



How, when, and why individuals with stage IV cancer seen in an outpatient setting are referred to palliative care: a mixed methods study

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Abstract

Purpose Early palliative care (PC) for individuals with advanced cancer improves patient and family outcomes and experience. However, it is unknown when, why, and how in an outpatient setting individuals with stage IV cancer are referred to PC.

Methods At a large multi-specialty group in the USA with outpatient PC implemented beginning in 2011, clinical records were used to identify adults diagnosed with stage IV cancer after January 1, 2012 and deceased by December 31, 2017 and their PC referrals and hospice use. In-depth interviews were also conducted with 25 members of medical oncology, gynecological oncology, and PC teams and thematically analyzed.

Results A total of 705 individuals were diagnosed and died between 2012 and 2017: of these, 332 (47%) were referred to PC, with 48.5% referred early (within 60 days of diagnosis). Among referred patients, 79% received hospice care, versus 55% among patients not referred. Oncologists varied dramatically in their rates of referral to PC. Interviews revealed four referral pathways: early referrals, referrals without active anti-cancer treatment, problem-based referrals, and late referrals (when stopping treatment). Participants described PC's benefits as enhancing pain/symptom management, advance care planning, transitions to hospice, end-of-life experiences, a larger team, and more flexible patient care. Challenges reported included variation in oncologist practices, patient fears and misconceptions, and access to PC teams.

Conclusion We found high rates of use and appreciation of PC. However, interviews revealed that exclusively focusing on rates of referrals may obscure how referrals vary in timing, reason for referral, and usefulness to patients, families, and clinical teams.

Keywords Palliative care · Referral · Oncology · Cancer · Qualitative · Interviews

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Introduction

Palliative care (PC) programs have experienced dramatic growth. In the USA, as of 2019, 72% of hospitals with fifty or more beds offered PC [5], with an increasing emphasis on integrating PC upstream in the outpatient setting [29, 32, 35]. Research shows that early introduction of PC leads to improved patient experience and quality of life [16, 20, 38, 44], less aggressive care at the end of life [17, 20, 35], and longer survival [2, 37, 39]. One study found that 57% of patients with stage IIIB and IV lung cancer in the Veterans Affairs health care system received inpatient or outpatient palliative care [37]. However, estimates suggest 60% of patients who would benefit from PC do not receive it [7]. The American Society for Clinical Oncology's 2012 provisional opinion called for initiation of PC at the time of diagnosis for patients with advanced cancer [36], and a 2017 update

recommended involving PC teams within 8 weeks of diagnosis [13]. The 2017 National Comprehensive Cancer Network guidelines recommend determining needs for specialist palliative care when a patient's prognosis is in the “months to years” range [9].

In oncology practices with embedded PC teams, research has demonstrated high oncologist satisfaction with PC, time savings for oncologists, and improved patient symptoms [33]. However, referring patients to PC teams soon after diagnosis when many patients are overwhelmed emotionally and logistically presents challenges [4, 25]. Physician experiences and beliefs may vary and influence their actual referral patterns [12, 25, 28]. A 2009 study surveying 170 primary care physicians found years of work experience and personal experience with PC was associated with more referrals [1].

There is little clarity about when, why, and how individuals are referred to PC in real-world community settings. The literature is sparse, and published referral rates range from 5% [43] to 75% [10]. The primary aim of this mixed methods project was to understand palliative care referrals through the following: (a) examining rates of referral to outpatient PC and hospice use for patients with stage IV cancer and (b) exploring reasons for referral to PC through in-depth interviews with oncology and PC teams.

Methods

The study took place at a large multi-specialty group in Northern California where an outpatient PC program was rolled out across four geographic areas between 2011 and 2014.

Electronic health record data

Data were retrieved from the Epic electronic health record (EHR) and linked to organizational tumor registry data for adult patients with a stage IV cancer diagnosed after January 1, 2012 who died before December 31, 2017. Referrals to PC were placed by oncologists or other physicians and were included if they occurred any time from 30 days prior to diagnosis until death. The first referral date was used if there were multiple referrals. Referrals from 30 days prior to diagnosis to 60 days after diagnosis were defined as “early.” Referrals to community hospice programs were not logged in structured fields in the EHR, so progress notes from any clinical encounter or specialty containing the word “hospice” were extracted and reviewed. If notes confirmed the patient received or died under hospice care, the patient was categorized as using hospice. When notes were unclear, two additional team members reviewed them and determined hospice utilization status.

