Palliative care in the public health system: how do physicians deal with their patients at the end of life?

Ricardo Pedrini Cruz, José Américo Serafim, Daniel Klug and Cledy Eliana Dos Santos

Abstract

Background: Patients with cancer are referred late to palliative care services (PCS). **Aim:** To analyse the time of referral to PCSs and the characteristics of patients that are referred. **Methods:** A retrospective cohort. All patients admitted in a single tertiary care institution were evaluated by the PCSs from February 1, 2018 to January 31, 2019. **Findings:** Among the 642 patients (557 patients with cancer) referred to PCSs: 7.47% died before evaluation, 13.08% died before transfer, and 15.6% died within 8 days after transfer. Out of all the patients with cancer included in the study, 85.28% had less than 2 months of PCS follow-up during their disease. In the last 30 days of life, 96.26% had were readmitted to hospital. A total of 94.09% of patients with cancer died in a hospital. **Conclusion:** These findings suggest that patients with cancer in Brazil are not referred early enough to PCSs. Early integration with PCS must be sought to improve the accuracy of referral.

Key words: ● care transfer ● end-of-life care ● late referral ● palliative care ● terminal patient

Palliative care is recognised as an essential specialty to relieve suffering and enhance a person's quality of life, especially in end-of-life care (Hearn and Higginson, 1998; Bell et al, 2009; Wright et al, 2010; Temel et al, 2010; Casotto et al, 2017). Unfortunately, the late referral to palliative care services (PCS) and the likely higher demand of palliative care needs of the population may even decrease palliative care access (Christakis and Iwashyna 1998; Wirth et al, 1998; Costantini et al, 1999; Lamont and Christakis, 2002; Good et al, 2004; Schockett et al, 2005; Humphreys and Harman, 2014; Gu et al, 2016; Higginson, 2016; Santos et al, 2019; AlMouaalamy et al, 2020; Hausner et al, 2021). Palliative care should not be mistaken with end of life or terminal illness (Aldridge et al, 2016; Schreibeis-Baum et al, 2016; Dixe et al, 2020; Flieger et al, 2020). Patients with cancer that had all their treatment followed by their surgeons or oncologists may often experience an abrupt transfer of care, or even an interruption of care from their previous doctors once referred to PCSs (Casotto et al, 2017).

Although early palliative care follow-up is systematically recommended in the literature, authors are not precise about when to start it and do not comment on how long patients should be followed-up by assistant team. This study aims to analyse the time of referral to PCSs and the characteristics of patients that are referred, evaluating the worrisome situation for patients in palliative care, especially those with advanced cancer.

Patients and methods

A retrospective cohort of patients treated during hospitalisation at Hospital Nossa Senhora da Conceição (HNSC) by the PCS was performed, from February 1, 2018 to January 31, 2019, based on electronic medical records. All registers related to PCS consultancy requests and direct hospital admissions were included in this period. Type of consultancy requests were evaluation; attendance/co-management, procedure and care transfer.

Descriptive statistics (proportions, means, medians and standard deviations) were used to describe patient characteristics and disease features. After hospital discharge, patients were followed-up by outpatient consultation. The date of first contact with the PCS was considered for the first consultancy, outpatient consultation or hospital admission in the PCS. This criteria was also assumed to consider previous contact with the PCS.

Ricardo Pedrini Cruz
MD, PhD, Department of Oncology, Hospital Nossa Senhora da Conceição, Brazil

José Américo Serafim
Department of Monitoring, Evaluation and Dissemination of Strategic Health Data and Information, Brazil

Daniel Klug
PhD, Teaching and Research Management, Hospital Nossa Senhora da Conceição. Av. Francisco Trein, Brazil

Cledy Eliana Dos Santos
Teaching and Research Management, Hospital Nossa Senhora da Conceição. Av. Francisco Trein, Brazil

Correspondence to: ricardoc@ghc.com.br

Cancer staging was performed according to American Joint Committee on Cancer 8th edition (Amin et al, 2018). Time of disease was calculated by the difference between death (or last contact) and the diagnosis data. Time of palliative care follow-up was calculated by the difference between death (or last contact) and the initial contact with the PCS. Follow-up data were collected until February 1, 2022. The study protocol was approved by the ethics committee.

Results

Electronic medical records were evaluated from 01/02/2018 to 31/01/2019. There were 932 records, including 833 consultancy requests and 99 PCS direct hospital admissions. The 932 records correspond to 642 different patients (320 women and 322 men). The mean age (n=642) was 64 years (SD +/-15, varying from 17 to 98 years) and a median of 65 years. The data is summarised in the flowchart (*Figure 1*) and the indication for hospital admission is summarised in *Table 1*.

