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How Far Along the Disease Trajectory? An Examination of the Time-Related Patient Characteristics in the Palliative Oncology Literature

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Abstract

Purpose—Adequate reporting of time-related patient characteristics is needed for research findings to be properly interpreted, applied and reproduced. Our objective was to characterize the time-related patient characteristics in palliative oncology studies and to examine the differences in time-related patient characteristics by various study characteristics.

Methods—We extracted time-related patient characteristics including actual survival, performance status, cancer stage, disease trajectory, study setting and eligibility criteria (life expectancy and performance status) from an established cohort of original palliative oncology articles published in 2004 and 2009.

Results—Among 742 original articles, 409 (55%) were case series. Only 247 (33%) articles reported actual survival, 157 (21%) reported actual performance status, 362 (49%) cancer stage, and 392 (53%) reported study setting. Based on all the available time-related characteristics, we were able to classify the studies into specific time-related categories in 378 (51%) studies. Among these, only 47 (13%) focused on patients in the last month of life. Compared to studies involving patients earlier in the disease trajectory, these studies were more likely to be case series (81% vs. 56%, $P=0.005$), retrospective (64% vs. 49%, $P=0.03$), and had a smaller sample size (median 20 vs. 61, $P=0.06$).

Conclusions—A majority of studies did not adequately report time-related patient characteristics. We also identified a gap in both the quantity and quality of studies involving patients in the last month of life. Our study has implications for study reporting and future directions for palliative oncology research.

Keywords

Palliative care; Research; Patient characteristics; Reporting; Survival; Performance status

Introduction

Over the past few decades, palliative care has evolved from a discipline that predominately provides care to patients in the last days of life to those living with life-limiting illnesses throughout the disease trajectory, ideally starting from the time of diagnosis of advanced disease.[1-3] Because patient care needs, treatment options and decision making are prognosis-dependent,[4-6] it is critical to ensure that research studies properly describe their patient population and inclusion criteria such that readers can apply the study findings to the appropriate patient population. For example, symptom burden and management strategies at the time of disease diagnosis, while receiving anti-cancer treatment, during the last weeks of life may be different from each other.[4, 7-9] Moreover, patients' desire for prognostic information decreases over time while caregivers' need increases.[10, 11] Thus, adequate description of time-related characteristics is essential.

We recently examined a cohort of over 1200 palliative oncology studies, and found significant variations in the study design, research topics and their reporting.[12, 13] To our knowledge, no study has specifically characterized the disease trajectory of study populations in the palliative oncology literature. A better understanding of which patient populations have been studied in the palliative oncology literature can help us to appreciate the extent of scientific literature and identify the gaps in research. Furthermore, characterization of the comprehensiveness of study population documentation may facilitate the development of standards for patient population reporting to improve generalizability of studies.

Our primary objective was to determine the time-related patient characteristics in Palliative Oncology studies. Our secondary objective was to examine the differences in time-related patient characteristics by various study characteristics. We hypothesized that a minority (<50%) of the palliative oncology literature focuses on patients with days to weeks of life expectancy and that the time-related characteristics of the study population are associated with specific study characteristics.

Methods

Literature search

The Institutional Review Board of the MD Anderson Cancer Center approved this protocol. This is a secondary analysis of our previous study that examined the quantity, scope and design of 1,213 palliative oncology studies.[12] In that study, publications were included if they were (a) related to both palliative care and oncology, and (b) published in the first 6 months of 2004 or 2009. These time frames allowed us to have a representative sample of publications over a 5 year period. We identified in MEDLINE, Scopus, CINAHL, Cochrane Library, PsychInfo, EMBASE and ISI Web of Science databases using both keyword and MeSH headings searches for "palliative care". Non-English articles, commentaries, editorials, dissertations, conference abstracts and letters were excluded. For the purpose of this study, we further excluded 365 studies in the initial search that were reviews and systematic reviews and 106 studies that did not involve patients or caregivers, resulting in a final cohort of 742 original articles.