Organizational tumor registry data included diagnosis date and tumor site group based on Surveillance, Epidemiology,

and End Results Program (SEER) group definitions. Death date was based on Social Security Administration (SSA) death file data and information entered into the EHR by providers. Patient demographic and clinical characteristics, as well as healthcare utilization were retrieved from the EHR. Primary oncologist was defined as the medical oncology or gynecological oncology physician the patient visited most frequently, and geographic division was this physician's location.

Provider data included specialty, geographic division, and rate of referral (patients referred to PC divided by all deceased stage IV patients seen by that provider). Referral rates were calculated for oncology providers who saw 10 or more patients during the study time period. To determine whether patients with short survival were being transferred directly to hospice care, we calculated the number of patients who died within 180 days of diagnosis and received hospice care. There are many differences across the four medical oncology geographic regions. Region A was the first to launch PC in 2011 and is the only region with offices for PC and medical oncology in the same office suite. Region D was the final area to launch PC in 2014. Gynecological Oncology providers are reported as a separate group.

Statistical analysis

Summary statistics were calculated; mean or median is reported (median for continuous variables which are right-skewed), along with the 10th and 90th percentile. *T* tests and chi-square tests were used for continuous and categorical variables, respectively, to compare early referral and later referral groups. Data management and analysis was conducted using SAS Enterprise Guide 7.1.

Interviews with clinical teams

In-depth interviews were conducted with members of teams managing these patients' cancer care in medical oncology or gynecological oncology and PC teams. A stratified sample of participants was recruited by specialty and role, through e-mailed invitations. Interviews occurred between September 2018 and April 2019 and included questions asking when, why, and how patients with stage IV cancer should be referred to the PC team (see Appendix 1). All participants provided informed consent and received a \$50 gift card. The researchers were embedded within the healthcare organization; the two researchers conducting interviews were a sociologist and public health researcher and were joined in coding by another researcher trained in qualitative methods. They adopted a constructivist approach to the analysis with the understanding that learning would result from the interaction between interview participants and researchers [6]. This research was approved by the health system's institutional review board.

Audio recordings of interviews were transcribed and imported into qualitative data analysis software (Dedoose version 8.2.14). Given the exploratory nature of this study, we adopted a grounded theory approach to analysis [15]. Two coders began analysis using both inductive and deductive techniques, i.e., capturing emerging ideas related to palliative care referral and identifying themes revealed in previous research. The team collaboratively developed a codebook, which was finalized after reaching saturation with themes relating to PC referral [18]. Each transcript was coded by one individual and then reviewed and recoded by another coder, with weekly meetings to reach consensus on coding questions and discuss emergent findings. Qualitative methods are reported following the Standards for Reporting Qualitative Research (SRQR) reporting guidelines [34].

Results

Palliative care referrals and hospice use

A total of 1334 patients were diagnosed with a stage IV cancer in this 6-year time period, and 705 (52.8%) died, with median survival from diagnosis of 250 days (about 8 months), 10th percentile 50 days and 90th percentile 858 days (Table 1). Of these 705 patients, 332 (47.1%) were referred to PC, and 257 (77.4%) had 1 or more PC visits. Of those referred, 161 (48.5%) were referred “early” (no later than 60 days after diagnosis). Overall, 52% of early referrals came from geographic region A (the first site to launch PC and with shared office space) even though it accounted for only 24% of the patients. Median time from diagnosis to referral was 15 days for early referrals (10th percentile 1, 90th percentile 46) versus 264 days for later referrals (10th percentile 76, 90th percentile 766) ($p < 0.001$). Median survival from diagnosis for early referrals was about 4 months (123 days, 10th percentile 35, 90th percentile 568), versus 14 months (422 days, 10th percentile 161, 90th percentile 1007) for those with later referrals and 7.5 months (224 days, 10th percentile 39, 90th percentile 839) for those never referred ($p < 0.001$). Referrals increased from 21 (6.3%) in 2012 to 89 (26.8%) in 2017 (not shown). Of 705 patients, 580 (82.3%) had notes referencing “hospice,” and 468 (66.4%) had clearly received hospice care. For 36 patients, the notes were ambiguous and were classified as not receiving hospice care. Of patients referred to PC, 263 (79%) received hospice care versus 205 (55%) of patients without PC referral.

