

Brief Report**Patients' Perspective of Timeliness and Usefulness of an Outpatient Supportive Care Referral at a Comprehensive Cancer Center**

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Abstract

Context. Current guidelines recommend early referral to palliative care for patients with advanced cancer; however, no studies have examined the optimal timing of referral from the patients' perspective.

Objectives. To examine patients' perceptions of timeliness of referral and its association with survival among patients with advanced cancer referred to an outpatient supportive care (SC) clinic.

Methods. This cross-sectional prospective study in an SC clinic at a comprehensive cancer center included patients aged 18 years or older with locally advanced, recurrent, or metastatic cancer. Patients were asked to complete an anonymous survey regarding the timeliness and perceived usefulness of SC referral within four weeks of their first SC consultation.

Results. Of 253 eligible patients, 209 (83%) enrolled in the study and 200 completed the survey. Median survival was 10.3 months. Most patients (72%) perceived that referral occurred "just in time," whereas 21% felt it was "late," and 7% felt "early." A majority (83%) found the referral useful, and 88% would recommend it to other patients with cancer. The perception of being referred early was associated with lower reported levels of pain ($P = 0.043$), fatigue ($P = 0.004$), drowsiness ($P = 0.005$), appetite loss ($P = 0.041$), poor well-being ($P = 0.041$), and lower physical ($P = 0.001$) and overall symptom distress ($P = 0.001$). No other associations were found between perceived timeliness and usefulness and patients' baseline characteristics.

Conclusion. Most patients with a median survival of 10 months perceived that SC referral was timely and useful. Patient care needs rather than the timing of advanced cancer diagnosis drove this perception of referral timing. Lower symptom burden was associated with the perception of being referred to early. *J Pain Symptom Manage* 2019;58:275–281. © 2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Supportive care, palliative care, referral, patients, perceptions

Introduction

Early referrals to palliative and supportive care (SC) are supported by Level 1 evidence.^{1–5} Early access to SC positively impacts end-of-life quality care indicators.^{6,7} Current guidelines from the American Society of Clinical Oncology recommend the routine

integration of SC into standard oncology care at the time of diagnosis of advanced disease.^{8,9} However, these recommendations are from the perspective of health care professionals.^{10,11}

No previous studies have examined the optimal timing of an SC referral from the perspective of patients. Our primary aim was to examine advanced

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cancer patients' perceived timeliness of their SC clinic referral. As secondary outcomes, we also examined 1) patients' perception of the usefulness of SC referral and clinic setting and operation; 2) if perceived timeliness correlated with the actual timing of referral; and 3) if perceived usefulness and timeliness were associated with patients' characteristics.

Methods

The Supportive Care Clinic

Patients are referred to our SC clinic at the discretion of their oncologists. On arrival, their vital signs are verified and patients wait for their consult in a large private room, equipped with a full hospital bed and chairs for the patients, family, and the SC interdisciplinary team. Patients are seen by the SC-trained nurse who performs a complete clinical evaluation using validated tools such as the Edmonton System Assessment Scale,¹² the Memorial Delirium Assessment Scale,¹³ the Eastern Cooperative Oncology Group (ECOG) performance status,¹⁴ and the Cut Down-Annoyed-Guilty-Eye-Opener questionnaire (CAGE) adapted to include drug use (CAGE-AID).¹⁵ The SC-trained nurse discusses the case with a board-certified palliative medicine specialist who then evaluates the patient/family and provides care recommendations.^{16,17}

Participants

The Institutional Review Board of The University of Texas MD Anderson Cancer Center approved this prospective study. Patients were included based on eligibility criteria: 1) advanced cancer diagnosis defined as locally advanced, recurrent, or metastatic; 2) 18 years of age or older; 3) to be seen at the SC clinic for a consultation; and 4) being able to read and speak English. Patients with an Memorial Delirium Assessment Scale score of 13 or higher and those deemed by the medical team to have severe symptom distress were excluded.

Data Collection and Measures

Between November 2015 and August 2016, patients attending the SC clinic were screened and approached by the research nurse after their initial consultation. Those willing to participate and who provided informed consent were contacted within three to 11 days from the first consultation to complete the survey via telephone. If they were not available, they were approached again at their first follow-up visit. Patients were reassured about the anonymity of the survey. The survey was developed by a panel of SC specialists after they had performed a comprehensive literature review. The survey encompassed 28 questions on patients' perceptions of timeliness and usefulness of the referral as well as

patients' attitudes and beliefs toward the SC clinic setting operation. Perception of timeliness was assessed by the survey item "I think my referral to MD Anderson Supportive Care was made" (responses ranged from "much too early" to "much too late") and usefulness by the agreement with the statement "In my opinion, overall, I feel that the referral to MD Anderson Supportive Care was useful."

