Good Quality Care for Cancer Patients Dying in Hospitals, but Information Needs Unmet: Bereaved Relatives’ Survey within Seven Countries

Dagny Faksvåg Haugen, Karl Ove Huffhammer, Christina Gerlach, Katrin Sigurdardottir, Marit Irene Tuen Hansen, Grace Ting, Vilma Adriana Tripodoro, Gabriel Goldrau, Eduardo Garcia Yanez, Wojciech Leppert, Katarzyna Wolszczak, Lair Zambon, Juliana Nalin Passarini, Ivete Alonso Bredda Saad, Martin Weber, John Ellershaw, Catriona R Mayland

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. A postbereavement survey was conducted 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 patient’s last days of life.

Results. Of 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% of 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% of 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 dying cancer patients 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. (ClinicalTrials.gov Identifier: NCT03566732). The Oncologist 2021;26:e1273–e1284

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 should pay particular attention to these issues when caring for patients with cancer.
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 multi-center 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 post-bereavement 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 cancer patient that did not involve cardiopulmonary resuscitation was accepted.

“Cancer patient” 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 non-participants, but not to register information about ethnicity/nationality and religious affiliation for non-participant 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).
| Country | 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 hospital) | 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 next-of-kin’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 who did not actively opt out. | 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) |
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 seemed acceptable because a previous study found no difference in terms of distress when approaching bereaved relatives 2 weeks and 6 weeks 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 (b)

Table 1. (continued)

| Country | 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 |
|---------|---------------------------------------------------------------------------------|---------------------------------------------|-----------------------------------|-------------------------|
| 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
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 ≤ .05 are considered statistically significant.

Definitions: The following definitions were used for the main explanatory variables. SPC team: interdisciplinary palliative care team with consultation available in both outpatient and inpatient settings, consisting of palliative care providers including doctors, nurses, pharmacists, social workers, counselors, and spiritual care providers.

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.
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%-58%) 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 non-participants 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 post-bereavement 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...
Table 2. Characteristics of the deceased patients and their next of kin (n = 914)

| Characteristic                        | Deceased patients, count (%) | Next of kin, count (%) |
|---------------------------------------|------------------------------|------------------------|
| **Gender**                            |                              |                        |
| Male                                  | 527 (58)                     | 298 (33)               |
| Female                                | 387 (42)                     | 610 (67)               |
| (Missing)                             | 0 (0)                        | 6 (1)                  |
| **Age, years**                        |                              |                        |
| 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**             |                              |                        |
| 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)                       |                        |
| Other                                 | 59 (6)                       |                        |
| (Missing)                             | 6 (1)                        |                        |
| **Cancer diagnosis**                  |                              |                        |
| 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)                        |                        |

(continued)
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

Table 2. (continued)

| Characteristic | Deceased patients, count (%) | Next of kin, count (%) |
|----------------|------------------------------|-----------------------|
| Specialist palliative care team involved in the patient’s care before death | Yes 572 (63) | No 334 (37) |
| | (Missing) 8 (1) | | |
| Care of the patient supported by an individualized care plan | Yes 416 (47) | No 460 (53) |
| | (Missing) 38 (4) | | |

*Missing data presented but not included in the percentage calculations.

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 of the time (1) (%) | Most of the 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  | 0.8 | 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.

© 2021 The Authors.
The Oncologist published by Wiley Periodicals LLC on behalf of AlphaMed Press.
Table 4. Mixed-effects multiple regression analyses for next of kin’s perception of the quality of care \((n = 833–841)\)

| Variable | Q30 doctors\(^a\) \((n = 833)\) | | | Q30 nurses\(^a\) \((n = 855)\) | | | Q31\(^b\) \((n = 841)\) | | |
|----------|--------------------------------|---|---|--------------------------------|---|---|--------------------------------|---|---|
| Intercept | 3.22 (2.82–3.62) | .02 | 3.57 (3.25–3.89) | .001 | 2.72 (1.11–6.69) | .08 |
| Country (ref.: U.K.) | | | | | | | | |
| 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) | | | | | | | | |
| 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 |
| Individualized 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.
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 the 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. 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.

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-Palatinate, 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. 2308.216); 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 inquiries 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, inquiries 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. CODE™ should not be altered without request.