Of all PC referrals, 71% were made by medical oncology or gynecological oncology providers, 12% by primary care providers, and 17% by other providers, e.g. hospitalists. Referral rates for 26 oncology providers (oncologists, physician assistants, and nurse practitioners) who saw at least 10

patients varied from 0 to 72% (mean = 19%) (Appendix 2). Six providers referred less than 5% of patients seen; one referred 72% of 92 patients seen, and 46/66 (70%) of these were early referrals. Another referred 43% of 117 patients with 21/50 (42%) being early referrals.

We speculated that patients not expecting to live long might go to hospice and not PC. Overall, 277 (39%) of all patients survived less than 180 days; 156 (56%) of these had no PC referrals, and of these, only 84 (54%) were seen by hospice (Appendix 2).

Interviews with clinical team members

Of 38 clinical team members invited by e-mail, 25 (65.8%) participated in an in-person interview, 3 actively declined, and 8 never responded or were lost to follow-up. Participants included 13 medical oncology or gynecological oncology (Onc) team members: 8 physicians and 5 nurse practitioners, nurses, and social workers; and 12 PC team members: 5 physicians and 7 nurse practitioners, nurses, social workers, and chaplains. Eighteen participants (72%) were female. Fourteen (56%) had been at the organization for less than 5 years. All described having discussions with patients about PC.

Clinical team members described 4 pathways for when and why referrals happen: (1) early referrals, (2) referrals without active anti-cancer treatment, (3) problem-based referrals, and (4) late referrals when disease progressed or treatment stopped (Fig. 1; Table 2). Of 9 oncology providers interviewed, 4 typically made early referrals, 3 made problem-based referrals, 1 made late referrals (when stopping treatment), and 1 almost never made referrals, instead providing holistic care and referrals to hospice: “I’m not a user of PC. I know the literature, but I’m old. I do what they [the PC providers] do.” (Onc#7).

Early referrals

Early referrals were based on the assumption that everyone with an advanced cancer should have access to concurrent PC. However, some oncologists noted that stage IV prostate or breast cancer had better long-term prognoses and would not be referred early. Early referrals happened within the first few visits:

“We know that it’s going to be an issue, eventually, so it’s always good to start them with palliative care earlier than later,” (Onc#5). These oncology providers believed early referrals reduced confusion about the distinction between PC and hospice. They also appreciated having a larger team providing concurrent care, e.g., “it takes a village.”

Table 1 Characteristics of 705 individuals with stage IV cancer diagnosed after January 1, 2012 and died before December 31, 2017