Patients' demographics (i.e., age, gender, religion, race, marital status), clinical characteristics (i.e., cancer diagnosis, Edmonton System Assessment Scale, and ECOG performance status at first consultation), and date of death or date of last contact were collected by chart review.

Statistical Considerations

For the primary outcome of estimating the proportion of patients who reported that their referral was late (including "late" and "much too late"), we planned to approach 209 patients expecting that 90% of them would agree to participate and that approximately 76% would complete the survey. The primary outcome was estimated with a standard error not larger than 0.04.

All data were summarized using standard descriptive statistics such as mean, standard deviation, median, range, and interquartile range (IQR) for continuous variables and frequency and proportions for categorical variables. Comparisons in continuous variables were carried out using Wilcoxon rank sum test between two groups or Kruskal-Wallis test among three groups. Association between two categorical variables were assessed using the chi-squared test or Fisher's exact test, whichever was appropriate. The overall survival time was calculated from research registration date to the date of death or last follow-up. Kaplan-Meier method was used to estimate the median overall survival times, and the log-rank test was applied to compare the difference in overall survival time between or among patient groups. All computations were carried out in SAS 9.3 (SAS Institute Inc., Cary, NC, USA), TIBCO Spotfire S+® 8.2 for Windows, and Cytel Studio 11.0.0.

Results

Of 253 eligible patients, 209 (83%) were enrolled in the study. Of these, nine were excluded from the final analysis because they did not fill out the questionnaire ($n = 2$) or did not answer the primary outcome survey question ($n = 7$). Thus, 200 of 209 patients were evaluable (response rate, 95%; Fig. 1). Patients' median age was 62 years, 56% were female, and 59% had an ECOG performance status of 2 or lower. Other patient characteristics are described in Table 1.

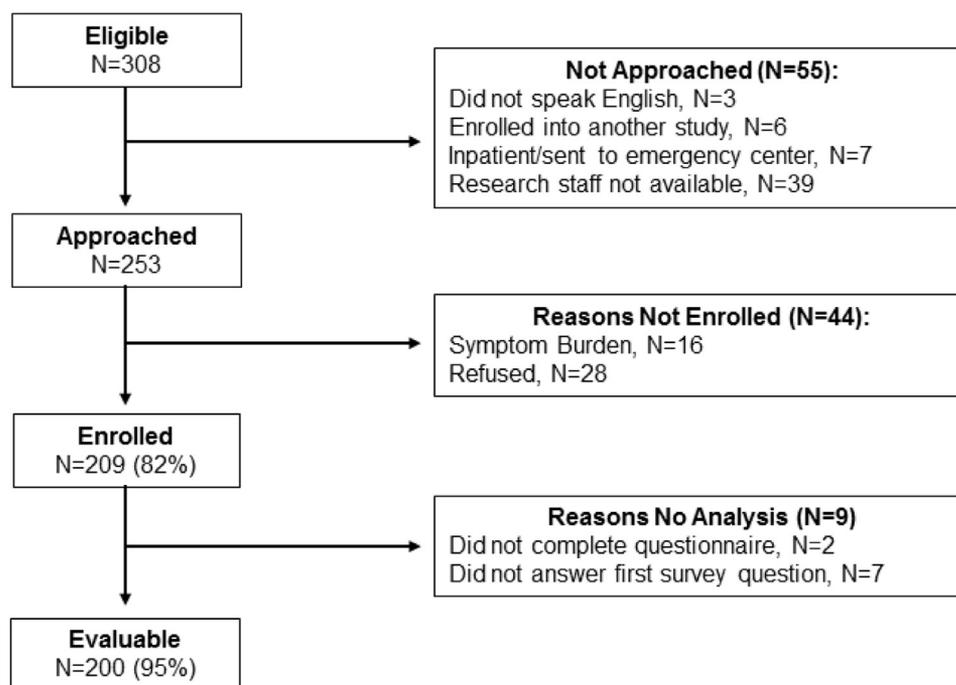


Fig. 1. Study flow diagram.