From the total 642 different patients, 557 (86.76%) had a cancer diagnosis. The cancer subtypes were distributed as *Table 2*. Type of consultancy requests (833) were for evaluation (45), attendance/co-management (371), procedure (19) and care transfer (398). Emergency doctors were responsible for 39.9% (372/932) of the solicitations. Care transfer to PCS was performed without consultancy request nor medical contact in 99 patients. It was the first contact with PCS for 95.3% (612/642) of patients. In addition, from the 99 patients that were transferred without medical consultancy request or medical contact, 55.1% (54) had no prior contact with PCS.

A total of 71% of patients were aware of their diagnosis in 71%, 85.2% of families were aware of the diagnosis (547/642). The disease prognosis was understood by 57.9% (372/642) of the patients and 81.4% (523/642) of their families.

Care transfer

From the total of 428 transfers to PCSs, 329 patients were transferred after a consultancy solicitation and 99 were transferred without any consultancy request or medical contact. Some 46.4% (199/428) and 59.5% (255/428) of PCS transfers did not have any previous PCS contact. From the patients transferred before a PCS evaluation, 58.8% (117/199) did not have any previous contact with a PCS.

Among the 642 patients: 7.47% of patients died before they were evaluated by the PCS and an additional 13.08% (84) died before they were effectively transferred to PCS. The median time of consultancy conclusion was less than a day (20 hours and 50 minutes). From all patients transferred to PCS (428), 15.6% (100) had 8 days or less of PCS follow-up during life (SD 211; median 16.6 days; varying from less than an hour to 2027 days).

The mean days of hospitalisation of patients in the PCS (n=428) was 8.6 days (SD 7.6, varying from 2 hours and 10 minutes to 46.4 days).

The patient

The performance status was evaluated by ECOG classification. There was 0.54% (five patients) ECOG 0, 4.29% (40) ECOG 1, 13.3% (124) ECOG 2, 32.83% (306) ECOG 3, 38.73%. A total of 361 patients recieved

Table 1. The indications for hospital admission

Clinical worsening	507 (54.4%)
Refractory pain	193 (20.73%)
Elective procedures (surgery, chemotherapy and clinical investigation)	84 (9.02%)
Bleeding (urinary, digestive and cervical tumor)	67 (7.2%)
Limb ischaemia	25 (2.69%)
Acute abdomen	22 (2.36%)
Stroke	10 (1.07%)
Spinal cord compression	8 (0.86%)
Others causes or not hospitalised	16 (1.72%)

Table 2. Cancer subtypes

Lung	120 (21.5%)
Colorectal	67 (12%)
Head and neck	43 (7.7%)
Breast	41 (7.3%)
Hepatobiliary	39 (7%)
Pancreas	37 (6.6%)
Oesophageal	33 (5.9%)
Hematopoietic	29 (5.2%)
Gastric	27 (4.8%)
Urinary system	26 (4.6%)
Prostate	24 (4.3%)
Unknown primary	19 (3.4%)
Cervix	17 (3%)
Sarcoma	9 (1.6%)
Ovary	7 (1.2%)
Uterus	5 (0.9%)
Central nervous system	4 (0.7%)
Others	10 (1.8%)

an Eastern Cooperative Oncology Group (ECOG) score of 4, and 5.58% (52) an ECOG score of 5. There were 4.72% without ECOG classification. During the initial evaluation, 24.5% (229/932) of patients were unconscious and 48 were already dead. The palliative performance scale (PPS) showed that only 21.5% (201/932) of the sample had PPS >50. In sum, more than a half of patients stayed mainly in bed/sitting during the day.

There were a total of 826 consultancy and direct service admissions due to cancer. This data corresponds to 557 different patients. Accordingly to their cancer stage, 1.4% were stage I, 4.5% were stage II, 10.6% were stage III, 82% were stage IV, 0.3% had no cancer stage completed, 0.3% had haematologic malignancy and 0.7% (4) primary brain tumor. Distant metastasis was present in 76.3% of patients. Almost a half (44.7%, 249/557) of these patients had no PCS follow-up during their disease. The median time of palliative care follow-up was 15 days, with a mean of 84.3 days. From all patients with cancer, 85.28% had less than 2 months of PCS follow-up during their disease.

Patients with cancer received a median of 15 days of palliative care follow-up (minimum 1 hour and 40 minutes; maximum of 2027 days). Since their diagnoses, they had a median of 307 days of cancer survival (minimum 1 day; maximum of 8473 days). The median and mean proportion of palliative follow-up time during the length of their disease was respectively 0.33% and 10.26%.

End-of-life quality

There were 508 known deaths from the total sample. Loss of follow-up was evidenced in 7.94% (51 patients), and no death registration in 12.93% (83 patients). In the last 30 days of life, 96.26% (489 patients) were readmitted to hospital and only 3.74% (19 patients) had no hospital readmission. From those with hospital readmission, 372 had only one, 110 had two and seven had three.