	All deceased stage IV cancer patients (N=705)		Patients not referred to Palliative Care (N=373)		Patients referred to Palliative Care (n=332)				Difference: early & later referral groups p value ^b
	Mean/ Median	(P10, P90) ^a	Mean/ Median	(P10, P90) ^a	Referred ≤60 days of diagnosis (N=161)		Referred >60 days post cancer diagnosis (N=171)		
					Mean/ Median	(P10, P90) ^a	Mean/ Median	(P10, P90) ^a	
Days from diagnosis to death (median)	250	(50, 858)	224	(39, 839)	123	(35, 568)	422	(161, 1007)	<0.001
Days from diagnosis to referral ^c (median)	62	(6 ^d , 562)	n/a	n/a	15	(1 ^d , 46)	264	(76, 766)	<0.001
Days from referral to death ^c (median)	90.5	(17, 474)	n/a	n/a	109	(18, 543)	83	(15, 383)	0.01
CCS score ^e (mean)	29	(12, 46)	26.6	(12, 43)	29.2	(11, 44)	34.1	(16, 51)	0.002
Age (mean)	69.1	(52, 87)	68.8	(51, 87)	71.4	(55, 89)	67.6	(50, 85)	0.008
	N	%	N	%	N	%	N	%	
Patients with ≥1 palliative care visits	268	38%	11	3%	121	75%	136	80%	0.34
Received hospice care ^f	468	66%	205	55%	125	78%	138	81%	0.95
Gender (female)	314	45%	168	45%	77	48%	69	40%	0.17
Race Ethnicity									0.5
Hispanic	60	9%	32	9%	16	10%	12	7%	
Non-Hispanic Asian	92	13%	57	15%	15	9%	20	12%	
Non-Hispanic African American	11	2%	7	2%	3	2%	1	1%	
Non-Hispanic Caucasian	409	58%	213	57%	98	61%	98	57%	
Other	28	4%	13	3%	5	3%	10	6%	
Unknown/Missing	105	15%	51	14%	24	15%	30	18%	
Marital status									<0.001
Married/life partner/significant other	401	57%	199	53%	81	50%	121	71%	
Divorced/widowed/separated/single	155	22%	89	24%	35	22%	31	18%	
Unknown/Missing	149	21%	85	23%	45	28%	19	11%	
Primary oncologist division									<0.001
Region A – Medical Oncology	168	24%	31	8%	83	52%	54	32%	
Region B – Medical Oncology	187	27%	103	28%	37	23%	47	27%	
Region C – Medical Oncology	213	30%	153	41%	24	15%	36	21%	
Region D – Medical Oncology	69	10%	38	10%	10	6%	21	12%	
Gynecological-Oncology	21	3%	11	3%	0	0%	10	6%	
No oncology visits	47	7%	37	10%	7	4%	3	2%	
Tumor site									<0.001
Lung and Bronchus	251	36%	130	35%	67	42%	54	32%	
Pancreas	92	13%	50	13%	32	20%	10	6%	
Other Digestive System	84	12%	46	12%	22	14%	16	9%	
Prostate	68	10%	30	8%	9	6%	29	17%	
Colon and Rectum	59	8%	37	10%	6	4%	16	9%	
Breast	26	4%	13	3%	6	4%	7	4%	
Other	125	18%	67	18%	19	12%	39	23%	

^a P10 and P90 indicate 10th and 90th percentile values

^b *p* values from chi-square test or *t* test of mean difference

^c Results were based on data of 332 patients who were referred to palliative care

^d Calculation includes negative values (indicating that referral to palliative care happened prior to the official date of the cancer diagnosis)

^e CCS (Clinical Classification Software) score was based on all encounters from January 1, 2012 to December 31, 2017 (https://www.hcup-us.ahrq.gov/toolssoftware/ccsr/ccs_refined.jsp)

^f Received hospice care calculated based on analysis of Epic progress note data

Referrals without anti-cancer treatment

Other early referrals were for a smaller group of patients who chose not to or were ineligible to receive active anti-cancer treatments because “they are too sick,” e.g., patients with poor functional status, dementia, or who opted out of conventional treatments.

“They don’t want to try chemo to buy a few more months, so they’re a ‘get them on board with a palliative person right away.’” (Onc#4)

Problem-based referrals

Some providers believed referrals should occur when problems arose, e.g., serious pain which the oncologist could not or did not want to manage, psycho-social needs, family support, or patients struggling to understand or accept their prognosis who were referred for “difficult coping around terminal illness.” (PC#6). Oncologists’ thresholds for wanting PC assistance varied based on their training, experience, philosophy, and willingness to let go: “A lot of time, we oncologists have a hard time letting go.” (Onc#9).