Data collection

We extracted time-related patient characteristics defined as the key variables that can inform readers on the patient population's disease trajectory. These included median (or mean if no median was available) actual survival, performance status [Eastern Cooperative Oncology Group (ECOG)[14], Karnofsky performance status (KPS)[15], Palliative performance scale (PPS)[16, 17], WHO score (WHO)[14, 18]], cancer stage (classified as local, locally advanced, metastatic and recurrent disease), disease trajectory (classified as diagnosis, active cancer treatment, no further cancer treatment, cured and after death), and study setting (classified as hospital inpatient, hospital outpatient, inpatient hospice, home palliative care (non-hospice), home hospice care and hospice day care). Relevant information in the eligibility criteria were also retrieved (e.g. life expectancy and performance status). We also reviewed the title and abstract for the presence or absence of terms used to describe disease trajectory (e.g. End of life, Terminal, Dying, Advanced). The time of contact for bereaved caregivers was also collected if applicable. For reporting purposes, we transformed KPS and PPS of 1-34%, 35-54%, 55-74% and 75-100% into ECOG performance status of 4, 3, 2, 1 and 0, respectively (which is corresponded to the same WHO score) based on previous reports.[18-21] We classified the study population into specific time-related categories based on all the available information: >6 months, >4-6 months, >1-3 months, >1-4 weeks, 7 days or less, or "unable to determine time frame".

The following study characteristics were collected previously: study type, year of publication, research subjects, research topic, relevance to pediatrics, country of origin of the corresponding author, journal type, journals the studies were published, study population, number of patients in the studies, cancer types, and study designs.[12]

Statistical Analysis

Descriptive statistics was used to summarize all time-related patient characteristics and study characteristics. We reported the proportion of studies that provided each time-related characteristic. We examined the association between the time-related categories (< 1 month, >1-6 months and >6 months) and specific study characteristics using the Fisher's exact test for categorical variables (e.g. year and journal type), and the Kruskal-Wallis test for continuous non-parametric variables (e.g. sample size). The time-related categories were collapsed in this analysis to ensure adequate numbers in each category. The Statistical Package for the Social Sciences Software (SPSS version 23, IBM Corporation, Armonk, New York) was used for statistical analysis. A two-sided P-value of <0.05 was considered to be statistically significant.

Results

Study characteristics

Our study consisted of 742 original articles. The study characteristics were summarized in Table 1. Among these studies, vast majority was case report/series (n=409, 55%), while randomized controlled trial was accountable for only 46 studies (6%). A majority of studies (n=415, 56%) focused on physical symptoms.

Reporting of time-related characteristics

Only 247 (33%) articles reported actual survival and 157 (21%) reported actual performance status of the study population (Table 2). Cancer stage, disease trajectory, study setting, and life expectancy and performance status under eligibility criteria were reported in only 362 (49%), 273 (37%), 392 (53%), 104 (14%) and 56 (8%) articles respectively. Based on all the available time-related characteristics, we were able to classify the studies into specific time-related categories in 378 (51%) studies.

Distribution of time-related characteristics

Table 3 shows the distribution of time-related patient characteristics among the articles that reported them and the corresponding median actual survival. The most common characteristics among the study populations included in the literature were metastatic disease (n=301, 83%) and ECOG performance status of 2 (n=63, 40%). There were only a small proportion that studied the last week of life (n=21, 6%) and patients with ECOG 4 (n=10, 6%). The actual survivals were consistent with what was expected for the time-related characteristics (Table 3).

Time-related terminologies

Time-related terminologies and the median survivals for patients included in the literatures which used those terminologies in title or abstract are shown in Table 4. Among those literatures, studies which used the term “Dying” had shortest median survival of 4 days. Study with the term “Terminal”, “End of life”, “End stage” had median survival of 77, 30 and 11 days respectively.

Association between time-related categories and study characteristics

As shown in Table 5, studies conducted in the last month of life were more likely to be case series (81% vs. 56% vs. 58%, $P=0.005$), retrospective in nature (64% vs. 45% vs. 55%, $P=0.03$), involving mixed tumor types (70% vs. 70% vs. 41%, $P<0.001$), and less likely involving therapeutics (32% vs. 52% v. 62%, $P=0.001$) or interventions (34% vs. 56% vs. 65%, $P=0.001$). There were also more likely to appear in palliative care journal (75% vs. 42% vs. 18%, $P<0.001$) and have a trend toward smaller sample size (median 20 vs. 61 vs. 60, $P=0.06$).

Discussion

This is the first study to systematically examine the time-related patient characteristics in the palliative oncology literature. Our study shows that a majority of studies did not adequately report time-related patient characteristics, making it difficult to clearly identify the patient population of the study. We also found a significant gap in the literature— only a small proportion of studies were conducted in the last month of life. Our study has important implications for study reporting and future directions for palliative oncology research.

