

1 **Factors affecting quality of end-of-life hospital care - a qualitative analysis**
2 **of free text comments from the i-CODE survey in Norway**

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18

19 **Abstract**

20 **Background** The ERANet-LAC CODE (Care Of the Dying Evaluation) international survey
21 assessed quality of care for dying cancer patients in seven countries, by use of the i-CODE
22 questionnaire completed by bereaved relatives. The aim of this sub study was to explore
23 which factors improve or reduce quality of end-of-life (EOL) care from Norwegian relatives'
24 point of view, as expressed in free text comments.

25 **Methods** 194 relatives of cancer patients dying in seven Norwegian hospitals completed the i-
26 CODE questionnaire 6-8 weeks after bereavement; recruitment period 14 months; response
27 rate 58%. Responders were similar to non-responders in terms of demographic details. 104
28 participants (58% spouse/partner) added free text comments, which were analyzed by
29 systematic text condensation.

30 **Results** Of the 104 comments, 45% contained negative descriptions, 27% positive and 23%
31 mixed. 78% described previous experiences, whereas 22% alluded to the last two days of life.
32 64% of the comments represented medical/surgical/oncological wards and 36%
33 palliative care units. Four main categories were developed from the free text comments: 1)
34 Participants described how attentive care towards the practical needs of patients and relatives
35 promoted dignity at the end of life, which could easily be lost when this awareness was
36 missing. 2) They experienced that lack of staff, care continuity, professional competence or
37 healthcare service coordination caused uncertainty and poor symptom alleviation. 3)
38 Inadequate information to patient and family members generated unpredictable and
39 distressing final illness trajectories. 4) Availability and professional support from healthcare
40 providers created safety and enhanced coping in a difficult situation.

41 **Conclusions** Our findings suggest that hospitals caring for cancer patients at the end of life
42 and their relatives, should systematically identify and attend to practical needs, as well as
43 address important organizational issues. Education of staff members ought to emphasize how
44 professional conduct and communication fundamentally affect patient care and relatives'
45 coping.

46
47 **Keywords:** Palliative care, cancer, bereaved relatives, death, quality of healthcare, survey,
48 free text comments, qualitative research, communication

50 **Introduction**

51 Relatives who experience the death of a close family member possess unique perspectives on
52 the patient's suffering and needs (1). These perspectives may provide access to prerequisites

53 for tailored and effective medical treatment (2), and also challenge the views of healthcare
54 professionals (3). Thus, relatives play a central role both as caregivers and as participants in
55 research illuminating how care for the dying person can be improved.

56 Ensuring high standards of care and support for patients dying from cancer and their relatives
57 is of major global importance and relevance (4). Good EOL care for cancer patients and their
58 relatives entails a high degree of coordination and availability of healthcare services (5).

59 Earlier studies have also identified patients' and families' unmet needs regarding information
60 and symptom relief (6), and how dignity at the end of life can be preserved by healthcare
61 personnel addressing these aspects of care (7).

62 To improve the care, we need to be able to assess the current quality of care in a reliable
63 manner. One internationally recognized method for evaluating care for dying patients is to ask
64 bereaved relatives through post-bereavement surveys (8-9). 'Care Of the Dying Evaluation'
65 (CODETM) is a recognised, validated post-bereavement questionnaire focused on both quality
66 of patient care and support for the relatives in the patient's last two days of life and the
67 immediate post-bereavement period (8). In addition to questions with pre-determined
68 response categories asking about nursing and medical care, symptom relief, communication,
69 emotional and spiritual support, and circumstances surrounding the death, responders may add
70 free text comments. The free text comments are not limited to the last two days of life; on the
71 contrary, responders are invited to comment on any aspect of care during the final illness
72 trajectory.