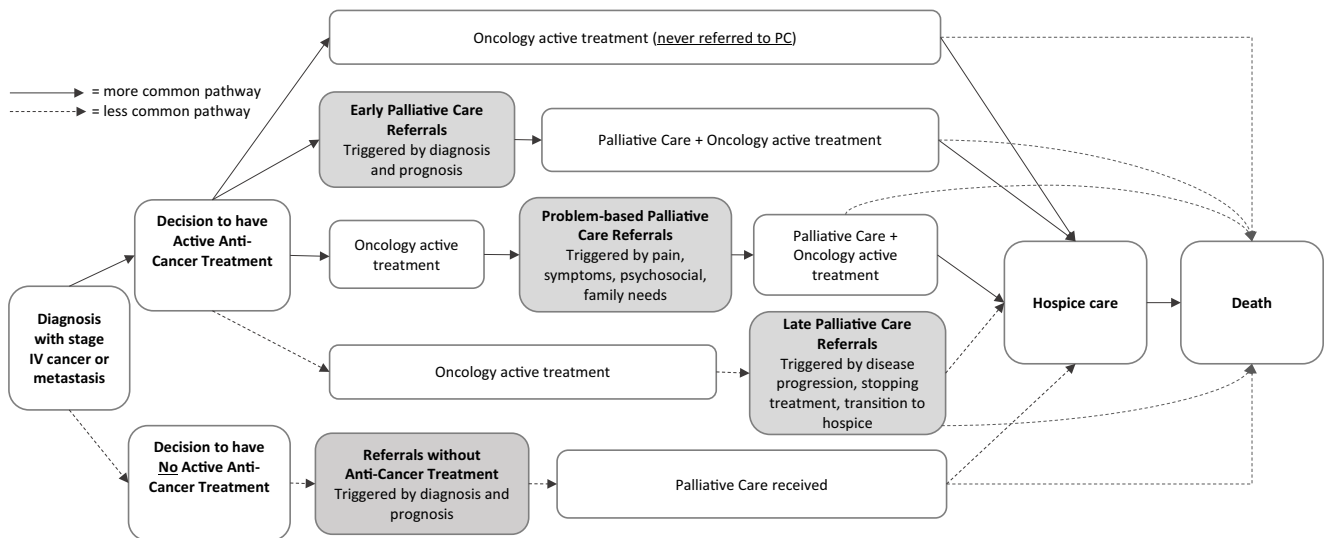


Fig. 1 Pathways to palliative care for individuals with stage IV cancer, as described in clinical team interviews

Some problem-based referrals also arose due to patients' lack of receptivity to earlier recommendations to begin PC.

"When I introduce it [earlier in journey], I would say about half the time people are interested. They may not want it right away. They often will say, 'Let me think about it.' And then when they start having a little more trouble, then I'll say, 'Remember we talked about palliative care earlier; I wonder if now would be a time to bring them in?' And then they might be open to it." (Onc#2)

Late referrals

Late referrals occurred when treatments stopped working, symptoms became unbearable, or patients were ready to transition to hospice. Both oncology and PC teams found late referrals problematic: "The transition with palliative care is very short, and then they kind of dump into hospice," (Onc#11).

"Oftentimes we see people who have more advanced symptoms that it would have been better for both the patient and our team to have sort of gotten on the ground floor of those symptoms... You know, had we been involved, her chemotherapy would have maybe been more tolerable or something like that." (PC#10)

PC team members noted that some oncologists who were older or had less PC familiarity referred patients who were

actively dying. These referrals, "sucked the energy out of palliative care" and left PC team members "distressed about it for weeks." (PC#4)

"I'd walk in and I'd say, 'Oh my God,' and the patient's actually dying, and we're not having a palliative conversation anymore. We're actually strangers walking in and saying, 'I'm sorry, your mom is actually dying right now. What we should be doing is, let's get her on hospice.'" (PC#4)

The semantics of palliative care

The language used to describe PC to patients was described as critically important because most patients know little about PC and conflate it with hospice (Table 3). Both teams stressed semantics: "I really emphasize the 'support' versus the 'palliative care' word." (PC#2). Oncology providers noted it was easier to make pain and symptom management the talking point with patients, rather than facing a poor prognosis and dying:

"It's an easier sell to say, 'Okay. Your pain medication's getting complicated. Dr. [oncologist] wants some advice from the experts and they're in palliative care.'" (Onc#4)

PC team members described using similar phrases but added context about understanding illness, treatments, prognosis, identifying patient preferences and values, and advance care planning.