There were 476 known deaths from cancer patients. Loss of follow-up was evidenced in 8.8% (49 patients) and no death registration in 5.75% (32 patients). In the last 30 days of life, 96.22% (458 patients) were readmitted to hospital and 3.78% (18) were not readmitted to hospital. From those with hospital readmission, 347 had only one, 106 had two and five had three. Chemotherapy was performed, in the last 30 days of life to 8.19% (39) of the 476 cancer patients who died. The place of death was at the hospital for 94.09% (448 in our hospital and 30 in other hospitals), and at home for 5.9%.

Discussion

The data demonstrated a worrying situation of end-of-life care and the stigmatised impression about palliative care as a synonym of end of life. Also, the data suggested a lack of concern about patients' wills and necessities. This scenario was worsened by the estimate of palliative care needs for the next years (Higginson, 2016; Santos et al, 2019).

Care transfer was the main type of consultancy request (47.8%). For the other 435 solicitations, an additional 19% were also transferred. An additional 99 patients were transferred without any request, totalising a desire for care transfer of 62.2% (580/932). This data is much higher than the 22.9% of care transfer evidenced in the literature (ALMouaalamy et al, 2020). From the 428 patients effectively transferred, 46.4% (199 patients) were completed before the PCS team evaluation, and 59.5% (255) did not have any previous contact. Analysing deaths, 7.47% (n=48) died before PCS consultancy evaluation, 13.08% (n=84) before care transfer to PCS was accomplished and 15.6% (100 patients) within 8 days of PCS follow-up, totalling 36.1% (232/642). These findings are aggravated by the median time for consultancy's response (<24h), suggesting a lack of empathy for patients' and their families' grief, and that the main objective of the attending physicians is the transfer of care of their terminally ill patients. The transition of care should be gradual, allowing the patient to establish a relationship with the PCS team, and, preferably, a co-management instead of care transfer.

Most of the consultancy requests were from emergency doctors (39.9%), differing from other services that were evidenced 38.6% by clinical oncologists, and 20.3% by emergency doctors (ALMouaalamy et al, 2020). In the hospital, the emergency doctor evaluated patients admitted to the emergency room, and decided which service each one should be transferred to, independent of the previous patient's team relationship.

The late referral can also be evidenced by poor clinical conditions. This cohort showed that 71.67% were ECOG 3 or 4 and 5.47% were ECOG 5 at the time of initial evaluation. Ghabashi et al (2021) showed that 97.1% of their patients were ECOG 4 and 77.6% had PPS ranging from 30–50%. This cohort evidenced a PPS >50 in only 21.5% (201/932), confirming the poor clinical condition of patients referred.

A total of 86.76% of the sample were patients with cancer (557/642). Other end-of-life pathologies (i.e. cardiac insufficiency and chronic obstructive pulmonary disease) should also be prevalent in care transfer solicitations. There are two main hypotheses to explain this discrepancy.

One may be related to a greater difficulty to recognise end-of-life care in patients with chronic pathologies by emergency doctors (Christakis and Iwashyna, 1998). Furthermore, some authors had already shown that advance care planning may be completed closer to death for patients with cancer (Tros et al, 2022). Another hypothesis is that patients with cancer are still as stigmatised as terminal patients. The latter is related to additional concern of lack of knowledge in cancer staging and treatment.

Advanced cancer stage is another variable that indicates late referral. Stage IV was evident in 82% of patients (457/557), and almost a half of patients (44.5%, 248/557) had no PCS follow-up during their disease. Late PCS referral seems to be a global reality (Christakis and Iwashyna, 1998; Wirth et al, 1998; Costantini et al, 1999; Lamont and Christakis, 2002; Good et al, 2004; Schockett et al, 2005; Humphreys and Harman, 2014; Gu et al, 2016; ALMouaalamy et al, 2020; Ghabashi et al, 2021). Patients with distant metastatic disease were 76.3% (425/557), similar to other services (Humphreys and Harman, 2014; ALMouaalamy et al, 2020; Monsomboon et al, 2022). Although many patients at stage IV can still be treated (Pedrini Cruz, 2022).

Patients with cancer had a median time of PCS follow-up of 15 days. During their disease, 85.28% (475) had less than 2 months of PCS follow-up. The data imply not only a late PCS referral, but possibly a lack of benefit for transfer of care. Palliation in the last 2 months of life may be better accepted by patients and their families by the physician who had followed them during their illness, knowing their wills, fears and clinical condition.

The late PCS referral has already been associated with a worse quality of care (Earle et al, 2005; Hui et al, 2014; Davis et al, 2015; ALMouaalamy et al, 2020). However, a survey that had been conducted by European medical oncologists found that 75% of oncologists either agreed, or strongly agreed, that patients with advanced cancer should receive concurrent palliative care and 74.5% of the medical oncologists agreed or strongly agreed that the best person to coordinate the palliative care for a patient with advanced cancer is the medical oncologist (Cherny et al, 2003). Although this survey cannot be extended to Latin-American oncologists' reality, this thought may also be present and could partially explain the late referral.

