 3 and 7 d after the death. Questionnaire pack sent out 6 wk postbereavement to all	Postal or online survey; one postal reminder to nonrespondents after 4 wk. (78% of the respondents answered to the first postage, 22% to the reminder. Only one participant answered online)

(continued)

Table 1. (continued)

	Study sites (type of hospital and wards; number of beds for study recruitment)	Method of identifying potential participants	Method of approach and recruitment	Data collection methods
			who did not actively opt out.	
Uruguay	2 private hospitals Medical, surgical, and emergency HDU wards, ICU ($n = 330$)	By the nurses from the specialist palliative care team, who visited the hospital wards on a regular basis	Verbal information by a nurse from the specialist palliative care team. If next of kin agreed to receive an invitation to the study, the nurse noted their telephone number. Later, interviews were coordinated by phone approximately 6 wk after the death.	Telephone interviews (about 50%) or face-to-face interviews in next-of kin's home or at the hospital. Interviews were conducted by nurses from the specialist palliative care team (but always someone not involved in the direct care of the patient and family in question)

Abbreviations: HDU, high dependence unit; ICU, intensive care unit; PCU, palliative care unit

Table 2. Characteristics of the deceased patients and their next of kin ($n = 914$)

	Deceased patients, count (%)[a]	Next of kin, count (%)[a]
Gender		
Male	527 (58)	298 (33)
Female	387 (42)	610 (67)
(Missing)	0 (0)	6 (1)
Age		
18–29	3 (0)	26 (3)
30–39	13 (1)	95 (11)
40–49	39 (4)	148 (16)
50–59	117 (13)	241 (27)
60–69	244 (27)	208 (23)
70–79	290 (32)	150 (17)
80–89	179 (20)	35 (4)
90+	29 (3)	0 (0)
(Missing)	0 (0)	11 (1)
Religious affiliation[b]		
Christian	732 (82)	703 (78)
None	117 (13)	141 (16)
Other	47 (5)	56 (6)
(Missing)	18 (2)	14 (2)
Relationship to patient (next of kin was:)		
Spouse/partner		411 (45)
Son/daughter		317 (35)
Brother/sister		67 (7)
Son-in-law/daughter-in-law		23 (3)
Parent		15 (2)
Friend		16 (2)
Neighbour		59 (6)
Other		6 (1)
(Missing)		0 (0)
Cancer diagnosis[c]		
Gastrointestinal, incl. pancreatic	321 (35)	
Respiratory organs	196 (21)	
Leukemia/lymphoma	100 (11)	
Urological, incl. prostate	83 (9)	
Breast	43 (5)	
Brain	34 (4)	
Gynecological	33 (4)	
Other	122 (13)	
(Missing)	2 (0)	
Type of ward where the patient died		
Medical or surgical ward	447 (49)	
Palliative care unit	231 (25)	
Oncology ward	119 (13)	
Intensive care unit	69 (8)	
Emergency unit	42 (5)	
(Missing)	6 (1)	
Specialist palliative care team involved in the patient's care before death		

(continued)

Table 2. (continued)

	Deceased patients, count (%)[a]	Next of kin, count (%)[a]
Yes	572 (63)	
No	334 (37)	
(Missing)	8 (1)	
Care of the patient supported by an individualised care plan		
Yes	416 (47)	
No	460 (53)	
(Missing)	38 (4)	

[a] Missing data presented but not included in the percentage calculations.

[b] Range for patients: Christian: 73% (Norway) to 92% (Brazil); none: 0% (Brazil) to 20% (Norway); other: 0% (U.K.) to 10% (Uruguay). Range for participants: Christian: 62% (Uruguay) to 92% (Brazil); none: 0% (Brazil) to 23% (Uruguay); other: 0% (UK) to 14% (Uruguay).

[c] 16 patients registered with two cancer types and 2 patients registered with three cancer types.