73 The project 'International Care Of the Dying Evaluation (CODE): quality of care for cancer
74 patients as perceived by bereaved relatives' (2017-2020) was funded by the Network of the
75 European Union (EU) and the Community of Latin American States (CELAC) on Joint
76 Innovation and Research Activities (ERANet-LAC) with the aim to advance the international
77 evidence-base in care for the dying (10). This involved undertaking an international survey of

78 relatives to cancer patients dying in hospitals in seven countries across Europe and South
79 America, by use of the international version of the CODE™ questionnaire (11). In Norway,
80 the call for improving end-of-life (EOL) care on all levels of the healthcare system has
81 recently been outlined in a Norwegian Official Report (NOU) (12). Research is warranted
82 specifically addressing the user-perspective and how to optimise care during the palliative
83 phase of incurable illness. The aim of the present study was to examine which factors improve
84 or reduce quality of EOL care for cancer patients from Norwegian relatives' point of view, by
85 examining free text comments from the ERANet-LAC CODE international survey in Norway.

86 **Methods**

87 *Design*

88 A multicentre, post-bereavement observational study was conducted in bereaved family
89 members of patients with cancer dying in the hospital setting, by use of the i-CODE
90 questionnaire (11). This qualitative sub study analyzed free text comments made by
91 Norwegian participants, addressing aspects of care during the final illness trajectory.

92 *Setting and participants*

93 Participants were next-of-kin to patients who had died on Medical, Surgical or Oncological
94 wards or on Palliative Care units in seven hospitals in Norway. Inclusion and exclusion
95 criteria are presented in Text box 1, and apply both to the main study and the qualitative sub
96 study. All free text comments were incorporated in the analysis.

Text box 1 Inclusion and exclusion criteria of participants

Inclusion criteria

- Relatives of patients with cancer dying an anticipated death in a hospital
- 18 years or older
- Being together with the patient in the hospital at least some of the patient's last two days of life
- Patient older than 18 years when he/she died
- Patient being hospitalized for at least 3 calendar days
- Capable of giving written informed consent, implicitly obtained by completing and submitting the questionnaire

Exclusion criteria

- Patient died suddenly and unexpectedly
- Relatives were unable to complete questionnaire due to linguistic barriers or cognitive impairment
- Staff assessed participation to be a huge burden for the relatives due to psychiatric illness or other severe condition

97

98 The hospitals are representative of Norwegian hospitals in general, with respect to size,
99 treatment levels and annual death rates. Demographic characteristics of patients and
100 participants are presented in Table 1.

101 *Table 1 to be inserted about here.*

102 *Data collection*

103 The recruitment period lasted from August 15th 2017 to September 15th 2018 in five
104 hospitals and from April to September 2018 in two hospitals. Eligible participants received
105 written and oral information about the study from healthcare personnel before leaving the
106 ward. Study information and the i-CODE questionnaire were sent by mail six to eight weeks
107 post bereavement to all eligible relatives who had not actively declined participation. One
108 reminder was sent to non-responders. Relatives returned the questionnaire by mail in prepaid

109 envelopes. Informed consent was implied when completing and submitting the questionnaire.
110 The open responses were explicitly solicited and foreseen in the questionnaire.

111

112 *Analysis*

113 Data analysis was performed by two of the authors (MITH and MAS) using systematic text
114 condensation (13). This analysis proceeds through the following steps: 1) Reading the
115 material to obtain an overall impression, bracketing preconceptions, 2) identifying units of
116 meaning, representing different aspects of the participants' EOL care experiences and coding
117 for these, 3) condensing and abstracting the meaning within each of the coded groups, and 4)
118 summarizing the contents of each coded group to generalized descriptions and concepts
119 reflecting the most important factors influencing EOL care, as perceived by the participants.
120 Categories and findings were developed from the empirical data using an editing analysis
121 style as described by Miller and Crabtree (14). All comments were also sorted as positive,
122 negative or mixed descriptions.

123

124 **Results**

125 **Participants**

126 One hundred and ninety-four bereaved relatives completed and returned the survey, (194/334,
127 response rate 58%). One hundred and four of these (58% spouse/partner) added free text
128 comments. Most of the 104 participants belonged to the age group 50 to 69 years, 67%
129 reported a Christian religious affiliation, and 39% were women.