As illustrated in this study, palliative care research covers a wide range of patient population from the time of diagnosis of life-limiting illness to death and bereavement. This diversity poses a major challenge because research findings for one patient population may not apply

to another. For instance, exercise has been found to be useful for cancer-related fatigue; however, much of the research was conducted in cancer survivors and those undergoing treatment,[22, 23] and only a few randomized trials have been carried out in patients with advanced cancer [24, 25] who typically have a poor performance status and may not be able to adhere to the exercise programs. Indeed, where the patient is along the disease trajectory can have a major impact on medical decision making.[4-6, 8] This highlights the importance of adequately describing the patient population for research findings to be interpreted, applied, reproduced, and combined.

Unfortunately, our study revealed that there was limited reporting of time-related patient characteristics. Two-thirds of the palliative oncology literature did not report actual survival and 80% did not report actual performance status. Also, other critical pieces of time-related information such as cancer stage, disease trajectory and study setting were reported in less than half of the studies. Ultimately, the patient population was not clearly recognizable in half of the studies. Poor reporting of these characteristics impedes knowledge translation and there remains much room for improvement.

To standardize study reporting, many scientific journals endorse reporting guidelines and checklists, such as CONSolidated Standards of Reporting Trials (CONSORT) for randomized trials,[26] the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE)[27, 28] and the REporting of studies Conducted using Observational Routinely-collected health Data (RECORD)[29] for observational studies. These guidelines state that study setting, eligibility criteria and population characteristics should be reported; however, these guidelines are not specific for palliative care and did not mention the need for time-related patient characteristics. Given the unique requirements for palliative oncology literature reporting, we believe that palliative care journal editors, reviewers and investigators should place a greater emphasis to ensure that patient characteristics are uniformly described, with adequate details for readers to understand who were the patients involved in each study. Although actual survival would be ideal, it requires extra work to collect this information and may not always be feasible. At the minimal, performance status, disease stage, disease trajectory, study setting and eligibility criteria (if applicable) should be consistently reported, particularly since our study confirmed that these variables can be highly informative of survival (Table 3).

Although end-of-life care is one of the most important domains of palliative care, our study highlighted the limited quantity and quality of literature involving patients in the last month of life, making it difficult to provide evidence-based care at life's end. Indeed, a vast majority of studies involving patients in the last month were case series, retrospective in nature and have a small sample size. There are multiple reasons contributing to this literature gap, including the fact that these patients often have a short survival and are rapidly declining in their health status. Another major obstacle is that these patients mostly have high distressing symptoms such as delirium[9, 30] and dyspnea, which make them difficult to enroll and also more likely to drop out of studies.[31] However, our experience conducting studies in this population suggests that many patients and families were still willing to participate in clinical trials because they recognize the meaning in helping others through research.[32] In the last days to weeks of life, assessment of patient-reported

outcome is particularly challenging, and clinicians often have to rely on surrogate reporting or clinician impression which may not be well validated. Because patients in the last weeks and days of life often experience significant distress and have unique care needs (e.g. terminal delirium,[30] palliative sedation,[33] discharge planning[34]), we need to conduct more high quality studies to shift the paradigm in the management of these issues and to improve care of the dying.

Traditionally, it has been difficult for researchers to prognosticate accurately and clearly define the inception cohort for patients in their last days of life. We recently conducted a prospective study and identified multiple signs of impending death among 357 cancer patients with high specificity (>95%) and high positive likelihood ratios (>10) for death in 3 days, which could help identify patients who have entered the last days of life, which may be useful as eligibility criteria for clinical trials focusing on issues related to the last days of life.[35-37] Acute palliative care units may be particularly appropriate setting for research because of the distress among patients and caregivers,[9, 38] the availability of the interdisciplinary team[39-41] and centralization of location.

Many terms used in the literature to describe a patient population such as “end-of-life” and “end stage” are poorly defined.[42] Our study helps to bring some clarity to this issue by examining the median survival associated with the use of these terms. We found that “end-of-life”, “terminal” and “end stage” generally referred to patients with weeks to months of survival, while “dying” was associated with generally days of survival. These findings are consistent with a conceptual framework proposed based on a systematic review.[43] Importantly, because there is much variation in the survival associated with these terms, it is important to clearly define these terms whenever they are used, and to provide adequate description of time-related characteristics to put these terms in context.