ERANet-LAC CODE Project Group: Core scientific group: Dagny Faksvåg Haugen, Katrin Ruth Sigurdardottir, Marit Irene Tuen Hansen, Karl Ove Hufthammer, Wojciech Leppert, Katarzyna Woloszczak, Eduardo Garcia Yanneo, Vilma Tripodoro, Gabriel Goldraij, Martin Weber, Christina Gerlach, Lail Zambon, Juliana Nalin Passarini, Ivete Bredda Saad, John Ellershaw, Grace Ting and Catriona R. Mayland.

Local study coordinators: Anne Kvikstad, Eva Gravdahl, Julia Bratke, Janet Bakken, Kristin Vassbotn Guldhaug, Christina Demmerle.

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.

AUTHOR CONTRIBUTIONS
Conception/design: Dagny Faksvåg Haugen, Christina Gerlach, Katrin Sigurdardottir, Vilma Adriana Tripodoro, Eduardo Garcia Yanneo, Wojciech

© 2021 The Authors.
The Oncologist published by Wiley Periodicals LLC on behalf of AlphaMed Press.
Leppert, Lair Zambon, Juliana Nalin Passarini, Ivete Alonso Bredda Saad, Martin Weber, John Ellershaw, Catrina Rachel Mayland

Collection and/or assembly of data: Dagny Faksvåg Haugen, Christina Gerlach, Katrin Sigurdardottir, Marit Irene Tuen Hansen, Grace Ting, Vilma Adriana Tripodoro, Gabriel Goldraj, Eduardo Garcia Yanneo, Wojciech Leppert, Katarzyna Wolczak, Juliana Nalin Passarini, Ivete Alonso Bredda Saad, Martin Weber, Catrina Rachel Mayland

Data analysis and interpretation: Dagny Faksvåg Haugen, Karl Ove Hufthammer, Christina Gerlach, Katrin Sigurdardottir, Marit Irene Tuen Hansen, Grace Ting, Vilma Adriana Tripodoro, Gabriel Goldraj, Eduardo Garcia Yanneo, Wojciech Leppert, Katarzyna Wolczak, Lair Zambon, Juliana Nalin Passarini, Ivete Alonso Bredda Saad, Martin Weber, John Ellershaw, Catrina Rachel Mayland

Manuscript writing: Dagny Faksvåg Haugen, Karl Ove Hufthammer, Catrina Rachel Mayland

Final approval of manuscript: Dagny Faksvåg Haugen, Karl Ove Hufthammer, Christina Gerlach, Katrin Sigurdardottir, Marit Irene Tuen Hansen, Grace Ting, Vilma Adriana Tripodoro, Gabriel Goldraj, Eduardo Garcia Yanneo, Wojciech Leppert, Katarzyna Wolczak, Lair Zambon, Juliana Nalin Passarini, Ivete Alonso Bredda Saad, Martin Weber, John Ellershaw, Catrina Rachel Mayland

DISCLOSURES

The authors indicated no financial relationships.

REFERENCES

1. World Health Organization 2020. Cancer. Available at https://www.who.int/news-room/fact-sheets/detail/cancer. Accessed April 27, 2021.

2. International Agency for Research on Cancer. Latin America and the Caribbean. Globocan 2020. Available at http://gco.iarc.fr/today/data/factsheets/populations/904-latin-america-and-the-caribbean-fact-sheets.pdf. Accessed April 27, 2021.

3. Pastrana T, Eisenchlas J, Centeno C et al. Status of palliative care in Latin America: Looking through the Latin America Atlas of Palliative Care. Curr Opin Support Palliat Care 2013;7:411-418.

4. Pastrana T, Torres-Vigil I, de Lima L. Palliative care development in Latin America: An analysis using macro indicators. Palliat Med 2014;28:1231–1238.

5. Centeno C, Lynch T, Garralda E et al. Coverage and development of specialist palliative care services across the World Health Organization European Region (2005–2012): Results from a European Association for Palliative Care Task Force survey of 53 countries. Palliat Med 2016;30:351–362.

6. The Economist Intelligence Unit. The 2015 Quality of Death index. Lien Foundation 2015. Available at https://www.eiuperspectives.economist.com/sites/default/files/2015%20Quality%20of%20Death%20Index%202015%20Final.pdf. Accessed April 27, 2021.