One hundred and forty-four (72%) patients reported that their referral was made “just in time,” 42 (21%) reported it as “late” or “much too late,” and 14 (7%) reported it as “early” or “much too early” (Fig. 2). Most patients responded that an SC referral should take place either at the time of cancer diagnosis (for themselves, 39%; for any patient, 54%; Table 2) or at the time of starting first chemotherapy (themselves, 27%; any patient, 24%). The majority reported that uncontrolled physical symptoms (themselves, 86%; any patient, 92%) and problems with anxiety or depression (themselves, 52%; any patient, 73%) should drive an SC referral. A considerable proportion stated that emotional distress of a family member should also be a reason for a referral to the SC clinic (their own family member, 47%; any patient’s family member, 66%). Most patients responded that SC referral should be triggered by patients’ needs (87%), disease status (66%), and prognosis (64%); and patients’ needs were indicated as the best trigger for a referral (50%).

The only associations between patients’ perceived timeliness of referral and their demographic and clinical characteristics were that patients’ perception of being referred early (“early” or “much too early”) was significantly associated with lower median self-reported scores for pain (3; IQR, 2–4; $P = 0.043$), fatigue (3; IQR, 1–3; $P = 0.004$), drowsiness (1; IQR, 0–2; $P = 0.005$), poor appetite (1; IQR, 0–4; $P = 0.041$), poor well-being (2; IQR, 1–3; $P = 0.041$), physical distress (14; IQR, 2–16;

$P = 0.001$), and overall symptom distress (15; IQR, 3–20; $P = 0.001$).

One hundred twenty-eight patients had died by the time of data analysis. The median overall survival was 10.3 months (95% CI, 7.0–14.3). There were no significant differences in median survival times among patients who perceived that they were referred early (“early” or “too early”; 21.4 months; 95% CI, 6.0–not reached), in time (8.3 months; 95% CI, 5.9–13.5), or late (“late” or “much too late”; 16.3 months; 95% CI, 7.3–not reached; $P = 0.13$).

Most patients (83%) felt that their referral was useful overall, and the vast majority (~88%) would recommend it to their friends, family members, and other patients (Table 3). Patients also rated usefulness of the referral very highly in helping them with symptom management (scale, 0–10; median, 8; IQR, 6–10), decision-making (median, 8; IQR, 5–10), and communication with other physicians and relatives (median, 7; IQR, 5–9).

A minority disagree with waiting in a private room instead of a shared waiting room (20%) having a hospital bed instead of examining table (16%) and disagree that clinic’s music (6%) and lighting (4%) decrease anxiety.

No significant association was found between patients’ perceived usefulness of SC referral and their characteristics (data not shown). Although all these patients had advanced cancer, 62% of the patients stated that chemotherapy could cure their cancer.

Table 1
Patients' Characteristics

Patients' Characteristics	Total (N = 200, 100%)
Age (median, IQR)	62 (51, 68)
Gender	
Female	111 (55.5%)
Race	
White	143 (73%)
Black	25 (13%)
Asian/Hispanic	9 (5%)
Other	18 (9%)
Religion	
Christian/Protestant	141 (70.5%)
Catholic	18 (9%)
Other	41 (20.5%)
Marital status	
Married	133 (66.5%)
Divorced	28 (14%)
Single	22 (11%)
Widowed	16 (8%)
Other	1 (0.5%)
Cancer diagnosis	
Gastrointestinal	35 (17.5%)
Lung	32 (16%)
Breast	26 (13%)
Genitourinary	21 (10.5%)
Gynecologic	20 (10%)
Head and neck	20 (10%)
Leukemia/lymphoma	3 (1.5%)
Other	43 (21.5%)
ECOG	
≤1	77 (39.5%)
2	91 (46.7%)
3	27 (13.8%)
ESAS (median, IQR)	
Pain	5 (2, 7)
Fatigue	5 (3, 7)
Nausea	0 (0, 3)
Depression	0 (0, 3)
Anxiety	1 (0, 5)
Drowsiness	3 (0, 5)
Appetite	4 (1, 6)
Dyspnea	1 (0, 3)
Well-being	4 (2, 6)
Sleep	5 (3, 7)
Psychological	2 (0, 6)
Physical	20 (13, 28)
SDS	23.5 (15, 35)

IQR = interquartile range; ECOG = Eastern Cooperative Oncology Group; ESAS = Edmonton Symptom Assessment Scale; SDS = Symptom Distress Score.

Only 37 patients (19%) responded that they were referred to the SC clinic by their own request; 161 (81%) stated that they were referred by their oncologists.