Table 3. Bereaved relatives' perceptions about "How much of the time was your relative treated with respect and dignity in the last 2 days of life?" by doctors and by nurses

Country	Profession	Resp.	Never (0), %	Some ofthe time (1), %	Most ofthe time (3), %	Always (4), %	Mean	SD	95% CI
Argentina	Doctors	104	2	7	18	73	3.5	0.9	3.3–3.7
Argentina	Nurses	103	2	16	19	63	3.3	1.2	3.0–3.5
Brazil	Doctors	103	0	8	17	75	3.6	0.8	3.4–3.7
Brazil	Nurses	104	0	15	18	66	3.4	1.1	3.1–3.6
Germany	Doctors	173	1	2	10	87	3.8	0.7	3.7–3.9
Germany	Nurses	181	0	3	13	84	3.8	0.6	3.7–3.9
Norway	Doctors	182	1	9	17	73	3.5	0.9	3.4–3.7
Norway	Nurses	191	0	4	12	84	3.8	0.6	3.7–3.9
Poland	Doctors	96	0	0	4	96	4.0	0.2	3.9–4.0
Poland	Nurses	99	0	0	7	93	3.9	0.3	3.9–4.0
United Kingdom	Doctors	95	7	6	11	76	3.4	1.2	3.1–3.7
United Kingdom	Nurses	100	3	2	6	89	3.8	0.8	3.6–3.9
Uruguay	Doctors	123	0	2	10	89	3.9	0.5	3.8–3.9
Uruguay	Nurses	124	0	1	9	90	3.9	0.4	3.8–3.9
Total	Doctors	876	1	5	13	81	3.7	0.8	3.6–3.7
Total	Nurses	902	1	5	12	82	3.7	0.8	3.6–3.7

Abbreviations: CI, confidence interval; Resp.: number of respondents.

Table 4. Mixed-effects multiple regression analyses for next of kin's perception of the quality of care (*n* = 833–841)

	Q30 doctors[a] (*n* = 833)		Q30 nurses[a] (*n* = 855)		Q31[b] (*n* = 841)	
Variable	Coef. (95% CI)	*p* value	Coef. (95% CI)	*p* value	OR (95% CI)	*p* value
Intercept	3.22 (2.82–3.62)		3.57 (3.25–3.89)		2.72 (1.11–6.69)	
Country (ref.: U.K.)		.02		<.001		.08
Argentina	0.32 (−0.19–0.83)	.20	−0.35 (−0.74–0.03)	.07	1.51 (0.69–3.27)	.30
Brazil	0.43 (−0.13–0.98)	.12	−0.22 (−0.64–0.20)	.29	1.45 (0.64–3.26)	.37
Germany	0.54 (−0.10–1.17)	.09	0.12 (−0.35–0.59)	.60	2.78 (1.20–6.43)	.02
Norway	0.23 (−0.23–0.69)	.29	0.12 (−0.23–0.47)	.49	2.35 (1.06–5.20)	.04
Poland	0.47 (−0.05–1.00)	.07	0.09 (−0.31–0.49)	.64	2.16 (0.53–8.74)	.28
Uruguay	0.62 (0.07–1.16)	.03	0.23 (−0.18–0.65)	.25	4.06 (1.60–10.33)	.003
Age (ref.: 18–59 years)		.64		.39		.33
60–79 yr	−0.05 (−0.20–0.10)	.50	0.07 (−0.06–0.21)	.30	1.12 (0.61–2.07)	.71
80+ yr	0.00 (−0.18–0.18)	.99	0.11 (−0.05–0.27)	.17	0.74 (0.37–1.49)	.40
Female gender	0.04 (−0.07–0.15)	.48	0.07 (−0.04–0.17)	.21	1.03 (0.65–1.64)	.90
PCU	0.29 (0.09–0.49)	.004	0.19 (0.02–0.36)	.03	6.32 (2.25–17.76)	<.001
SPC team	−0.07 (−0.21–0.07)	.32	−0.12 (−0.25–0.00)	.05	0.96 (0.57–1.62)	.87
Individualised care plan	0.10 (−0.04–0.24)	.16	0.09 (−0.04–0.22)	.17	1.60 (0.93–2.75)	.09

[a] Linear mixed-effects regression model. The question was "How much of the time was s/he treated with respect and dignity in the last two days of life?," with possible responses ranging from 0 (Never) to 4 (Always).

[b] Logistic mixed-effects regression model. The question was "Overall, in your opinion, were you adequately supported during his/her last two days of life?" (yes/no).