Early palliative care is recommended (Zimmermann et al, 2014; Bakitas et al, 2015; Blackhall et al, 2016; Ferrell et al, 2017; McDonald et al, 2017; Bouleuc et al, 2019; Vanbutsele et al, 2020), although authors are not precise about when to start it, and how long patients should be followed. In this cohort, the proportion of palliative time follow-up by the PCS during the length of cancer had a median of 0.33% and a mean of 10.26%, suggesting that they are referred to PCS at the end of life. Fortunately, not all patients with cancer will evolve with metastatic and terminal disease, therefore, patients with increased risk factors for relapse or progression should be prioritised for referral.

Palliative care at the end of life depends on the patient's and family's ability to understand the disease and prognoses, and the misunderstandings of regarding prognosis have already been explored (Pronzato et al, 1994; Chan and Woodruff, 1997; Gattellari et al, 1999; Sapir et al, 2000; Chow et al, 2001; McGrath, 2002; Clayton et al, 2005; Robinson et al, 2008; Temel et al, 2011; Chen et al, 2013; Ghandourh, 2016). During the first PCS contact, 71% of patients and 85.2% of families were aware of pathology diagnosis, and the disease prognosis was known by 57.9% and 81.4%, respectively. A possible explanation about the difference between family's and patient's understanding can be related to Latin culture, which tends to give bad news to the family, establishing the conspiracy of silence (Lemus-Riscanevo et al, 2019). This scenario, which combines a late PCS referral with the lack of disease understanding by patients and families, is inadequate to end-of-life care.

Some factors are associated with worse end-of-life care, such as hospital readmission in the last 30 days of life, chemotherapy in the last 30 days of life, low/absence follow-up by a PCS, number of transitions of care and place of death (Earle et al, 2003; Guo and Jacelon, 2014; Prigerson et al, 2015; Bähler et al, 2016; Zhang et al, 2018, Abdel-Razeq et al, 2019; Soares et al, 2020; Virdun et al, 2020; Gusmano et al, 2021; Johnson and Ellis, 2021; Woldie et al, 2020; 2022; Broekman et al, 2022; Formoso et al, 2022; Dowd et al, 2023). In the last 30 days of life, 96.26% (489/508) had hospital readmission, and only 3.74% (19) died without hospital readmission. From those with hospital readmission, 372 had only one, 110 had two and seven had three readmissions. Hospital readmissions are necessary due to clinical indications, but they clearly decrease a person's quality of life, especially for those at the end of life.

Chemotherapy was administered to 6.07% of patients in the last 30 days of life, less than was previously reported (Earle et al, 2004; Rochigneux et al, 2017; Low et al, 2017; Abdel-Razeq et al, 2019; Zhang et al, 2018; 2020; Soares et al, 2020; Broekman et al, 2022; Formoso et al, 2022; Woldie et al, 2022). There are many variables that influence whether chemotherapy was adminstered in the last 30 days of a patient's life, such as patient performance status, cancer type, cancer stage, comorbidities, cancer treatment accessibility, patient age and others. In this cohort, because only terminal patients were referred to PCS, it is possible that when analysing all patients with cancer, the percentage of patients who had had chemotherapy administered in the last 30 days of life may increase.

The data showed that most patients died in a hospital (94.09%). Many doctors assert that the a person's place of death is related to the quality of their end of life (Freund et al, 2012; Gomes et al, 2012; Jeurkar et al, 2012; Davies et al, 2019; Verhoef et al, 2020). Recently, this belief has been questioned (Hoare et al, 2022). Some authors reported that 73.9% of their patients died at home or in a palliative care unit (Fauci et al, 2012). Unlike other countries, Brazil does not have hospices as part of public health, and this could explain the discrepancy between findings. Some have shown that end-of-life patients prefer to die at home, varying from 49–100% (Higginson and Sen-Gupta, 2000; Gomes et al, 2012; Aoun and Skett, 2013; Gomes et al, 2013; Hunt et al, 2014; Davies et al, 2019). Unfortunately, the preference is not always possible (Bell et al, 2009), due to variable factors, including clinical symptoms' home treatment limitations, specialised illness care needs, psychological and structural family capacity, costs for residence adaptation and caregiver and hospice availability and costs. A study in England showed that 73.9% preferred to die at home, but only 13.3% achieved it (Hunt et al, 2014). Also, a systematic review showed that the missing data in the studies could bias them to the agreement that 'home is the preferred place of death' (Hoare et al, 2015).

Limitations and strengths

There are some limitations of the study. First, as a retrospective study, inherent bias is inevitable. Second, this cohort is based on a single institution study involving one tertiary hospital, which may limit the study's data generalisation to other services. Third, the study evaluated only patients that were referred to PCS, so it is not possible to generalise findings to the other patients not under PCS.

One strength of the study is the low loss of follow-up (8.26%). Another strength is that the study allowed all of the patient variables to be analysed, identifying risk factors that are not possible in the nationwide studies.