Discussion

To our knowledge, this is the first study to examine advanced cancer patients' perceptions of their own referral to an outpatient SC clinic. The vast majority perceived that their referral occurred at an appropriate time. Interestingly, patients' care needs drove the perception of timing of referral rather than the time of diagnosis. Furthermore, patients felt that the

referral was overall useful, and very few had negative impressions toward the SC clinic's physical environment and functioning. Our findings are reassured by the fact that patients answered the survey anonymously.

We found that the actual timing of referral as measured from the first consult to death was approximately 10 months, which is relatively early. Prior studies suggest that SC referrals are generally felt to occur exceedingly late in the disease trajectory as judged by caregivers and health care professionals.^{11,18–21} In a multicenter survey study among bereaved family members of patients with cancer, Morita et al. found that almost 50% of them perceived that the timing of their relative referral to an SC unit was "late" or "too late."¹¹ Similarly, in a recent qualitative study by McCaughan et al., SC specialists also stated that patients with hematologic cancer are frequently referred to "late" in the disease course to their SC specialized services. In contrast, 72% of our survey participants with a median survival of 10 months perceived their access to SC occurred promptly.

Our study population was referred at a time point of the illness trajectory when SC interventions have been demonstrated to have positive effects on the patient and health care–related outcomes.^{1,3–5}

These timely referrals are likely being driven by two main factors: 1) Our SC program has been able to achieve a high level of integration at our institution. This is supported by the fact that our institution has several of the major indicators of SC integration recently identified by an international panel of palliative oncology experts²² and by our previous data showing that the clinical activity of the SC program and the median time from first outpatient SC consultation to death has been increasing over the last 10 years.^{23–25} 2) Oncologists are likely more aware of the benefits of a timely SC referral as the evidence supporting it has grown rapidly in the last few years, and oncologists' societies have been making efforts to promote early referrals.^{8,9} Therefore, our previous data together with our current findings suggest that once SC has achieved a deeper degree of integration within an institution and reasonable penetration among oncologists, SC referrals will occur timely enough also to be perceived as appropriate and useful by most patients being referred.

Although most patients felt that their referral occurred "in time," some (7%) perceived to have been referred "early" or "too early," which was significantly associated with a lower symptom burden. Hence, patients with low symptom distress might not have perceived yet the full extension of benefits of the SC referral as this may take more time to occur. This highlights the important role of oncologists and

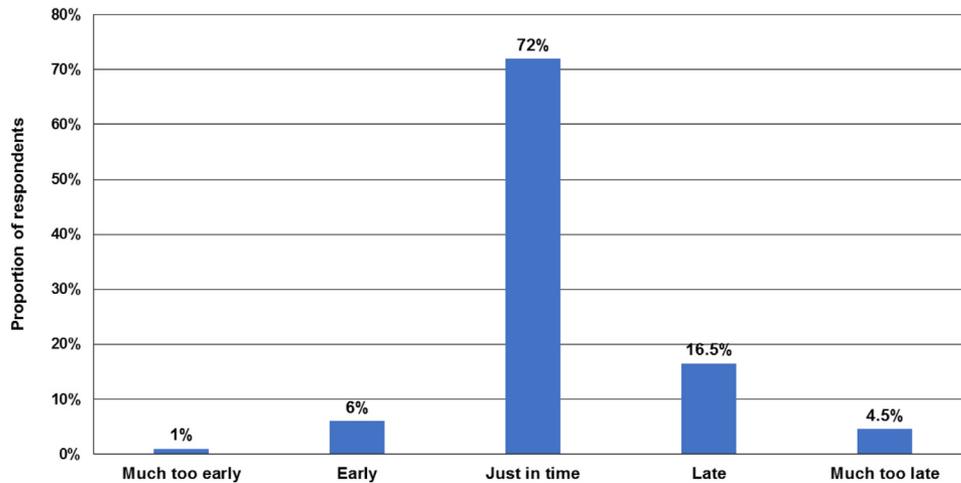


Fig. 2. Patients' perceived timeliness of the supportive care referral ($n = 200$).

SC teams in enhancing patients' understanding about SC services and all its benefits at the time of referral to improve patients' adherence, especially if they are mainly referred to receive SC interventions that will need multiple encounters to effectively take place.²⁶

We found that not all patients perceived the referral to be made "in time," which may suggest that referrals based only on oncologists' clinical judgment might not be the ideal referral model as clinicians may have different thresholds to trigger a referral and various levels of SC training and understanding.²⁷ The alternative approach would be to have automatic triggers such as disease stage and prognosis to refer patients automatically, in a similar way performed in randomized trials of early outpatient SC.^{27,28} However, although some studies have shown that using automatic triggers may improve the number of referrals and timing of SC access,^{29,30} this model is also limited by resources and the possibility of creating conflict between oncologists and the SC team as the former would not be involved in the referral process.³¹ Therefore, perhaps a combined model in which standardized referral criteria are provided to oncologists to enhance their ability to identify patients who are in most need of a referral would be more suitable. This is supported by results of a recent Delphi study with a panel of palliative oncology experts³¹ and by the fact that most patients in our cohort indicated that patients' needs were the most appropriate referral trigger. However, further research is necessary to evaluate the outcomes of the combined approach.