Table 2 Types of referrals to palliative care, definitions, and illustrative quotes from clinical team interviews

Type of referral	Example
Early referrals: referrals made for any poor prognosis patient (not due to an identified need) but based on the assumption that PC team should be in place prior to problems surfacing	“I make a point to maybe not during the first visit, unless they have a lot of issue going on that require social work help... otherwise, I bring it up with the second or third visit. Not just when they turn the corner for the worst.” (Onc#3)
Referrals without anti-cancer treatment: made for patients who are ineligible for or choose not to pursue any anti-cancer treatment	“If they don't do treatment, what they need to do?... Usually, if they are too sick and they are not going to do any treatment, we do definitely introduce hospice, but in some cases, maybe we just say, ‘Okay. Why don't we have palliative care involved and then they can bridge them to hospice?’” (Onc#5)
Problem-based referrals: made when problems surface such as pain and symptoms, psycho-social needs, family support, advance care planning or end-of-life conversations	“I refer for pain control, and I refer for cases where my team can no longer handle it on their own. So, it's a really difficult situation, really difficult support, or lack of support, and of course, pain and the patient having a really hard time facing the fact that they are dying, no matter how much we try and have that conversation. They cannot accept the fact that they are dying, and we ask for palliative care to step in.” (Onc#9)
Late referrals: referrals made when there is no longer any anti-cancer treatments available and often results in quick transition to hospice care	“I think we do a pretty good job with pain management, and I've not had to use palliative care so much for pain management. Often too, they'll go right into hospice - that's the only thing too, is the transition with palliative care is very short, and then they kind of dump into hospice.” (Onc#11)

Benefits and challenges

The reported benefits of PC (Table 4) included better pain and symptom management, flexible visits (e.g., at home or during infusions), expanded teams, better advance care planning, illness understanding and prognostic awareness, end-of-life preparation, easier hospice transitions, and improved end-of-life experiences: “They talk about the power of attorney, the Physician Orders for Life-Sustaining Treatment (POLST), getting affairs ready with the family. I think they try to get that ball well aligned before things get worse and worse.” (Onc#1).

Barriers to referrals included patient receptivity, differences among oncologists, the time and cost to patients, “promising” new cancer treatments/research, and PC availability (Table 4). Availability concerns included wait times, lack of evening/weekend on-call, a desire for co-located teams (in clinics without it), and a limited staffing model to see patients urgently. Care team members recommended “re-branding” or “re-labeling” PC to minimize association with hospice (PC#2). Oncologists reported some patients would not try PC due to “cost and time,” or because they were too overwhelmed, “it's sort of often in one ear out the other.” (PC#10).

Some oncologists feared that PC erodes hope, “I think palliative care can take away any hope,” (Onc#11), or “So many

of these patients come and see me because they want that two percent hope.” (Onc#10). New cancer treatments and research also introduced uncertainty about when PC referral should occur: “With the new treatments, even in Stage 4, they could be around for years,” (PC#5).

Discussion

Analysis of EHR data for 1334 patients with stage IV cancer found that 705 (52.8%) died within the 6-year study period, and of these 332 (47%) were referred to PC. Among referrals, 48.5% were “early,” i.e., within 60 days after diagnosis. Median time from diagnosis to death was 4 months for patients referred early versus 14 months for later referrals. Shorter median survival for patients with early referrals suggests providers may be using poor clinical condition or anticipated poor prognosis to decide when to refer.

Patients referred to PC more frequently received hospice care than patients not referred (79% versus 55%). Median survival of 3 months after PC referral date indicates many patients were eligible for hospice care when referred to PC. Higher rates of hospice use among patients referred to PC suggest that PC facilitates hospice transitions.