130 **Free text comments**

131 Of the 104 comments, 45% contained negative descriptions, 27% positive and 23% mixed.
132 78% described previous experiences, whereas 22% alluded to the last two days of life (Table
133 2).

134

Table 2 Characteristics of free text comments (n = 104)

	n (%)
Negative descriptions	47 (45)
Positive descriptions	28 (27)
Mixed descriptions (both positive and negative)	24 (23)
Other comments (related to the questionnaire itself)	5 (5)
Describing only the last two days	23 (22)
Describing experiences before the last two days	81 (78)
From palliative care units	37 (36)
From medical/surgical wards	46 (44)
From oncology wards	21 (20)

135

136 Four main categories were developed from the free text comments: 1) Participants described
137 how attentive care towards the practical needs of patients and relatives promoted dignity at
138 the end-of-life, which could easily be lost when this awareness was missing. 2) They
139 experienced that lack of staff, care continuity, professional competence or healthcare service
140 coordination caused uncertainty and poor symptom alleviation. 3) Inadequate information to
141 patient and family members generated unpredictable and distressing final illness trajectories.
142 4) Availability and professional support from healthcare providers created safety and
143 enhanced coping in a difficult situation. Below, we elaborate on these findings.

144

145 **Attentive care towards practical needs promoted dignity at the end of life**

146 Several participants described the importance of practical needs being met by healthcare
147 personnel, e.g. allowing them to sleep in the patient`s own room, or facilitating meaningful
148 activities such as playing music, lighting candles and being together day and night. They
149 valued the opportunity to be present and close to their family member as much as possible.
150 Feeling welcome and allowing unlimited access made it easier for them to care and support
151 the patient. This was also deeply appreciated at earlier stages of the illness trajectory when the
152 patient`s condition worsened, not only during the terminal phase.

153 *“Fortunately, almost everyone was very positive, caring, and brought newspapers,*
154 *magazines, coffee, and biscuits. A pat on the back, encouraging words, the little*
155 *extra things that made it easier for us to be relatives. We were allowed to stay there*
156 *all the time, night and day, which lightened the situation both for us and for her.”*
157 *(Informant 37)*

158 Other participants outlined how they missed practical help supplying food and drink during
159 hospital stays with their relatives in the last phase of life. They described how they either had
160 to leave the patient to obtain a meal, or ask friends to come by with something to eat.
161 Facilities such as free parking were also needed. Participants emphasised how they did not
162 want to go away from their family member and that practical issues then became a burden.
163 Being terminally ill in a room shared with other patients deprived dignity from their next of
164 kin. In the terminal phase of the patients` illness, discussions about potential transfers to other
165 units in the hospital or to the community setting, were experienced as distressing. It troubled
166 them and gave the impression that they themselves, as well as the patient, were an
167 inconvenience to the staff and a perceived burden to the hospital.

168 *“As a relative, it is both an unpleasant and very sad experience to feel that your*
169 *closest family member is a nuisance to the hospital. Choices made by the hospital*
170 *may convey respect and dignity – or the opposite.” (Informant 82)*

171 Some participants also described how essential a calm and peaceful environment was to their
172 overall experience of the last phase of their family member's life. One of them elaborated on
173 how noise from another family's expressive grieving following another patient's death in the
174 room next door installed fear and sadness to their own dying relative and themselves. No
175 explanation or support was given by the staff, and this experience haunted them for quite a
176 while, reducing dignity and comfort at the end of life.

177

178 **Insufficient healthcare services caused insecurity and poor symptom alleviation**

179 The consequences of staff shortage were described as compromising safety and treatment.
180 Participants explained how they were fearful of leaving their family members, if they were
181 weak or had difficulty standing up, mindful of the risk of falls on the ward. They also tried to
182 be present during meals in order to assist family members who were having difficulty eating
183 patients. The regular practice of reduced staff numbers during weekends was experienced as
184 hazardous. Participants felt responsible for observing their family member patient and
185 reporting to the staff if they perceived that medication was needed to help with pain control or
186 restlessness. They did not feel comfortable in this role, and suspected that their uncertainty
187 might have delayed pain relief.