Similarly, the terms “Palliative care” and “Hospice care” are sometimes used interchangeably among clinicians and patients. A recent systematic review examining the definitions of these terms clarifies that “Hospice Care” represents a community branch of “Palliative Care”.[44, 45] Other branches of “Palliative Care” include inpatient and outpatient palliative care programs in the acute care facilities and home-based palliative care programs. Consistent with this model, our current study supports that the survival of patients in hospice studies was generally in terms of weeks, while the survival of patients in acute palliative care programs was generally in terms of months (Table 3).

Our study has a certain limitations. First, we examined only literatures published within two 6-months periods, which could result in sampling error. Second, this is a secondary analysis of previous study which examined the publications in 2004 and 2009 only. Although the findings should remain relevant, further studies are needed to examine the more recent literature. Third, this study only included oncology related publications and the findings may not be generalizable to other areas of palliative care. Strengths of this study include the large sample size and the detailed characterization of multiple time-related patient characteristics and study characteristics.

Conclusion

We systematically examined the reporting of time-related characteristics in palliative oncology literature. A majority of studies did not adequately report time-related patient characteristics. Only a small proportion of study was conducted in the last month of life and they were mostly retrospective case series. This study underscores significant opportunities for investigators and the greater scientific community to improve the quality of reporting and both the quantity and quality of research on patients in their last weeks to days of life.

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Table 1

Original Article Characteristics (N=742)

Characteristics	N (%)
Year	
2004	299 (40)
2009	443 (60)
Research method	
Case series	409 (55)
Cross sectional	103 (14)
Cohort	66 (9)
Qualitative	77 (10)
Population	21 (3)
Randomized Controlled Trials	46 (6)
Other ^a	20 (3)
Study type	
Retrospective	338 (46)
Prospective	404 (54)
Study population ^b	
Patients	675 (91)
Caregivers	94 (13)
Health care professionals	23 (3)
Study topic	
Physical	415 (56)
Psychosocial	127 (17)
Communication/Decision making	53 (7)
Health services	93 (13)
Other ^c	54 (7)
Cancer type	
Mixed	503 (68)
Specific tumor type	239 (32)
Pediatrics	22 (3)
Therapeutic studies	313 (42)
Interventional studies	342 (46)
Location of corresponding author	
Africa	7 (1)
Asia	128 (17)
Australia	41 (6)
Europe	299 (40)
Latin America	8 (1)

Characteristics	N (%)
North America	259 (35)
Journal type	
Palliative Care	332 (45)
Oncology	127 (17)
Other ^d	283 (38)
Median sample size (Interquartile range)	53.5 (15-180)

^aStudies with mixed methodologies

^bThe percentage adds up to above 100% because many studies involve various type of study population

^cIncluded topics on spirituality, complimentary medicine, quality of life, education and research

^dNone-oncology and non-palliative care journals, such as general medicine, surgical or pediatric journals

Table 2

Reporting of Key Time Related Characteristics

Characteristics	N (%)
Actual	
Survival	247 (33)
Performance status ^a	157 (21)
Eastern Cooperative Oncology Group score	73 (10)
Karnofsky performance scale	69 (9)
WHO performance status	11 (1)
Palliative performance scale	7 (1)
Cancer stage	362 (49)
Disease trajectory ^b	273 (37)
Study setting ^c	392 (53)
No actual time-related patient characteristics reported	71 (10)
Eligibility criteria for study population	
Prognosis	104 (14)
Performance status	56 (8)
No actual characteristics or eligibility criteria reported	60 (8)
Able to classify into time-related categories ^d	378 (51)

^aThere were 3 studies reported multiple types of performance status

^bWe classified the patients according to their disease trajectory into the following groups: Diagnosis, Active cancer treatment, No further cancer treatment, Cured and After death

^cWe classified study settings as follow: Hospital inpatient, Hospital outpatient, Inpatient hospice, Home palliative care (non-hospice), Home hospice care and Hospice day care

^dTime-related categories were >6 months, >4-6 months, >1-3 months, >1-4 weeks and 7 days or less according to time-related patient characteristics