Conclusion

The present study evidences a worrisome situation for patients in palliative care, especially those with advanced cancer. These findings suggest that palliative care is perceived as a synonym of end-of-life care in Brazil. To change this paradigm, the accuracy of PCS referral must be improved, and PCSs must be integrated early in the treatment of patients with cancer. *IJPN*

Statement of interest: None

Abdel-Razeq, Hikmat, Omar Shamieh, Mahmoud Abu-Nasser et al. Intensity of cancer care near the end of life at a tertiary care cancer center in Jordan.J Pain Symptom Manage. 2019; 57(6):1106–1113. https://doi.org/10.1016/j.jpainsymman.2019.02.016

Aldridge, Melissa D, Jeroen Hasselaar et al. Education, implementation, and policy barriers to greater integration of palliative care: a literature review. Palliat Med. 2016; 30(3):224–39. https://doi.org/10.1177/0269216315606645

ALMouaalamy N, AlMarwani K, AlMehmadi A et al. Referral time of advance cancer patients to palliative care services and its predictors in specialized cancer center. Cureus. 2020; 12(12):e12300. https://doi.org/10.7759/cureus.12300

Amin Mahul B, Stephen B Edge, Frederick L et al. American Joint Committee on Cancer Cancer Staging Manual. Springer: 2018

Aoun Samar M, Kim Skett. A longitudinal study of end-of-life preferences of terminally-ill people who live alone. Health Soc Care Community. 2013; 21 (5):530–535. https://doi.org/10.1111/hsc.12039

Bähler C, Signorell A, Reich O. Health care utilisation and transitions between health care settings in the last 6 months of life in Switzerland. PloS One. 2016; 11(9): e0160932. https://doi.org/10.1371/journal.pone.0160932

Bakitas Marie A, Tor D Tosteson et al. Early Versus delayed initiation of concurrent palliative oncology care: patient outcomes in the ENABLE III randomized controlled trial. J Clinic Oncol. 2015; 33(13):1438–1445. https://doi.org/10.1200/JCO.2014.58.636

Bell CL, Somogyi-Zalud E, Masaki KH. Methodological review: measured and reported congruence between preferred and actual place of death. Palliat Med. 2013; 23(6):482–490.

Blackhall LJ, Read P, Stukenborg G et al. CARE track for advanced cancer: impact and timing of an outpatient palliative care clinic. J Palliat Med. 2016; 19(1):57–63. https://doi.org/10.1089/jpm.2015.0272

Bouleuc C, Burnod A, Angellier E et al. Early palliative care in oncology. Bulletin Cancer. 2019; 106(9):796–804.

https://doi.org/10.1016/j.bulcan.2019.04.006

Broekman K, Maaike A, van der Aa Hans W et al. End-of-life care for patients with advanced ovarian cancer in the Netherlands: a retrospective registry-based analysis. Gynecol Oncol. 2022; 166(1):148–153. https://doi.org/10.1016/j.ygyno.2022.04.017

Casotto V, Rolfini M, Ferroni E et al. End-of-life place of care, health care settings, and health care transitions among cancer patients: impact of an integrated cancer palliative care plan. J Pain Symptom Manag. 2017; 54(2):167–175. https://doi.org/10.1016/j.jpainsymman.2017.04.004

Chan A, Woodruff RK. Communicating with patients with advanced cancer. J Palliat Care. 1997; 13(3): 29–33. https://doi.org/10.1002/cncr.11815

Chen Aileen B, Cronin A, Weeks JC et al. Expectations about the effectiveness of radiation therapy among patients with incurable lung cancer. J Clinical Oncol. 2013; 31(21):2730–2735. https://doi.org/10.1200/JCO.2012.48.5748

Cherny NI, Catane R et al. Attitudes of medical oncologists toward palliative care for patients with advanced and incurable cancer: report on a survery by the European Society of Medical Oncology Taskforce on Palliative and Supportive Care. Cancer. 2003; 98(11):2502–2510. https://doi.org/10.1002/cncr.11815

Chow EL, Andersson R, Wong M et al. Patients with advanced cancer: a survey of the understanding of their illness and expectations from palliative radiotherapy for symptomatic metastases. Clinical Oncol. 2001; 13(3): 204–208. https://doi.org/10.1053/clon.2001.9255

Christakis NA, Iwashyna TI. Attitude and self-reported practice regarding prognostication in a national sample of internists. Arch Int Med. 1998; 158(21):2389–2395. https://doi.org/110.1001/archinte.158.21.2389

Clayton JM, Phyllis NB, Martin HN. Tattersall. 2005. The needs of terminally ill cancer patients versus those of caregivers for information regarding prognosis and end-of-life issues. Cancer. 2005; 103(9):1957–1964. https://doi.org/10.1002/cncr.21010

Costantini M, Toscani F, Gallucci MC et al. Terminal cancer patients and timing of referral to palliative care: a multicenter prospective cohort study. J Pain Symp Managem. 1999; 18(4):243–252. https://doi.org/10.1016/s0885-3924(99)00084-6