188 *“There were way too few people at work. As relatives, we didn't dare to leave him.*
189 *We had to look after him ourselves all the time and tell which medication he*
190 *needed.” (Informant 103)*

191 Lack of continuity among doctors was another important aspect affecting their overall
192 experience and treatment. There were many different doctors involved in the provision of care
193 both in the outpatient clinic and during hospital admissions, meaning frequent re-telling of the
194 history. It was regarded as very disturbing when a doctor, whom patients and families had not

195 previously met, imparted new and crucial information. Continuity was asked for both during
196 initial investigations and the following treatment phase, as well as coordination of care instead
197 of fragmentation. The latter could create a feeling of chaos where no one actually had overall
198 control, expressed in strong wordings such as “15 months of mess” and “too many cooks spoil
199 the broth”. Uncertainty remained about how much cooperation occurred between different
200 medical specialists and their family doctor.

201 *“The illness history had to be told over again at every visit, and there was no*
202 *coordination of care between the general practitioner, the doctor at the local*
203 *hospital and the university clinic.” (Informant 88)*

204 Lack of competence could also deeply affect participants’ experience of the quality of care at
205 the end of life. Some described how inexperienced nurses administered pain medication but
206 left the room in a hurry without addressing other needs, e.g. having a conversation about the
207 challenging situation. Another participant outlined how their family member being confused
208 and helpless due to the underlying disease did not receive respectful and adequate care,
209 interpreted by the relatives as relating to lack of knowledge among staff. These family
210 members missed being on a palliative care unit and desired an increased competence of staff
211 who care for dying patients. The organization of care through the final illness for cancer
212 patients was also questioned.

213 *“My husband was admitted for pain relief. He was in a lot of pain, and the staff*
214 *didn’t manage to alleviate his suffering. He should have been admitted to a*
215 *palliative care unit. It’s impossible to understand why a cancer patient at the end of*
216 *life must be admitted to the department responsible for the initial tumour*
217 *treatment.” (Informant 63)*

218 **Inadequate information generated unpredictable and distressing illness trajectories**

219 Participants wanted to know more about what the last days of life would be like, and felt they
220 themselves often had to request this information. They missed critical information during
221 initial discussions, or needed to have this repeated. Some thought doctors avoided giving
222 honest information, and although they could appreciate the challenges when delivering bad
223 news, most preferred to have clear-cut information. It was difficult for them to understand
224 what was going on with their family member, for instance, when intravenous fluids had been
225 discontinued. The lack of explanations caused additional distress. They also underlined the
226 importance of an update on the latest development in between visits. Even when the patient's
227 condition worsened and imminent death was suspected, information could still be delayed and
228 unclear, expressed as "beating about the bush". Not knowing that the patient was approaching
229 a terminal phase could deprive them from precious time together.

230 *"I was not adequately informed that the end was near during his last days of life.*
231 *Had I known, I could have been present the last hours he had left to live, but*
232 *unfortunately, that was not the case. I am being haunted daily by the fact that I was*
233 *not there when he died." (Informant 26)*

234 Participants also described receiving too little information upon discharge. Some explained
235 how they were told their next of kin would die, but missed emotional support. Written
236 information could be of help, but could not replace supportive conversations for building trust
237 and gaining clarifications. Participants stated they had important knowledge about the patient
238 that was not asked for, and wished they could have been more involved. It was perceived as a
239 huge burden when they met healthcare professionals who did not understand their wishes and
240 needs e.g. place of care, level of treatment. Several viewed the time from the last cancer
241 treatment until the terminal phase to be the most difficult period, in which they felt
242 abandoned.