Table 3Time-related Patient Characteristics and Survival ^a

Characteristics	Number of studies (%) ^a	Median survival in days (IQR) ^b
Cancer stage ^c	362 (100)	
Local	33 (9)	165 (26-354)
Locally advanced	162 (45)	148 (90-220)
Metastatic	301 (83)	132 (70-211)
Recurrent	15 (4)	144 (94-246)
Disease trajectory ^c	273 (100)	
Active cancer treatment	160 (59)	143 (84-261)
No further cancer treatment	157 (58)	77 (37-175)
Diagnosis	2 (1)	NA
Cured	2 (1)	NA
After death	39 (14)	NA
Study setting ^c	392 (100)	
Inpatient	207 (53)	58 (24-148)
Outpatient	137 (35)	122 (61-209)
Home palliative care (non-hospice)	54 (14)	75 (59-104)
Inpatient hospice	53 (14)	28 (16-71)
Hospice day care	5 (1)	NA
ECOG Performance status	157 (100)	
0	4 (3)	311 (311-311)
1	38 (24)	180 (150-245)
2	63 (40)	121 (090-186)
3	42 (27)	58 (24-84)
4	10 (6)	23 (12-47)
Time-related categories ^d	378 (100)	
7 days or less	21 (6)	3 (3-6)
>1-4 weeks	26 (7)	19 (14-24)
>1-3 months	87 (23)	61 (46-75)
>4-6 months	114 (30)	142 (115-165)
>6 months	130 (34)	266 (222-383)

Abbreviations: ECOG = Eastern Cooperative Oncology Group, IQR = Interquartile range

^a Among the studies that reported the time-related characteristics^b Median survival only based on studies that reported actual survival (247 studies)^c The percentages add up to above 100% because some studies fall under multiple categories

^dTime-related categories were >6 months, >4-6 months, >1-3 months, >1-4 weeks and 7 days or less according to time-related patient characteristics

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Table 4

Time-related Terminologies Used in Study Topic and Abstract

Terminologies	Number of studies <(%) ^a	Median survival in days (IQR) ^b
Advanced	123 (17)	114 (57-179)
End of life	30 (4)	63 (24-122)
Terminal	77 (10)	42 (25-84)
End stage	11 (2)	25 (14-60)
Dying	19 (3)	4 (3-16)

Abbreviations: IQR = Interquartile range

^a Among the studies that reported the time-related characteristics^b Median survival only based on studies that reported actual survival (247 studies)

Table 5

Association between Time-Related Patient Characteristic categories and Study Characteristics (N=378)

Study Characteristics N (%)	Number of Studies categorized by Time-related Patient Characteristic N (%)			P-value
	<1 month 47 (13%)	1-6 months 201 (53%)	>6 months 130 (34%)	
Year				
2004	17 (36)	79 (39)	54 (42)	0.80
2009	30 (64)	122 (61)	76 (58)	
Research method				
Case series	38 (81)	112 (56)	75 (58)	0.005
Cohort / Randomized controlled trials	4 (9)	38 (19)	34 (26)	
Cross section studies	4 (9)	28 (14)	16 (12)	
Other	1 (2)	23 (11)	5 (4)	
Study type				
Retrospective	30 (64)	90 (45)	72 (55)	0.03
Prospective	17 (36)	111 (55)	58 (45)	
Study topic				
Physical	27 (57)	132 (66)	91 (70)	0.12
Psychosocial	9 (19)	24 (12)	10 (8)	
Health services	6 (13)	24 (12)	12 (9)	
Communication / Decision making	5 (11)	8 (4)	7 (5)	
Others	0 (0)	13 (6)	10 (8)	
Cancer type				
Mixed	33 (70)	141 (70)	53 (41)	<0.001
Specific tumor type	14 (30)	60 (30)	77 (59)	
Pediatrics	2 (4)	3 (1)	4 (3)	0.30
Therapeutic studies	15 (32)	105 (52)	81 (62)	0.001
Interventional studies	16 (34)	113 (56)	85 (65)	0.001
Location of corresponding author				
Africa	0 (0)	3 (2)	2 (1)	0.38
Asia	7 (15)	49 (24)	27 (21)	
Australia	3 (6)	9 (5)	5 (4)	
Europe	23 (49)	77 (38)	48 (37)	
Latin America	0 (0)	0 (0)	4 (3)	
North America	14 (30)	63 (31)	44 (34)	
Journal type				
Palliative Care	35 (75)	84 (42)	24 (18)	<0.001
Oncology	2 (4)	38 (19)	35 (27)	
Other	10 (21)	79 (39)	71 (55)	

Study Characteristics N (%)	Number of Studies categorized by Time-related Patient Characteristic N (%)			P-value
	<1 month 47 (13%)	1-6 months 201 (53%)	>6 months 130 (34%)	
Median sample size (IQR)	20 (1-213)	61 (21-184)	60 (16-137)	0.06

Abbreviations: IQR = Interquartile range