Davies A, Todd J, Bailey F, Gregory A, Waghorn M. Good concordance between patients and their non-professional carers about factors associated with a 'good death' and other important end-of-life decisions. BMJ Support Palliat Care. 2009; 9(3):340–345. https://doi.org/10.1136/bmjspcare-2015-001085

Davis MP, Temel JS, Balboni T, Glare P. A Review of the trials which examine early integration of outpatient and home palliative care for patients with serious illnesses. Ann Palliat Med. 2015; 4(3):99–121. https://doi.org/10.3978/j.issn.2224-5820.2015.04.04

Dixe, Maria Dos Anjos, Irene Dixe de Oliveira Santo, Saudade Lopes et al. Knowledge and myths about palliative care among the general public and health care professionals in Portugal. Int J Environm Res Public Health. 2020; 17(13). https://doi.org/10.3390/ijerph17134630.

Dowd A, Davies M, Short S et al. Dying at home: enablers and barriers. Int J Palliat Nurs. 2023; 29(7):326–333. https://doi.org/0.12968/ijpn.2023.29.7.326

Earle CC, Bridget ANeville et al. Trends in the aggressiveness of cancer care near the end of life. J Clini Oncol. 2004; 22(2):315–321. https://doi.org/10.1200/JCO.2004.08.136

Earle CC, Bridget AN, Landrum MB et al. Evaluating claims-based indicators of the intensity of end-of-life cancer care. Int J Qual Health Care. 2015; 17(6):505–509. https://doi.org/10.1093/intqhc/mzi061

Earle CC, Park ER, Lai B et al. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. J Clin Oncol. 2003; 21(6):1133–1138. https://doi.org/10.1200/JCO.2003.03.059

Fauci J, Schneider K, Walters C et al. The utilization of palliative care in gynecologic oncology patients near the end of life. Gynecologic Oncol. 2012; 127(1):175–179. https://doi.org/10.1016/j.ygyno.2012.06.025

Ferrell, Betty R, Jennifer S et al. Integration of palliative care into standard oncology care: american society of clinical oncology clinical practice guideline update. J Clinical Oncol. 2017; 35(1):96–112. https://doi.org/10.1200/JCO.2016.70.1474

Peterson FS, Chui K, Koch-Weser S. Lack of awareness and common misconceptions about palliative care among adults: insights from a national survey. J General Int Med. 2020; 35(7):2059–2064. https://doi.org/10.1007/s11606-020-05730-4

Giulio F, Marino M, Guberti M, Giuseppe Grilli R. End-of-life care in cancer patients: how much drug therapy and how much palliative care? record linkage study in Northern Italy. BMJ Open. 2022; 12(5): e057437. https://doi.org/10.1136/bmjopen-2021-057437

Freund K, Weckmann MT, Casarett DJ et al. Hospice eligibility in patients who died in a tertiary care center.J Hosp Med. 2021; 7(3):218–223. https://doi.org/10.1002/jhm.975

Gattellari MPN, Butow MH, Tattersall SM Dunn, MacLeod CA. Misunderstanding in cancer patients: why shoot the messenger? Ann Oncol. 1999; 10(1):39–46. https://doi.org/10.1023/a:1008336415362

Ghabashi EH, Sharaf BM, Kalaktawi WA, Calacattawi R, Calacattawi AW. The magnitude and effects of early integration of palliative care into oncology service among adult advanced cancer patients at a tertiary care hospital. Cureus. 2021; 13(5):e15313. https://doi.org/10.7759/cureus.15313

Ghandourh WA. Palliative care in cancer: managing patients' expectations. J Med Rad Sc. 2016; 63(4):242–257. https://doi.org/10.1002/jmrs.188

Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat Care. 2012; 12:7. https://doi.org/10.1186/1472-684X-12-7

Gomes BIJ, Higginson N, Calanzani J et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. Ann Oncol. 2012; 23(8):2006–2015. https://doi.org/10.1093/annonc/mdr602

Good PD, Cavenagh J, Ravenscroft PJ. Survival after enrollment in an Australian palliative care program. J Pain Sympt Manag. 2004; 27(4):310–315. https://doi.org/10.1016/j.jpainsymman.2003.12.011

Guo Q, Cynthia SJ. An integrative review of dignity in end-of-life care. Palliat Med. 2014; 28(7):931–940. https://doi.org/10.1177/0269216314528399

Gusmano MK, Rodwin VK, Weisz D et al. Variation in end-of-life care and hospital palliative care among hospitals and local authorities: a preliminary contribution of big data. Palliat Med. 2021; 35(9):1682–1690. https://doi.org/10.1177/02692163211019299

Xiaoli G, Cheng W, Chen M et al. Timing of referral to inpatient palliative care services for advanced cancer patients and earlier referral predictors in mainland China. Palliat Support Care. 2016; 14(5):503–509. https://doi.org/10.1017/S1478951515001212