243 *“We were left all by ourselves after the last chemotherapy, and wished we had*
244 *further follow-up. We felt all alone and had to contact the hospital ourselves upon*
245 *demand. The time from the last treatment until the last two weeks of life was the*
246 *hardest period for us.” (Informant 99)*

247 **Professional support from healthcare providers created safety and enhanced coping**

248 Other participants expressed deep gratitude and solely positive feelings in their feedback to
249 the hospital staff. It was clear that easy access to advice from healthcare professionals whom
250 they knew, provided great comfort and support. Availability and time to explain all aspects of
251 a matter conveyed empathy and security that enabled relatives to cope with the situation.
252 Being treated in a respectful, professional manner created a trusting and confident relationship
253 with the doctor and nurses in charge. Professionalism encompassed willingness to elaborate
254 information to the extent that every family member involved understood what was at stake.
255 This included giving priority to and space for important conversations with children and
256 grandchildren. Participants noticed how staff managed to remain professional and
257 compassionate despite limited resources, and went above and beyond expectations to meet the
258 needs of patients and their families.

259 *“I think nurses deserve all the respect they can get. They perform their duties in a*
260 *professional manner and at the same time act incredibly humane. To me as a son I*
261 *felt that the nurses conveyed real tenderness and understanding when helping the*
262 *patient.” (Informant 65)*

263 The opposite experience was described amongst those who faced episodes of professional
264 misconduct in terms of insensitive communication, unsympathetic gestures or broken
265 promises. They pointed at incidents that may have been details or involuntary violations for
266 staff but ended up adding a further burden to their strain. Some had been told they would

267 receive a phone call from the hospital department after the death, but never received it. Others
268 sensed a lack of empathy and support when being informed that there was nothing more that
269 could be done for their family member. Relatives and patients felt insecure when the doctor
270 was not properly prepared for a consultation or forgot appointments. The impact of wording
271 and mode of expression was emphasised:

272 *“Nurses need to be more aware of how they express themselves regarding family*
273 *members’ choices. I was extremely tired the last week before my sister’s death and*
274 *needed to go home and rest. For about three weeks, hospital staff who assessed she*
275 *was dying, regularly called me, and when I needed a break, the attending nurse said*
276 *I ought to stay. Yet she didn’t die. Relatives need acceptance when sleep is*
277 *required!” (Informant 89)*

278

279 **Discussion**

280 Our findings add new knowledge describing how lack of information may lead to more
281 distressing and unpredictable illness trajectories both for patients and their relatives. The
282 results illuminate how practical needs can generate dilemmas and strain when family
283 members themselves have to leave the patient for food or rest, or experience undignified
284 settings. This underlines the importance of paying attention to the “small things” that matter
285 most (15). The detailed descriptions of how organizational aspects of EOL care influenced
286 symptom relief and relatives’ support expand our understanding of how crucial these
287 conditions are for adequate treatment and care. We believe our results can be used by
288 healthcare managers when improving services in their institutions.

289 Participants wished healthcare personnel to be both professional and compassionate. Relatives
290 associated professionalism with good skills both in terms of delivering high standard care as

291 well as adequate information. Compassion is linked to empathy and ranked by patients and
292 family members to be among their most important healthcare needs, yet difficult to define
293 (16). This understanding of professionalism presupposes a distinction between these two
294 attributes, which is challenged by Nortvedt and Nortvedt (17). They argue that
295 professionalism in healthcare does not necessarily need to be associated with an objective
296 distance, which seems incompatible with care and proximity. On the contrary, clinical
297 professionalism requires sensitivity and thoughtfulness as key elements of the healthcare
298 personnel-patient-relationship. Factors that may foster or inhibit an appropriate understanding
299 and communication of the patient's experiences are important to acknowledge during
300 healthcare professional education (18). A biomedical approach for instance to the patient's
301 pain, is also needed in order to provide adequate symptom relief while maintaining the
302 necessary professional distance. Yet this does not rule out the will to get involved in patients'
303 personal setting, which is so deeply appreciated by our participants. Getting to know the staff
304 and building trust in a vulnerable situation were crucial for their assessment of quality care.
305 Being aware of the relational reality of care may challenge the traditional ideal of detachment
306 in the medical encounter, avoiding situations in which patients may be "harmed" in the
307 absence of care (19).