Abbreviations: Coef., regression coefficient; CI, confidence interval, OR, odds ratio; PCU, palliative care unit; Q, question; ref., reference; SPC, specialist palliative care

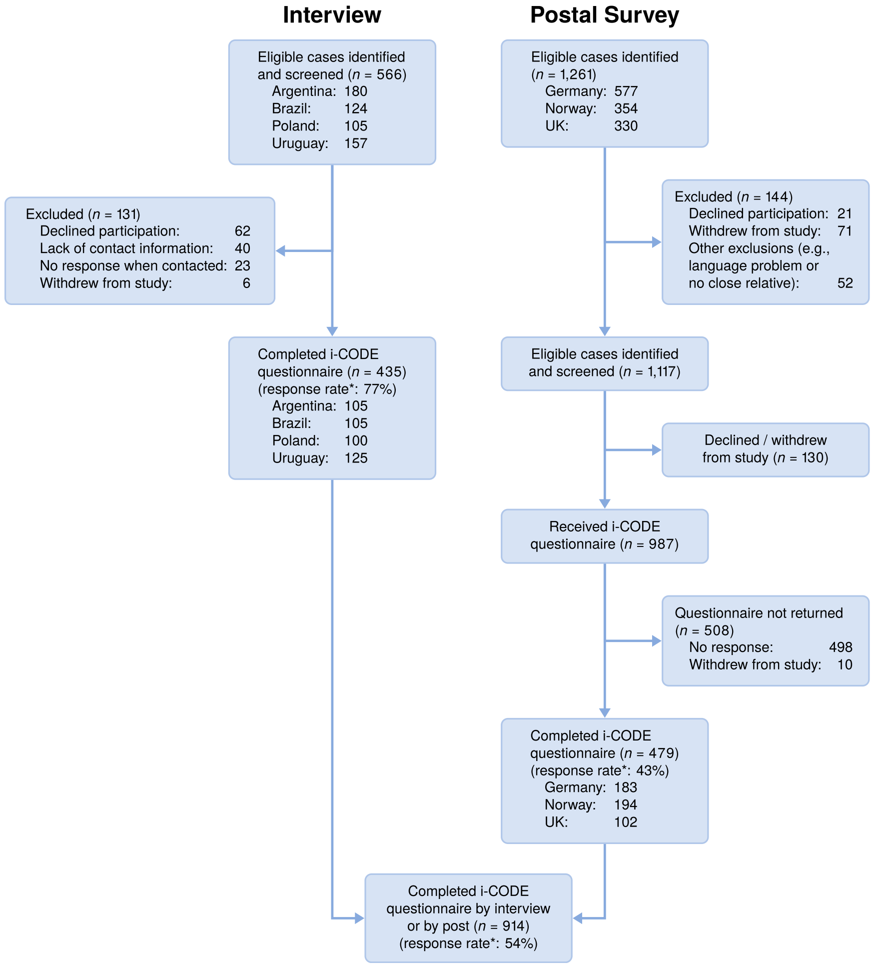

Figure 1. Comparison of interviewer versus postal questionnaire administration. *Response rate for the screened patients. Abbreviation: i-CODE, international version of the Care Of the Dying Evaluation.

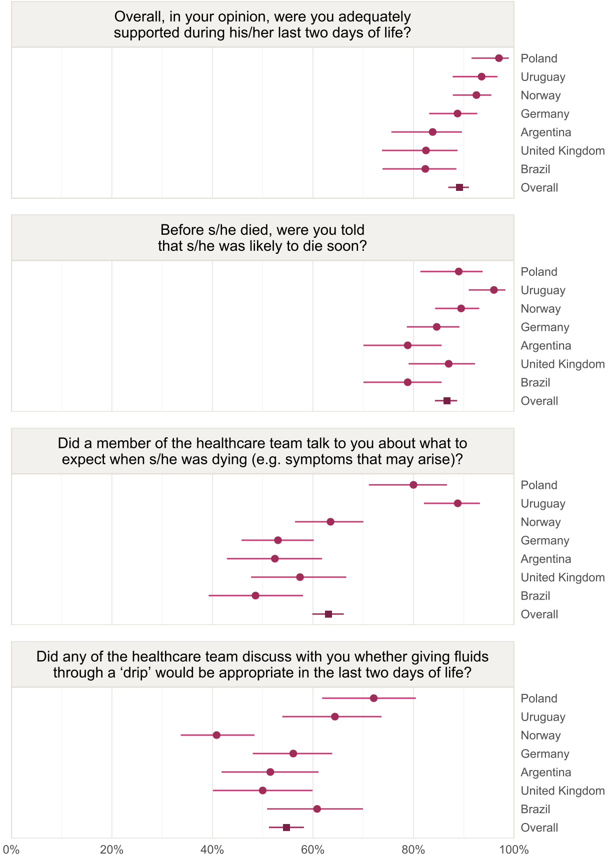

Figure 2. Bereaved relatives' perceptions about support and about specific aspects of communication in the last days of the patient's life (question 31, $n = 884$, question 23, $n = 905$; question 24, $n = 904$; question 17, $n = 780$). Mean scores with 95% confidence intervals.