Table 3 Language used by oncology and palliative care team members to describe palliative care to patients**Extra layer of support**

“Our focus is to support you and everything that goes along with that, and to figure out what’s most important to you in going through this, and what your concerns are, and we have kind of multidisciplinary team to help support all the different areas of things that might be going on, because we know that when you have serious illness, there can be symptoms, and education, and family support and emotional support, and financial concerns.” (PC#5)

Pain and symptom management experts

“They’re just another layer of care and their whole specialty is kind of symptom management. These guys all go to school to learn how to manage patient symptoms.” (Onc#2)

Psycho-social and family support

“They’re really there for psychological support to help you cope with this, and then they are also there for your family because they are also going through this journey with you, and they are really, really good at what they do.” (Onc#8)

Convenient and flexible visits

“When you are here getting chemo, they can come by and see you when you are here, so save another trip.” (Onc#3)

Help for the oncologist

“This is the additional service that can help you and help me. Help me take care of you better because I’m trained at caring for all the cancer treatment and this and that, but I need help caring for your pain better. It’s not just about the pain. It’s about how your family is dealing with this. How you are dealing with this, personally, emotionally.” (Onc#3)

Focus on what is important to you

“I’ll say, we do what’s called palliative care - this is scary for patients who have serious medical problems, and our hope is that as you continue to seek aggressive medical care, we could try to help focus on your symptom managements, improve your overall quality of life, help you get to these appointments, and make sure that we address what your goals of care are. How do you want to be medically treated, especially if things are not going well for you?” (PC#4)

Advance care planning

“Our role is to help maximize quality of life... We also try to help by talking about goals of care and treatment options, and helping people sort through if there’s decisions to make. We’re like an independent sounding board, and we do not have any agenda, other than to help people get the care that’s important to them that fits them... we help people with documents which make their wishes clear, in case of emergency, if they want them.” (PC#7)

Some oncologists at this organization almost never referred to PC, while others referred a majority of their patients. This research complements Le et al.’s finding that clinicians’ confidence in and beliefs about PC influence referrals [28]. The referral types described by clinicians in interviews suggest that referrals are typically based either on patients’ needs, “problem based referrals,” or time-based, based on time since diagnosis as in “early referrals,” as noted by Hui et al. [19]. Waiting to refer until problems surfaced sometimes leads to crisis or late referrals resulting in quick hospice transitions and the perception of “dumping” patients into hospice, which was problematic for oncology and PC teams and likely for patients as well.

Lack of patient receptivity to PC referral was also cited as an obstacle to early referrals in interviews. Many patients with advanced cancer do not understand that treatment is unable to cure their disease [41]. Patients’ “illness narratives” about fighting for a cure [26, 27] and the hope for new treatments and “rescue” [22] may also complicate introducing hospice and PC. Inadequate discussion of prognosis, and more time spent discussing treatment plans and logistics, dubbed the “stage IV shuffle” [3], may also compromise patients’ ability to make informed decisions.

Oncology teams endorsed many benefits of PC, but the language used to describe PC to patients required strategic messaging. Oncology and PC teams emphasized that PC was an “extra layer of support,” but the PC team added more messaging about prognostic awareness, quality of life, and advance care planning [21, 42]. Some oncology team members expressed reservations and fear that PC would erode patient hope. Challenges recounted included availability and access to PC teams, variation in oncologist referral practices, and patient misconceptions about and receptivity to PC. Given that oncologists report some patients are unwilling to consider PC at the time of diagnosis, a change in public perception and education may be a necessary first step toward expanding access to concurrent palliative care. A broader public education campaign may be necessary, as may adopting alternative language in patient interactions, such as “supportive care” rather than “palliative care” [11, 31].

These findings suggest several methods for enhancing PC referrals. Co-located oncology and PC services and relationship-building between departments may promote referrals. Eligibility algorithms [23] and EHR triggers [8, 14] may also prove beneficial as we shift toward population health strategies. However, while some evidence suggests making early PC standard care may improve patient quality of life [40], PC as a specialty may not have the capacity to meet the needs of all patients if early referrals become common [24, 30]. Additionally, new cancer treatments and research may lead to uncertainty about which cancers are incurable and pose dilemmas for clinicians determining PC eligibility.