7. Knaul FM, Farmer PE, Krakauer EL et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: The Lancet Commission report. Lancet 2018;391:1391–1454.

8. Global Atlas of Palliative Care. 2nd ed. London: Worldwide Hospice Palliative Care Alliance and World Health Organization, 2020. Available at http://www.thewhpa.org/resources/global-atlas-on-end-of-life-care. Accessed April 27, 2021.

9. ERANet-LAC. ERANet-LAC 2nd Joint Call on Research and Innovation 2016. Available at https://www.eucalac-platform.eu/sites/default/files/280116_calltext-final.pdf. Accessed April 27, 2021.

10. Brighton LJ, Bristowe K. Communication in palliative care: Talking about the end of life, before the end of life. Postgrad Med 2016;92: 466–470.

11. Yamaguchi T, Maeda I, Hatanou Y et al. Effects of end-of-life discussions on the mental health of bereaved family members and quality of patient death and care. J Pain Symptom Manage 2017;54:17–26.

12. Baillie J, Anagnostou D, Sivell S et al. Symptom management, nutrition and hydration at end-of-life: A qualitative exploration of patients’, carers’ and health professionals’ experiences and further research questions. BMC Palliat Care 2018;17:60.

13. Mayland CR, Lees C, German A et al. Caring for those who die at home: The use and validation of ‘Care Of the Dying Evaluation’ (CODE) with bereaved relatives. BMJ Support Palliat Care 2014;4:167–174.

14. Mayland CR, Williams EMI, Ellershaw JE. Assessing quality of care for the dying: The development and initial validation of a postal self-completion questionnaire for bereaved relatives. Palliat Med 2012;26:897–907.

15. Mayland CR, Williams EM, Addington-Hall J et al. Does the ‘Liverpool Care Pathway’ facilitate an improvement in quality of care for dying cancer patients? Br J Cancer 2013;108: 1942–1948.

16. Mayland CR, Williams E, Ellershaw JE. How well do current instruments using bereaved relatives’ views evaluate care for dying patients? Palliat Med 2008;22:133–144.

17. World Health Organization. Palliative care. 2020. Available at https://www.who.int/news-room/fact-sheets/detail/palliative-care. Accessed April 27, 2021.

18. Kupeli N, Candy B, Tamura-Rose G et al. Tools measuring quality of death, dying, and care, completed after death: Systematic review of psychometric properties. Patient 2019;12: 183–197.

19. Mayland CR, Gerlach C, Sigurdardottir K et al. Assessing quality of care for the dying from the bereaved relatives’ perspective: Using pre-testing survey methods across seven countries to develop an international outcome measure. Palliat Med 2019;33:357–368.

20. Casaretto DJ, Crowley R, Hirschman KB. Surveys to assess satisfaction with end-of-life care: Does timing matter? J Pain Symptom Manage 2003;25:128–132.

21. R Core Team. R: A language and environment for statistical computing. Vienna: R Foundation for Statistical Computing, 2019.

22. Vogt A, Stiel S, Heckel M et al. Assessment of the quality of end-of-life care: translation and validation of the German version of the “Care of the Dying Evaluation” (CODE-GER) – A questionnaire for bereaved relatives. Health Qual Life Outcomes 2020;18:311.

23. Ferrell BR, Temel JS, Temin S et al. Integration of palliative care into standard oncology care: American Society of Clinical Oncology Practice Guideline update. J Clin Oncol 2017;35: 96–112.

24. Radbruch L, Payne S. White Paper on standards and norms for hospice and palliative care in Europe: Part 2. Eur J Palliat Care 2010;17: 22–32.

25. Care of dying adults in the last days of life. NICE guideline [NG31]. 2015. National Institute for Health and Care Excellence. Available at https://www.nice.org.uk/guidance/ng31. Accessed April 27, 2021.

26. Tripodoro VA, Goldraj G, Daud ML et al. Analysis of the results of a palliative care quality program for the last days of life. Ten years of experience [in Spanish]. Medicina (B Aires) 2019; 79:468–476.

27. Choi JY, Chang YJ, Song HY et al. Factors that affect quality of dying and death in terminal cancer patients on inpatient palliative care units: Perspectives of bereaved family caregivers. J Pain Symptom Manage 2013;45:735–745.