Hausner D, Tricou C, Deepa Wadhwa JM et al. Timing of Palliative care referral before and after evidence from trials supporting early palliative care. Oncol. 2021; 26

(4):332–340. https://doi.org/10.1002/onco.13625

Hearn J, Higginson IJ. Do specialist palliative care teams improve outcomes for cancer patients? a systematic literature review. Palliat Med. 1988; 12(5):317–332. https://doi.org/10.1191/026921698676226729

Higginson IJ, Sen-Gupta GJ. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. J Palliat Med. 2000; 3(3):287–300. https://doi.org/10.1089/jpm.2000.3.287

Higginson IJ. Research challenges in palliative and end of life care. BMJ Support Palliat Care. 2016; 6(1):2–4. https://doi.org/10.1136/bmjspcare-2015-001091

Hoare S, Antunes B, Kelly MP, Barclay S. End-of-life care quality measures: beyond place of death.BMJ Support Palliat Care. 2022; epub. https://doi.org/10.1136/spcare-2022-003841.

Hoare S, Morris ZS, Kelly MP, Kuhn I, Barclay S. Do patients want to die at home? A systematic review of the UK literature, focused on missing preferences for place of death. PloS One. 2015; 10(11):e0142723. https://doi.org/10.1371/journal.pone.0142723

Hui D, Hyun Kim S, Roquemore J et al. Impact of timing and setting of palliative care referral on quality of end-of-life care in cancer patients. Cancer. 2014; 120(11):1743–1749. https://doi.org/10.1002/cncr.28628

Humphreys J, Harman S. Late referral to palliative care consultation service: length of stay and in-hospital mortality outcomes. J Community Support Oncol. 2014; 12(4):129–136. https://doi.org/10.12788/jcso.0034

Hunt KJ, Shlomo N, Addington-Hall J. End-of-life care and achieving preferences for place of death in England: results of a population-based survey using the VOICES-SF questionnaire. Palliat Med. 2014; 28(5):412–421. https://doi.org/10.1177/0269216313512012

Neha J, Farrington S, Craig TR et al. Which hospice patients with cancer are able to die in the setting of their choice? results of a retrospective cohort study. J Clin Oncol. 2021; 30(22):2783–2787. https://doi.org/10.1200/JCO.2011.41.5711

Johnson LA, Ellis C. Chemotherapy in the last 30 days and 14 days of life in african americans with lung cancer. Am J Hospice Palliat Care. 2021; 38(8):927–931. https://doi.org/10.1177/1049909120969125

Lamont EB, Christakis NA. Physician factors in the timing of cancer patient referral to hospice palliative care. Cancer. 2002; 94(10):2733–2737. https://doi.org/10.1002/cncr.10530

Lemus-Riscanevo P, Carreño-Moreno S, Arias-Rojas M. Conspiracy of silence in palliative care: a concept analysis. Indian J Palliat Care. 2019; 25(1):24–29. https://doi.org/10.4103/IJPC.IJPC_183_18

Low D, Merkel EC, Menon M et al. Chemotherapy use at the end of life in Uganda. J Glob Oncol. 2017; 3(6):711–719. https://doi.org/10.1200/JGO.2016.007385

McDonald J, Swami N, Hannon B et al. Impact of early palliative care on caregivers of patients with advanced cancer: cluster randomised trial. Ann Oncol. Eur Soc Med Oncol. 2017; 28(1):163–168. https://doi.org/10.1093/annonc/mdw438

McGrath P. End-of-life care for hematological malignancies. J Palliat Care. 2002; 18(1):39–47

Monsomboon A, Chongwatcharasatit T, Chanthong P et al. Characteristics and factors associated with mortality in palliative patients visiting the emergency department of a large tertiary hospital in Thailand. BMC Palliat Care. 2022; 21(1):115. https://doi.org/10.1186/s12904-022-01009-z

Pedrini Cruz R. Death with dignity: are we providing adequate palliative care to cancer patients? Eur J Cancer Care. 2022; 31(6):e13512. https://doi.org/10.1111/ecc.13512

Prigerson HG, Bao Y, Manish A et al. Chemotherapy use, performance status, and quality of life at the end of life. JAMA Oncol. 2015; 1(6):778–784. https://doi.org/10.1001/jamaoncol.2015.2378

Pronzato P, Bertelli G, Losardo P, Landucci M. What do advanced cancer patients know of their disease? A report from Italy. Support Care Cancer. 1994; 2(4):242–244. https://doi.org/10.1007/BF00365729

Robinson TM, Alexander SC, Hays M et al. Patient-oncologist communication in advanced cancer: predictors of patient perception of prognosis. Support Care Cancer. 2008; 16(9):1049–1057. https://doi.org/10.1007/s00520-007-0372-2