This study was limited to one health system with a staggered roll-out of outpatient PC between 2011 and 2014. Our analysis did not control for availability of PC by site, and the interviews took place 4–7 years after local roll-out. Cross-sectional EHR data was limited to individuals with a stage IV cancer who died within a 6-year period. A majority of patients diagnosed with a stage IV cancer died within the 6-year period for which we have data; however, survival information is missing for those who survived beyond the study time period. There may be selection bias in interview participants and recall bias in interviews themselves. We explored care team descriptions of conversations, but we do not know how patients perceived those conversations.

Table 4 Benefits and challenges to accessing palliative care as described by clinical team members

Benefits	Challenges
<p><i>Pain and symptom expertise</i></p> <p>“It’s pain support. Pain management is such a big issue. I do it when I can but that’s when they are on minor stuff. Norco or something that when they are getting Dilaudid every two, three hours and still having pain, I know better to get someone to help.” (Onc#3)</p>	<p><i>Patient fears/misunderstanding about PC</i></p> <p>“I think it [palliative care] allows the possibility that things are not going well. And so, some people are absolutely terrified of even peeking under that. They want nothing to do with palliative care because they see it as right before hospice...” (PC#2)</p>
<p><i>Team care</i></p> <p>“We get bogged down by the nitty gritty of the details of medicine that sometimes another person and perspective, the patients might open up things to them that they may not open up [to us] because they may view them differently... The more input we get from the patients, the better care that we can give them.” (Onc#13)</p>	<p><i>Generational differences in oncologist use of palliative care</i></p> <p>“In my opinion, the young oncologists are so much more pro-palliative care... The older docs, I feel, refer patients to us who are dying. We’ve walked into a patient situation, like into a clinic room and said, this patient is actively dying - he needs to be in hospice.” (PC#4)</p>
<p><i>Improve end-of-life experience</i></p> <p>“I think the patients feel they get more support. Their family knows what’s going on. They have affairs set up well in advance. I think from that standpoint it reduces a lot of the chaos, sometimes. Because sometimes toward the very end, I’ve seen patients where they aren’t set up with anything and there’s scrambling, there’s a lot of freaking out.” (Onc#1)</p>	<p><i>Potential disconnect between Oncology and Palliative Care goals</i></p> <p>“I feel that there is sometimes some disconnect with respects to our goals and their goals... And the difficult thing that I have is, the palliative care person comes back and says, ‘Oh my gosh - this lady has Stage 4 disease. How come you did not talk to her about treatment goals?’” (Onc#10)</p>
<p><i>Easier transitions to hospice</i></p> <p>“Just so much easier to talk about hospice when that time comes. They’ve been mentally prepared all along.” (Onc#3)</p>	<p><i>Time and cost of PC</i></p> <p>“Time. Like sometimes they are coming in for so many visits, and the palliative care wants another visit. Cost, there’s a copay with that of course.” (Onc#8)</p>
<p><i>Longer/more flexible visits</i></p> <p>“Patients are so complicated. They require so much care and hand holding, really. It’s just too much to take care of all at once in like 15 or 20 min, so it’s really nice that the palliative care people can see them and really talk and tease out a lot of the struggles that they are dealing with.” (Onc#8)</p>	<p><i>New cancer treatments/research</i></p> <p>“Oncology is changing so fast right now with treatment options. And so, you know, it used to be that stage IV was synonymous with a year prognosis or less. And that’s totally not the case for a lot of cancers right now.” (PC#7)</p>

In summary, we found high rates of referral to outpatient PC and positive assessments of PC by oncology teams; however, there was dramatic variability in timing of referrals, oncologists’ referral patterns, and beliefs about when to refer. Future research could elucidate patient and family perspectives on referral to PC and experiences with earlier and later referrals. We do not know how referral to PC for non-cancer diagnoses may differ. The interviews reveal lingering questions about variation in the timing of, and reasons for, PC referral. This exploratory study demonstrates that exclusively focusing on rates of referrals may obscure how PC referrals vary in timing, reason for referral, and usefulness to patients, families, and clinical teams.

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Data and/or code availability The authors do not have permission to share the electronic health record dataset or interview transcript dataset. Requests to see further data can be directed to the corresponding author.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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