Our findings suggest that from the patients' perspective, stand-alone clinics might be a more interesting model of outpatient SC delivery compared with embedded SC clinics where the lack of physical space and shared control over clinic organization between oncology and SC teams restrict the possibility of having private rooms, larger beds, more specialized

members of the SC team in place, and making changes in the clinic physical environment and functioning.^{27,32,33}

It is of interest that more than 60% of the patients with advanced cancer after one visit with a palliative care specialist continued to express that their cancer is curable. This misperception has been shown to vary according to patients' demographics, clinical characteristics, country of origin, and the amount of SC exposure,³⁴⁻³⁷ and it indicates the need for strategies to improve prognostic awareness and communication in future studies. This finding might also be related to the increase in the level of uncertainty

Table 2
Timeliness of Supportive Care Referral

Question/Statement ^a	When I Should be Referred, n (%)	When Others Should be Referred, n (%)
At the time of my diagnosis of cancer	76 (39)	103 (54)
At the time when I start my first chemotherapy	52 (27)	47 (24)
At the time I am told cancer has come back after treatment	46 (24)	29 (15)
When I have no more cancer treatment options	15 (8)	14 (7)
Never	4 (2)	0 (0)
When my/their physical symptoms are not well controlled	171 (86)	175 (92)
When I/they have problems with depression/anxiety	103 (52)	138 (73)
When my/their family is having emotional distress regarding my disease	92 (47)	125 (66)
At other occasions	12 (6)	0 (0)

^aQuestions answered unexclusively; percentage is higher than 100%.

Table 3
Perception of Usefulness of Referral and Additional Survey Questions

How Useful was... ^a	Respondents (n)	Median (IQR)
having the nurse visit with you before the doctor's visit?	199	9 (7, 10)
referral to SC in helping to manage your symptoms?	199	8 (6, 10)
referral to SC in helping you make decisions regarding your disease?	195	8 (5, 10)
referral to SC to helping you communicate with your other physicians/care teams?	199	7 (5, 9)
referral to SC to helping you communicate with family/friends regarding your disease?	197	7 (5, 9)
Additional survey statements	Respondents (n)	Agree or Strongly agree
Overall I feel that the referral to SC was useful	199	164 (83%)
I would recommend referral to SC to other patients with cancer	199	174 (87.5%)
I would recommend referral to SC to my friends and family members with cancer	199	176 (88.5%)
I had an understanding of what SC is before my first visit to the center	197	86 (44%)
My oncologist explained very well what to expect from the referral before my SC visit	198	91 (46%)

IQR = interquartile range; SC = supportive care.

^aQuestions answered using a numerical scale (0 = very useless, 5 = neither useless nor useful, 10 = very useful).

about the prognosis of cancer in an era of immunotherapy and experimental treatments. In the past, we have known that doctors who convey a negative prognosis or less optimistic message are perceived as less compassionate and caring by patients.³⁸

This study has limitations. It was performed in a large academic tertiary cancer center where the SC program is integrated. Our findings may not generalize to other patient populations receiving SC at institutions with different levels of SC development and local resources. We acknowledge that not every patient with advanced disease at MD Anderson Cancer Center receives an SC referral before death.³⁷ Therefore, our results could have been different if all patients with advanced cancer were able to access SC and have their perceptions toward their referral examined. Further efforts will be needed to reach these patients. In addition, the median survival among “early,” “in time,” and “late” groups was not statistically different. We also did not examine patients’ perception of usefulness of other core components of SC (i.e., illness understanding, advanced care planning) that may need longitudinal care to occur. Future studies should evaluate patients’ perception of an SC referral at different disease time points.

In conclusion, most patients perceived that SC referral was timely and useful and patient care needs drove this perception of referral timing rather than timing of advanced cancer diagnosis. Perceived timeliness of referral did not correlate with the actual timing of SC access. Lower symptom burden was associated with the perception of being referred to early.

Disclosures and Acknowledgments

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