308 Learning professionalism is closely linked to developing an identity as healthcare personnel.
309 Professional identity may be described as a representation of self, achieved in stages over time
310 during which the characteristics, values, and norms of the individual thinking, acting and
311 feeling like a physician or nurse are formed (20). This process is increasingly addressed and
312 debated in medical education and training, including Norway (21). Nurses have traditionally
313 had a greater theoretical understanding and increased focus on how their professional conduct
314 and identity are linked to the quality of care that is delivered (22). Our findings suggest that
315 institutions caring for patients and their relatives at the EOL should have an increased

316 attention towards and measures for adequate training of their staff in these matters. A special
317 focus is needed on preserving dignity at the end of life, as described by Chochinov (23). His
318 model incorporates attitude, behavior, compassion and dialogue as the main areas in which
319 healthcare professionals can ensure patients' dignity, and describes in detail how to achieve
320 the required skills (24). Another perspective is added by Allmark, who draws a distinction
321 between "death with dignity" and "death without indignity" (25). Using this distinction, the
322 responsibility of healthcare professionals is to ensure indignities are minimized, e.g.
323 controlling pain and respecting patients' decisions and wishes.

324 Palliative care encompasses family members in a particular way that increases quality of care
325 (26). Acknowledgement of the importance of the healthcare professional-family carer
326 relationship is pertinent, due to the potential impact on both perceptions of patient care and
327 the subsequent grieving process (27-28). Our participants imparted how they had vital and
328 relevant knowledge about the patient's needs, knowledge which was not asked for or taken
329 into account, as also reported in other studies (29-30). This omission diminished the quality of
330 care of the terminal illness trajectory in terms of inadequate symptom relief as well as unmet
331 wishes about place of care. Relatives also experienced this lack of interest as hurtful and
332 insensitive. Comprehensive communication skills should be strived for in all settings treating
333 patients in need of palliative care (31-32). As modern hospital strategies emphasize user
334 perspectives to be incorporated into care, there is a need to further formalize and ensure this
335 development (33).

336 **Strengths and limitations**

337 Free text comments are used to supplement standardized questionnaires with additional
338 perspectives participants might have on the topic of investigation, including in the palliative
339 care setting (28). It is recognized that informants having very good or very poor experiences

340 are more likely to provide qualitative free-text responses (34). Even so, valuable nuances can
341 be distinguished which otherwise would have been missed in solely quantitative data
342 collection (32, 35). Our study comprised a representative sample of both participants and
343 hospitals in Norway, adding transferability to our findings. Few informants reported another
344 religious affiliation than Christianity, making it less likely that the results will be transferable
345 to a different cultural and religious setting. We obtained a representative sample of patients
346 and relatives in palliative cancer care, as gastrointestinal and lung cancer accounted for the
347 majority of deaths, and most patients were older than 60 years. There were no major
348 differences between the group adding free text comments and the group with no comments.
349 Only 22% of the comments described aspects of care during the last two days of life, which
350 was the main focus of the i-CODE study. Thus, our findings describe factors of EOL care that
351 participants regarded as important over a longer time span.

352 The majority of comments belonged to relatives of patients dying outside palliative care units.
353 We have not performed separate qualitative analysis in the different subgroups and are unable
354 to compare the results across units. However, differences between subgroups will be analyzed
355 in the main quantitative study. We do not know for sure if the reference relative in the
356 hospital was the same as before admission, but the questionnaire was sent to the person
357 designated as “main relative” in the hospital records. Data regarding length of illness and
358 degree of information received by the patient and relatives about the illness were not
359 collected, except from knowing it was cancer with short life-expectancy.

360 Analysis was conducted in collaboration between two of the authors, a nurse (MITH) and a
361 physician (MAS). Our clinical background from palliative care in the nursing home setting
362 (MITH) as well as thoracic medicine and cardiology (MAS) provided a broad framework for
363 discussions on analytical choices but also influenced which findings to be emphasized. The

364 other authors, being experienced oncologists and palliative care specialists, critically
365 challenged and revised the categories to clarify perspectives and presuppositions.