Rochigneux P, Raoul JL, Beaussant Y et al. Use of chemotherapy near the end of life: what factors matter?" Annal Oncol. 2017; 28(4):809–817. https://doi.org/10.1093/annonc/mdw654

Dos SCE, Campos LC, Barros N et al. Revista Da Associacao Medica Brasileira. 2019; 65(6):796–800

Sapir R, Catane R, Kaufman B et al. Cancer patient expectations of and communication with oncologists and oncology nurses. Support Care Cancer. 2002; 8(6):458–463. https://doi.org/10.1007/s005200000163

Schockett ER, Teno JM, Miller SC, Brad S. Late referral to hospice and bereaved family member perception of quality of end-of-life care. J Pain Symptom Manag. 2005; 30(5):400–407. https://doi.org/10.1016/j.jpainsymman.2005.04.013

Schreibeis-Baum HC, Xenakis LE, Chen EK et al. A Qualitative inquiry on palliative and end-of-life care policy reform. J Palliat Med. 2016; 19(4):400–407.

CPD reflective questions

- How prepared do you feel to support an end-of-life cancer patient?
- Do you feel that care transfer is the best choice to patients and their relatives during the last months of their illness?
- Does your health system have the necessary support to allow patients to die at home?

Key points

- Although early palliative follow-up is systematically recommended in the literature, authors are not precise about when to start it and how long patients should be followed
- Late referral to PCS is often identified at different hospitals and services
- An abrupt transfer of care may worsen the already fragile condition, increasing the feeling of abandonment and hopelessness
- Death dignity is worsened by late PCS referral
- Dying with dignity is mistakenly thought of as dying at home
- Although many studies identified dying at home as a patient and family will, near the end-of-life patients and their families pursue hospital admission
- The proportion of palliative follow-up time during the length of disease may be a tool to evaluate the quality of palliative care
- Constant emergency team capacitation in palliative care is required to improve the accuracy of PCS referral.

https://doi.org/10.1089/jpm.2015.0296

Soares LG, Gomes RV, Palma A, Japiassu AM. Quality indicators of end-of-life care among privately insured people with cancer in Brazil. Am J Hosp Palliat Care. 2020; 37(8):594–599. https://doi.org/10.1177/1049909119888180

Temel JS, Greer JA, Admane S et al. Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer. J Clin Oncol. 2011; 29(17):2319–2326. https://doi.org/10.1200/JCO.2010.32.4459

Temel JS, Greer JA, Muzikansky A et al. Early Palliative care for patients with metastatic non-small-cell lung cancer. New Eng J Med. 2010; 363(8):733–742. https://doi.org/10.1056/NEJMoa1000678

Tros W, van der Steen JT, Liefers J et al. General practitioners' evaluations of optimal timing to initiate advance care planning for patients with cancer, organ failure, or multimorbidity: a health records survey study. Palliat Med. 2022; 36(3):510–518. https://doi.org/10.1177/02692163211068692

Gaëlle V, Van Belle S, Surmont V et al. The effect of early and systematic integration of palliative care in oncology on quality of life and health care use near the end of life. Eur J Cancer. 2020; 124:186–193. https://doi.org/10.1016/j.ejca.2019.11.009

Verhoef MJ, Nijs E, Horeweg N et al. Palliative care needs of advanced cancer patients in the emergency department at the end of life. Support Care Cancer. 2020; 28(3):1097–1107. https://doi.org/10.1007/s00520-019-04906-x

Virdun C, Luckett T, Lorenz K et al. Hospital patients' perspectives on what is essential to enable optimal palliative care: a qualitative study. Palliat Med. 2020; 34(10):1402–1415. https://doi.org/110.1177/0269216320947570

Wirth A, Smith JG, Ball DL et al. Symptom duration and delay in referral for palliative radiotherapy in cancer patients: a pilot study. Med J Aust. 1998; 169(1):32–36. https://doi.org/10.5694/j.1326-5377.1998.tb141475.x

Woldie I, Elfiki T, Kulkarni S et al. Chemotherapy during the last 30 days of life and the role of palliative care referral, a single center experience. BMC Palliat Care. 2022; 21(1):20. https://doi.org/10.1186/s12904-022-00910-x

Wright AA, Keating NL, Tracy A et al. Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. J Clin Oncol. 2020; 28(29):4457–4464. https://doi.org/10.1200/JCO.2009.26.3863

Zhe Z, Chen ML, Gu XL, Cheng WW. Use of palliative chemotherapy near the end of life: a retrospective cohort study. Palliat Med. 2020; 9(5):2809–2816. https://doi.org/10.21037/apm-20-273

Zhe Z, Chen ML, Gu XLet al. Palliative chemotherapy near the end of life in oncology patients. Am J Hospice PalliatCare. 2018; 35(9):1215–1220. https://doi.org/10.1177/1049909118763338

Zimmermann C, Swami N, Krzyzanowska M et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. Lancet. 2014; 383(9930):1721–1730