**Good quality care for cancer patients dying in hospitals, but information needs not met: bereaved relatives’ survey within seven countries**

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**Running head**: International Care Of the Dying Evaluation

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**Key words**

Terminal care; palliative care; survey and questionnaire; proxy; bereaved relatives; quality of healthcare

**Abstract**

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

**Methods** Post-bereavement survey by post, interview, or via tablet in Argentina, Brazil, Uruguay, UK, 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 post-bereavement. Primary outcomes were 1) how frequently the deceased patient was treated with dignity and respect, and 2) how well the family member was supported in the patients’ last days of life.

**Results** From 1683 potential participants, 914 i-CODE questionnaires were completed (response rate 54%). About 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 intervals 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 dying cancer patients from the bereaved relatives’ perspective across several countries on two continents. Our findings suggest many elements of good care were practised but improvement in communication with relatives of imminently dying patients is needed. (**Word count 250)**

**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.
* Healthcare 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 healthcare systems have been recognized.7 While 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, while Brazil, among others, is characterized by generalized palliative care provision, but without integration of palliative care services into mainstream healthcare 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 2nd 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 dying cancer patients.

In response to the ERANet-LAC call, the current study aimed to conduct an international observational study of bereaved relatives to cancer patients 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 illness10, 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.

**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 United Kingdom (UK).

The patient cohort consisted of adult cancer patients 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 which 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.

*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’ (CODETM) questionnaire (Supp. file 1).13 CODETM is a shortened, more user-friendly version of the original instrument, ‘Evaluating Care and Health Outcomes – for the Dying’ (ECHO-D), 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 CODETM assesses both quality of patient care and the level of family support, representing the fundamental ‘pillars’ of palliative care.17 It is comprised of 32 main questions with 10 additional questions focused on demographic details. CODETM 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)
* 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 CODETM as an instrument, with some strong psychometric properties, which would benefit from further development and validation.18 Hence, pre-testing survey methods helped ensure the CODETM 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](http://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 a SPC service which functioned as the local contact for the study. The study period commenced on 15th August 2017, with the last eligible patients included on 15th September 2018. Due to lengthy procedures for ethical approval, the UK joined the study from 1st October 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, as a previous study found no difference in terms of distress when approaching bereaved relatives six weeks and three months after the death.20 Additionally, it was in keeping with the time frame used within our pre-testing study.19

The study was originally intended as a postal survey, but due to 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 iCODE 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 (Appendix). Participants gave written informed consent. In Norway and the UK, 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:

1. 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);
2. 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, standard deviations (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) (Supp. file 1).

We also investigated if there was an association between the presence of SPC and the participants’ perceptions about 1) whether the patient was treated with dignity and respect (by doctors and by nurses, question 30, part ‘a’ and ‘b’), and 2) 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 1) did the patient die on a PCU (Specialist Palliative Care Unit), 2) was a SPC team involved in the patient’s care before death, and 3) 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. *P*-values ≤ .05 are considered statistically significant.

*Definitions:* The following definitions were used for the main exploratory variables:
Specialist Palliative Care Team (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 Palliative Care Unit (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.24Individualized 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, while 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%) (Figure 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 (Supp. 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. About 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 inter-country variation was 3.3 to 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 (Figure 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 to other wards (Table 4). For doctors, the score difference was 0.28 (CI: 0.10–0.46; *P* = 0.003), and for nurses, it was 0.17 (CI: 0.01–0.33; *P* = 0.04).

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 (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.

On the other hand, 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 (inter-country range 79% to 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%) (Figure 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 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 healthcare workers are needed to improve the cultural approach towards 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 healthcare 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 post-bereavement 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 healthcare 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 post-bereavement questionnaires assessing quality of care, the ‘CODE’TM 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 pre-testing 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 post-bereavement 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 since all the hospitals had a SPC service. Additionally, although Poland included general hospital wards, the majority of participants were recruited from PCU’s 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 healthcare 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 dying cancer patients across several countries on two continents. Our findings suggest that many elements of good care for dying patients were practised. At the same time, areas for improvement were identified, with communication by healthcare professionals with relatives of dying patients being the most pertinent across the study sites.

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**Declaration of conflicts of interest**

The authors declare that there are no conflicts of interest.

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**Figure Legends**

Figure 1. Comparison of interviewer versus postal questionnaire administration. (\*) Response rate for the *screened* patients.

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.

**Appendix**

**Ethical Approval**

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 (HRA) and East of England – Cambridge East Research Ethics Committee, UK (IRAS project ID 225922; REC 17/EE/0302); National Research Ethics Commission (CONEP), Brazil (ref. 2.308.216); and Committee on Bioethics from the ‘Mutualista Asociacion Hospital Evangelico’, Uruguay (ref. 29/5/2017/01).

**Authorship**

DFH, CG, KS, VAT, EGY, WL, LZ, JNP, IABS, MW, JE and CRM all contributed to the design of the study. DFH, CG, KS, MITH, GT, VAT, GG, EGY, WL, KW, JNP, IABS, MW and CRM collected the data. DFH and KOH undertook the data analysis. DFH, KOH, CG, KS, MITH, GT, VAT, GG, EGY, WL, KW, LZ, JNP, IABS, MW, JE and CRM contributed to the interpretation of the data. DFH, KOH and CRM drafted the manuscript and all authors read and approved the final manuscript.

**Data management and sharing**

Data are archived at the Norwegian Centre for Research Data (NSD) 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’TM 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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