366 **Conclusions**

367 Our findings suggest that hospitals caring for cancer patients at the end of life and their
368 relatives, should systematically identify and attend to practical needs, as well as address
369 important organizational issues. Education and training of staff members ought to emphasize
370 how professional conduct and communication fundamentally affect patient care and relatives'
371 coping.

372 **Declarations**

373 **Ethics approval and consent to participate**

374 The study was approved by the Regional Committee for Medical and Health Research Ethics,
375 Western Norway (2017/640/REK vest). Participants were informed that return of the
376 questionnaire was viewed as consent to participate.

377 **Consent for publication**

378 Not applicable.

379 **Availability of data and material**

380 Access to the dataset is restricted, but may be considered upon reasonable request to the
381 corresponding author.

382 **Competing interests**

383 The authors declare that they have no competing interests.

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394 **Authors’ contributions**

395 DFH, KRS and CRM conceived the study and participated in the design of the study, data
396 collection and interpretation of the data. MITH and AK contributed to the study design, data
397 collection and interpretation of the data. MITH and MAS contributed to analyzing the data.
398 MITH, MAS, DFH and CRM contributed to drafting the paper. All authors read, revised and
399 approved the final version of the manuscript.

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404 **Abbreviations**

405 EOL: End-of-life

406 CODE: Care Of the Dying Evaluation

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Table 1 Characteristics of deceased patients and bereaved relatives (n=194)

	With free text comments from bereaved relatives (n = 104) n (%)*	Without free text comments from bereaved relatives (n = 90) n (%)*
Patients		
Age (years)		
18-29	1 (1)	0 (0)
30-39	1 (1)	3 (3)
40-49	7 (7)	5 (6)
50-59	13 (13)	13 (14)
60-69	30 (29)	25 (28)
70-79	34 (33)	31 (34)
≥ 80	17 (16)	11 (12)
NA	1 (1)	2 (2)
Gender		
Female	41 (39)	27 (30)
NA	1 (1)	2 (2)
Cancer diagnosis		
Breast	6 (6)	5 (6)
Gastrointestinal	37 (36)	29 (32)
Respiratory organs	27 (26)	19 (21)
Urological, incl. prostate	10 (10)	16 (18)
Leukaemia and lymphoma	9 (9)	5 (6)
Other	17 (16)	21 (23)
Died in a palliative care unit (PCU)		
	37 (36)	41 (46)
Specialist palliative care team involved (outside PCU)		
	41 (39)	27 (30)
	mean (range) median	mean (range) median

Length of last admission (days)	12 (3-80) 9	11 (4-48) 9
	With free text comments (n = 104) n (%)*	Without free text comments (n = 90) n (%)*
Bereaved relatives		
Age (years)		
18-29	2 (2)	0 (0)
30-39	7 (7)	4 (4)
40-49	16 (15)	11 (12)
50-59	32 (31)	21 (23)
60-69	26 (25)	26 (29)
70-79	17 (16)	24 (27)
≥ 80	3 (3)	2 (2)
NA	1 (1)	2 (2)
Gender		
Female	70 (67)	66 (73)
NA	4 (4)	2 (2)
Relationship to patient		
Husband/Wife/Partner	60 (58)	59 (66)
Son/Daughter	35 (34)	19 (21)
Brother/Sister	4 (4)	5 (6)
Son-/Daughter-in-law	0 (0)	2 (2)
Parent	2 (2)	2 (2)
Friend	1 (1)	1 (1)
Other	1 (1)	1 (1)
NA	1 (1)	1 (1)
Religious affiliation		
Christian	70 (67)	76 (84)
Muslim	0 (0)	1 (1)
Hindu	1 (1)	0 (0)
Jewish	1 (1)	0 (0)
Any other religion	5 (5)	2 (2)
None	26 (25)	8 (9)
NA	1 (1)	3 (3)

509 *Due to rounding of decimals, all columns do not add up to exactly 100%.

510 NA, not answered

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