28. Miyashita M, Morita T, Sato K et al. A nationwide survey of quality of end-of-life care in designated cancer centers, inpatient palliative care units, and home hospices in Japan: The J-HOPE study. J Pain Symptom Manage 2015;50:38–47.

29. Schelin ME, Sallerfors B, Rasmussen BH et al. Quality of care for the dying across different levels of palliative care development: A population-based cohort study. Palliat Med 2018;32:1596–1604.

30. Verkissen MN, Leemans K, Van den Block L et al. Information provision as evaluated by people with cancer and bereaved relatives: A cross-sectional survey of 34 specialist palliative care teams. Patient Educ Couns 2019;102:768–775.

31. Steinhauser KE, Voils CI, Bosworth H et al. What constitutes quality of family experience at the end of life? Perspectives from family members of patients who died in the hospital. Palliat Support Care 2015;13:945–952.

32. Virdun C, Luckett T, Davidson PM et al. Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families rank as being most important. Palliat Med 2015;29:774–796.

33. Virdun C, Luckett T, Lorenz K et al. Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important. Palliat Med 2017;31:587–601.

34. Sakashita A, Morita T, Kishino M et al. Which research questions are important for the bereaved families of palliative care cancer patients as they die in the hospital? Palliat Med 2014;28:526–535.

35. Sspk, Hufthammer, Gerlach et al. e1283

www.TheOncologist.com

The Oncologist published by Wiley Periodicals LLC on behalf of AlphaMed Press. © 2021 The Authors.
patients? A nationwide survey. J Pain Symptom Manage 2018;55:379–386.

35. Sinuff T, Dodek P, You JJ et al. Improving end-of-life communication and decision making: The development of a conceptual framework and quality indicators. J Pain Symptom Manage 2015;49:1070–1080.

36. Mori M, Morita T, Igarashi N et al. Communication about the impending death of patients with cancer to the family: A nationwide survey. BMJ Support Palliat Care 2018;8:221–228.

37. Wright AA, Zhang B, Ray A et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA 2008; 300:1665–1673.

38. Miyajima K, Fujisawa D, Yoshimura K et al. Association between quality of end-of-life care and possible complicated grief among bereaved family members. J Palliat Med 2014;17:1025–1031.

39. Yamashita R, Arao H, Takao A et al. Unfinished business in families of terminally ill with cancer patients. J Pain Symptom Manage 2017; 54:861–869.

40. Mayland C, McGlinchey T, Gambles M et al. Quality assurance for care of the dying: Engaging with clinical services to facilitate a regional cross-sectional survey of bereaved relatives’ views. BMC Health Serv Res 2018;18:761.

41. Mayland CR, Mulholland H, Gambles M et al. How well do we currently care for our dying patients in acute hospitals: The views of bereaved relatives? BMJ Support Palliat Care 2017;7:316–325.

42. Davies AN, Waghorn M, Webber K et al. A cluster randomised feasibility trial of clinically assisted hydration in cancer patients in the last days of life. Palliat Med 2018;32:733–743.

43. Hui D, Dev R, Bruera E. The last days of life: Symptom burden and impact on nutrition and hydration in cancer patients. Curr Opin Support Palliat Care 2015;9:346–354.

44. Gent MJ, Fradsham S, Whyte GM et al. What influences attitudes towards clinically assisted hydration in the care of dying patients? A review of the literature. BMJ Support Palliat Care 2015; 5:223–231.

45. White N, Oostendorp LI, Minton O et al. Palliative care training in undergraduate medical, nursing and allied health: A survey. BMJ Support Palliat Care 2019 [Epub ahead of print].

46. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: Can proxies provide reliable information? Soc Sci Med 2003; 56:95–109.

47. Calanzani N, Higginson IJ, Koffman J et al. Factors associated with participation, active refusals and reasons for not taking part in a mortality followback survey evaluating end-of-life care. PLoS One 2016;11:e0146134.

48. Bailey SJ, Cogle K. Talking about dying: How to begin honest conversations about what lies ahead. London: Royal College of Physicians, 2018. Available at https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-how-begin-honest-conversations-about-what-lies-ahead. Accessed April 27, 2021.

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